Developing the occupational therapy practice in a local community health team working with adults with learning disabilities:
An action research study

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Abstract

Background

This research study emerged from the on-going quest of a team of occupational therapists to demonstrate that a local occupational therapy practice: was meeting the needs of adults with learning disabilities; was effective and achieving the objectives of the employing organisation; and was complying with the expectations of the College of Occupational Therapists regarding evidence based practice.

Purpose

The purpose of this study was to seek and to *generate evidence* on which to evaluate and improve a local community based occupational therapy practice with adults with learning disabilities.

Methods

Action research methodology was used in which the local occupational therapists were engaged as co-researchers over three stages. Stage one: essential criteria for occupational therapy assessments for adults with learning disabilities were developed. No standardised assessments were identified that could meet all of these criteria. Stage two: perceptions of occupational therapy assessment were gathered from a sample group of adults with learning disabilities, their carers and other stakeholders. Stage three: changes were made to occupational therapy practice in response to the findings of stage two and in order to meet referral to treatment targets imposed by the employing organisation. Data were collected on the changes made to occupational therapy practice, and how they were implemented, through the use of action learning sets and questionnaires. The perceptions of a new sample of participants with learning disabilities and other relevant people involved, about the occupational therapy practice that they had received, were ascertained. Throughout the whole study, data were collected from multiple sources using interviews, questionnaires and co-researcher discussions and reflections. The primary method of data analysis was thematic, with some descriptive analysis. Data from different sources were triangulated to develop key findings.

Findings

The participants with learning disabilities were able to provide valuable insights about their perceptions of occupational therapy practice. There was evidence that occupational therapists provided occupation focussed assessments and interventions which had a positive effect on the occupational performance of adults with learning disabilities. The occupational therapists used professional reasoning in their assessments and interventions with adults with learning disabilities rather than a standardised, formulaic approach. This ensured a flexible, holistic and person-centred approach which worked in a dynamic community context. Occupational therapists, as a service, creatively adapted their practice in response to organisational demands whilst maintaining occupational therapy principles.

Conclusions

The practice-based evidence generated from this research study could be relevant and transferable for other occupational therapy services working with adults with learning disabilities and contributes to the occupational therapy body of evidence within this speciality.

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Glossary

Carer

The person identified by the selected participants with learning disabilities as their carer. This could be family members or paid support staff.

Changes in occupational therapy practice/New ways of working

These terms refer to the changes made by the local occupational therapists in stage three of this research study. The occupational therapists used the term 'new ways of working' and this terminology is present in some of the quotations cited, but this has been changed in this research study to avoid confusion with other published documents.

Client constellation

The client, his or her carer and any other people who are directly involved, or concerned about, the client's occupational therapy assessment and intervention.

Lead researcher

This is the researcher who is carrying out this study. She is also an occupational therapist practising within the team that is being investigated. Her clinical work will be investigated and reviewed in the same way as the other researchers. However, any direct interviewing of her own clients will be completed by another member of the OT co-researcher group.

Learning Disabilities

A learning disability has been defined as '*the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development'* (Department of Health 2001 p14).

'Intellectual disabilities' is a term used, in place of 'learning disabilities' in some publications. As this research study is practice based, learning disabilities is used as this is the term commonly used in services in the United Kingdom where the study is based.

‘People with learning disabilities’ cover a wider range of needs with no clear distinction between the categories. The British Institute of Learning Disabilities suggests the following categories and definitions:

> ‘People with profound intellectual and multiple disabilities’ have the highest level of need and very limited abilities to communicate and understand.
>
> ‘People with severe learning disabilities’ may have some ability to use words or signs and need support to manage most of their everyday activities.
>
> ‘People with moderate learning disabilities’ can usually manage some tasks and communicate but will need some support.
>
> ‘People with mild learning disabilities’ can usually communicate and manage most of their daily living tasks. They may need support to understand or to manage more complex issues.
> (The British Institute of Learning Disabilities 2015)

Personal consultee

Someone who knows the person who lacks capacity in a personal capacity who is able to advise the researcher about the person who lacks capacity’s wishes and feelings in relation to the project and whether they should join the research (Department of Health 2008).

Occupational Therapist

‘Occupational therapists work with people ‘to achieve health, well-being and life satisfaction through participation in occupation’ (College of Occupational Therapists 2009).

OT co-researchers

The group of occupational therapists who work in the local community health service for people with learning disabilities and agreed to take part in the study as the co-researchers.

Participants with learning disabilities

Adults with learning disabilities who had been assessed by an occupational therapist from the service and were invited to participate in specific parts of the projects.

The action research fieldwork

Any activity completed in contribution to the research study.

The research study

This refers to this thesis.

Abbreviations

ABAS	Adaptive behavioural assessment system
ADL	Activities of daily living
AHP	Allied health professionals
AMPS	Assessment of motor and process skills
CMOP-E	Canadian model of occupational performance and engagement.
COT	The College of Occupational Therapists. The professional body for occupational therapists in the United Kingdom.
CRASP	Title of model of action research developed by Zuber-Skerritt 1996: ***C****ritical (and self-critical) collaborative enquiry* ***R****eflective practitioners being* ***A****ccountable and making the results of their enquiry public* ***S****elf-evaluating their practice and engaged in* ***P****articipatory problem-solving and continuing professional development.* (Zuber-Skerritt 1996, p85)
DH	Department of Health
EBP	Evidence based practice
ESI	Evaluation of social interaction
HALO	Hampshire assessment of living with others
MOHO	Model of human occupation
NHS	The National Health Service
OT	Occupational therapy/therapist. (Only used for the OT co-researchers, in appendices documents or direct quotes).
OTIPM	Occupational therapy intervention and process model
RTT	Referral to treatment

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Chapter one: Introduction and context

1.1 Introduction

The publication of the government white paper: *Valuing People: a New Strategy for Learning Disability for the 21st Century* (Department of Health 2001) initiated a new approach to health and social care services for people with learning disabilities. The focus was on *'improving the lives of people with learning disabilities and their families and carers, based on the recognition of their rights as citizens, social inclusion in local communities, choice in their daily lives and real opportunities to be independent'* (Department of Health 2001 p9). In response to this publication, the occupational therapy professional body, the College of Occupational Therapists, conducted reviews of occupational therapy principles as they related to practice with people with learning disabilities (COT 2003 and 2013a). The lead researcher had been working as an occupational therapist with adults with learning disabilities for more than twenty years at the start of this study in 2007. During this time, she had led on the development of the College of Occupational Therapists' Principles for education and practice in services for adults with learning disabilities (COT 2003), summarised in Table 1.1, and had become aware of the lack of published evidence that could be referenced in order to develop this document. The principles were produced by consulting with occupational therapists working with adults with learning disabilities across the United Kingdom.

Table 1.1: Occupational therapy services for adults with learning disabilities: Principles for education and practice (COT 2003)

Principle 1	Occupational therapists working in learning disability services provide a service for people whose primary reason for referral relates to the effect of their learning disability upon their occupational performance.
Principle 2	People with learning disabilities need to be enabled to have choice and influence over their occupational therapy intervention.
Principle 3	People with learning disabilities have the right to access generic health and social care.
Principle 4	Occupational therapy services should be provided in partnership with the person with learning disabilities, his or her carers and all relevant agencies.

This work on developing the COT practice principles highlighted that occupational therapists specialising in working with people with learning disabilities within the

United Kingdom, practised in a variety of settings and took on different roles. Some of these occupational therapists only addressed the physical disability needs of people with learning disabilities as this was often because the specialist services for other people with the same condition excluded this client group. The first COT practice principle clarified that the role of occupational therapists working with this client group was to focus on working with people in regards to their occupational performance needs that were a result of their learning disability rather than primarily be focused on needs that had developed from other conditions. Often, occupational therapists stated that they wanted to keep to the COT principles but were prevented from doing so by the managers in their services who were usually not occupational therapists. These occupational therapists did not feel empowered to ensure that they were delivering interventions in relation to their core remit.

From this consultation, there had been a consensus reached on the practice principles, however there was little evidence available on what people with learning disabilities and their carers thought about the occupational therapy practice that they received. Another finding was that assessments used by occupational therapists working with adults with learning disabilities were not usually standardised. However, the principles included the statement: *'standardised assessments should be used whenever possible'* COT 2003, p3). This prompted the lead researcher to reflect on the expectations of the professional body and how these did not always match the experiences of occupational therapists who were working with adults with learning disabilities across the United Kingdom. The lead researcher, from her own experience and reports from the occupational therapy contributors, was aware that non-standardised occupational therapy assessments were perceived as being useful, in that they met the specific local needs of people with learning disabilities and were well received.

In 2013 the practice principles (COT 2003) were reviewed and updated. The previous four practice principles became eight core principles and are set out in Table 1.2. Principle 5 states that outcomes of interventions should be measured and there was a continued emphasis on the need for standardised assessments where possible but stated that *'occupational therapists may also use a range of non-standardised assessments where appropriate'* (COT 2013a, p2). In the same year the College of Occupational Therapists recommended the use of standardised outcome measures *'to demonstrate the delivery of high quality and effective' services'* (COT 2013b, p1). This reflects the higher value attributed to quantitative

research than to qualitative research in the hierarchy of evidence to support evidence based practice (Holm 2000). It is still a requirement of COT and the Health and Care Professions Council (HCPC) that *'Occupational therapy should be underpinned by evidence-based practice'* (COT 2015b, p1) and occupational therapists must confirm they are undertaking continuing professional development which includes the expectation to use standardised assessments and outcome measures.

Table 1.2: Eight core principles for occupational therapists working with people with learning disabilities (COT 2013a)

Principle 1	Occupational therapists should provide a unique occupational role and perspective
Principle 2	Occupational therapists should assess the impact of the person's learning disability on their occupational performance.
Principle 3	Occupational therapists should offer interventions to people with learning disabilities that focus on engagement in occupation and enabling independence.
Principle 4	Occupational therapists should work collaboratively with others to meet the needs of people with learning disabilities.
Principle 5	Occupational therapists should measure the outcomes of occupational therapy interventions for people with learning disabilities.
Principle 6	Occupational therapists should promote recognition of occupational therapy with people with learning disabilities.
Principle 7	Occupational therapists need to creatively respond to the impact of health and social care policy on occupational therapy with people with learning disabilities.
Principle 8	Occupational therapists need to develop skills to work with adults with learning disabilities.

1.2 Developing the evidence base for the local practice

In March 2007 the author met with a group of senior occupational therapists working in the local service who initially identified the need for a new standardised assessment tool to be developed. Occupational therapists assess people's daily living skills and provide intervention to develop these skills, and/or make recommendations for their support needs. These assessments can be carried out in various ways usually involving observing the person carrying out some aspects of daily living combined with interviewing the person himself and/or the carer. Assessments can be recorded by using standardised tools or more informal

observations, interviews and checklists. This meeting was the start of this research study which aimed to be a collaborative process seeking to understand what was happening in the local occupational therapy service, to identify any concerns and to work together to address these to develop and improve practice.

1.3 The structure of the local occupational therapy service in the research study

The lead researcher was an occupational therapist working with adults with learning disabilities in a community health team covering two London Boroughs. The management of this service changed during the period of the research study. At the start of the study, the occupational therapists were employed by a primary care NHS (National Health Service)Trust and managed within health services, this changed to a joint management arrangement with social services and then the service was reorganised again so that the occupational therapists were employed by an acute hospital trust. The occupational therapy service adapted to the different management restructures whilst maintaining a service to the client group.

The occupational therapists from both boroughs met regularly and worked according to the same policies and procedures. The local occupational therapy team accepted referrals regarding any adult with a learning disability who was living within the local catchment area of two London Boroughs. There was an estimated population of 3000 adults with learning disabilities living within this area, although only approximately half of these would be known to services. The occupational therapy service was part of two multi-disciplinary teams of specialist professionals working for adults with learning disabilities across health and social care agencies. The occupational therapists worked in close collaboration with other professionals within the multidisciplinary teams such as clinical psychologists, speech and language therapists and clinical psychologists to provide specialist assessments and interventions to adults with learning disabilities. The occupational therapists' assessments of individual clients with learning disabilities were used by other professions such as general practitioners (GPs) and social workers to help them make decisions about client needs and referral to other services.

It is a challenge to define occupational therapy practice in this speciality as people with learning disabilities have a wide range of needs. There are often carers and

others involved in supporting the person with learning disabilities. The occupational therapists, therefore, need to have a flexible and adaptable approach to ensure that the person with learning disabilities understands and can communicate his or her view and be supported to ensure the work is a collaboration partnership. In this research study, occupational therapists when working with adults with learning disabilities in the local service, needed to be client centred by using a process-driven model of practice that starts from identifying the occupational performance needs that are the concern of the individual.

1.4 Factors influencing the development of occupational therapy practice with people with learning disabilities

Occupational therapy practice with adults with learning disabilities has constantly been developing and is influenced by factors such as professional training; occupational therapy evidence base and policies; the philosophy and policy regarding services for people with learning disabilities; the local service management and remit and the experiences of working with individuals with learning disabilities. At the start of the research study a number of factors were considered to influence occupational therapy practice development, these are illustrated in Figure 1.1. The local occupational therapists were aware that all of these factors needed to be taken into consideration when reviewing how the service was delivered and what needed to be improved. It was not clear to what extent each of these factors influenced the local practice and if addressing the priorities of one of these parties would be detrimental to another. These factors were developed into the thematic concern of the study.

Figure 1.1: Factors that were considered to influence occupational therapy practice

1.5 The focus of this study

The initial broad focus of this research study was to find, or develop, a standardised occupational therapy assessment tool that could be used to measure the outcome of occupational therapy interventions with adults with learning disabilities. The intention, thereafter, was to further develop and improve the practice of occupational therapy by the local community health team working with adults with learning disabilities. However, it was found, during the first stage of the research study, that standardised assessments were difficult to apply in practice with adults with learning disabilities. Also, the information derived from standardised assessments was limited in its usefulness and relevance to local practice. The exploration of the perceptions of adults with learning disabilities, their carers and others involved who

had experienced an occupational therapy assessment moved the focus of the research away from standardised assessment towards a broader evaluation of the local occupational therapy practice and how this developed. *The overall purpose of the research study, therefore, was to explore the effects of current occupational therapy practice with adults with learning disabilities in a community health team and to generate evidence on which to base practice.* As the research study was devised to identify and work with the concurrent concerns raised from practice, the study moved in directions that could not be pre-planned. This research study was therefore flexible so that it could broaden its scope to address the findings and changes that occurred as part of a real occupational therapy practice.

1.6 The methodology used in this research study

The research study originated from the desire of the local occupational therapists working in the community to generate evidence to support their practice, in line with the practice principles recommended by the College of Occupational Therapists (COT 2003 and 2013a). In order for any changes to be implemented they had to be accepted by the local occupational therapy group. The design of the research study, therefore, needed to involve all the local occupational therapists and unqualified support workers at all levels as they were the experts in how occupational therapy was practised in their service and would be the agents of change. The review of the literature (Chapter two) highlighted that occupational therapy practice with people with learning disabilities was under-researched. The local occupational therapists wanted to ensure that the service they provided was of a good quality and of value to people with learning disabilities but, to do this, they needed to generate the evidence to support their practice. Action research was chosen as the methodology (Chapter three) as it appeared to fit the circumstances of the local occupational therapists and allowed them to engage fully in the research as co-researchers.

Zuber-Skerritt and Fletcher (2007) have described Action Research as having two purposes. It is involved in *action* that is intended to make a useful change to the occupational therapy practice and *research* that aims to contribute to the body of knowledge of occupational therapy practice with adults with learning disabilities. The requirements, set out by Zuber-Skerritt and Fletcher (2007), were that action research needs to be: practice orientated, participative, use multiple perspectives of knowing and seek to develop new knowledge in theory and practice. These

requirements were met by the overall purpose of this action research study and were used to set the objectives of the stages of the action research fieldwork.

The purpose of this study was to evaluate the current occupational therapy practice conducted by a local community health team working with adults with learning disabilities and to further develop and improve practice based on the evidence generated **(Practice orientated).**

The action research fieldwork objectives to meet the purpose and address the thematic concern were:

- To actively engage the local occupational therapists to participate in the study in partnership with the lead researcher. **(Participative).**
- To collect data on the perspectives and judgements of the occupational therapists, selected people with learning disabilities, their carers and others involved in their support network and to review relevant literature and policy. **(Using multiple perspectives of knowing).**
- To seek to be creative and innovative in exploring what influenced occupational therapy practice development within the local context. **(New knowledge in theory and practice).**

1.7 The thematic concern of the research study

This research study emerged from the on-going quest of a team of occupational therapists to seek and to *generate evidence* on which to evaluate and improve their local practice with adults with learning disabilities. They were aware of the multiple influences on their practice illustrated in Figure 1.1 and needed to provide evidence for all these groups. The goals of the occupational therapists were:

(i) to demonstrate that they can meet the needs of adults with learning disabilities.

(ii) to demonstrate to their employers that the service they provided to people with learning disabilities was effective and achieving the service objectives

(iii) to meet the demands of the professional body (the College of Occupational Therapists) for evidence based practice in line with the core principles for occupational therapists working with people with learning disabilities (COT 2003 and 2013a).

1.8 Structure of the thesis

Davis (2007) suggests that action researchers work in a dynamic and evolving way that is difficult to write up in a linear-structured format. Zuber-Skerritt and Fletcher (2007) recommend that action research studies need to be considered as two parts which consist of the action research field work and the action research thesis.

The action research *fieldwork* was a collaborative process of gathering and interpreting data with the occupational therapists. The fieldwork involved collecting and analysing a large amount of data which continued throughout all stages of the research and influenced each subsequent action in various ways. The focus in the first stage of this research study was originally on standardised occupational therapy assessments, but changed direction to a broader evaluation of occupational therapy practice. This was due to a number of issues: the findings from stage two (described in Chapter six), organisational demands and new ideas generated from the occupational therapists at the start of stage three (set out in Chapter seven).

The action research *thesis* needed to have a logical and concise structure so that the reader could understand and follow the research process. The action research thesis was an independent study by the lead researcher which included: *'planning the thesis, acting in the fieldwork, observing and evaluating the field work and reflecting on the results … in the light of the literature …and theoretical framework leading to the thesis' argument and contribution to knowledge in the field'* (Zuber-Skerritt and Fletcher 2007, p422). Figure 1.2 is a diagrammatic representation of this research study adapted from the model proposed by Zuber-Skerrit and Fletcher (2007).

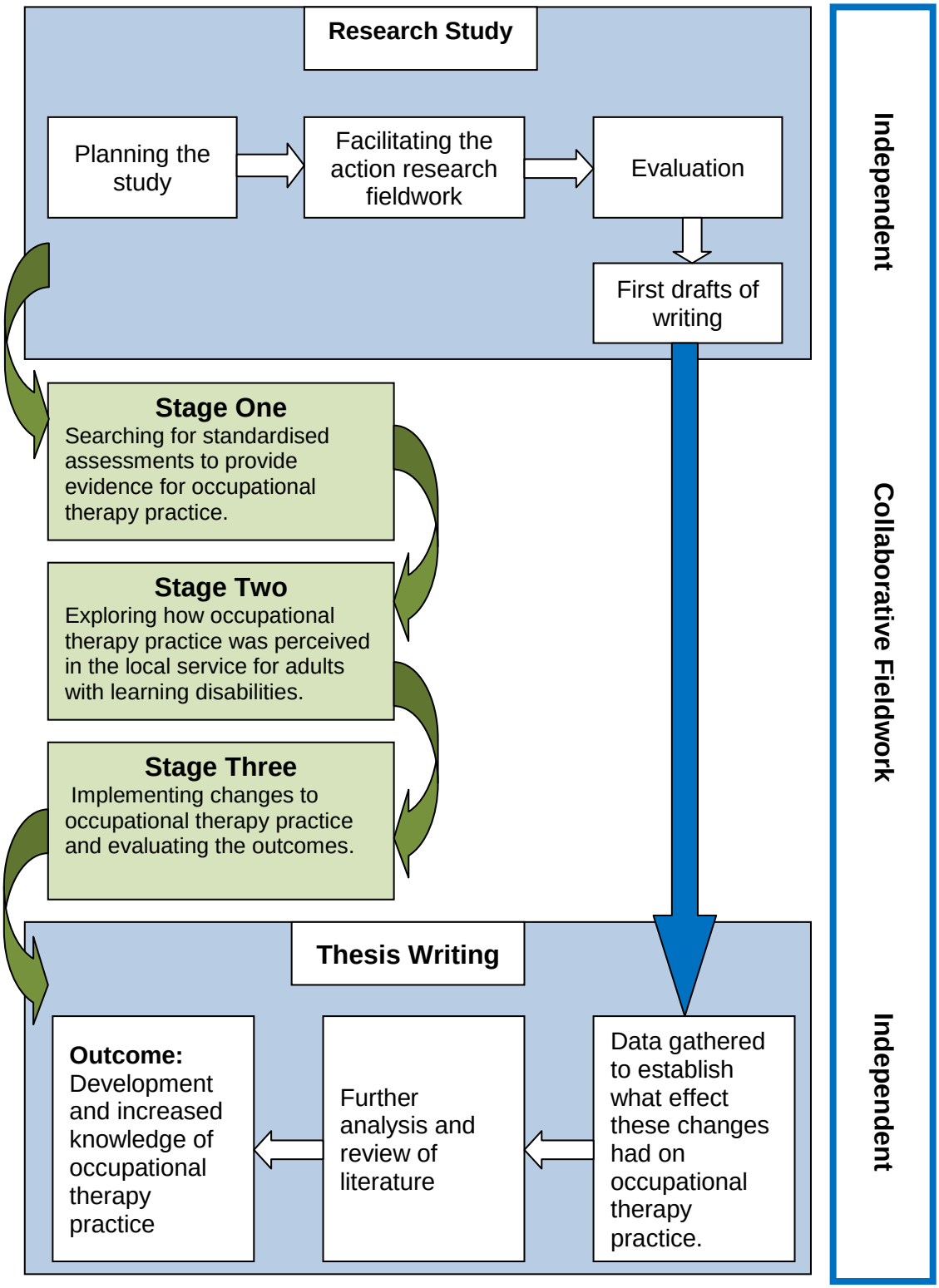
The research fieldwork is presented, in the thesis, as occurring in three stages, each of which is underpinned by the thematic concern.

- **Stage 1 (Chapter four)**
  The occupational therapists' search for standardised assessments to provide evidence / measures of outcome, for the practice of community occupational therapy with adults who have learning disabilities.
- **Stage 2 (Chapter five and six)**
  An exploration of how existing local occupational therapy practice was perceived by adults with learning disabilities, carers and other professions and stakeholders.

- **Stage 3 (Chapter seven and eight)**
  Implementation of the changes to occupational therapy practice. Exploration of how the local occupational therapy practice was perceived by adults with learning disabilities, carers and other professions/stakeholders after the changes.

All the action research fieldwork is listed in chronological order in appendix A.
The action research methodology has resulted in the thesis being structured in a less traditional format than might be expected had other methodologies been used. The literature relating to the research study evolved over the course of the action research process. As suggested by Dick (1997) the literature was gathered to define the initial research aim which focused on standardised occupational therapy assessments. This is set out in Chapter four as it was used to plan the first stage of the study. As data were collected and analysed at each stage of the fieldwork, new literature then became relevant which was then accessed and reviewed and so the majority of the literature is reviewed in Chapter two. The inquiry took place in the context of occupational therapy practice within a community team for adults with learning disabilities in the National Health Service in England between 2007 and 2013 and therefore, policies and legislation that affected the occupational therapy practice needed to be taken into consideration throughout the study. Policy and legislation is discussed within the literature chapter and as relevant to each stage of the fieldwork.

Figure 1.2: Diagrammatic representation of relationship between action research fieldwork and the action research thesis in this research study adapted from Zuber-Skerritt and Fletcher 2007, p421



1.9 Summary

This introductory chapter has set the scene for the context of the inquiry, including the purpose of the study and its thematic concern; the methodology chosen; and how the thesis is structured.

A review of the literature, which is explored in Chapter two revealed that there was a limited evidence base for community occupational therapy practice with adults with learning disabilities. The local employer and the professional body (the College of Occupational Therapists) required evidence to support local occupational therapy practice and recommended that standardised assessments be used as outcome measures of occupational therapy interventions with adults with learning disabilities. This action research study originated from the desire of the local occupational therapists to respond to these requirements and to find, or generate, evidence on which to base their practice and thereby enhance the community occupational therapy service they provided to adults with learning disabilities. As the action research fieldwork progressed, the focus moved from standardised assessments to a broader evaluation of the occupational therapy service from multiple perspectives.
Action research was chosen as the methodology to provide flexibility and to allow for changes to practice as new findings emerged from each stage of the research.

Chapter two: Literature review on occupational therapy practice with adults with learning disabilities

2.1 Introduction

Chapter one has set out the thematic concern that had arisen from the local occupational therapy practice at the start of this research study. This chapter explores published literature and relevant policy regarding the practice of occupational therapy when working with adults with learning disabilities. This includes how practice is influenced by context, policy and occupational therapy theory and how this has developed over time. The literature review includes legislation and policy, relevant to the local community occupational therapy service as well as books and published articles in peer reviewed journals. The initial literature review that focused on occupational assessments was updated throughout the action research fieldwork and is described separately (see Chapter four). The focus of the research study broadened to evaluate occupational therapy practice as a result of the findings of stage two and so the scope of the literature search expanded. The local occupational therapists, as part of their individual continual professional development, reviewed articles, pursued their own studies, attended professional conferences and shared their reflections and learning from these with their peers which also contributed to the literature sources. The literature was explored again at the end of the fieldwork and during the thesis writing process as the findings led to different literature being reviewed than had been at the start. In addition, new literature continued to be published. This literature chapter was therefore extended and revised at the end of the research process.

The search for literature on occupational therapy practice for adults with learning disabilities working in the community presented some challenges. The glossary sets out the definition and categories describing adults with learning disabilities as commonly used in services within the United Kingdom. However, the terminology to describe adults with learning disabilities varies widely between countries and across time periods. This could even be within the same publication over the same time period for example: the British Journal of Occupational Therapy published studies referring to people with learning disabilities (Hawes and Houlder 2010; Ball and Shanks 2012; Finlayson et al 2014; Ineson 2015), and also studies referring to people with intellectual disabilities: (Samadi 2011; White and MacKenzie 2015 and Mills et al 2016) over the same time period. Other terminology used in published studies included: mental

retardation, mental handicap, neurodevelopmental disabilities, mental disabilities and severe and profound multiple disabilities. Search terms used therefore needed to include an extensive list of options followed by a manual review of the context of each article to clarify its relevance (see Appendix B). Some studies revealed by this search related to people with specific conditions rather than a general diagnosis of learning disabilities for example: Down's syndrome (Daunhauer and Fidler 2011). Other studies included people with learning disabilities as part of a wider study on services for people with a range of disabilities. Arikawa et al (2013) presented two case studies, one person with Asperger's syndrome who did not have a learning disability and another with a learning disability and a visual impairment. Some studies use the American definition of learning disabilities that refers to a specific difficulty in learning such as dyslexia and so these articles needed to be identified and excluded as they were not relevant for this study.

Following the literature search, studies were excluded that were not considered relevant to the local occupational therapy practice with adults with learning disabilities in the context of working in the community within the United Kingdom. Articles that were identified in the search and then manually excluded included the following subjects: physiotherapy, cognitive behavioural therapy and articles that exclusively referred to children (see Appendix B). Studies were excluded if they were not directly related to occupational therapy practice such as the study by Lin et al (2006) regarding rehabilitation services provided by all professions in Taiwan and other studies related to the supported employment in institutional settings such as: Lancioni et al (2013), Italy; Liu et al (2013) Hong Kong; Suzuki et al (2008) Japan; and (Samadi (2011) Iran. In some of these studies, occupational therapists were not specified as being involved even though they were published in occupational therapy journals. The study by Smith et al (2010) was excluded as, although occupational therapists were involved and it was based in the United Kingdom, the context was an in-patient forensic unit. The search was limited to studies published from 1990 onwards as this was when community practice was more often occurring within the United Kingdom and so would be more likely to be relevant to the local context.

A further challenge to the literature search was that occupational therapy practice working with adults with learning disabilities does not fit neatly into a specific grouping and so data bases covering allied health professions, medical, psychological and social care publications needed to be searched. A final search was made to using EBSCOST and selecting all potential data bases (see Appendix B). Each of the searches

completed identified some new studies but did not identify all that were reviewed within this research study. A full systematic search of all potential studies was not therefore found to be possible but the triangulation of the findings using the different search methods has achieved the identification of the 47 peer reviewed published articles that have been cited in this research study. The manual review that excluded articles by only considering the title and abstract may have resulted in some relevant studies being missed. It would be expected that other relevant studies may exist that may not have been revealed due to other terms used, for example if the study was about occupational therapy as part of multi-disciplinary practice.

The chapter explores the literature on how occupational therapy practice working with adults in the United Kingdom developed and how this related to the context and policy.

2.2 The historical context of occupational therapy practice with adults with learning disabilities

The practice of occupational therapists working with adults with learning disabilities has evolved over time in the United Kingdom and was influenced by service philosophy and settings. In the past, occupational therapists worked in institutions such as large hospitals or day centres for adults with learning disabilities. People with learning disabilities, by definition, have difficulties with social functioning, so occupational therapists' focus has always been '*on the ability or competence of an individual and the skills needed to live as full a life as possible'* (Locke et al 2009, p248). This experience of practice evolving and developing is not unique to occupational therapists working with adults with learning disabilities. Occupational therapy practice has a history of constant change as it adapted to working within different settings and services resulting in a *'developmental sequence in the acquisition of knowledge'* (Hagedorn 2001, p20). Creek (2003) suggests that from this process, occupational therapy constructs developed which include a shared value, belief and knowledge base that includes the belief that there is a basic human need to act by performing tasks and activities which *'places demands on the individual to learn, adapt and respond, therefore, action facilitates change and personal development'* (Creek 2003, p28). Yerxa (2014) suggested that occupational therapy *'practice is …the implementation of our belief in the inherent wholesomeness of activity'* (Yerxa 2014, p12) and acknowledged that this has developed differently in various countries as people organise their activities into routines that relate to their culture. Occupational therapy practice is affected by ''*the*

context of social, political, economic, ethnic and gender circumstances and values…[and]… it is recognised that this reality will continue to evolve in relation to internal and external developments' (Creek 2003, p10). Hagedorn (2001) suggests that it was not until the 1960s that occupational therapists started to develop their own professional theories and body of knowledge.

Schön (1991) suggested that a professional knowledge base was traditionally seen in terms of a model of technical rationality where problems were solved by using scientific knowledge. This led to occupational therapy applying similar principles to those that had been used in established professions such as medicine and so the occupational therapy professional started to identity with a reductionist philosophy based in rationalism and logical positivism and focused on the biomedical model of disability in which a problem or condition was identified and treated.

Schön (1991) suggested that from the early 1960s there were concerns about the limitations of traditional professional practice and knowledge. The technical rationality perspective of problem solving ignored that, in the real-world, practice situations are unique, can be complex and do not have clear remits or predictable outcomes. Often non-technical processes are required to identify what the problem is that needs to be addressed in a specific context and so practitioners use *'artistic ways of coping with these phenomena'*. Schön (1991) used the metaphors of *'high, hard ground where practitioners can make effective use of research-based theory and technique and… swampy lowland where situations are confusing "messes" incapable of technical solution'* (Schön 1991, p42). The practitioner in attempting to meet scientific rigour may be constrained by this process and so fail to address what was most relevant for the client.

In the United Kingdom, exposures in the British press in the 1960s highlighted the abuse and poor treatments that some people with learning disabilities were experiencing in hospital settings. This led to the publication of the white paper Better Services for the Mentally Handicapped (DHSS 1971) that led to the policy of moving people with learning disabilities out of institutional, medically-led settings to be living ordinary lives in the community taking into account their wishes and rights. A social model of disability, rather than a medical model came to be adopted by practitioners as services changed to become more community focused and person-centred. Wolfensberger (1972) built on theories from Scandinavia, where people with learning disabilities had been supported in community settings from the 1950s, to criticise the

existing institutional practices in North America. He proposed that services should be organised taking into account the 'normalization' principle which he described as the *'utilization of means which are as culturally normative as possible in order to establish and /or maintain personal behaviours which are as culturally normative as possible'* (Wolfensberger 1972, p28). These principles continue to influence policies for services to support people with learning disabilities in this country.

Law et al (1995) re-emphasised the person centred approach to occupational therapy practice underpinned by the concepts of autonomy, choice and that each person has their own perspectives on what is important for them in their lives. They have the right to be provided with information about their occupational therapy so they can be enabled to make their own decisions. Person centred practice *'involves therapeutic rapport and a collaborative relationship'* (Fisher 2009, p52) with the person and the occupational therapist working in an equal partnership and sharing the responsibility to meet goals that reflect his or values. The importance of person centred practice continues to be a central focus of occupational therapy with the expectation that occupational therapists are committed to *'person-centred practice and the involvement of the service user as a partner in all stages of the therapeutic process'* (COT 2015a, pv).

In the United Kingdom, Jones (1995) reported that there had been rapid changes in how services for adults with learning disabilities were being provided and advocated for occupational therapists to change from their traditional approaches that emphasised the developmental acquisition of skills in segregated settings to a competency based approach developing skills in the place where the person needs to use them. The previous emphasis on working directly with people with learning disabilities in an institutional setting was replaced with more '*emphasis on consultation and teaching roles with carers and or others, whilst maintaining the occupational basis for intervention'* (Locke et al 2009, p248).

The changes in services appeared to have resulted in a review of the role and remit of occupational therapy within this specialism which was explored in four studies. Llewellyn (1991) and Tannous et al (1999) explored the perceptions of occupational therapists working with people with learning disabilities in Australia and Lillywhite and Atwell (2003) completed a similar study in the United Kingdom. Adams (2000) gathered the views of health and social care managers, members of the community learning disability team, house managers and support staff in England. The findings of these

small scale studies suggested that occupational therapists working with adults with learning disabilities were supporting people to enhance their independence and quality of life. Occupational therapists were perceived as complementary and enriching to the multidisciplinary team approach. However, there were some concerns regarding how the occupational therapy role was understood by others and the restrictions on the occupational therapists' ability to work holistically due to the expectations of other professionals or service demands.

The Government White Paper, Valuing People (Department of Health 2001) addressed how people with learning disabilities should be supported in England and clarified that they should not be excluded from generic services. For example: some services had been developed to provide equipment to address the physical needs of a person with learning disability and this was provided to the exclusion of other interventions. This resulted in people with learning disabilities being excluded from receiving the expertise and up-to-date knowledge of the specialist occupational therapists in these specific conditions and also not receiving the specialist occupational therapy to address the occupational performance concerns that were directly related to having a learning disability. In the United Kingdom, the principles for practice were developed (COT 2003) (see Table 1.1) to clarify the role of occupational therapists working in this specialism. *Valuing People Now: A new three year strategy for people with learning disabilities 'making it happen for everyone'* (Department of Health 2009) emphasised the need for partnership structures to be in place so that agencies including health and social care could work closer together.

The context of services described in some of the international literature regarding occupational therapy practice working with people with learning disabilities would often not meet the expectations of the practice principles (COT 2003, Table 1.1) and so it can be a challenge to consider the findings as relevant and ethical evidence to apply to practice. The contexts are often institutionalised settings such as residential homes, day service provision or sheltered workshops. Mahoney et al (2016) completed a study to review how people with learning disabilities demonstrate occupational engagement in a day service in the United States of America. No occupational therapists worked in this facility and one to two day centre staff worked with groups of eight to twelve adults with learning disabilities in sessions lasting one to two hours. The authors acknowledged that staff struggled to engage with more than one person at a time within these groups but did not recommend that a more person-centred service approach may be beneficial. Cullen and Warren (2013) reviewed an occupational

therapy service for adults with learning disabilities in Ireland and found that the occupational therapy role in this speciality was poorly understood. However, the most common interventions were addressing the physical mobility needs of adults with learning disabilities.

2.3 Models of practice in occupational therapy

Occupational therapists follow conceptual models to guide their practice. Kielhofner (2009) states that conceptual models of practice are made up of: theory; practice resources such as assessments, interventions and case examples; research; and feedback from practice and that they are a critical influence on practice quality. Duncan (2008) states that the reflective use of robust models of practice by occupational therapists *'can result in occupationally conceptualized, theoretically based, evidence-informed thinking'* Duncan 2008, p14).

Kielhofner (2008) suggested that occupational therapy models can be used to guide every day practice but are also constantly changing as research findings, experiences and insights contribute to the professional knowledge base and they are refined in practice. Yerxa (2014) asserted that *'no single theory or body of scientific ideas is likely to encompass all of the issues arising in practice'* (Yerxa 2014, p14). Yerxa (2014) suggests that occupational therapy '*practice creates the puzzles, frustrations, critical incidents or irritations which raise new questions for the profession'* (Yerxa 2014, p12). Seymour et al (2012) states that occupational therapy conceptual models support recording of assessment and intervention and evaluation and developing evidence based practice but caution that these are always simplifications of the real world. Rather than standardising practice, they enable occupational therapists to work in a client-centred way to meet individual needs *'basing practice on an occupational therapy conceptual model enables practitioners to more effectively articulate their clinical reasoning'* (Seymour et al 2012, p182).

Seymour et al (2012) state that *'all of the occupational therapy conceptual models are based on philosophical underpinnings of the profession with the concepts of humanism, holism and occupations being central tenets'* (Seymour et al 2012, p180). Occupational therapy conceptual models support clinical reasoning within a professional conceptual structure. The occupational therapist is challenged to understand and *'to analyse the unique occupational difficulties each individual faces in*

daily life within their own environments' (Seymour et al 2012, p181). However, occupational therapy conceptual models should not be applied rigidly to restrict practice, as '*to be responsive practitioners, occupational therapists need to continually reflect on and adapt their practice'* (Seymour et al 2012, p184).

Fisher (2013) proposed that the central concern of occupational therapists should be 'occupation focused'. Other factors can then be considered such as the environment, personal factors or body function in relation to how these affect occupation. Interventions use occupation-based methods. The model of practice needs to reflect the concepts of: *'people as occupational beings, the impact of occupational challenges on their lives, and the power of occupation as a therapeutic change agent'* (Fisher 2013, p 98). Fisher (2013) therefore, concluded occupational therapists need to adopt occupation focused conceptual models and cited the Model of Human Occupation (MOHO) (Kielhofner 2009), the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al 2007) and the Occupational Therapy Intervention and Process Model (OTIPM) (Fisher 2009) as meeting this expectation. These three models have different approaches and are briefly described.

Duncan (2010) stated that the Model of Human Occupation *'was developed following, and in response to, a reductionist and medically driven period in occupational therapy's history'.* It was first developed in 1980 as a guide for occupation-focused practice. The model has been developed and there is an extensive international research base of collaboration between occupational therapy practitioners and researchers. Kielhofner (2002) originally based the model on open system theory. The model has been developed over time and is now underpinned by dynamic systems theory. People are considered to conduct their lives via four inter-related components: volition (the motivation for occupation); habituation (the patterns and routines of occupation); performance capacity (the abilities required to perform occupations); and occupational environment (physical and social).

The Model of Human Occupation provides an extensive range of assessment tools derived from the model and *'is the most evidence-based model in relation to assessment'* (Seymour et al 2012, p185). Section 4.4.3 discusses one of the assessments Occupation Screening Tool MOHOST (Parkinson et al 2006). See Appendix G for a list of assessments based on the Model. However, Seymour et al (2012) state that it is important to understand the concepts of the model and the underpinning theory than just using the assessments. There needs to be a

differentiation between the model and the assessment tools. Each of the occupational therapy models are a guide for professional thinking rather than directing how to assess and provide intervention.

The Model of Occupational Performance (Law et al 1990) was developed by a task force of the Canadian Association of Occupational therapists. The model was based on the Concepts of Occupational Therapy (Reed and Sanderson 1983) which was described by Boniface (2012) as a theory rather than a true model of practice. In this theory, the individual is considered as someone who needs a balance of self-care, productivity and leisure. The person's individual aspects and how they interacted with the environment are taken into account. In 1997 the model was revised and re-named the Canadian Model of Occupational Performance (CMOP) (Townsend et al 1997) and ten years later it was further developed as the Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al 2007). This revised version emphasised engagement and human occupation as the core domain of occupational therapy with spirituality as a central component. Sumsion et al (2011) describe the person's unique spirituality as embedded within all parts of the model but states that this lacks a clear definition. Sumsion et al (2011) state that the CMOP-E is a client-centred social model that defines occupational therapy professional interest domains as:

- The person who has affective, cognitive and physical components.
- Occupations of self-care, productivity and leisure.
- The environment which is made up of physical, cultural, institutional and social components.

These three domains constantly interrelate and disruptions in one or a lack of balance can lead to occupational dysfunction.

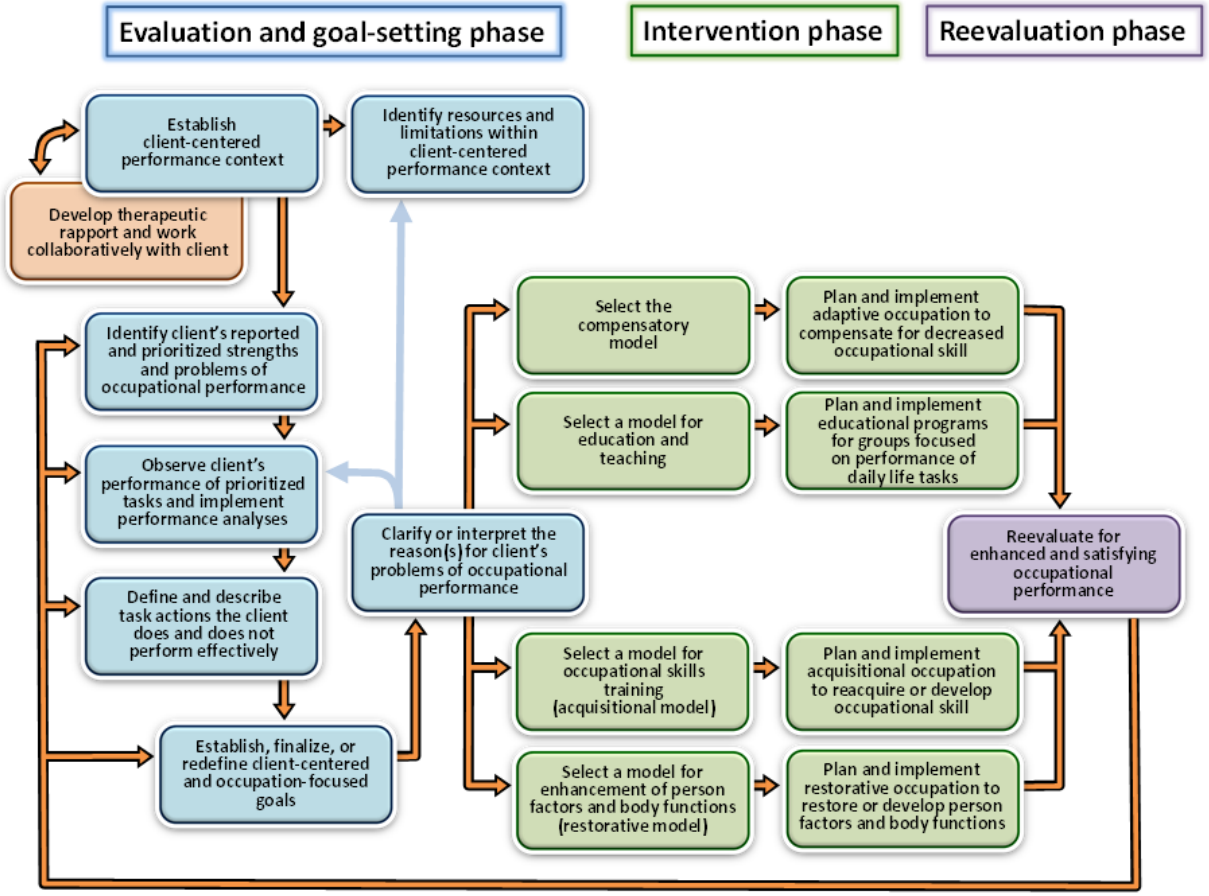
CMOP-E can be used by occupational therapists, working with people of any age. The components of the model can be considered to support understanding of '*the person's occupational limitations and how these affected occupational performance'* (Sumsion et al 2011, p85). Sumsion et al (2011) report that CMOP-E is a clear conceptual framework that is used throughout occupational therapy. However, they have criticisms that there is not a clear framework to guide practice and there is a need for more literature in regards to how the model is applied outside of Canada. The Canadian Occupational Performance Measure (COPM) (Law et al 1994) was developed to be used with CMOP-E as an outcome measure. It asks the person to identify where they are having difficulties in the three occupation performance areas and to self-rate these.

The Occupational Therapy Intervention and Process Model (OTIPM) is a professional reasoning model that '*provides …a conceptual structure for linking related knowledge and models of practice to the core knowledge of* [the] *profession'* (Fisher 2009, p21). This is illustrated in Figure 2.1. OTIPM is based on the assumption that each person is unique and will engage in activities that have a purpose and meaning to them. Fisher (2009) stated that *'the therapeutic use of occupation is our primary "means" for promoting our clients' abilities to engage in occupation, and our clients achieving engagement in meaningful and purposeful occupation is our primary "end"* '(Fisher 2009, p1). Fisher also stated that when using the OTIPM, practice and theory are integrated and there is a structure to support evidence based practice.

The client-centred performance context is established using a natural conversation rather than a rigid interview format. Observation of the person engaging in occupation is then expected. This can be unstructured observations or by using standardised assessments developed for use with the OTIPM such as the Assessment of Motor and Process Skills (AMPS Fisher and Bray Jones 2014) or the Evaluation of Social and Interaction (ESI, Fisher and Griswold 2015). The quality of occupational performance is assessed in terms of physical effort, efficiency, safety, independence, social appropriateness and satisfaction. The information gathered is then analysed by the occupational therapist using a framework of ten inter-related dimensions: environmental, role, motivational, task, cultural, social, societal, body function, temporal and adaptation. The occupational therapist uses this comprehensive information to collaborate with the client to determine his or her goals and priorities, and implement client-centred intervention.

Fisher (2009) advocated that, towards the end of the 'Evaluation and goal setting phase' during the step: *'Establish, finalise or redefine client-centred occupation-focused goals'* (see Figure 2.1), the occupational therapist may choose to use other conceptual models and theories as appropriate to support this process as appropriate to address the specific need. Fisher (2009) states that the OTIPM gives a conceptual structure to link theory, knowledge and approaches from a variety of profession specific or generic fields to guide professional reasoning when planning and implementing occupational therapy.

Figure 2.1: The occupational therapy intervention and process model (OTIPM) Fisher (2009)



Adapted from: Fisher, A. G. (2009). *Occupational Therapy Intervention Process Model: A model for planning and implementing top-down, client-centered, and occupation-based interventions.* Fort Collins CO: Three Star Press. (Revised June 2013)

Downloaded from http://www.innovativeotsolutions.com/content/otipm/ on 1/6/2016 and used with permission (see Appendix C)

Fisher (2009) and Seymour et al (2012) state that each of the occupation centred models described (MOHO, CMOP-E and OTIPM) have strengths and recommend their use by occupational therapists. They recommend the need for the occupational therapist to have the flexibility to use the concepts of a variety of models if these are appropriate for the circumstances. Conceptual models of practice are expected to evolve so that they support rather than dictate practice. This flexible approach in the use of conceptual models allows occupational therapists to use their professional reasoning to make decisions in their practice that best meets individual need. However, there are challenges for occupational therapists to use different conceptual models in practice. They need to develop a clear understanding of the different models and approaches in order to use these appropriately. MOHO, CMOP-E and OTIPM have extensive theories and literature and case examples that have been published which occupational therapists need time to read, understand and reflect on in practice. Occupational therapists need to be able to clearly explain their practice to their colleagues and so using multiple models could become confusing. Another challenge is that terms such as 'models' and 'theories' are not consistently defined in occupational therapy literature. For example Figure 2.1 illustrates the OTIPM overarching model, but at the start of the Intervention Phase there is a choice of four 'models' for intervention which could be defined in other literature as 'approaches'.

Boniface (2012) reported that the MOHO and CMOP were developed following concerns that occupational therapists were practising in various ways and there was a need for universal principles to guide and structure occupational therapy practice and research. The emphasis appeared to be on meeting organisation and professional standards by ensuring that a single conceptual model was used. The CMOP-E was developed to improve quality and consistency across Canada and the MOHO originated in the United States of America but both have influenced practice internationally including the United Kingdom. Two research studies: Boniface et al (2008) and (Wimpenny et al 2010) used action research methodology to embed a specific model to be used universally by all staff in two different occupational therapy services in the United Kingdom. Boniface et al (2008) adopted CMOP-E and Wimpenny et al (2010) used MOHO. The motivation for adopting a consistent model was to meet organisational expectations and to demonstrate the value of occupational therapy. Both of the studies (Boniface et al 2008 and Wimpenny et al 2010) successfully implemented the changes to practice using the methodology of

engaging the occupational therapist as co-researchers to develop their practice. The findings were that the conceptual models supported the occupational therapists' reflection on practice and professional reasoning skills. Time was needed to embed the changes into practice and the occupational therapists needed to have the flexibility to develop their own processes. The studies by Boniface et al (2008) and Wimpenny et al (2010) implied that the expectation for all occupational therapists to be guided by a single conceptual model universally within an occupational therapy service could demonstrate good practice. The studies did not report in detail how individual occupational therapists adapted to this uniform use of one conceptual model and how it affected their practice. However, from the findings, even though there was a universal model to guide practice, the occupational therapists were not rigidly working in a consistent way but were able to develop their own practices. The advantage of a service adopting one conceptual model is that expertise and an understanding of the concepts can be developed across all the occupational therapists within a service so that there is support from peers and terminology can be clarified. However, there are concerns that this universal expectation of adopting one conceptual model, if applied too rigidly could restrict the flexibility of occupational therapists to use their professional reasoning and work in an individualised client-centred way as recommended by Fisher (2009) and Seymour et al (2012).

Occupational therapy models of practice are all based on theoretical concepts, however, Hagedorn (2001) and Fisher (2009) propose that occupational therapy models can be divided into two categories: theory-driven and process-driven patterns for planning and implementing occupational therapy intervention. MOHO and CMOP-E could be argued to some extent to be more theory-driven models as there are clear components used by occupational therapists to guide their clinical reasoning before meeting and working with a client. These filter the information gathered to fit with the theoretical model adopted and so can result in *'affecting and limiting subsequent actions'* (Hagedorn 2001, p55). The theory-driven approach ensures that the service can be provided in a consistent way and allows evidence based practice to be more easily measured. It allows '*a coherent and consistent basis for practice and eliminates unnecessary deliberation. It promotes the development of expertise within a defined field'* (Hagedorn 2001, p56).

Occupation-focused conceptual models such as MOHO and CMOP-E could be described as theory-driven as their focus is on the various components of human

occupation that are defined in the concepts. The assessment tools aim to gain an understanding of the components of the model and often have standard questions used for each person. However, there are concerns that these theory-driven occupational therapy models expect the needs of the client group to follow certain patterns and so, if not used flexibly, can restrict the opportunity to be innovative. Fisher (2009) suggests that the theory driven pattern of reasoning can simplify occupational therapy thinking with the advantage that intervention can be completed quicker. However, she suggests when following this approach *'the occupational therapist necessarily adopts a more narrow perspective, and as a result, may ignore information or methods that are beneficial, but that do not fit the model of practice selected'* (Fisher 2009, p 20).

In contrast to models of practice with a theory-driven approach seeking consistency of practice for every client, is the process-driven approach where the primary concern is driven by the client's agenda. The occupational therapist first meets with the client and gathers information relating to his or her occupational performance concerns before making decisions about intervention approaches. The process driven approach allows the occupational therapist to have the flexibility to choose the assessment and intervention that is most appropriate for the client and the situation and '*demands a highly versatile and competent therapist [who] is confident in clinical reasoning'* (Hagedorn 2001, p56). Fisher (2009) proposed that the OTIPM could be considered *'closer to the pattern of reasoning'* (Fisher 2009) of the process-driven approach. However, in the real world of occupational therapy practice it is hard to make such a clear distinction between theory and process driven approaches. All three of the identified occupation-focused conceptual models are client-centred in which the occupational therapist needs to work flexibility and use his or her professional reasoning to meet the individual need. The extent to which the occupational therapists practices in a process or theory driven way is more likely to be how rigidly the model and assessment processes are applied rather than the conceptual model adopted. Therefore, rather than defining an occupational therapy model of practice as process or theory driven most are more likely to be on a continuum between the two.

2.3.1 Models of practice used by occupational therapists with adults with learning disabilities

Occupational therapy conceptual models can be used with all client groups and there are no specific recommendations for a specific model to use with adults with learning disabilities. A review of occupational therapists working with adults with learning disabilities identified that some of them valued models of practice and MOHO and CMOP-E were cited as two that were currently in use (Lillywhite and Haines 2010). Two studies (O'Neal et al (2007) and Parkinson et al (2009)) explored the theoretical concepts on which occupational therapists working with adults with learning disabilities based their practice.

O'Neal et al (2007) reviewed the use of theoretical models that guide the practice of occupational therapists working with adults with learning disabilities in residential services for adults with learning disabilities in the United States of America. The study used a wider definition of theory than conceptual models of practice. Questionnaires were sent to occupational therapists across the country asking specific questions regarding a set list of theories. One hundred and forty nine questionnaires were returned in which the occupational therapists were asked to state which of twelve selected theoretical models they used. The findings were that some of the occupational therapists were not familiar with these theories. Sensory integration and biomechanical theories were reported to be frequently used. Only 26% of the occupational therapists who responded rated the importance of theory as 'high' in their practice. It was also noted that there was a reduced use of theory reported by occupational therapists who had been practising the longest. It was stated that '*if practitioners do not use theory, their clinical reasoning may not be formulated on logical or defendable grounds'* (O'Neal et al 2007, p82-83).

However the lack of use of theories by the occupational therapists reported in the study by O'Neal et al (2007) may have been due to some of these not being so relevant in their role of working with adults with learning disabilities. Brown and Chien (2010) stated that bottom up assessments are common in occupational therapy services which follows the reductionist focus on impairments in function such as strength or range of movement. This approach can reflect the scientific approach and does not consider that knowledge can be generated by: *'interpretive, explanatory theories inductively derived from studying health professionals' perspectives on their practice'* (Higgs and Titchen 2001, p529). It appeared that in

the study by O'Neal et al (2007) there may have been an expectation that the occupational therapists should have been working in a reductionist way using evidenced based practice from established theories. However, It was reported that the occupational therapists did not consider theory useful in their decision making as they preferred to start from the client's specific context and to use reflection to make practical changes with one stating that this provides *'meaningful workable solutions for individuals'* (O'Neal et al 2007, p82). The occupational therapists' responses that they start from a person centred focus on identified problems of occupations, appeared to be similar to Fisher's (2009) view that practice should be occupation-focused. In this study 37% of the respondents reported that they used MOHO frequently, OTIPM and CMOP-E were not mentioned in this study and so it is not known if other occupational therapy models of practice were available for them to use or if these were listed on the questionnaire.

Parkinson et al (2009) completed an audit of occupational therapists working in different specialist areas, including some who worked with adults with learning disabilities, in one mental health organisation in the United Kingdom. The study was in response to a concern that occupational therapists in some settings were not always able to focus on their unique role of occupation because of expectations to provide more generic interventions within multi-disciplinary teams. The findings of this study were that the average percentage of time spent by occupational therapists in occupation-focused tasks was only 65.9%. However, in contrast, the group of occupational therapists who worked with adults with learning disabilities were found to use occupation-focused assessments over 90% of the time. This would appear to indicate that these occupational therapists were able to work with their clients in an occupation-focused way and were not having the same pressures to work generically as some of the other occupational therapists in the mental health trusts.

O'Neal et al (2007) suggested that occupational therapists working with adults with learning disabilities in the context of institutional settings in the United States struggled to relate theory to practice and that this was similar to studies of occupational therapists working with other cognitive difficulties. This would suggest that the use of theories with this client group may be more difficult. In a similar way Seymour et al (2012) and Fisher (2009) suggest that some terminology and concepts used in some conceptual models of practice may not be meaningful to all client groups. Concepts such as spirituality in the CMOP and volition in MOHO can be difficult for an adult with learning disabilities to understand and making the terms

more accessible can alter the meaning. Some conceptual models of practice rely on clients to have insight and self-report. CMOP-e and MOHO have many assessments that rely on self-reports and interviews. In contrast OTIPM with its emphasis on observations and natural conversation can be adapted to meet the needs of this client group. The use of complex language in models can be a barrier to client-centred practice and to collaborative working with carers or other professionals.

Most of the literature on occupational therapy interventions with adults with learning disabilities presented in Section 2.4.2 does not refer to a conceptual model of practice. The exceptions are Kottorp et al (2003c) in which OTIPM was used in a single case study and Melton (1998) in which MOHO was referenced within the discussion but it was not known if this model was used by the occupational therapists in their practice. It is, therefore, not known what, if any, occupational therapy conceptual model of practice guided the professional reasoning of the occupational therapists in the majority of the studies.

The literature search described in Section 2.1 did not reveal any examples of the use of CMOP-E with adults with learning disabilities although the authors maintain that it can be used with all client groups. Hawes and Houlder (2010) described the introduction of the use of an assessment based on the MOHO within an occupational therapy service working with adults with learning disabilities in the United Kingdom. The article focused on the specific assessment tool rather than the model. Hawes and Houlder (2010) concluded that the use of the assessment tool *'provided an evidence based model that is simple, logical and appropriate for use with most people with learning disabilities'* (Hawes and Houlder 2010, p567). However, there were concerns that the tool focused on deficits rather than people's strengths which was not compatible with the philosophy of the service working with adults with learning disabilities and the tool was not suitable for people with severe learning disabilities. The theory and application of MOHO includes three case studies of occupational therapists who describe the use of the model with adults with learning disabilities within different editions (Kielhofner et al 1995, 2002 and 2008). Two of these are adults with moderate to severe learning disabilities living in institutional settings within the United States of America. In one of these cases the occupational therapist based her observational assessments on MOHO to formulate an understanding of a man's volition, roles and environment to share with his support staff so that they could provide more positive behavioural support. The other case was a young woman with additional physical disabilities in which the

occupational therapists was working on developmental skills so that she could move on to the next level of training. This involved the young woman needing to develop assertiveness skills to cope with the demands of the other people in this next level group. In both these cases it is difficult to relate to the practices in the local service within the United Kingdom as the institutional settings were often the barriers to enabling these adults to meet their own individual occupation- performance goals. The focus of the occupational therapist appeared to be enabling the person to manage the environments and other people, than to focus his or her own occupational-focused goals. The third case study was a woman with mild learning disabilities living in the United Kingdom. The assessments described relied on interviews and she was reported to provide short passive responses. The goals identified by the woman were not all occupational-focused and some were met by other professions. For example: to improve seizure control was met by community nursing, although the occupational therapist did later support the client to manage her activities to avoid times when seizures may occur. Another goal was to improve speech difficulties and this was referred to a speech and language therapist to address. The occupational therapists in all three cases emphasised the need for informal as well as formal assessments when working with this client group. It was concluded that: *'together the cases illustrated how, by respecting clients' volition, therapists can open up possibilities for truly client-centred practices that empower clients to more fully participate in occupational life'* (Kielhofner et al 2008, p 354). However, these limited case studies did not appear to emphasise the client centred, occupation- focused goals as would be expected in OTIPM.

2.3.2 The model of practice used by the local occupational therapy service working with adults with learning disabilities.

The occupational therapists working in the local service with adults with learning disabilities choice of conceptual model on which to base their practice evolved during the course of this research study. Unlike the studies by Boniface et al (2008) and Wimpenny et al (2010), there were no external expectations as to which model to use and no perceived concern regarding a lack of occupation centred practice. Instead, the decision to adopt each of the models of practice was made by the local occupational therapists. As described in Section 2.3.2, any of the identified occupation-focused models of practice can be used when working with adults with learning disabilities. The body of evidence on the use of these models and the

development of new ones is on-going. Most of the evidence as to the use of the occupational therapy models with adults with learning disabilities set out in Section 2.3.2 was not published at the start of this research study in 2007 and so not accessible to the local occupational therapists.

Occupational therapy models of practice originate from personal models which reflect that specific therapist's unique experience. Hagedorn (2001) argues that occupational therapy *'needs the impetus of personal model building in order to develop its theory and practice. It needs therapists who can capture, analyse and communicate their personal practice for the benefit of others'* (Hagedorn 2001, p59). For this research study, the local occupational therapy service for adults with learning disabilities was made up of staff with a variety of personal and professional experiences. Therefore each would be likely to have developed a personal model of practice to some extent. This research study explored how occupational therapy practice developed as a whole service as well as how individuals developed. However, within an occupational therapy service there needs to be some form of uniformity of provision so that people can receive an equitable service and so that the remit can be understood. The need for occupational therapists to develop their individual practice is also important. The service can support the individual by '*reflecting on personal practice and discussing it with others, using supervision actively and keeping up to date with the professional literature'* (Hagedorn 2001, p59) as well as producing local guidelines and procedures to ensure the practice of the whole service develops.

The local occupational therapists had initially based their practice on the concepts of Reed and Sanderson (1983 and had then by the start of this research study, the local service had adopted the Canadian Model of Occupational Therapy Performance (Townsend et al 1997). There had been some exploration and discussions on the use of MOHO (Kielhofner 2009). Many of the assessments that had been developed for use in each of the occupational–focused models had been explored by the local occupational therapists (see Chapter four). The local occupational therapists made the collective decision to adopt OTIPM (Fisher 2009) as their conceptual model of practice during the time period of this research study following their reflective discussions (described in Chapter four). Three of the occupational therapists then attended a training course on the OTIPM facilitated by Professor Ann Fisher in which there were opportunities to discuss and reflect on concepts of the model in relation to their experiences of local practice.

The decision to use OTIPM by the local occupational therapists evolved over time within practice, rather than a more academic or evidenced-based process. All the conceptual models of practice use complex language to explain theory and concepts. However, the OTIPM with its emphasis on collecting information through natural conversation and observation was found to be more compatible by the local service when working with adults with learning disabilities. The local occupational therapists working with adults with learning disabilities completed top-down evaluations that focused on the perceptions and needs of the person with learning disabilities in relation to the occupations that he or she wanted or needed to perform. The OTIPM theoretical assumptions were considered to be compatible with the local occupational therapists' practice knowledge and the assessment processes were adapted to meet the OTIPM (see Section 4.5).

There is limited evidence of how conceptual models of practice are used with adults with learning disabilities and this is a gap in the literature. How the local occupational therapists practised using OTIPM is explored throughout the thesis. The extent to which the use of OTIPM as an occupation-focused conceptual model supported the local occupational therapists to articulate their professional thinking and influence practice decisions, as proposed by Duncan (2008 and Seymour (2012) is discussed in Chapter nine.

2.4 Occupational therapy practice for adults with learning disabilities: Priorities for research

During this research study, a national review of occupational therapy and people with learning disabilities was published by the College of Occupational Therapists (COT) (Lillywhite and Haines 2010) in which focus groups of occupational therapists working with people with learning disabilities in the United Kingdom were used to explore to what extent the Practice Principles (COT 2003) (see Table 1.1) were being met. The findings stated that occupational therapists have a '*unique understanding of the importance of engagement in occupation and are passionate about their person-centred and practical role, which focuses on independence and requires them to be adaptable, flexible and creative problem-solvers'* (Lilllywhite and Haines 2010, pix) but there continued to be a limited evidence base. The study report identified gaps in the current body of knowledge and made recommendations

of the key areas for occupational therapy research in the field of people with learning disabilities (see Table 2.1). Four of these areas, (highlighted in yellow) had already been identified by this research study as gaps in the literature and are explored in turn.

Table 2.1: COT key areas for research regarding occupational therapy with people with learning disabilities, (Lillywhite and Haines 2010, p 54)

1.	Occupational therapy with people with learning disabilities from a wider perspective than what occupational therapists say about their own practice. This should include the perspectives of key stakeholders, including in particular people with learning disabilities themselves and their families.
2.	The effectiveness of specific occupational therapy interventions and outcome measures that can demonstrate this.
3.	Standardised occupational therapy assessments that better meet the needs of and are accessible to people with learning disabilities. This may include: – research into the development of new or adaptation of existing assessments to better meet their needs; – research to enable a consensus to be reached about which adaptations can be made to currently used standardised assessments (such as the AMPS) without compromising standardisation of the assessments.
4.	The impact of eligibility criteria and targets regarding waiting times on the quality of the interventions of occupational therapists (and others in community teams) with people with learning disabilities.
5.	How students and newly qualified occupational therapists can best be enabled to develop the necessary skills to work with people with learning disabilities.
6.	How occupational therapists can best support people with learning disabilities to gain employment.
7.	The views of occupational therapists in mainstream services regarding how people with learning disabilities can best be enabled to access their services.
8.	How best to address the shortage of occupational therapy posts within the learning disability field.

1-4, highlighted in yellow, are the key areas that directly relate to this study.

2.4.1 The perspectives of adults with learning disabilities and their families and key stakeholders

The importance of gaining the views of adults with learning disabilities was highlighted in one of the earliest published papers cited in this literature review which concluded that: *'until adult clients' opinions are sought, the compatibility, or other-wise, of their views with therapist perspectives will not be known'* (Llewelyn 1991, p331). Tannous et al (1999), Adams (2000) and Lillywhite and Atwell (2003) also acknowledged that the omission of gathering the perceptions of adults with

learning disabilities, as well as those of carers and advocates, was a significant limitation in their studies. Adams (2000) reported that due to '*the timing of the interviews, it was not possible to include the clients themselves'* and this omission did *'detract from the richness and wholeness of the findings'* (Adams 2000, p19). In other studies directly related to occupational therapy with adults with learning disabilities such as Francisco and Carlson (2002), Kottorp et al (2003a, b and c) and Hällgren and Korttorp (2005), the views of people with learning disabilities were not mentioned. Only one of the intervention studies described in Section 2.4.2 (Melton 1998) gathered the views of people with learning disabilities. Most of the other studies did state that this omission was a limitation of their quest to increase their understanding of occupational therapy practice.

Historically, people with learning disabilities were not considered as being able to engage in research and were often excluded. It was acknowledged that some people with learning disabilities would not be able to give their view of their experiences due to their inability to comprehend and/or communicate because of their cognitive difficulties but others would be able to contribute. If people with learning disabilities were involved, they were seen as 'subjects' to be researched. An example of this was a study by Rogers et al (1998) where 'subjects' *'were identified as appropriate participants on the basis of their verbal ability'* (Rogers et al 1998, p123). This excluded anyone who was not considered able enough to communicate at the level set by the researchers. Rogers et al (1998) reported that interviewing people with learning disabilities was difficult as they may have a lack of understanding of concepts such as: time, future and feelings, or may not be able to communicate these ideas in a meaningful way. However, the authors did endeavour to include people with learning disabilities even though it was not at that time common to do this. They addressed the difficulties with interviewing people with learning disabilities by *'rephrasing questions at different times throughout the interview'* (Rogers et al 1998, p124). Melton (1998) also limited her participants to those who were able to complete written consent and recommended that future research needs to consider methods for gathering the views of people less able to verbalise.

The Mental Capacity Act (2005) that covers England and Wales stated: *'a person must be assumed to have capacity unless it is established that they lack capacity'* (Department for Constitutional Affairs 2007, p19). People with learning disabilities need to be supported to enable them to understand what they are being asked to

do. Researchers need to weigh up the benefits and potential difficulties with involvement of people who lack capacity. This may need to involve a carer, advocate or someone else who knows the person well at the first stage to ensure that the person's individual communication needs are met. If it is established that a person lacks the capacity to consent to participate in research they can still be included if the research meets the specified conditions in accordance with the Act and it is approved by an appropriate body such as an Ethics Committee. The research needs to be of benefit to that person or to other people with similar conditions and would be less effective if it only involved people who had capacity. This is relevant for this research study as it affects people with learning disabilities of all levels of capacity as defined by the Act. The research must not be harmful and there needs to be a minimum risk of the process causing restriction or distress. The person must be happy to take part and a family carer or independent advocate must also agree that they can take part in the research. Any act or decision made on behalf of someone who lacks capacity needs to consider the person's best interest and the option chosen had to be the one *'that is less restrictive of the person's rights and freedom of action'* (Department for Constitutional Affairs 2007, p19).
In 2006 the Department of Health funded a group of people with learning disabilities to complete a research study entitled 'Let me in I'm a researcher'. The foreword stated that research had been historically completed without involving people with learning disabilities and that the study had *'helped to highlight good practice … in terms of genuine involvement and empowerment'* (DH 2006, p8). Their report recommended that researchers needed to be flexible in their methods to ensure that they can effectively engage with people with learning disabilities. They concluded that when people with learning disabilities are *'involved at the heart of the research in effective ways they make a huge difference…the research covers different questions and different information'* (DH 2006, p87).

Health services in England now focus on the importance of 'patient experience' and '*ensuring people have a positive experience of care'* (DH 2012, p5). The Friends and Family Test, that asks for real time feedback as to whether or not the person would recommend the service to other people, is one of the indicators that was rolled out nationally from April 2013. The need to seek the views of adults with learning disabilities about their health care was recognised in 2001 when the Government's White Paper 'Valuing People' set out the agenda of rights and inclusion and the recognition *'that those with learning disabilities …have an active voice when discussing their health needs'* (Redmond 2005, p76). The 'Complain for

Change Campaign' launched by Mencap and the Parliamentary and Health Services Ombudsman (PHSO) in May 2014 stated that *'people with a learning disability are one of the groups least likely to raise a complaint with the PHSO'* (Mencap, 2014). This highlighted the on-going concern that people with learning disabilities have difficulties in being able to express their views and have these listened to and addressed. The NHS Constitution for England set out personal pledges to all patients that included: *'to inform you of research studies in which you may be eligible to participate'* (DH 2013, p8). This means that health researchers have a responsibility to ensure that they do not exclude potential participants in a discriminatory way. The constitution goes on to say that patients need to be offered *'easily accessible, reliable and relevant information in a form you can understand, and support to use it'* (DH 2013, p9). The various policies and campaigns have highlighted the importance of gathering the views of adults with learning disabilities but reveal that this is an on-going issue that is more complex than with the general population.

There have been more recent studies published in occupational therapy literature seeking the perceptions of people with mild learning disabilities but not specifically about their occupational therapy experience. Hällgren et al (2014) interviewed one hundred and twenty adults with learning disabilities about their use of technology such as mobile telephones, cashpoint machines, ovens etc. White and Mackenzie (2015) interviewed five women with mild to moderate learning disabilities, who were able to give their informed consent about their social networks. Other studies have included people with severe learning disabilities as participants. Finlayson et al (2014) interviewed 113 adults with learning disabilities about the impact of injuries that they had sustained. Joint interviews were completed with participants with learning disabilities and their carers together. They then followed up this first study by purposively sampling ten of the participants who ranged from people with mild, moderate, severe and profound learning disabilities to complete semi-structured interviews. *'the interviews were tailored to the individual, with their carer present where appropriate to assist with their preferred communication style'* (Finlayson et al 20014, p408).

Mahoney et al (2016) interviewed and observed ten adults with learning disabilities and significant impairments who were considered by staff difficult to engage in activities. They were observed participating in activities within a day service facilitated by staff who were not occupational therapists. The findings were that it is

possible for people who were unable to verbally express their views to indicate their choices and preferences. This was done by observing what the participants did and what they focused their attention on which *'demonstrated choice, involvement, and the meaning they found in engagement in adapted occupations'* (Mahoney et al 2016, p5). Ineson (2015) completed a case study on one person with severe learning disabilities regarding accessing employment. She interviewed the person with learning disabilities and two other key people in that person's life. The interview with the participant with learning disabilities was carried out with a support worker and occupational therapy student also present. The participant was able to give yes and no answers and point to pictures. These more recent occupational therapy published studies have emphasised the importance of involving people with learning disabilities in research and valued their contribution. However, none of these asked people with learning disabilities specifically about their experience of occupational therapy. Ball and Shanks (2012) explored why obtaining the views of people with learning disabilities has continued to be an issue for occupational therapists. They sent questionnaires to seventy occupational therapists working with adults with learning disabilities in the United Kingdom and then interviewed twelve of them regarding how they get feedback about their practice from people with learning disabilities. Three people with learning disabilities were involved in planning the research including devising the questions to be asked. The study concluded that '*occupational therapists struggle to obtain meaningful unbiased feedback'* (Ball and Shanks 2012, p475) from adults with learning disabilities as they did not have the time, resources, confidence or skills.

Roeden et al (2011) interviewed people with mild learning disabilities about their relationships with their carers. This study was unrelated to occupational therapy but concluded that *'clients with mild intellectual disabilities, without any severe additional cognitive or physical limitations, are usually capable of expressing their opinions about a relatively abstract subject matter'* (Roeden et al 2011, p405). They also concluded that *'research has demonstrated that the client's positive opinion about the quality of the working alliance is a much stronger predictor of a positive treatment outcome than the opinion of the professional involved'* (Roeden et al 2011, p398). Schön (1991) suggested that practitioners need to have a reflective relationship with the person they are working with and make their technical expertise meaningful and accessible. Therefore the occupational therapist needs to collaborate with the adult with learning disabilities to understand the experience from his or her perspective so that they both reflect on what they have learnt from the

unique experience. This would indicate that, to understand occupational therapy practice in this research study, it would be essential to explore the perceptions of people with learning disabilities who have received a service as to how useful this was for them and how they perceived the working relationship with the occupational therapist.

Section 2.2 described the findings by Llewellyn (1991), Adams (2000) and Lillywhite and Atwell (2003) that occupational therapists have been identified as part of multi-disciplinary teams and that there were positive and negative aspects to this. A recommendation was that '*further research is needed into the perceptions of roles by other professionals*' (Lillywhite and Atwell 2003, p135). Section 2.2 described how Adams (2000) explored the views of health and social care professionals as to their perceptions of occupational therapy services. However, there have been limited studies published since, that have considered the perceptions of other key stakeholders and carers on occupational therapy. In a study not directly related to occupational therapy, Bowey et al (2005) used focus groups to obtain views of various groups: family carers, day centre workers, community learning disability team professionals and housing association workers on the housing and support needs of a sample group of people with learning disabilities. Bowey et al (2005) argue that all professionals involved with a person with learning disabilities have a key role in identifying a person's future needs. Inter professional collaborative working is required to meet the needs of people with learning disabilities. Carers often felt excluded by professionals when planning for the person with learning disabilities to move on. The study concluded that people with learning disabilities need support to make informed choices and that the views of carers also need to be considered. McDougall et al (2014) considered the needs of carers of adults with learning disabilities in remote rural areas in Australia. The study explored the impact of their caring role on their own occupational engagement rather than their perception of how the occupational therapy received by the person they support.

The literature review identified that although the need and importance of exploring the perceptions of adults with learning disabilities, their carers and other key stakeholders, of their experiences of occupational therapy practice was emphasised, there was a significant gap in that these perceptions continued to be missing from the majority of studies.

2.4.2 The effectiveness of specific occupational therapy interventions and outcome measures that can demonstrate this

The literature search of peer-reviewed published studies on occupational therapy interventions with adults with learning disabilities (see Section 2.1) identified a limited number of intervention focused articles that have some relevance to the context in which the local occupational therapy service works. As described in Section 2.2, there is a difficulty with using some of the international studies when seeking evidence regarding occupational therapy practice with adults with learning disabilities as many appear to be based in services that do not reflect the context or philosophy of the local United Kingdom community occupational therapists and so the findings are not always relevant or applicable. However, some international studies have been set in a community context and have been included here alongside studies based in the United Kingdom.

Melton (1998) used interviews to explore the perceptions of five people with mild learning disabilities regarding their experiences of preparing meals as part of their occupational therapy intervention. The participants had worked with senior occupational therapists who were members of community learning disability teams in the South West of England. The findings were that the participants with learning disabilities perceived that the occupational therapists had provided a flexible, personalised approach in which their wishes were respected. The study concluded that '*occupational therapy is valuable for teaching skills to and empowering clients with mild learning disabilities*' (Melton 1998, p109).The study focused on the experience of meal preparation but it was acknowledged that this task was just one of the aspects of the occupational therapy intervention experienced. It also recommended that as each participant had a different perspective of the meaning of cooking, occupational therapy intervention needed to be individualised to ensure that it was relevant for each individual.

Kottorp et al (2003c) completed single case studies of three women with moderate learning disabilities living alone in flats in Sweden with carers providing support at key times during the day. They were described as needing 'limited support' and they gave signed permission to be involved in the research. The occupational therapists used the OTIPM (described in Section 2.3) to work with the women on developing the activity of daily living skills (ADL) that they identified as important for them. This was similar to the approach used by the local occupational therapy service based in

the United Kingdom. The women were first assessed completing two activities of daily living tasks using the AMPS (Bray-Jones and Fisher 2014). The women were then provided with eight to ten occupational therapy intervention sessions working on developing their skills and teaching them new ways of adapting how they completed their chosen tasks. They were then reassessed and the pre and post intervention scores were compared using the standardised assessment measure. The findings were that the women's ADL process ability scores improved but their ADL motor ability scores and their insight into their difficulties did not change. However, the results needed to be viewed with caution due to variability and fluctuation in the women's scores at different times. The authors suggested that it was difficult to separate change due to occupational therapy intervention from other reasons such as changes in the women's mood or environment. This was then followed up by two of the authors Hällgren and Kottorp (2005) who described the first study (Kottorp et al (2003c) as a pilot and evaluated a refined intervention programme for five people with mild, and one with moderate, learning disabilities also in Sweden. They completed baseline assessments using the AMPS (Bray-Jones and Fisher 2014) over one to two months, intervention over two to three months and reassessment after occupational therapy had been completed one, three and six months later. As in the pilot study, the authors were able to demonstrate a beneficial change and this was sustained after six months. However, the changes were not found to be generalisable to other tasks that the people with learning disabilities needed to undertake. The study suggested that occupational therapy, using adaptive and restorative techniques, can improve occupational performance. It was found that effective change had been achieved over one to five occupational therapy sessions. There were recommendations made for further studies to review if these changes could be generalised from specific tasks to consider if the need for assistance in daily living skills could be reduced.

A study by Wennberg and Kjellberg (2010) explored how to support adults with learning disabilities to develop their time management skills and widened this to include other areas. They described how in Sweden cognitive assistive devices are prescribed to people with disabilities if they are thought to be helpful in enabling them to increase their independence in daily living skills. The devices described were hand held computers with a variety of programs to support time management and budgeting. This included a timer that displays a series of dots which provides a count down and a beep when the time has been reached and weekly schedulers with texts, pictures or voice prompts. Seven occupational therapists identified people

with learning disabilities who had been prescribed a device. It was not clear from the study how much, if at all, the occupational therapists were involved in assessing the need for the device, the prescription of it or providing advice on how to use it. Semi structured interviews were completed of nine adults with mild learning disabilities who could communicate verbally and had been prescribed a device in the previous two years. The findings were that the participants reported that using these devices increased their participation in their daily life as they were more independent in organising their time and money without needing to be reminded by other people. However, some had experienced stigma in using the device as it drew attention to them as needing support. The recommendation was that occupational therapists need to review how the devices were being used once they had been prescribed and that there was a need for further research of the longer term benefits of using this technology. Applegate et al (2008) also showed, through a single case study, some benefit from a computer programme to assist with learning to tell the time. The studies by Applegate et al (2008) and Wennberg and Kjellberg (2010) reviewed the use of specific technology rather than a focus on occupational therapy intervention. The local occupational therapists may consider strategies to address similar issues as part of their intervention to enable adults with learning disabilities to meet their overall occupation performance goals and so may find aspects of these studies useful.

There are a few studies on the use of sensory integration with adults with learning disabilities. The studies by Reisman (1993) based in the United States of America and Soper and Thorley (1996) in the United Kingdom completed studies in large institutions and so these contexts were very different from current community practice. Soper and Thorley (1996) noted that behaviours that were considered challenging reduced in sensory sessions but returned when the patients returned to their wards. However, they concluded that sensory experiences need to be a part of people's everyday lives and recommended that carers need to be enabled to understand the possible meanings of the behaviours of the people they support. Green et al (2003) completed a study on two adults with learning disabilities and autism and their findings were that there were some positive changes for one out of the two following sensory integration therapy. Although the study had a narrow focus on the effect of sensory integration other factors were noted that affected the outcome such as the lack of a consistent support, the environment and addressing communication needs and so emphasised the need for a more holistic focus to intervention to gain positive outcomes. Whilst recommending an urgent need for

more research in this area so that recommendations could be made for practice, the authors noted that *'defining the context by which behaviours can be measured with some degree of reliability distorts the concepts of 'spontaneous' and 'appropriate', which underpin the very nature of adaptive responses'* (Green et al 2003, p461). Urwin and Ballinger (2005) completed a study with five people with severe/moderate learning disabilities and tactile sensory modulation problems. Sensory integration therapy as an occupational therapy intervention was found to be effective in improving functional behaviour and reducing maladaptive behaviours immediately after the session. However, the authors suggested that, as the occupational therapists adapt their sensory integration intervention to each individual, measuring can be inconsistent. Urwin and Ballinger (2005) recommended that there needed to be further standardisation of methods to replicate the findings. However, they also recommended that there was a need for collaboration with carers to ensure that people receive an appropriate sensory diet throughout the day, which cannot be measured in strict trial conditions. None of these studies considered the perceptions of the people with learning disabilities involved, although they were likely to be people that could not express their views and observing their behaviours would have been assumed to have been an indication that the intervention was supporting them to be calmer or more engaged. There were no perceptions of carers presented.

Perez et al (2012) interviewed ten occupational therapists in one area of Australia who were interested in positive behavioural support in their intervention with people with learning disabilities. Occupational therapists who worked in a variety of settings with children and with adults were asked questions regarding their contribution to positive behavioural support. The findings suggested that the occupational therapists had a role as part of multi-disciplinary practice and included supporting people to develop their skills, identify and address their sensory preferences and to provide support and training to carers. Positive examples were given by the respondents in which occupational therapy intervention had succeeded in decreasing challenging behaviours. The study concluded that occupational therapy is well placed to provide positive behavioural support but this needs to be documented to develop the evidence base. However, this study only considered the perspective of the occupational therapists involved.

All of the studies were able to demonstrate some evidence that the occupational therapy intervention studied had been effective. The evidence of occupational therapy intervention in all of these studies provides some insights into some specific

aspects of practice and collectively can be used to start to build up a body of knowledge of the effectiveness of occupational therapy when working with adults with learning disabilities. However, the authors acknowledged the limitations within their studies and recommended that further research was required. The studies were all small in nature and context specific. Kottorp et al (2003c) suggested that large group trials are not always *'ethical or practical for use in clinical settings'* (Kottorp et al 2003c, p52) and so the findings need to be considered as to what could be relevant in other settings rather than the intention that they would directly apply universally. In these studies the aspect of occupational therapy intervention was confined to narrow parameters so that it could be measured in the search for rigorous outcome evidence. Evidence using strict trial situations can be useful to help to demonstrate the effectiveness of interventions that will usually be provided in more flexible individual circumstances. However, many of the studies described were restricted to a narrow aspect of occupational therapy which did not appear to reflect its wider holistic nature. Only one study (Melton 1998) used qualitative methods to explore the views of people with learning disabilities to establish the outcomes of one specific aspect of occupational therapy. The views of occupational therapists had been collected by Perez et al (2012) as well as the previous general perceptions of practice collected in studies described in Sections: 2.2: Llewellyn (1991); Tannous et al (1999); Lillywhite and Atwell (2003) and Section 2.4: (Lillywhite and Haines 2010).

In order for occupational therapy practice to develop there is an expectation that research should be used to develop evidence. The assumption is that appropriate research evidence is available that can be applied to practice. However it is acknowledged that evidence based practice '*takes into account the integration of the best available research evidence, together with the practitioner's clinical expertise and the service user's values and* goals' (COT 2015b, p1). The limited literature retrieved for this study is similar to the findings of Llewellyn (1991), Tannous at al (1999), Lillywhite and Haines 2010), Goodman et al (2009) and others who have reported concerns regarding the lack of published papers or texts on the role of occupational therapists working with adults with learning disabilities. As a result '*influences on thinking and practice of the new practitioner often come from trusted colleagues and by trial and error'* (Goodman, et al 2009, p xi). Occupational therapy practice appears to have developed mainly by using knowledge gained from occupational therapy undergraduate training, and from experienced occupational therapists sharing their knowledge and expertise with colleagues. However,

although the authors acknowledge that learning from experienced practitioners can be useful, they were concerned that this *'leaves gaps in the specific evidence shared across the profession to support, underpin, motivate and promote occupational therapy practice in this field'* (Goodman, et al 2009, p xi). The College of Occupational Therapists recommends that the emphasis should be on using research-based and peer reviewed evidence and cautioned against a wider view of evidence of practice: *'whilst these can provide valuable perspectives and examples of practice, they are not usually research-based and have not been peer reviewed. They cannot, therefore, be assumed to offer robust evidence and you would need to be very cautious about the context in which you use any information from these publications'* (COT 2015b, p4).

The lack of published research evidence regarding occupational therapy practice with adults with learning disabilities is also reflected in nursing. Griffiths et al (2007) carried out a systematic review of published papers and concluded that many of the studies were also small in scale and: *'the extent of learning disability nursing research is limited in quantity and its ability to provide reliable, generalisable or trustworthy insights'* (Griffiths et al 2007, p ii). The authors suggested that this may be useful to guide practice but was not considered robust research evidence.

All the research articles reviewed which focused on occupational therapy practice with adults with learning disabilities recommend that more robust research is required but the lack of studies may indicate that methods of evaluating and presenting practice with people with learning disabilities may not be compatible with the expectations of peer-reviewed journals. Practice that is relevant to people with learning disabilities may not be of a nature that can be measured effectively or ethically within the rigour of scientific enquiry. The literature review identified a limited number of research studies that identified the effectiveness of occupational therapy intervention and many of these had a narrow focus. Further exploration of how to gather evidence of effectiveness of occupational therapy practice encompassing the person-centred, holistic and individual nature of intervention appears to be needed and is a gap within the literature.

2.4.3 Standardised occupational therapy assessments that meet the needs of adults with learning disabilities

The concerns of the local occupational therapists regarding the assessment processes they were using in relation to the practice principles established by the College of Occupational Therapists (COT 2003 and 2013a) are outlined in Chapter one. The literature on occupational therapy assessments for use with adults with learning disabilities was reviewed by the occupational therapists as part of the fieldwork for stage one of the research study. Therefore this part of the literature review is presented in Chapter four (see Sections 4.2 and 4.4).

The initial gap in the literature was the limited number of published occupational therapy assessment tools that could be used with adults with learning disabilities. The literature identified that, although the expectation of the professional body for occupational therapists was that standardised outcome measures should be used to demonstrate the effectiveness of a service, their use was limited in practice with adults with learning disabilities. Assessments often needed to be adapted so that they were accessible for adults with learning disabilities, could be understood and did not cause distress, but this affected the standardisation. There were also concerns that a standardised measure is unlikely to encompass the holistic nature of occupational therapy intervention. Therefore, how occupational therapists should best carry out their assessments of adults with learning disabilities was identified as a gap in the literature. There were also no studies that included the perception of adults with learning disabilities, their carers and other stakeholders of the occupational therapy assessments.

2.4.4 The impact of service expectations on the quality of the interventions of occupational therapists

A briefing paper endorsed by the professional bodies of the main professions who work with adults with learning disabilities, including the COT, set out recommendations for community services for adults with learning disabilities in the United Kingdom. The paper promoted the on-going need for multi-agency community learning disability teams across health and social care. Although services may be from various agencies, it emphasised the need to provide seamless joined up services to the people with learning disabilities and their carers. The reports recommended that *'Person-Centred Practice and individual service design*

should be at the heart of the commissioned and provided specialist community learning disability health team practice' (National Learning Disability Professional Senate 2015, p7). Demonstration of the effectiveness of community learning disability teams for individuals with learning disabilities and their families was recommended. However, professionals, including occupational therapists, were challenged: '*to be tolerant, gentle, patient, empathetic, mature and respectful, and must be open to intense analysis of how their actions or the situations they operate in may be the 'problem' that needs addressing rather than adopting a traditional treatment model'* (National Learning Disability Professional Senate 2015, p20). The briefing paper recommended that practitioners need to be critically reflective and have on-going personal contact with people with learning disabilities to ensure that their practice follows an inclusion agenda rather than making outdated assumptions.

In this research study, the local occupational therapists were practising within a context of continual development and change. McSherry and Warr (2006) proposed that modernisation of healthcare have many complex drivers which include health policy, increased patient expectations and changes in society. Practice development supports the modernisation by ensuring continual quality improvement across the whole multi-disciplinary health system. McSherry and Warr (2008) state that excellence in practice is the role and responsibility of all. However *'excellence is an ever-changing and a very nebulous concept to define and articulate making it perhaps never achievable because it is always changing'* (McSherry and Warr 2008, p28). Person-centred care needs to be the focus of practice development. It also includes collaborative partnership working and an understanding of organisational and professional cultures. However, working across multiple agencies *'provides a challenge to ensure that changes occurring as a direct result of modernisation maintain equity, equality, efficiency and effectiveness of services'* (McSherry and Warr 2006, p59).

This research study explored how the local occupational therapists based in the United Kingdom developed their practice, whilst undergoing service changes and meeting the expectations of new policies and processes. An example of this was that during the action research fieldwork, the local occupational therapists were expected to meet the service expectation to implement the 'referral to treatment times' (RTT) framework following guidance that was published in March 2010 (DH 2010). The allied health professional (AHP) RTT guide is a framework for measuring waiting times for patients accessing National Health Services including occupational

therapy. This was '*aimed at improving patients' experiences of NHS AHP services, ensuring they receive high quality care, in the right place, and reducing the time they wait for treatment'* (Transforming Community Services DH 2010, p5) (see Section 7.2). A study by Pawson et al (2016) into how the similar expectation of waiting list management by GPs in the NHS in England suggested that the *'literature is replete with accounts of unanticipated problems and unintended effects'* (Pawson et al 2016, pv). Pawson et al (2016) state that managing referrals to services '*depends on synchronising a complex array of strategic, organisational, procedural and motivational changes'* (Pawson et al 2016, pvi) which results in four areas of potential conflicts of interests:

- Referrers can have different motivations;
- There is a need to reduce costs but also to provide a person-centred service;
- The people involved in the referral chain have different levels of expertise and remits;
- A fair and equitable service needs to be provided but there is an increased awareness of the various options and the expectations of choice

Pawson et al (2016) commented that there was an increase in demand for health services due to members of the general public being well-informed of health interventions and their expectation to be offered a choice. There were no studies on how occupational therapy services working with adults with learning disabilities were managing the RTT AHP targets and if their experiences were similar to the findings of Pawson et al (2016).

The local occupational therapists needed to demonstrate to their employing organisation that they were meeting policy and service expectations and that the service they provided to people with learning disabilities was effective. However, they also needed to consider the recommendation from the COT review of learning disability services that '*occupational therapists must have a vision that enables them to anticipate developments and to lead on such developments rather than follow policy demands'* (Lillywhite and Haines 2010, pvii). Kinsella and Whiteford (2009) suggested if service expectations are different from the values of the occupational therapists, they find subtle ways to maintain their professional autonomy without direct confrontation and so service policies are either accommodated into occupational therapy practice or actively resisted. Kinsella and Whiteford (2009) recommend that occupational therapists need *to 'engage critically with social trends, prevailing discourses and political ideologies'* so that they can share their practices within these contexts and contribute to the knowledge base of occupational therapy.

A significant gap in the literature was the lack of studies that had explored how organisational expectations and demands, such as the need to meet waiting list targets, affect the quality of occupational therapy in learning disability services and the perceptions of adults with learning disabilities and carers in regard to any changes imposed.

2.5. Occupational therapy practice knowledge

Section 2.4.2 highlighted that, although the expectations of the occupational therapy professional body (COT) were that practice should be based on peer reviewed published research, the evidence in relation to occupational therapists working with adults with learning disabilities was limited and did not necessarily encapsulate their holistic practice. Taylor (2007) recommends the use of a wider perspective regarding evidence–based occupational therapy practice that involves *'using the breadth of potential sources of evidence conscientiously, judiciously, explicitly and critically, within a framework of reflection and critical reasoning'* (Taylor 2007, p4). She suggests that evidence-based practice, occupational therapy and research processes are similar in that they all start with a problem, make a plan, carry this out and evaluate the outcome.

Upton et al (2014) carried out a systematic review of published research on the attitudes of occupational therapists to evidence based practice (EBP) and highlighted that, although occupational therapists were generally motivated to use evidence, there were barriers that prevented them from doing so such as: lack of time, little support from the service they worked in and their perceived need for more training to be able to do this. Recently graduated occupational therapists were found to be more likely to use evidence based practice than those who had been working for more than five years. *'Therapists raised concerns regarding the relevance and applicability of research evidence to clinical practice problems'* (Upton et al 2014, p32). It was found that many occupational therapists relied on their own personal experience to make decisions. In two studies it was reported that: *'worryingly…despite positive attitudes towards EBP, therapists continually relied on colleagues as a source of clinical decision making'* (Upton et al 2014, p34). This appeared to suggest that, in a similar way to Goodman et al (2009) (see Section 2.4.2), information that was found through external research was valued above

occupational therapy practice expertise that appeared to be dismissed as invalid. In contrast, Morrison and Robertson (2015) used an action research methodology to consider the experiences of evidence-based practice of new occupational therapy graduates in New Zealand. This was a small scale study of five participants who worked in different settings and had four monthly on-line collaborations. They started their study by exploring how externally produced findings could be incorporated into practice but identified that '*senior therapists' knowledge was identified as the most useful form of evidence'* (Morrison and Robertson, 2015, p4) to support their practice. Samuelsson and Wressle (2015) reported similar challenges for occupational therapists in applying evidence based practice to those found in the study by Upton et al (2014) such as: not having the time or knowledge to access and apply research as well as noting evidence does not exist for many aspects. Hitch et al (2014) stated that *'the exclusive use of scientific knowledge is an inaccurate reflection of the everyday experiences of health providers'* (Hitch et al 2014, p593).

The expectation to use evidence based practice was not always compatible with the need to provide real world person-centred practice. Creek's (2003) description of occupational therapy as a 'complex intervention' reflects the need for occupational therapists to be able to make observations and take into account the perceptions of the various people involved. As person centred practice '*requires balancing professional knowledge and client needs'* (Samuelsson and Wressle 2015, p175) occupational therapists use their expertise to decide if the external evidence is appropriate to be used. Reagon, et al (2010) proposed in an opinion piece that evidence based practice is important but that this should not just rely on formal research but should include accounts from expert occupational therapists, case studies, outcomes of interventions, reflection on practice, and training courses. Occupational therapists should use evidence as it is relevant to each individual clinical situation in order to manage the complexity and uncertainty of practice as *'client centred practice embraces both the uncertainty and unpredictability of health care as it makes genuine attempts to empower individuals'* (Reagon et al 2010, p285).

Services based on philosophies such as humanistic, normalization and social models of disability and emphasising a person-centred focus on occupation do not fit in easily with the systematic review of evidence and traditional evidence gathering models. Turner and Knight (2015) completed a systematic review of published

articles on occupational therapy professional identity and reported that some therapists had difficulty describing what they do and justifying their interventions within multi-disciplinary teams. They noted a tension between the medical model and occupational therapy. Blair and Robertson (2005) suggested that ways of generating knowledge about occupational therapy practice need to be consistent with the profession's traditions and ontological assumptions. They suggest that *'occupational therapy lies on a medical/social fault line and, as such, is theoretically eclectic and epistemologically pluralistic'* (Blair and Robertson 2005, p275). Therefore, a reliance on hard evidence and clear procedures to justify practice cannot give a full understanding of occupation focused person-centred practice.

A driver for this research study was that the lead researcher and the local occupational therapists were confident in their practice but had difficulty justifying what they did against the standards they perceived to be set by their professional body. As discussed in Section 2.2, Schön (1991) rejected the model of technical rationality as it could not explain how practitioners are able to manage the *'relationship between the kinds of knowledge honoured in academia and the kind of competence valued in professional practice'* (Schön 1991, p vii). However, some of the radical criticism of the professions appeared to reject *'the legitimate parts of the professional's claims to extraordinary knowledge'* (Schön 1991, p295). Instead Schön proposed that there is an epistemology of practice based on the idea of reflection-in-action which links problem solving and reflective inquiry. Situations in practice are often characterised by '*uncertainty, uniqueness, and value conflict'* (Schön 1991, p49). His assumptions were that *'competent practitioners know more than they can say'* (Schön 1991, pviii) as they use practical competence and professional artistry to manage these situations. This includes the use of tacit and intuitive knowledge which they reflect on during and after their decision making process. Schön (1991) considered that professional knowledge is *'inherently unstable'* (Schön 1991, p15) as it changes to keep up with demands of new practice knowledge and theory and constant learning from each unique encounter. He proposed that this knowledge needed to be demystified and opened up to inquiry by practitioners using *'critical self-reflection'* (Schön 1991, p290). He rejected the traditional view that knowledge is always generated by external researchers and applied to practice and instead proposed that *'practitioners may become reflective researchers in situations of uncertainty, instability, uniqueness and conflict'*(Schön 1991, p308). Research is carried out by professionals where theories are tested and actions applied immediately to their practice. Reflective practice takes into account

the need for professional accountability and client rights *'although the reflective practitioner should be credentialed and technically competent, his claims to authority is substantially based on his ability to manifest his special knowledge in his interactions with his client'* (Schön 1991, p296).

A study by Bezzant (2008) considered how nurses developed their practice skills working with people with delirium and dementia. Bezzant (2008) proposed that '"*informal" practice-based experiential knowledge that allows practitioners to place the learning into the context of their personal values and beliefs, effecting changes in behaviour to accompany the learning'* (Bezzant 2008, p143) is more effective than formal teaching. Rather than experts providing technical knowledge, practitioners need to develop ownership and internalisation of the learning. This *'emancipatory approach considers practitioners as partners, sharing responsibility for learning; working towards enlightenment'* (Bezzant 2008, p144). Bezzant (2008) suggests flexible approaches focusing on specific work place cultures and reflecting on experiences can sustain long-term change. McSherry and Kell (2007) suggested that practice development is used to generate *'evidence from practice in order to inform innovation and change'* (McSherry and Warr 2008, p9). It occurs in the practitioners' own setting as they strive to improve standards and quality to meet client needs.

Blair and Robertson (2005) recommended adopting Schön's (1991) epistemology of practice as a means of inquiry as it is compatible with the occupational therapy values of person-centred empowerment and enablement. They described the epistemology as '*the idea of practice that is based upon reflexivity, collaboration and the pursuit of social transformation'* (Blair and Robertson 2005, p270). Occupational therapists need to seek to understand how they are integrating theory and experience in their practice and reflect on this, so that they can learn from this process. '*This emphasises reasoning and judgement and seeks to enhance practice by greater introspection and thoughtfulness about individual problem posing and problem solving' (*Blair and Robertson 2005, p270). Reflective practice is therefore used to address the rigour and relevance of occupational therapy practice and to generate knowledge.

Higgs and Titchen (2001) also built on the theories of Schön (1991) and acknowledged that health practice by nature is uncertain due to human context and on- going changes. They stated that knowledge and practice are interdependent as

'knowledge arises from and within practice, and practice is the purpose of professional knowledge' (Higgs and Titchen 2001, p526). Practice knowledge according to Higgs and Titchen (2001) is made up of propositional knowledge generated from research and theory, professional craft knowledge (similar to Schön's (1991) professional artistry) arising from practice experience and personal knowledge generated from the person's own experience. They suggested that practitioners use their professional craft and personal knowledge to *'tailor their propositional/scientific knowledge to the specifics of the particular client and the particular context. This capacity is facilitated by metacognitive and deliberative reflective processes'* (Higgs and Titchen 2001, p528). Similarly to Blair and Robertson (2005), Higgs and Titchen emphasise that occupational therapists need to think about the thought process they used during therapeutic interactions and reflect on these in order to evaluate their practice and create practice-based knowledge. They assert that professionals need to be accountable for their practice and critically review and share the knowledge they develop from doing this. However, it was acknowledged that *'the transformation of implicit or tacit practice knowledge into articulated or demonstrated professional craft knowledge and propositional knowledge is a major challenge' '*(Higgs and Titchen 2001, p530).

Titchen and Ersser (2001) assert that professional artistry or professional craft knowledge *'is derived not only through practice, but also through critical reflection, critique and debate'* (Titchen and Ersser 2001, p55). They state that practice based knowledge can be validated, using a critical social science tradition, by engaging in critical reflection and discussions with peers to seek consensus. This can then extend to colleagues in other organisations. In the local service, the occupational therapists engaged with other colleagues within the organisation and in local and national professional forums. An example of this process was the development of the original practice principles by the College of Occupational Therapists (COT 2003) (see Chapter one). This practice knowledge that can be developed from critically exploring knowledge from experiences in practice, theories or research evidence can then be applied to practice and evaluated via the same critical reflection process.

Kinsella and Whiteford (2009) reflected on how knowledge is generated in occupational therapy. They proposed that the development of occupational therapy theory is not neutral but *'complex and contextually bound'* (Kinsella and Whiteford 2009, p249) and stated that the dual relationship between theory and practice

needed to be recognised. They suggested that the emphasis on traditional forms of evidence implies that their experiential knowledge, which has most influence on their practice, is less valid and suggested that this can result in a difference between what occupational therapists do in practice and what they report. They suggest that this results in 'hidden' practices as the occupational therapists are not able to match the expectations of this traditional evidence base with the realities of their practice. Kinsella and Whiteford (2009) emphasised the need for occupational therapists to be able to act autonomously and with integrity by reconceptualising practice knowledge to include traditional evidence but also multiple perspectives, professional reasoning, synthesis of evidence from different sources and experience. This should be applied to specific individuals to meet their identified needs as part of reflective practice.

2.5.1 Professional reasoning

There has been an increasing number of studies regarding the concept of occupational therapists' professional reasoning skills which describe the thinking processes of planning, implementing and reflecting on practice which *'tend to remain unseen and are rarely articulated'* (Turner and Alsop 2015, p741). A recent systematic review of literature on professional reasoning in occupational therapy states that occupational therapists have a *'strong, often tacit, yet consistent approach to the delivery of services which is guided by a shared philosophy, enabled by supporting theories, and put into practice every day through the way we think'* (Unsworth and Baker 2016, p5). Hitch et al (2014) stated that occupational therapists need to have a wider view of how theory and evidence integrate into practice and that sources of evidence should include other aspects of practice such as ethical behaviour and professional judgement. Samuelsson and Wressle (2015) acknowledged that evidence for occupational therapy practice includes research findings but can also include '*clients' self-reports and subjective outcome measures, which corresponds with occupational therapists' conception of clinical reasoning as a complex process that takes multiple factors into account'* (Samuelsson and Wressle 2015, p175).

Boyt Schell and Schell (2008) built on Schön's (1991) concept of professional artistry in reflective practice to consider the development of professional reasoning in occupational therapy. They suggested that professional reasoning is a high level

of skill that is developed from experience and critical reflection. The skills required include an understanding of the client, person-centred values, skills learnt from experiences in practice and being able to use creative imaginative approaches to address unique problems. They suggest that *'both the practice context in which care occurs and the therapist's own skills set are factors that therapists reason about when deciding on what care to actually provide'* (Boyt Schell and Schell 2008, pxv). Although some guidance on how to practice is available they argued that occupational therapists need to make multiple decisions based on the individual encounter with the person they are working with. They base their understanding on the work by Schön (1991), which he referred to as reflection-in action, in that professionals usually need to act immediately without time for extensive reflection. Boyt Schell and Schell (2008) suggest that occupational therapists' practice decisions can be guided by scientific or technical information *'but much of practice requires a multitude of nuanced decisions and actions'* (Boyt Schell and Schell 2008 p6) rather than specific guidance or processes. Professional reasoning is used to decide what and how it can be applied to practice.

Dreyfus (2004) described a five stage model of adult skills acquisition that progresses from novice, advanced beginner, competent, proficient to expert. The novice stage relies on rules, that can be followed exactly, but experts have built up experience which results in their ability to make an *'immediate intuitive situational response'* (Dreyfus 2004, p180). Therefore, occupational therapy 'e*xperts are more intuitive and take reflexive actions based on past practice and greater understanding of the situation'* (Boyt Schell and Schell 2008, p10). This model implies that the linear application of a piece of evidence or a standardised assessment to practice without adapting it or questioning the findings is the level of a novice. Reasoning about how the assessment findings or evidence contributed, or not, to the unique practice situation by considering the subtleties of the nuanced responses is the higher level thinking processes of the expert. As has been discussed in Section 2.4 many of the studies on why occupational therapists do not use evidence based practice tended to be dismissive of more experienced staff or people who rely on colleagues and peers for knowledge. It could be argued that some of these experienced occupational therapists are carrying out intuitive, expert practice but may not be able to articulate this in a way that can be understood in the narrow parameters of traditional evidence based practice. As professional reasoning uses intuitive processes *'much of the current research is inadequate to completely comprehend the complexities of reasoning that occur in the real-life context of*

professional practice' (Boyt Schell and Schell 2008, p6). Boyt Schell and Schell (2008) identified different aspects of professional reasoning from their own and other studies (see Table 2.2) to support occupational therapists in identifying and articulating their reasoning processes in practice. They suggested that occupational therapists may use any of the following eight aspects of reasoning: scientific, diagnostic, procedural, narrative, pragmatic, ethical, interactive and conditional; or a combination of them.

Table 2.2: Different aspects of reasoning in occupational therapy summarised from Boyt Schell and Schell 2008, p7

Aspect of reasoning	Description and focus
Scientific reasoning	Applied logical and scientific methods. Theory based decision making. Evidence.
Diagnostic reasoning	Cause and nature of conditions.
Procedural reasoning	Intervention routines for identified conditions- science based or local habits/culture
Narrative reasoning	Make sense of occupational performance on daily lives in specific circumstance.
Pragmatic reasoning	Practical reasoning- therapy needs vs realities and resources available.
Ethical reasoning	Analysing an ethical dilemma, systematic approach to moral conflict
Interactive reasoning	Collaborative problem solving with client
Conditional reasoning	Blending of all for purposes of flexibility, responding to changing conditions, predicting client future.

Boyt Schell and Schell (2008) stated that the occupational therapy profession '*now feels very comfortable in viewing professional reasoning and reflection as a means of excavating, examining and passing on theories in use'* (Boyt Schell and Schell 2008, p414). They proposed that research to understand professional reasoning requires longitudinal studies to consider changes over time and to link what therapists were thinking with their actions.

Morley (2007) explored the experiences of recently qualified occupational therapists and how they needed critical appraisal from more experienced colleagues and facilitated reflective practice to develop professional reasoning skills, *'personal autonomy and professional development'* (Morley 2007, p332). A study by Dougherty et al (2016) explored the perspectives of six occupational therapists working with children based in schools. The findings were that evidence is defined

differently from the perspective of research and of practice. The occupational therapists' perceptions were that there are two major categories of evidence:

- Internalised, in which external evidence is synthesised using a personal knowledge base built up from professional experience and expertise;
- Evidence gathered for the specific intervention which includes multiple observations, verbal and written reports from the client and all involved.

Professional reasoning was reported to occur in practice and was perceived to be unique to each therapist who had developed this knowledge over time. The occupational therapists were continually gathering and synthesising information and testing the effectiveness of their interventions with clients throughout their practice. They concluded that '*the emphasis on research influencing practice has created a de facto dearth of evidence-based practice knowledge about the use of therapists' expertise and about how the nature of evidence in practice might inform research'* (Dougherty et al 2016, p288). They recommended that further investigation of evidence building in practice is required to *'reconceptualise practice base evidence recognising client, therapist and research evidence as equally important'* (Dougherty et al 2016, p294).

Practice based evidence can be understood as a combination of external evidence, professional reasoning and reflection in action. However, it has been acknowledged that there are challenges in finding evidence for client centred, intuitive reflective occupational therapy practice.

2.6 Summary

This chapter has reviewed the literature related to the practice of occupational therapy with adults with learning disabilities in a community setting. Four of the key areas for research recommended by the COT review (Lillywhite and Haines 2010) were explored in this chapter and identified as having significant gaps in the literature. The four areas (Table 2.1) were: the need to gather evidence of occupational therapy practice from the perspective of adults with learning disabilities, carers and other key stakeholders; the effectiveness of occupational therapy interventions; assessments that are appropriate for adults with learning disabilities; and the impact of service expectations on the quality of occupational therapy interventions. These areas were all related to the thematic concern, identified by the local occupational therapists at the start of this research study,

which was introduced in Chapter one (Section 1.7). The thematic concern which underpinned this study was the quest of the local occupational therapists to seek and generate evidence on which to evaluate and improve their local practice with adults with learning disabilities.

The research question for this study arose from the thematic concern and was as follows:
what is the evidence that the local community occupational therapy service for adults with learning disabilities is:

(i) meeting the needs of adults with learning disabilities;
(ii) achieving the service objectives of the employer; and
(iii) meeting the expectations of the professional body (the College of Occupational Therapists) for evidence-based practice in line with the core principles for occupational therapists working with people with learning disabilities (COT 2003 and 2013a).

The expectation from the professional body appeared to be that occupational therapists should be basing their practice on 'evidence' that had been obtained through research that was traditionally seen as separate from actual practice to demonstrate rigour and justify their actions. However, the limited literature regarding the practice of occupational therapy with people with learning disabilities living in the community often had a narrow focus that did not reflect holistic occupational therapy practice. Occupational therapy practice based knowledge is developed from professional experience, reasoning and reflection. However, as much of real life occupational therapy practice uses hidden or intuitive processes it is difficult for these to be shared and presented within current research studies and this is seen as a challenge but a gap in the literature.

Several gaps were identified in the literature on occupational therapy with adults who have learning disabilities which the research study aimed to address:

- Obtaining the perceptions of adults with learning disabilities, who have experienced occupational therapy was identified as a gap in the literature. Only one study (Melton 1998) used qualitative methods to explore the views of people with learning disabilities in relation to the relevance of occupational therapy to their lives (Section 2.4.1).

- Historically, people with learning disabilities were regarded as lacking the ability to participate in research and were often excluded. More recent occupational therapy studies have highlighted the importance of involving people with learning disabilities in research and have valued their contribution. However, none of the studies asked people with learning disabilities specifically about their experience of occupational therapy (Sections 2.4.1 and 2.4.2).

- The perceptions of the carers of people with learning disabilities and other stakeholders of occupational therapy practice are also important but their views continue to be missing from most studies (Section 2.4.1).

- Many of the studies focused on a narrow aspect of practice which did not reflect the wider holistic nature of occupational therapy or the conceptual model of practice used (Sections 2.3 and 2.4.2).

- Practice that is relevant to people with learning disabilities can be difficult to measure effectively, or ethically, within the rigour of scientific enquiry. Further exploration is needed on methods of gathering evidence of the effectiveness of occupational therapy which encompass the person-centred, holistic and individual nature of intervention (Section 2.4.2).

- There were limited studies on occupational therapy assessment tools that can be used with adults with learning disabilities (Section 2.4.3).

- There were no studies identified on how the need to meet service expectations, such as meeting waiting list targets, impacted on the quality of occupational therapy services for adults with learning disabilities (Section 2.4.4).

- There is a limited body of evidence on occupational therapy practice based knowledge and how this develops for all client groups and more specifically when working with adults with learning disabilities. Occupational therapy practice knowledge needs to include professional reasoning, multiple perspectives, evidence from experience as well as traditional evidence (Section 2.5).

- Boyt Schell and Schell (2008) proposed that research to understand professional reasoning requires longitudinal studies to consider changes over time and to link what therapists were thinking with their actions. The views of the occupational therapists and their reflections on their practice provide an essential insight into how and why a service for people with learning disabilities develops (Section 2.5.1).

The overall purpose of this study was to evaluate the current occupational therapy practice conducted by a local community health team working with adults with learning disabilities and to further develop and improve practice based on the evidence generated. The action research objectives (Section 1.6) aimed to address the gaps identified in the literature review.

Action research was selected as the methodology for this study as it offered the flexibility required to evaluate practice from multiple perspectives. It also allowed for the demands, expectations and policies of the service (employer) to be taken into account. The details of the methodology are discussed in Chapter three.

Chapter three: Methodology of the inquiry

3.1 Introduction

The initial driver for this research study, described in Chapter one, was that the local occupational therapists were confident in their practice but were aware of the limited published evidence and standardised assessments available to justify their work. Schön (1991)described this experience in his examination of how a range of professionals in various fields continued to *'feel profoundly uneasy because they cannot say what they know how to do, cannot justify its quality or rigor'* (Schön 1991, p69). He rejected the positivist approach and model of technical rationality as this could not explain all of real world practice and instead proposed that professionals have tacit knowledge and patterns of actions that they have developed from their experiences. This professional knowing is reflection-in- action defined as when professional problem solving is linked with reflective inquiry. Schön (1991) proposed that professional practice is more than just applying theories and research findings and so his epistemology of practice involved reflective practitioners using their professional artistry as well as their technical knowledge. Reflection on this knowing in action can help to reveal how the practitioners apply their knowledge to make these reasoned actions. Based on Schön (1991)'s epistemology of reflective practice, it would be expected that occupational therapists make decisions and actions in their practice that are often unplanned, even when they are following research based theories or techniques. The methodology for this research study, therefore, needs to be flexible to allow the local occupational therapists to explore and develop their practice-based knowledge and artistry within the spontaneity and uncertainty of the local service context.

Action Research was selected as the methodology for this research study. It has been used in a variety of ways but usually incorporates a review of a situation to identify a concern; an attempt to change this by using a participatory and consensual approach to finding solutions, monitoring the action and gathering data to describe what has been learnt from the change process; and generating knowledge (Winter and Munn-Giddings 2001, McNiff and Whitehead 2011, Bellman 2003). Stringer (2007) described action research as *'a systematic approach to investigation that enables people to find effective solutions to problems they confront in their everyday lives'* (Stringer 2007, p1). Action researchers acknowledge that real

life is complicated and the expertise in solving problems is not found in centralised policies but in the action of those involved such as professionals, clients and families.

The methodology needed to be consistent with the occupational therapy core values and beliefs so that the outcomes would be more likely to be congruent with the professional experiences of the local occupational therapists. It was also important to choose a methodology that could be easily understood and perceived as relevant by the occupational therapists so that they would be motivated to participate in the inquiry and develop their practice. Occupational therapists' explicit critical value base is that people are healthy if they can do the things they need and want to do effectively and are satisfied with the balance of their occupations. Occupational therapists, therefore, work collaboratively with others to seek new improved ways of doing things. Action research, with its emphasis on starting at the problem within its context and working together to seek solutions was compatible with the views and understanding of the local occupational therapists as it had a similar approach to the occupational therapy intervention and process model (OTIPM) that they had adopted in their practice. (see Figure 2.1). The methodology needed to involve the local occupational therapists in a process of change and innovation within their work with adults with learning disabilities and sought to understand how they interact and respond to events. Action research could fulfil this as it '*is closely linked to practice and … can be undertaken by practitioners'* (Winter and Munn-Giddings 2001, p3).

Hart and Bond (1995) were among the first researchers to use action research in health and social care settings in the United Kingdom. They set out seven criteria of action research:

- Educative base
- Deals with individuals as members of social groups
- Problem-focused
- Involves a change intervention
- Aims at improvement and involvement
- Cyclical process which links research, action and evaluation
- Founded on a research relationship; involving participants in the change process.

Bellman (2003), like Hart and Bond, suggested that the action research process is educative, but also empowering for the practitioners. It is carried out with people not on people and so is interested in all participants' interpretations of events. It seeks reality but recognises that phenomena can be represented from different perspectives. As action research values multiple accounts, large quantities of data can be collected through both quantitative and qualitative methods. Quantitative research can be problematic as it can fail to take into account social concepts and contexts and, as has been explored in Chapter two, there are limitations in being able to measure the holistic and individualised nature of occupational therapy practice in this way. However, qualitative research can be perceived as lacking generalisability and validity due to the small samples used. Williamson (2012a) argues that action research may have features of qualitative and quantitative traditions but is different from other research paradigms as the researcher's aim is to collaborate with the participants in order to change an aspect of their situation. It is *'a process by which change is achieved and new knowledge about a situation is generated'* (Williamson 2012a, p7). This matches the intention of this study in that the researcher planned to work with the local occupational therapists as an equal partner to improve the local practice. As action research is collaborative, only the approach can be planned in advance, methods and strategies have to be developed in the field of practice. Identifying the problem, planning and evaluating are interlinked in a dynamic way and so findings are fed back to participants throughout the process to inform the decision making process for the next stage.

3.2 Action research in occupational therapy

Morton-Cooper (2000) Waterman et al (2001) and Hart and Bond (1995) have all stated that action research has been used in health care and is compatible with the person-centred approach and health philosophies. Health care action research *'can result in the initiation of change at the level of both individual professional practice and organisational structures and processes'* (Hart and Bond 1995, p4). This research methodology potentially has a useful role in achieving the goals of the NHS. The following benefits were envisaged: enabling innovation, improving healthcare, developing knowledge and understanding in practitioners and involving users and NHS staff. Coghlan and Casey (2001) suggested that the use of action research to improve practice was increasing in health services. Researchers who are also health care practitioners are *'already immersed in the organisation and*

have a pre-understanding from being an actor in the processes being studied' (Coghlan and Casey 2001, p674). This process can contribute to the generation of theory by utilising this professional knowledge to understand the reality of health service situations.

At the start of this research study there were only a few published articles describing occupational therapists undertaking action research. More recently, action research has been used in occupational therapy to consider how to increase the use of academic theory by practitioners (Welch and Dawson 2007, du Toit, et al 2010, Wilding 2011, Wilding et al 2012 and Reed and Hocking 2013). These studies aimed to address the theory-practice divide in various ways by increasing the practising occupational therapists' understanding of theory and supporting them to reflect on their new learning. For example, Wilding et al (2012) used academics to promote an educational foundation to foster professional confidence and scholarship with the practising occupational therapists; Reed and Hocking (2013) introduced a theoretical framework to the occupational therapists; Welch and Dawson (2007) surveyed occupational therapy staff about their skills in using evidence from research within their practice. All these studies focused on the occupational therapists and what they thought about using the new theories introduced to them from people who were external to their service or practice area and all reported positive benefits from the responses of the occupational therapists involved. However, Welch and Dawson (2007) acknowledged that *'introducing these initiatives created a sense of unrest in the service'* (Welch and Dawson 2007, p461) as the occupational therapists were challenged to change their practice. In all of these studies there was little consideration of what knowledge and theory could be gained by the occupational therapists' own practice but rather an assumption from the academics or policy providers that the practitioners' lack of theoretical knowledge needed to be addressed. Exceptions to these were the studies by Morrison and Robertson (2015), described in Section 2.5. that concluded that evidence from experienced practitioners was more useful than other forms of evidence-based practice and Morley (2007) that suggested that critical reflection supported by more senior colleagues enabled new practitioners to develop practice knowledge, described in Section 2.5.1. All the authors suggested that action research methodology did appear to be useful for occupational therapists to consider how theory and practice interrelate.

None of the studies cited started from investigating what was already happening in occupational therapy practice and how this was perceived by the occupational therapists themselves, the people they worked with and other stakeholders involved. Whalley Hammell (2011) suggests that occupational therapy theories are dominated by Western perspectives and that *'scientific and professional integrity requires theories to be informed by a diversity of perspectives'* (Whalley Hammell 2011, p32). The local occupational therapists in this research study work with people with learning disabilities in a multicultural area and need to ensure that the occupational therapy provided and the theory that may emerge from the inquiry allow for the client voice to be heard and multiple perspectives to be valued. This research study on occupational therapy practice development valued the experience of the local occupational therapists, as the experts in their own practice and sought to work in partnership with them to identify areas for change. Knowledge and theory would be developed from this process as practice based evidence.

3.3 The action research model selected for this research study

The plan for this research study was to identify the practice based knowledge that already existed in the local service and engage with the local occupational therapists as autonomous practitioners who were motivated to change and improve what they do. Practice was explored in collaboration with the occupational therapists by primarily using an inductive methodology to gather data so that theory can then be *'generated and built through analysis of, and interaction with, the empirical data'* (Grix 2004, p113). For this research study, the occupational therapists in the local service initially identified the thematic concern of the lack of evidence to support their practice. They took the responsibility to evaluate their practice as a group and then from multiple perspectives to consider if their practice was meeting the COT Practice Principles (COT 2003, see Table 1.1). This was completed in repeated cycles of planning, implementing actions, evaluating and critically reflecting on this process. The local occupational therapy practice context met the characteristics of the definition of action research agreed at the first symposium on action research held in Brisbane 1989 (Zuber-Skerritt and Fletcher 2007). These were that:

- The local occupational therapists developed their own practice, by interlinking their actions and reflections.

- Questions were raised by the local occupational therapists regarding their practice and data were gathered and analysed with them.
- The local occupational therapists participated in the decision making in a democratic way as autonomous and reflective practitioners.
- The local occupational therapists collaborated and were critically reflective within their team.
- The local occupational therapists were reflective practitioners as they learnt by this process of planning, doing and reflecting.

Many authors have described different action research typologies. Williamson (2012a) outlined major strands of action research but stated that these overlap with each other and are not clearly distinct. The strands included: '*human inquiry, cooperative inquiry and action science/inquiry which are concerned with 'human experience and engagement'* (Williamson 2012a, p15), and participatory action research which is community based where the researchers and participants are equal and work together to change their own lives. Carr and Kemmis (1986) proposed that there are three typologies: technical, practical and emancipatory. Hart and Bond (1995) developed an action research typology based on four broad traditions: the experimental approach which is a scientific approach to social problems; organisational productivity and quality; professionalising which is informed by professional practice; and the empowering approach which is *'an explicit anti-oppressive stance to working with vulnerable groups'* (Hart and Bond 1995, p 44). Carr and Kemmis (1986)' action research typologies include emancipatory which is equivalent to Hart and Bond's empowering typology. Hart and Bond's typology was developed to attempt to simplify the complexity of action research but the authors acknowledged that this was not able to encompass the full *'fluidity and dynamism of action research'* (Hart and Bond 1995, p 44). These typologies overlap in practice as the action research cycles evolve.

The dominant stance for this research study was envisaged to be professionalising as defined by Hart and Bond (1995) as the local occupational therapists were working together with the lead researcher to change their practice. However, it was important that people with learning disabilities would not be excluded from this research study as they were the essential reason for the local occupational therapy practice. Redmond (2005) and Gilbert (2004) both argue that adults with learning disabilities should be fully involved in research rather than just being participants. Kramer et al (2011) recruited people with learning disabilities as co-researchers who

took the lead in designing the study, gathering and analysing data. Gilbert (2004) reviewed the literature with *'the aim of demonstrating the richness, ingenuity and potential of research involving people with learning disabilities'* (Gilbert 2004, p299). However, he found that there were gaps in the literature particularly for people with severe learning disabilities and suggested that *'the challenges include: the attitudes of professionals, the diversity and complexity of lay groups, knowledge, power relationships, resources (both personal and financial), and values'* (Gilbert 2004, p298). He distinguished between 'participatory' research where people with learning disabilities participate with the support of people without learning disabilities, and 'emancipatory' research where people with learning disabilities were in control of the process that aimed for social change. Gilbert (2004) recommended that research with people with learning disabilities should aim to be emancipatory but suggested that '*participatory research can be viewed as a transitional phase towards emancipatory research'* (Gilbert 2004, p300).

In their practice, the local occupational therapists provide a short period of assessment and intervention for each individual person with learning disabilities with whom they work. Therefore, it would be unlikely that researchers with learning disabilities would choose to research occupational therapy in isolation as there would be other more long-term topics of interest that may affect their lives. This may be why the recent occupational therapy literature that explores views of people with learning disabilities was not focused on occupational therapy practice (see Section 2.4.2). However, obtaining the perceptions of people, who have experienced occupational therapy was identified as a gap in the literature and was considered essential by the local occupational therapists in order to be able to improve the service provided for this group. Gilbert (2004) suggested that people with learning disabilities should be seen as 'experts' who should be consulted about research that affects them as *'the involvement of people with learning disabilities in the research process strengthens the quality and relevance of the research'* (Gilbert 2004, p301). Therefore, although this research study only recruited the occupational therapy staff as co-researchers, people with learning disabilities were considered a crucial voice and so were recruited as participants for their expertise at key points in the action research fieldwork.

Williamson (2012a) suggests that action research is methodologically diverse but has often been linked to critical theorists who sought social change. Post-positivism or critical realism *'can be understood as a research paradigm placed between both*

positivism and interpretivism' (Grix 2004, p 84) in which the gap between the positivist's 'how' and the interpretivist's 'why' is bridged. Williamson (2012a) proposed that the action researcher needs to choose the strand of action research that meets the needs of the local setting. Grix (2004) outlined characteristics of critical realism which appeared to apply to this research study. These included the need to observe and understand but also to explain and interpret in order to have a fuller understanding of the occupational therapy practice. Chapter two has explored Schön (1991)'s epistemology of reflective practice and how services for adults with learning disabilities were influenced by the critical theorist who questioned the authority of professionals and normalisation which supported the rights of people with learning disabilities. Therefore, the action research model chosen for this study was one that was influenced by the Frankfurt School of Critical Theory and other philosophies with its focus on participation, empowerment and change and the understanding that there are multiple ways of knowing.

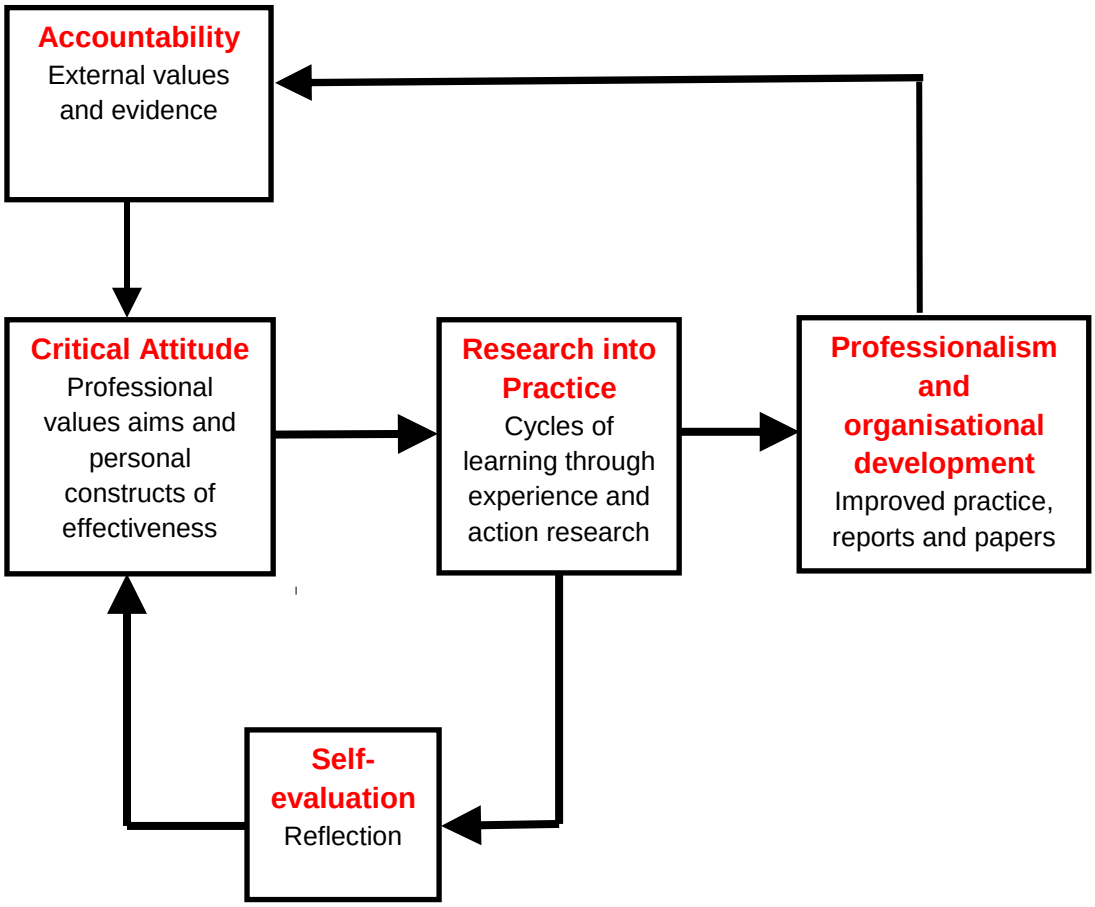
The action research model for this research study was based on the CRASP model of action research (Zuber-Skerrit's 1996) as it was developed for professionals who were working towards making organisational change and so was compatible with the professionalising and participatory typology. The CRASP model is a '*collaborative, critical and self-critical inquiry by practitioners….into a major problem or issue of concern in their own service'* (Zuber-Skerritt 1996, p 84). The title of the model uses the first letters of the five key distinct parts of organisational change which are:

> *'**C**ritical (and self-critical) collaborative enquiry by*
> ***R**eflective practitioners being*
> ***A**ccountable and making the results of their enquiry public*
> ***S**elf–evaluating their practice and engaged in*
> ***P**articipatory problem-solving and continuing professional development'*
> (Zuber-Skerritt 1996, p85).

The model starts from the assumption that professionals are autonomous and so, when practising within an organisation or system, they need to review any policy, theory, evidence or other expectation in relation to their own professional values and constructs of effectiveness. This requires both individual and collaborative reflection to consider how practice can develop taking into account the service demands. Action research contributes to knowledge about practice and theory. *'Knowledge in practice relates to practitioners improvement and transformation of their workforce practices into ones that are new, unique and different from past practices in the*

particular system' (Zuber-Skerritt and Fletcher 2007 p419). The theoretical knowledge is developed by critical and self-critical reflection of the whole action research process. See Figure 3.1 for a representation of the CRASP model.

Figure 3.1: The CRASP model of action research for management and organisation development (Zuber-Skerritt 1996, p86)



The CRASP model (Zuber-Skerritt 1996) was developed from action research studies involving educationalists and managers working to change their organisation systems and contribute towards their professional development. The model acknowledged that the action researchers needed to be accountable to agencies external to their local team, for example: they needed to ensure that they were complying with national and organisation policies. The CRASP model was adopted for this research study as it appeared to be able to take into account the multiple factors that were considered to influence occupational therapy practice as represented in Figure 1.1.

Zuber-Skerritt (1996) suggested that, in order to change practice, professionals need to critically reflect on their values and how they perceive their effectiveness. This is achieved through cycles of learning in action research which include self-reflection and invited criticism from stakeholders. The result of the action research is intended to develop the practitioners' critical attitude and to change their practice in response to this. The findings of the research are made public so that they can be used as a tool to influence developments in the practitioners' profession and organisation. There is an emphasis on revealing value systems, norms and conflicts which may be the underlying reason for the problem that is being researched. The model reflected the occupational therapists' experience that change in the health and social care setting in which they worked was *'evolving and on-going'* (Zuber-Skerritt 1996, p96). The action research was planned in line with this model to be in stages or spirals of: planning, observing, reflecting, and then revising the plan. The local occupational therapists needed to work collaboratively, develop a shared vision and be empowered and motivated to change.

3.4 The action research design and methods used in this study

Section 1.7 described how this research study consists of: the action research fieldwork and the action research thesis that are distinct parts but inter-related (see Figure 1.2). The action research fieldwork was completed in collaboration with the local occupational therapists and the action research thesis was completed by the lead researcher independently.

Action research, in contrast to traditional research does not have a rigid definition or concept as it is a *'flexible, pragmatic, approach to problem solving'* (Altrichter et al 2002, p126) that undergoes a process of redefining in each new context. The plan was for this to be an inductive study which explored the local occupational therapy practice and how this was perceived by others and so there needed to be flexibility so that the research process could adapt to explore the relevant concerns as the findings emerged. The principles of the CRASP (Zuber-Skerritt 1996) model were followed but were integrated with the existing organisational culture and suggestions and innovations were encouraged rather than being restricted by the planned methodology or agenda. The methods used in the research study evolved to meet

the emerging needs and findings, and the drivers for change developed over time. This open ended methodology could be described as *'untidy haphazard and experimental'* (McNiff and Whitehead 2011, p35) and during the action research fieldwork this was sometimes found to be the case. However, it was expected that reframing of the model would be required during the action research process by those involved who were *'from a position of being close to the issue'* (Coghlan and Brannick 2010, p61) but the overall purpose of the research study would remain constant throughout. This imprecision of the plan of action was consistent with an action research methodology. The CRASP model and the extent to which this study was framed within it are discussed in the summaries at the end of each stage of the action research fieldwork (see Sections 4.7, 6.5 and 8.9).

The action research fieldwork consisted of three stages which are summarised in Figure 3.2. The findings from each stage influenced the design of the next. Stage one is described in Chapter four, stage two in Chapters five and six, stage three in Chapters seven and eight. All the action research fieldwork activities are listed in chronological order in Appendix A. However, as the action research fieldwork continued over six years and generated a large amount of data, including twenty-two group meetings with the local occupational therapists as well as other activities, not all of this was possible to analyse and include in this thesis. Individual activities of the OT co-researchers and the lead researcher such as informal discussions or individual reflections could not be recorded. The action research thesis had a starting and finishing point but occupational therapy practice development was a continuous process that started before any of the existing occupational therapists were in post and continues beyond the end of this study.

The requirements of action research as recommended by Zuber-Skerritt and Fletcher (2007) (see Section 1.5) were that action research needs to be: practice orientated, participative, use multiple perspectives of knowing and seek to develop new knowledge in theory and practice. These requirements were used to develop, in collaboration with the OT co-researchers, the action research fieldwork objectives for this study. Each of the three stages of the action research fieldwork had its specific objectives relating to the overall purpose and objectives of the study. These are summarised in Table 3.1. The objectives of each stage of the fieldwork were developed to meet the overall purpose of this research study in collaboration with the OT co-researchers.

Figure 3.2: The stages of the action research fieldwork for this study and methods used for data generation

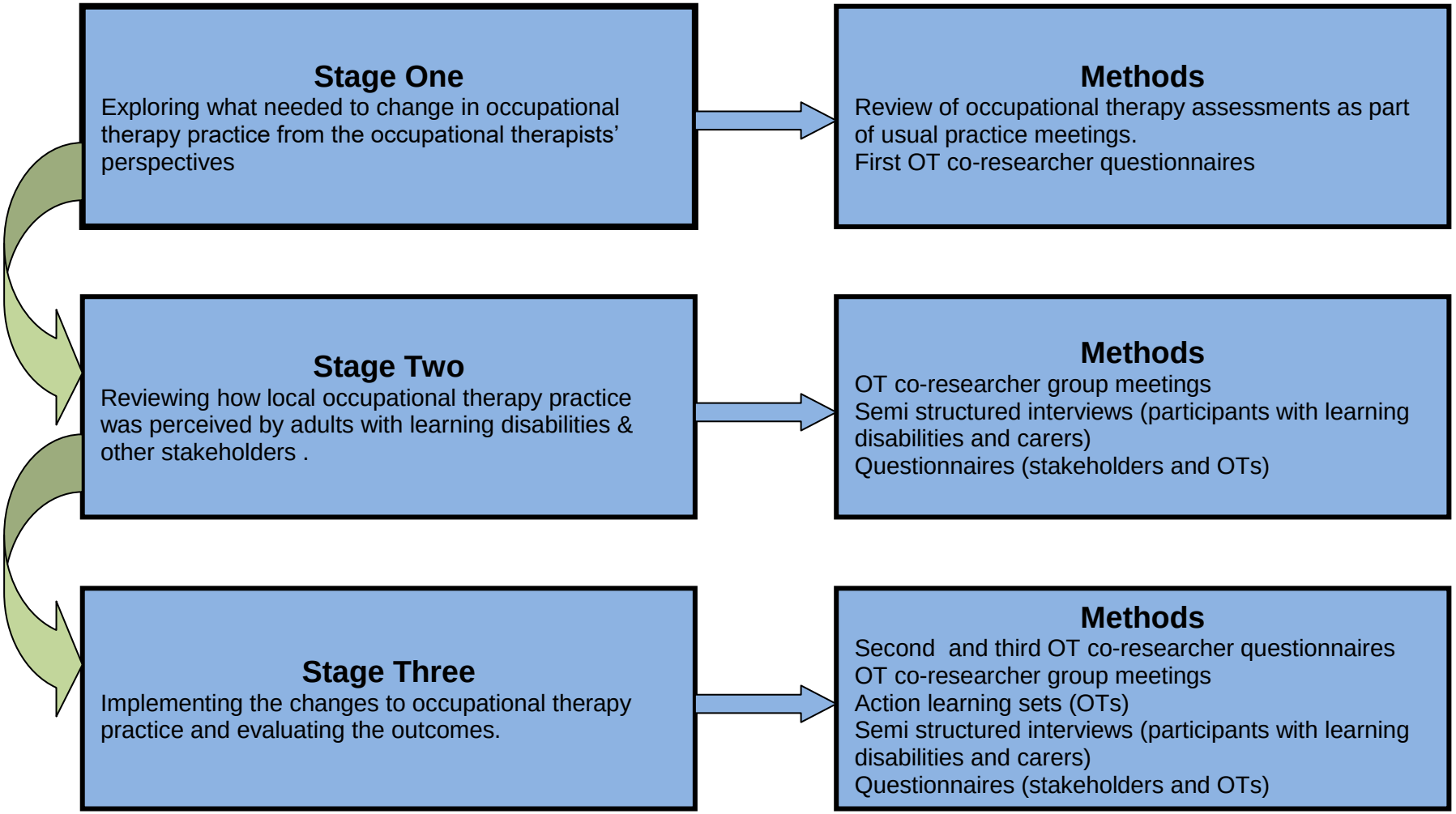


Table 3.1: Summary of purpose and objectives of the action research fieldwork

Overall purpose of the research study: To evaluate the current occupational therapy practice conducted by a local community health team working with adults with learning disabilities and to further develop and improve practice based on the evidence generated **(Practice orientated).**			
Overall objectives	**Stage one objectives**	**Stage two objectives**	**Stage three objectives**
To actively engage the local occupational therapists in the study, in partnership with the lead researcher, to find or generate evidence to support practice **(Participative).**	>To explore with the local occupational therapists any gaps or concerns that needed to be addressed by the research study. >To define what is required for an occupational therapy assessment tool for adults with learning disabilities.	>To engage the occupational therapists in the local team as co-researchers so that they can be agents of change of their own practice development.	>To continue to engage with the OT co-researchers as the agents of change of their own practice to identify key areas of concern and how to address these. >To implement the changes to the occupational therapy practice. >To evaluate how the changes were implemented.
To collect data on the perspectives and judgements of the occupational therapists, selected people with learning disabilities, their carers and others involved in their support network as well as relevant literature and policy. **(Using multiple perspectives of knowing).**	>To review the availability of published standardised assessments used by occupational therapists for this client group. >To consider if there are existing assessment tools that could meet the criteria identified as important in phase one.	>To explore the perceptions of a sample group of people with learning disabilities, their carers and other people involved regarding the occupational therapy assessments that had recently been undertaken.	>To explore the perceptions of a new sample group of people with learning disabilities, their carers and other people involved regarding the occupational therapy that they have received following the implementation of the changes in occupational therapy practice.
To seek to be creative and innovative in exploring what influenced occupational therapy practice development within the local context. **(New knowledge in theory and practice).**	>The occupational therapists to agree on an assessment tool that could be piloted in practice that could address the gaps or concerns and meet the requirements that emerged.	>To ascertain how the occupational therapy assessment process was perceived in order to identify any areas for improvement. >To explore any other themes that may have emerged regarding occupational therapy practice development.	>To explore how the OT co-researchers perceived their practice following the changes, in order to identify what went well and what still needed to change. >To explore any other themes that may have emerged from the data gathering process.

3.4.1 Reflexivity

The importance of reflexivity as a part of ensuring rigour and trustworthiness in qualitative research is widely acknowledged (Finlay, 1998; Finlay and Gough, 2003; Koch and Harrington, 1998). Reflexivity refers to a process of self-reflection to generate awareness of how the researcher's background, role, actions, feelings and perceptions influence the research process and its outcomes. Reflexivity throughout the research improves the transparency of the research process and the credibility of the findings (Darawsheh, 2014; Finlay and Ballinger, 2006). Through reflexivity the researcher acknowledges that they have an impact on the research setting and also that the setting has an impact on the researcher. This is of special importance in action research where the researcher and co-researchers are also participants in the study (Williamson *et al,* 2012).

Situating the researcher in this study is made explicit in Section 3.4.2 and the context of the study setting is Sections 1.3, 3.4.3 and the changing nature of the study setting is considered within each stage of the study and in the discussion chapter. Similarly the wider professional context within which the study is located is reflected upon in all chapters, particularly through the reporting of how this has influenced the direction and design of the research process and the feelings and perceptions of the researcher and co-researchers conducting the study.

An important method for promoting reflexivity in this study was the meetings of the co-researchers. These meetings provided opportunity to reveal, discuss and challenge pre-conceptions, assumptions and perspectives. Examples from these discussions appear in the findings of each stage of the research study and the reflection sections of the findings chapters (Sections 4.6, 6.4, 7.6, and 8.8) provide some detail about this reflexive process.

Winter (1996) set out six principles that are central to the action research process and have been adopted as a structure for enabling reflexivity within this research study:

1. **Reflexive critique** is a process of becoming aware of your own subjective biases and recognising that claims can be open to other interpretations. Section 3.4.2 describes the role of the lead researcher and how she kept reflective notes following meetings, interviews and supervision sessions throughout the research

study process. This provided an audit trail of changes in her understanding and perceptions that influenced changes in the research process and particularly the interpretation of the analysis of the data. Section 3.4.5.3 sets out the assumptions that the lead researcher made explicit assumptions that she made when interpreting the data acknowledging the influence of her own interpretative judgements on the analysis. The fieldwork supported the lead and co-researchers to question their expectations and their assumptions about their practice. In the report of each stage of the study expectations are made clear. The reflective sections in the findings chapters are used to reveal how practice was questioned and some interpretations and judgements were made and changed.

2. **Dialectic critique** is a process of understanding relationships between the phenomena in context. These relationships are interdependent but also diverse and so *'it is this instability which gives it an inherent tendency to change'* (Winter 1996 p 21). The discussions in the OT co-researcher groups included the parts of practice that all agreed to be their collective social reality or 'consensually validated' and also revealed where there were elements of practice where there were differences in views or which were less clear. These would often be a focus for change. An example of this was when the local occupational therapists were reviewing their assessment processes in Stage one (see Section 4.6).

3. **Collaboration**- The role of the local occupational therapists as co-researchers is described in Section 3.4.2. As co-researchers, all the views were of equal importance to contribute to understanding of occupational therapy practice. The extent of the engagement varied during the action research fieldwork. Therefore the insights gained from the different perspectives added to the credibility of the findings, rather than only revealing the views of the lead researcher. See Section 6.4.2 for one example of where this is recorded within the thesis.

4. **Risking disturbance**- The OT co-researchers and the lead researcher were undergoing a change process which was likely to question and disrupt the established ways of practising. The lead researcher needed to ensure that the OT co-researchers were aware that she was undertaking this same process and that it was anticipated that all would learn from this process. Chapter Seven describes how decisions on changes in practice were made and implemented. Section 7.6.1 outline some reflections of the lead researcher at this time,

Sections 8.7 and 8.8 outline some of the perceptions of the co-researchers when they reflected on how the changes had affected their practice.

5. **Creating plural structures**- The research study was developed to take into account the perceptions of all involved in the occupational therapy practice. The thematic concern (detailed in Section 1.7) in which the local occupational therapists were striving to address the needs of adults with learning disabilities, met the demands of their employer and the expectations of the COT meant that the research study had to encompass multiple interpretations and actions. The findings would need to explicitly address any contradictions and differing interpretations of occupational therapy practice from these plural structures. The local occupational therapy practice operates within a plural system of on-going demands and expectations that constantly change and challenge practice. Practice needs to be considered as part of the messy real world with on-going collaboration seeking multiple truths. Therefore, the findings have included details of the multiple accounts of occupational therapy practice which are followed by a discussion which contains an account of how the data were interpreted by the lead researcher. This level of detail has been retained to provide the reader with the opportunity to make other interpretations, acknowledging that there can be multiple versions of the same data (see Section 6.3, 8.4 and 8.5).

6. **Theory and practice internalised**- Winter (1996) stated that for action researchers theory is used to question practice but also practice questions theory. Theory and practice *'comprise mutually indispensable phases of a unified change process'* (Winter 1996 p25) He suggests people act on their personal assumptions and theories and then the results of what they did enhance their knowledge. There is a need to explicitly and continuously critically review and justify theory and practice and how they influence each other. This action research study initially commenced from the assumption that evidence based on standardised assessments should inform and develop local occupational therapy practice (see Section 1.6) but these assumptions were challenged and refined as the action research study progressed. These challenges and refinements continued beyond the end of this study.

3.4.2 The role of the lead researcher

The lead researcher was an occupational therapist who worked within the local team of occupational therapists prior to and throughout the action research study. Bellman (2012) states that: *'there is more likelihood of a successful outcome if the action researcher is an insider'* (Bellman 2012, p68). McNiff and Whitehead (2011) state that the action researcher is considered an agent of change who influences others and is also affected by the process. The lead researcher was *'not neutral but an active intervener making and helping things happen'* (Coghlan and Brannick 2010, p18). She had an understanding of the organisational culture, the nature of the work and the demands and challenges of the occupational therapy service. Access to client information and management support already existed due to the lead researcher's professional role and duties. However, her role as a clinical and research lead but not an operational manager provided some distance from the everyday work of the occupational therapists. This separation increased during the course of the action research fieldwork as the lead researcher became less involved in clinical work within the service and so this resulted in occasionally having a more outsider perspective.

It was an advantage in this research study that the lead researcher was close to the data and had knowledge and experience of the service. Changes such as: how the service was managed or the introduction of new policies would already be understood and so it was possible to adapt the study to take these circumstances into account. This would have been more complicated if the lead researcher was not part of the service as time would have been needed to brief the researcher and renegotiate the remit. Coghlan and Brannick (2010) highlighted that there could be challenges for insider researchers. Assumptions could be made by the lead researcher who may not have the objectivity of an outside researcher to ensure that the data had been fully considered. There may be occasions when disagreements were ignored due to role conflict or personal relationships. The purpose of the study was to develop occupational therapy practice but also for the lead researcher to complete a PhD thesis. These two purposes could have been in conflict and therefore in order to address these concerns, the lead researcher needed to be reflexive which is defined by Blair and Robertson (2005) as being self-aware of the potential issues regarding subjective claims to knowledge and power relationships and allowing these to be critically scrutinised. This was done by keeping notes when writing up meetings and interview transcripts and discussing any concerns

with her academic supervisors. It was important to ensure that the lead researcher actively listened to all the local occupational therapists and allowed the process to evolve. This involved reflecting with the local occupational therapists to check if they had reached a consensus regarding the identification of the problems and how these would be addressed. Coghlan and Brannick (2010) state that the lead researcher learns about her own professional role and work, by ensuring that her *'beliefs, values, assumptions, ways of thinking, strategies and behaviour and so on are afforded a central place of inquiry'* (Coghlan and Brannick 2010, p18). The lead researcher made notes of her own perceptions when writing up each OT co-researcher group and completed the OT co-researcher questionnaires to record her feelings about the action research fieldwork. Some of these are recorded at in the reflective sections at the end of each action research fieldwork stage (Sections 4. 6, 6.4.2 and 8.8).

The design of the action research fieldwork was led by the lead researcher with continuous input and consensus from the local occupational therapy staff group. Using the concept of emancipatory action research by Zuber-Skerritt (1996), the lead researcher collaborated with the local occupational therapists to improve their understanding of their work and empower them to transform their practice within the local context.

The action research thesis was completed independently by the lead researcher and consisted of four main phases as set out by Zuber-Skerritt and Fletcher (2007):

> *'Planning the thesis – (research and writing)*
> *Acting in the fieldwork*
> *Observing and evaluating the field work, and*
> *Reflecting on the results of the fieldwork in light of the literature and his/her theoretical framework leading to the thesis' argument and contribution to knowledge in the field'* (Zuber-Skerritt and Fletcher 2007, p422).

The writing process was considered to be a separate action research cycle in which a meta-analysis of all of the findings of the action research fieldwork was completed and is referred to in this study as the action research thesis.

Zuber-Skerritt and Fletcher (2007) stated that action research has an underlying phenomenological paradigm and so the assumption is that knowledge is created from experience and the person's perception of the meaning of this following

reflection. Theory is then derived from the triangulation of the data of the multiple perspectives of these experiences collected via various methods. *'The nature, behaviour and minds of human beings constitute a complex whole, which cannot be observed objectively or be understood accurately through a part, by outside researchers'* (Zuber-Skerritt and Fletcher 2007, p423). Winter (1996) states there can then be grounds to select an interpretation if several findings from different methods seem to converge. This process of investigation of professional experienced '*links practice and the analysis of practice into a single, continuously developing sequence'* (Winter 1996, p13). The lead researcher, as an insider researcher, was not a neutral observer but used reflexivity to interpret and construct knowledge from her perspective and practice experience. Throughout the process the lead researcher used an epistemological reflexivity, described by Gray (2014) as a consideration of assumptions, the nature of the knowledge and how the study could have been completed more effectively. There was also personal reflexivity in which the lead researcher reflected on how personal assumptions may have influenced the study and how the process impacted on the researcher's views (see reflective sections).

3.4.3 Engaging the local occupational therapists in the action research fieldwork.

During stage one of the action research fieldwork, the occupational therapists informally participated in the research as part of their regular staff meetings where they would come together and reflect on their work and develop their practice. From the start of stage two onwards, the occupational therapists were formally recruited as OT co-researchers to participate as the experts in how they completed their own practice. They were asked to work collaboratively to define the occupational therapy practice areas of concern and to implement any changes. See Appendix A for a full list of all the action research fieldwork which covered the time period April 2007 to June 2013.

In April 2010, at the end of stage one of the action research fieldwork, all the occupational therapists and occupational therapy support staff working in the local learning disability team were formally invited to take on the role of OT co-researchers to be actively involved in the research process rather than 'subjects' to be researched. They were given an information sheet and it was explained that they

were invited to sign up for the duration of the action research fieldwork but no end date was specified. All the members of the occupational therapy team agreed to take part and signed the consent forms (see Appendix D for copies of the forms). It was made clear in the information sheet that the OT co-researchers could leave the research study at any time and that if new occupational therapy staff were recruited, they would be invited to participate. The finding of Welch and Dawson (2007) that their action research study was found to have caused some disruption and uneasiness for the occupational therapists involved was taken into consideration for this study. The perceptions of the OT co-researchers were sought throughout the action research fieldwork so that the lead researcher could be made aware of any issues and adjust the research study as appropriate. The timing, frequency and agenda of the OT co-researcher meetings, for example, were negotiated by the lead researcher with the OT co-researchers so that they reflected their current needs and they were motivated to proceed. The OT co-researchers signed up for the full research study but were able to choose whether or not to attend individual meetings or complete surveys or questionnaires.

Table 3.2: Demographic details of the occupational therapy team in the local study at the end of stage one and beginning of stage three

	Stage One	**Stage Three**
Participants:	9 OT co-researchers 1 lead researcher:	7 OT co-researchers 1 lead researcher
Number of years since qualified:	2, 4, 11, 13, 14, 15, 19, 23, 31 (and 1 staff not qualified)	5, 14, 16, 17, 18, 22, 26,34
Where they trained:	8 UK, 2 outside of the UK	6 UK 2. outside of the UK
Number of years working in the service:	0, 2, 4, 4, 10, 10, 12, 18, 18, 22	5, 7, 7, 13, 13, 15, 21, 21
Staff grades (Agenda for Change):	3 band 8s 3 band 7s 3 band 6s 1 OT support staff	3 band 8s 3 band 7s 2 band 6s
Gender	9 female 1 male	7 female 1 male

All nine of the occupational therapy staff in post were recruited as OT co-researchers. This reduced to seven by the beginning of stage three as two staff left

the service and were not replaced. The lead researcher was included in the numbers as she was also a member of the occupational therapy team (see Table 3.2). The length of time the OT co-researchers had worked in the service ranged from one who had only been working for two months to one having worked for twenty-two years. Towards the end of the research study, the occupational therapy service merged with another Borough and the team of occupational therapists increased by three. However, as most of the action research field work had been completed by this time and that the only task left was to review and reflect on the process, the lead researcher in consultation with the OT co-researchers did not consider it would be appropriate to recruit these new occupational therapists to the study. The remaining seven OT co-researchers continued until the end of the action research fieldwork which was June 2013 (see appendix A for timeline).

3.4.4 Methods used to collect data

This research study was of a naturalistic design and data were collected in a variety ways from the action research fieldwork to develop an holistic understanding of the local occupational therapy practice. The three stages of the action research fieldwork and the methods for data collection used in each are summarised in Figure 3.2. An overall meta-analysis of all the data was completed by the lead researcher for the action research thesis. This continued as a constant series of cycles of reflecting on practice, identifying and asking questions, taking actions to seek the answers, collecting data, interpreting the data, reflecting on the emerging meaning, checking with the OT co-researchers and re-engaging with the literature throughout these stages and continued into the writing stages (see Figure 1.2).

3.4.4.1 OT co-researcher meetings

The main method used in the action research fieldwork was the lead researcher meetings with the local occupational therapists as a group for discussions and reflections leading to actions for change. These forums were where the decisions regarding the action research fieldwork were agreed, progress was reviewed and on-going reflection of practice took place. Blair and Robertson (2005) define reflective practice as the process of reflecting on how theory and experiences are integrated either during or after an event, The data collected for this study therefore, included the discussions of the local occupational therapists as they collectively critically reviewed their practice and how this related to the findings from the

fieldwork, service expectations and other evidence available to them. The occupational therapists shared their experiences and developed their understanding of their practice as part of this process. This was compatible with the action research working definition presented by Zuber-Skerritt and Fletcher (2007)

The lead researcher facilitated the group reflective discussions that were part of the usual service development meetings in stage one, and set up formally as OT co-researcher meetings in stages two and three. At the start of each meeting the lead researcher introduced the stage of the fieldwork and summarised the previously agreed key messages and actions. Within the meetings, the OT co-researchers were encouraged to be actively engaged in questioning and evaluation as they reflected on their practice and the findings of the research study as it progressed. The formal OT co-researcher meetings were recorded and transcribed by the lead researcher so that she was free to be a participating member of the group and so that the process could be further reflected upon and analysed. If all the views and decisions were made in the OT co-researcher group meetings, there was a concern that only the dominant views of the OT co-researchers may be shared and that other views could be suppressed. During the lead researcher's transcribing of the OT co-researcher meeting she was able to further review the level of engagement and collaboration of the OT co-researchers. If the lead researcher became aware that an OT co-researcher's view had not been considered by the group or that some members were quieter, she made a conscious effort to revisit these themes and to ask if there were other perspectives. At times, the sessions were split into smaller groupings so that members could reflect with fewer people as this may have been a preference for some of the OT co-researchers. However, it was not possible to record these small group conversations and so the lead researcher had to rely on brief summaries that were fed back when the smaller groups re-joined the wider meeting. In stage three, action learning sets were established in which the OT co-researchers met in two smaller groups depending upon the Borough in which they worked.

3.4.4.2 OT co-researcher questionnaires

Much of the action research fieldwork took place within the OT co-researcher group meetings, however questionnaires were also used to capture individual reflections from the OT co-researchers and the lead researcher as self-evaluation of practice was an important part of the CRASP model (see Figure 3.1). Questionnaires are not usually recommended in action research as a main data collection as '*they do not*

help to generate the forms of collaborative problem solving that action research requires' (Gray 2014 p340). However, a range of methods is required to gain an *'adequate picture of any human activity'* (Gillham 2000, p81). Questionnaires were, therefore, used in this research study as they were *'valid for discovering information that could not be ascertained in any other way, or for evaluating the effect of an action research intervention'* (Gray 2014, p340).

The OT co-researchers were invited to complete OT co-researcher questionnaires (see Appendix E) at the following points of the action research fieldwork:

End of stage one	April 2010
Start of stage three	June 2011
End of stage three	June 2013

The questionnaires were not used at the start of stage one as during this preliminary stage, the local occupational therapists had not yet been formally recruited to the study as co-researchers.

The aim of these questionnaires was to ensure that all the OT co-researchers' views could be taken into account so that people who preferred to reflect and write down their views rather than speak within a group could be 'heard'. This was an opportunity to consider all the OT co-researcher views without being influenced by what their colleagues may have already said. Gillham (2000) suggested some advantages of using questionnaires were that they could be completed in the person's own time with less likelihood of being influenced in their response than if the researcher was present. However, the disadvantages included a potentially low response rate, any misunderstandings could not be clarified, the researcher would not know why respondents selected a specific answer and the responses to open questions can be difficult to analyse.

The first OT co-researcher questionnaire was devised by the lead researcher with some closed questions to ascertain information about the OT co-researchers' qualifications and experiences (the responses are presented in Table 3.2). The rest of the questionnaire was semi-structured with more open questions to encourage views and opinions to be expressed. The purpose of the first questionnaire was to review if the proposed actions from stage one, phase two, still met the perceived needs of the local occupational therapists prior to the start of stage two. The questions were on the OT co-researchers' perceptions of what was important for an occupational therapy assessment and their expectations of participating in the action

research fieldwork. The second and third questionnaires were amended slightly to take into account the new direction of the research study, but as far as possible, the same questions were asked each time so that some comparison of responses could be made.

Due to the lead researcher's familiarity with the OT co-researchers, she was able to identify who had made which response. It was, therefore, made clear when the questionnaires were distributed that the lead researcher would know what each OT co-researcher had responded but that only an amalgamated version of the results would be shared with the OT co-researcher group. All the questionnaires were coded so that the name of the OT co-researcher was not entered. The completed questionnaires were stored securely by the lead researcher to maintain confidentiality. When the findings from the questionnaires were shared, the responses were not attributed to individual OT co-researchers as the questionnaires were designed to be for self-reflection and to capture any issues that OT co-researchers may not have been able to say in a group setting or directly to their colleagues. Ethical issues in relation to the collaboration with the OT co-researchers are explored in Section 3.6.

The lead researcher and the OT co-researchers' contributions were coded so that direct quotes could be attributed to them from stage two onwards so that the extent to which all the OT co-researchers actively participated could be considered.

3.4.4.3 Other data collection methods

During the three stages of the action research fieldwork, other specific methods of data collection were used including semi-structured interviews to gain the views of adults with learning disabilities and their carers and three different questionnaires to further understand the views of the local occupational therapists and the other stakeholders involved in the occupational therapy assessments. The OT co-researchers were involved in the decisions regarding the data collection methods. These are described in detail in the chapters relating to the action research fieldwork stages in which they were used.

3.4.5 Data Analysis

The lead researcher and OT co-researchers, as described in the Zuber-Skerritt (2006) CRASP model in Section 3.3, needed to have a critical attitude where they constantly reflected on their practice. Any new findings, policy or other experiences were considered as to the compatibility with their occupational therapy and personal values. The OT co-researchers reflected on how their perceptions may have changed and then used their professional reasoning to consider if they needed to change their practice in response. The OT co-researchers were aware that they were actively attempting to change their own practice by participating in the action research fieldwork and it was anticipated that this would also have an impact on their own professional development. The data analysis method needed to be flexible so that the lead researcher could present data and findings to the OT co-researchers for continual critical review throughout the fieldwork. An inductive approach to the analysis was, therefore, chosen to reveal occupational therapy practice knowledge from the unique reality of the local service which included dealing with unique person centred situations, the use of professional reasoning and coping with service demands.

Bray et al (2000) describe collaborative inquiry as an open process which has no pre-set answers. It would be expected that there may be clarity or confusion as new data constantly emerged. *'Meaning arises and submerges, is tacit and articulated, and deals with data one moment and the means of gathering data the next'* (Bray et al 2000, p89). The challenge in this research study was to capture the emerging meaning from the data gathered and to test this by continuing through the cycles of action and reflection. The OT co-researchers were asked to act as 'member checkers' to agree the current perspective on their practice and to reach consensus to move on to the next action to ensure cultural credibility as suggested by Williamson et al (2012b).

The lead researcher was aware that her own *'construction of knowledge'* (Gray 2014, p606) was not made as a neutral observer and that interpretations she had made and the choice of issues that had arisen in discussion that she had considered important and those that she had dismissed may not have always been the same as those of the OT co-researchers. The process of transcribing the OT co-researcher meetings increased the lead researcher's familiarisation with the data and enabled her to consider emerging themes including what was moving the project forward and

what factors may have been inhibiting the progress. The lead researcher's summary of the themes and actions from the previous session were fed back to the OT co-researchers to check and amend the lead researcher's view to ensure that there was a consensus of the interpretations and the planned actions that arose from them. If the lead researcher's summary did not match the OT co-researchers' views this was discussed and reviewed in the meeting. Differences in opinions and debate were expected and encouraged as the views and experiences of all the OT co-researchers needed to be recognised so that they could contribute their multiple ways of knowing regarding their professional values and constructs of effectiveness. Practical approaches to support this process that were used, as suggested by Gray (2014), included the use of the group of OT co-researchers to *'encourage dialogue and the critical exchange of ideas'* (Gray 2014, p606) actively collecting the individual perspectives of the OT co-researchers and the lead researcher within the OT questionnaires and maintaining a schedule of the action research fieldwork so that progress and actions were recorded (see Appendix A). The action research fieldwork process was recorded and reflected upon by the lead researcher and is summarised at the end of each stage.

Data were analysed during the action research fieldwork using techniques that were specific for the different methods being used. In this research study, data were collected from multiple informants and by different methods to provide a rich picture of the occupational therapy practice. Dick (1997) referred to this multiple data collection as 'dialectic'. Emerging themes were noted and reflected back to the OT co-researchers in the meetings and they were asked if these findings were meaningful to them. This probing enabled the data and interpretations to become more focused. The main purpose of the analysis during the fieldwork stage was to identify where change was needed and practical and to negotiate with the OT co-researchers as to what action they were motivated to take.

3.4.5.1 Thematic analysis

The thematic analysis process was completed in multiple cycles throughout the action research process. In stage one of the action research fieldwork thematic analysis was used to identify the themes from the occupational therapists' discussions regarding their practice knowledge of occupational therapy assessments. This approach was more formally used and described in stages two and three to analyse the data regarding the perceptions of people with learning disabilities, their carers and other stakeholders of the occupational therapy practice

that they had experienced. During the meta-analysis, the phases were revisited to redefine and name the themes and to search for repeated patterns of meaning that were significant across the meta-data corpus (see Table 3.3). The final process was interpretation of the significance of these final themes to seek for broader meanings and implications in relation to the literature and occupational therapy practice within this field. The writing of the thesis is identified as phase six of the thematic analysis process as it is considered '*an integral part of analysis'* (Braun and Clarke 2006 p 86) (see Table 3.4).

Qualitative thematic analysis, as described by Braun and Clarke (2006), is *'the method for identifying, analysing and reporting patterns (themes) within data'* (Braun and Clarke 2006, p80) and enables the data to be organised and described in rich detail. Thematic analysis was used in this research study as the authors argued that it: *'offers an accessible and theoretically flexible approach to analysing qualitative data'* (Braun and Clarke 2006, p77). Unlike grounded theory or discourse analysis, thematic analysis is more accessible as it does not need a detailed technical or theoretical knowledge to apply the approach. The method of analysis needed to be a process that was acceptable and understood by the busy local occupational therapy practitioners who were not actively immersed in research theories and techniques. The method also needed to be flexible to be used to consider data from numerous sources such as: responses from the participants with learning disabilities, their carers, stakeholders and the discussions and reflections in the OT co-researcher meetings.

Braun and Clarke (2006) describe thematic analysis as a flexible tool that searches for themes and patterns in data to find meanings and that this is a core skill for qualitative analysis that is not specific to one epistemological position. *'Through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data'* (Braun and Clarke 2006, p78). The definitions and terminology used by Braun and Clarke to describe how data are coded and themes identified were adapted by this research study (see Table 3.3). As this research study initially considered the data within the stages of the fieldwork the term 'data corpus' was used for all the data collecting in that stage. Therefore a new term of 'meta-data corpus' was used to define all the data collected across the entire research study. *'A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set'* (Braun

and Clarke 2006, p81). Themes are discovered due to active thinking and reviewing and creating links. The themes within the data in stage two, were as far as possible identified using an inductive approach in which the themes were related to what had been said and not linked to any pre-conceived theory or expectation. In stage three, a theoretical analysis was used to consider how the changes in practice had affected the themes and problems identified in stage two. This is further described in Section 8.2.2.

Table 3.3: Data collection and recording: glossary of terms based on Braun and Clarke (2006, p79)

Data item	Each individual piece of data collected: e.g. .a transcription of an individual interview.
Data extract	Individual coded chunk of data identified and extracted from a data item
Sub-Theme	Interesting/notable issue found in a data item.
Theme	Patterns made of sub themes.
Data set	All the data collected for a specific aspect of the action research study.
Data corpus	All the data collected for each stage of the action fieldwork.
Meta data corpus	Term used in this research study to include all the data collected for the action research thesis.

Braun and Clarke (2006) set out six steps of thematic analysis which are expected to be applied flexibly (see Table 3.4). The lead researcher followed this process to review the data to identify patterns and themes. Unlike in quantitative analysis, the importance of themes was not related to a calculation of how often they occurred but to if they provided an insight into occupational therapy practice. The thematic analysis used in this research study was a 'contextualist' method. This is described by Braun and Clarke (2006) as being from the critical realist tradition in which experiences of the people involved are considered within the wider meaning of their local context, which in this research study was the local occupational therapy practice.

Table 3.4: Phases of thematic analysis summarised from Braun and Clarke (2006, p 87)

Phase	Description of the process
1. Familiarizing with the data	Transcribing, reading and re-reading- noting ideas.
2. Generating initial codes	Coding interesting features of the data across entire data set
3. Searching for themes	Collating codes into potential themes, gathering all data relevant items to each.
4. Reviewing themes	Checking if themes work in relation to level 1 and level 2. Generating a thematic map.
5. Defining and naming themes	On-going analysis to refine each theme and the overall story- defining each theme clearly.
6. Producing the report	Final opportunity for analysis. Selecting extract examples, relating back analysis to the literature and research question.

During the action research fieldwork stages, data extracts, initial codes and preliminary themes were shared with the OT co-researcher group to reflect on if these appeared to be relevant and authentic when compared with their own interpretations of their practice experiences. The OT co-researcher discussions were used to question first assumptions, and then to share and compare the various perspectives in order to open up the debate to *'create maximum opportunity for challenge, surprise and mutual learning'* (Winter and Munn-Giddings 2001, p20). The data were collected from several sources in order to gain multiple perspectives. Bellman (2003) suggested that from the triangulation of data sources and the sharing and discussion with co-researchers *'congruent perceptions'* (Bellman 2003, p90) could emerge. These could then prompt the OT co-researchers to reflect, plan and take actions to change their occupational therapy practice.

3.4.5.2 Descriptive analysis

A descriptive analysis of the responses to the various questionnaires that were used in the action research fieldwork was undertaken. A more complex statistical analysis was not conducted as only a maximum of ten questionnaires were completed each time and so the numbers would have been too small. The findings of the questionnaires were shared with the OT co-researchers in the meetings and used to initiate discussions and influence the direction of the on-going fieldwork. This provided an opportunity for the lead researcher to check with the OT co-researchers if they agreed with her interpretations of any ambiguous responses.

3.4.5.3 Meta-analysis

As has already been discussed, following the completion of the action research fieldwork the lead researcher continued to complete a meta-analysis of all of the findings to complete the action research thesis. This meta-analysis was a reflective process completed by the lead researcher in reviewing the whole data and how this related to the literature. During the process of writing the thesis the lead researcher took into account the central principles of the action research process proposed by Winter (1996). This included having: a reflexive critique to be aware of personal biases and a dialectic critique which was working to understand relationships between the phenomena in the context of occupational therapy practice.

The lead researcher made the following assumptions when analysing the data:

- The sub-themes and themes needed to capture the reality of what was being experienced in the local practice.
- There were multiple perceptions and all these views were important to capture. The collection of data from multiple sources was complex but essential to capture the reality of the current situation.
- The responses of the participants with learning disabilities were essential to the research study. It was, therefore, important that data collection processes were accessible for these individuals so they would be able to express their views. The data analysis process would also need to be adapted to ensure these valuable perceptions could be developed into identified themes even if the data extracts were shorter or not as well expressed as those of other respondents.
- The OT co-researchers had an essential role in the action research fieldwork as experts in their own practice and in contributing to the data analysis process, checking of the lead researcher's interpretations and planning actions.
- The direction of the research study was flexible to allow for the important themes from practice to emerge.
- There was an expectation that both positive aspects and problems would be identified and a change would be needed to improve the local occupational therapy practice.

Occupational therapy practice needed to be understood by gaining contributions from a range of stakeholders and considering these multiple interpretations. This process provided opportunity for the local occupational therapists to be continuously

challenging and critically reflecting on their practice. Winter and Munn-Giddings (2001) state that the collaborative process needs to be a positive and empowering experience for the co-researchers so that the insights from this practical involvement can be valued by those involved.

3.5 Quality in studies using action research

Action research has been considered as unique due to *'its participatory character, its democratic impulse and its simultaneous contribution to social science and social change'* (Meyer 2000, p178). However, the close collaboration with the participants can result in action researchers being criticised for subjectivity as they are not independent of the situation being researched. The lead researcher needed to have *'"critical subjectivity":* (by making) *high-quality, critical and self-aware judgements'* (Williamson 2012b, p38) and acknowledging her own subjectivity. In action research cultural validity is important in that the participants agree that the findings are appropriate to their situation and are enabled to challenge the researcher's interpretations of emerging themes. Action research relies on participants to communicate openly and to express their different views and perceptions. (Higgs and Andresen 2001) report that in the critical paradigm the goal is to improve and empower people to collaboratively change their own situation. Winter (1996) recommended that '*Action researchers need to follow a vigorous intellectual discipline, ensuring that the conclusions of work are broadly based, balanced and comprehensively grounded in the perceptions of a variety of others'* (Winter 1996, p17). The quality of the study will therefore need to be judged in terms of whether or not the people who are involved consider it to be trustworthy and congruent with their experiences and if they consider that it had led to an improvement in their situation.

As there are many perspectives of a situation, validity in action research involves ensuring methodological triangulation in which data are collected from different sources and places. The action researcher needs to be *'frequently cycling and recycling between action and reflection so that issues are examined in different ways'* (Williamson 2012a, p38). The areas of agreement and the differences can then be identified and used to refine the emerging themes. This requires an investment in time to ensure that there is evidence that the researcher has actively collaborated in order to fully understand the local context.

Zuber-Skerritt and Fletcher (2007) stated that in order for an action research study to be of quality, it needs to demonstrate *'rigour in the action research methodology', (and be) …explicit about assumptions ...reflective, critical, self-critical and ethical'* (Zuber-Skerritt and Fletcher 2007, p418). Table 3.5 sets out the quality requirements that Zuber-Skerritt and Fletcher (2007) recommend. The purpose of the research study and the objectives of the action research fieldwork stages were based on these (see Section 1.5). Section 10.3 outlines to what extent these requirements were met.

Table 3.5: Action research quality standards requirements (Zuber-Skerritt and Fletcher 2007, p418)

Requirements:
Practice orientated- improving practice.
Participative- including all stakeholders and others affected by the results.
Focussed on significant issues relevant to selves and community/organisation
Using multiple perspectives of knowing, triangulation of appropriate methods and theories and connecting their own judgements to discussion in the current literature
Rigour in action research methodology and creative innovation. Contributing something new to knowledge and theory.
Explicit about assumptions so that readers and examiners may see appropriate criteria for judging the quality of work. Reflective, critical, self-critical and ethical.

This study took place in the local occupational therapy service and the methods were not designed to be replicable by others. Instead the intention was to work with the local occupational therapists to establish *'internal credibility'* (Williamson 2012b, p39), with a clear connection to the local situation and the changes that occurred. There was an expectation that the findings of this study would reveal new understandings of occupational therapy practice which would be relevant and transferable to other similar occupational therapy services working with adults with learning disabilities.

3.6 Ethical issues

Section 3.1 has described action research as being carried out with people who take action to resolve their concerns and generate knowledge through this process. However, many writers such as Atwal (2002), Morton-Cooper (2000) and Holloway

and Wheeler (2002) acknowledge that there can be challenges using action research. Action research studies are often multi-dimensional, as the method evolves during the process, and so are not easy to classify. This can also create problems with obtaining informed consent as research participants will not know everything that may happen or be expected of them at the start. Some studies have not been able to maintain the change after the project has finished as success is reliant on the skills of the researcher and how well the research participants work together and the circumstances of the setting. Action research can be lengthy because of the cyclical nature and so may use more time and resources than other research methods. However, Williamson (2012a) argues that other traditional research approaches can be focused on abstract theory rather than practical issues, they often identify problems but do not act to address them and researchers are separate from their subjects. He describes action research as *'a third paradigm because of the involvement of researchers and their collaboration with participants and their explicit remit of changing for the better aspects of the clinical and/or social worlds of participants'* (Williamson 2012b, p36-37).

The actions taken in the fieldwork for this research study needed to be in accordance with the occupational therapists' roles and within the remit and expectations of the organisation which employed them as the work was deeply embedded within this. Stage one of the action research field work commenced prior to gaining ethical approval as it was a natural extension of the local occupational therapy service's practice development. During this preliminary stage, the local occupational therapists were motivated to be involved in the research in a more in-depth way and to ascertain the perceptions of people with learning disabilities and others who had experienced their practice. Ethical approval was granted by the Joint South London and Maudsley and The Institute of Psychiatry NHS Research Ethics Committee on 21/12/2009 (see Appendix F). This ethics committee was selected as it was approved for studies that involved people who may not have capacity to consent to be involved in research. It had been anticipated that some of the potential participants with learning disabilities would be able to understand and be fully informed about the research process and the implications of taking part and others would lack the capacity to consent even when support had been provided to make the information accessible. Personal consultees, as set out in the Mental Capacity Act 2005, were approached to ensure that adults with learning disabilities, who lacked the capacity to consent, could be offered the opportunity to participate in this

research study. The issues about interviewing participants with learning disabilities are further explored in Chapter five, Section 5.2.

This action research study was based in the lead researcher's work place and the ethical approval included agreement by the local employer that the study could go ahead. However, the occupational therapists' management structure changed during the action research fieldwork on two occasions and so the participation of the local occupational therapists needed to be renegotiated at these times to ensure that the service managers were in agreement that the research study was compatible with the needs of the service delivery. All the local occupational therapy staff including those who were not qualified were invited to become OT co-researchers so that their contribution would be influential in the study. Many of the studies considered in the literature review in Chapter two such as Creek (2003), and Tannous et al, (1999) for example only included experienced or expert qualified occupational therapists within their studies. However, as the intention of this research study was to consider occupational therapy practice development within the local service it was important that all staff should be included as each one of them had a valuable contribution to make and it would not have been ethical to exclude them. During the recruitment process of the OT co-researchers it was made clear that participation in the research study was optional and that they could withdraw at any time (see information and consent forms Appendix D). A specific question in the OT co-researcher questionnaires asked them if they were happy to participate. Each aspect of the action research fieldwork such as attendance at the meetings, completion of questionnaires and selection of people that they had recently worked with as potential participants to be interviewed, were all optional. Declining involvement in one or more of these aspects did not exclude them from participating in the others. However, as all of the occupational therapy staff were recruited the action research fieldwork and the occupational therapy practice were not clearly separated. The decision of individual staff members to opt out would have been respected, although it probably would have been difficult for staff to decline as they may have been concerned about what their colleagues would have thought and may have felt excluded from professional support and learning. The lead researcher was observant about any concerns regarding engagement in the research study and ensured that the OT co-researcher meetings continued to be clearly demarcated as separate from usual practice meetings. The lead researcher negotiated the times and venues for the OT co-researcher meetings with the local occupational therapists and these could be re-scheduled if other priorities arose.

The lead researcher only accessed information regarding the specific occupational therapy practice of each of the OT co-researchers from what they were willing to share as part of the action research specific activities.

For most research studies, the lead researcher needs to be objective and demonstrate that he or she has not influenced or introduced bias to the study. However, in this action research study, the lead researcher was an insider-researcher and so had a remit of sharing her reflections and having an influence on the direction of the study. The lead researcher must also balance the role of being part of the research with the responsibility to ensure that all the views of the co-researchers and the other participants were represented and the issues of bias and subjectivity were taken into account and limited as much as possible. This included ensuring that the views of the quieter or less articulate responders were not marginalised by the more dominant voices.

All participant identifiable information was removed from all documents and replaced by code. All data, which included audio recordings, questionnaires, transcripts of interviews and group meetings and completed consent forms, were stored in a locked filing cabinet on NHS premises and/or filed on an encrypted NHS computer system. All data will be kept for the maximum of ten years from when it was collected which is March 2020 and will then be destroyed. Some aspects of the data collected were shared by the lead researcher with the OT co-researchers so that they could participate in the data analysis process and discuss and reflect on the emerging themes and findings. How the data would be stored and used was explained on all the participant information sheets provided (see Appendices D, H and I) and explained in person to all participants who were interviewed prior to obtaining consent. All participants were made aware that they could withdraw from the study at any time. The OT co-researchers were aware of each other's contributions within the OT co-researcher meetings but responses to the questionnaires were amalgamated by the lead researcher to ensure that individual contributions could not be identified by the other co-researchers. As the study took place within the lead researcher's own service, the OT co-researchers as a group could potentially be identified. Therefore all care was made to remove any contributions that could be identified as being from an individual OT co-researcher and the findings were shared with the OT co-researchers throughout the fieldwork so that any concerns could be addressed.

It was acknowledged that this lack of anonymity may have inhibited the OT co-researchers to respond openly if they had negative views to share. In order to address this, the information sheet (see Appendix D) had explained that any concerns that the OT co-researchers may have had could be raised with the team manager who was not part of the occupational therapy profession and as with any work issues, general concerns could be raised with the individual member of staff's line manager or a formal complaint could be raised. The purpose of this research study was to consider how occupational therapy practice developed within the local service. As part of the study of occupational therapy practice there was a need to take into account differences of opinions between colleagues and to be aware of the hierarchy of structure within the service, where some members have managerial and supervisory responsibility for others. These factors exist within the local occupational therapy service and are part of the context of the investigation. Hypothetically, it would be expected that difficulties in sharing information may also have been a problem if there had been an external researcher. There may have been a reluctance to share practice concerns with a person who was not from the service as this may have been considered disloyal. There could have been less trust as to how this information would have been used as an external researcher may have been unaware of sensitive or potentially difficult issues. The OT co-researcher questionnaire responses, and if these had been influenced by the lack of anonymity, are briefly discussed in Chapter ten.

3.7 Summary

Action research was chosen as the methodology for this research study as it used a critical social science tradition to empower the local occupational therapists to collaboratively learn about and develop their own practice. The methods used in this research study were qualitative as they explored the local occupational therapy practice using small samples. The lead researcher participated with the local occupational therapists and data were collected from multiple perspectives in order to gain new knowledge of occupational therapy practice development and theory. Action research findings need to be considered in terms of being meaningful and authentic for the participants.

This research study was based in the context of the local community occupational therapy service for adults with learning disabilities and the claims for knowledge are

related to the development of the local occupational therapy practice. The research study also sought to contribute to the professional knowledge as to how occupational therapy could best be practised and improved for this speciality. This research study was based on Zuber-Skerritt (2007)'s CRASP model and the focus was on the local occupational therapists working collaboratively with the lead researcher to develop their practice. Data were gathered from the discussions in group settings and also individual reflections using questionnaires. The action research fieldwork was completed with the local occupational therapists over three stages and the specific methods used at each stage were not all planned in advance but evolved as part of the collaborative enquiry. Data were analysed mainly by thematic analysis. The action research thesis was completed by the lead researcher and involved a meta- analysis of the findings of the action research and re-engagement with the literature in order to develop practice based on research findings in order to meet the overall purpose of the study and to address the fieldwork objectives (stated at the end of Chapter one).

Chapter four: Stage one - the local occupational therapists' search for a standardised assessment to support evidence-based practice in working with adults with learning disabilities

Stage one commenced in 2007 when the local occupational therapy service was part of a primary care trust and managed by health professionals (see Section 1.2). The local occupational therapists were confident in their practice but understood that there was an expectation from their professional body (COT) to demonstrate evidence based practice specifically in the use of standardised assessments (see Chapter one, Section 1.3 and Tables 1.1 and 1.2).

In stage one the lead researcher collaborated with the local occupational therapists to explore the current use of assessments by the local community health team working with adults with learning disabilities and to further develop and improve practice based on the evidence generated. Gray (2014) acknowledges that a group of people will have differing views and opinions and describes these different realities as "constructions". The lead researcher's role was, therefore, *'to bring people with divergent views and perceptions together so that they can collectively formulate a joint construction'* (Gray 2014, p333).

4.1 Introduction and context of stage one

The action research fieldwork for stage one was conducted in three phases which are illustrated in Figure 4.1. The objectives of stage one in relation to each of the phases are shown in Table 4.1.

Figure 4.1: Diagrammatical representation of stage one of the action research fieldwork

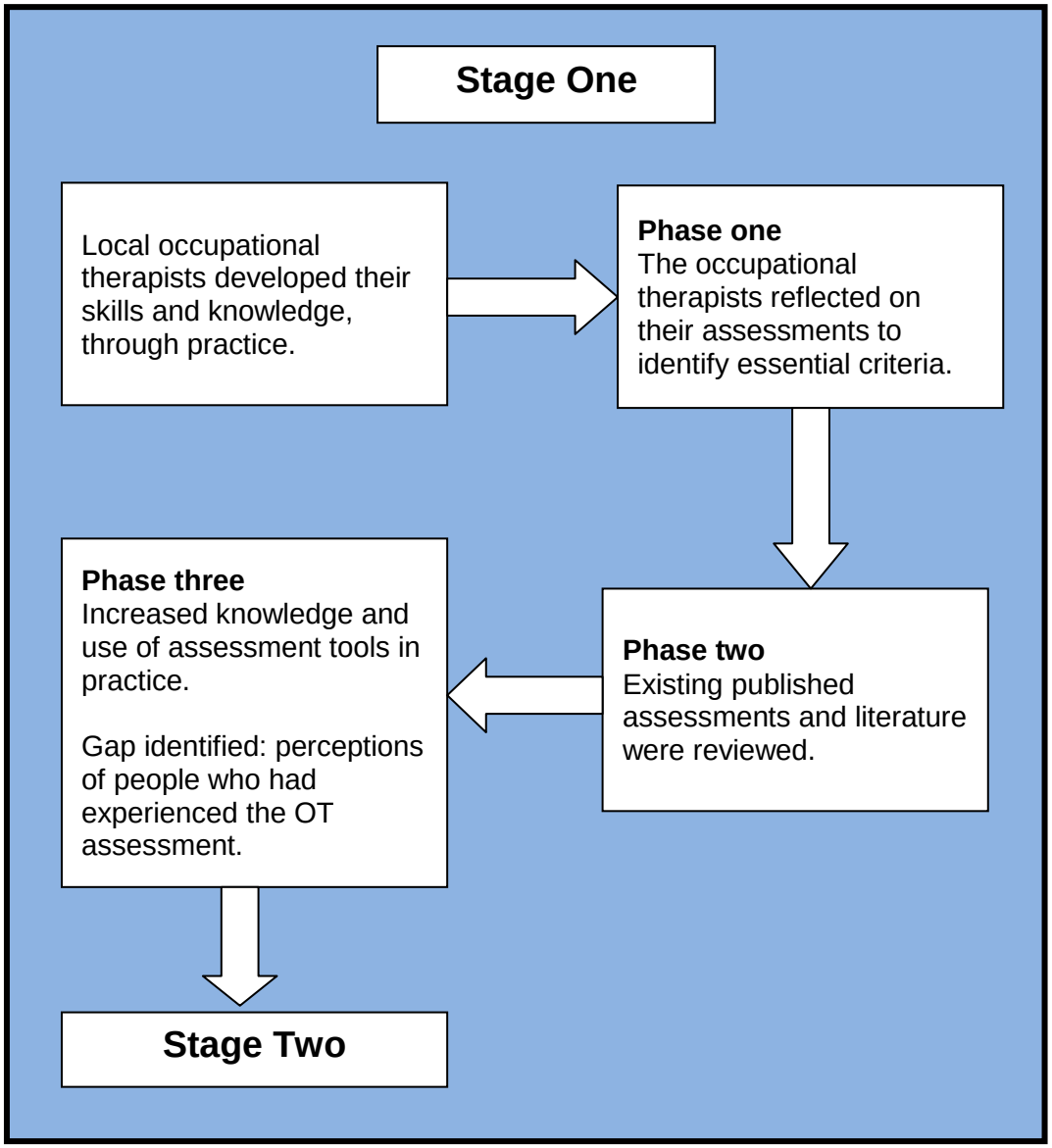


Table 4.1: Objectives of stage one

Stage one objectives	Actions
Phase one: Objectives	**Phase one: Actions**
To explore with the local occupational therapists any gaps or concerns that needed to be addressed by the research study To define what is required for an occupational therapy assessment tool for adults with learning disabilities	The lead researcher met with the local occupational therapists to explore the need for a standardised assessment and to identify any problems that could be addressed by the research study The local occupational therapists met to discuss and generate essential criteria for an occupational therapy assessment tool for adults with learning disabilities
Phase two: Objectives	**Phase two: Actions**
To review the availability of published standardised assessments used by occupational therapists for this client group To consider if there are existing assessment tools that could meet the criteria identified as important in phase one	The lead researcher reviewed published standardised occupational therapy assessments for use with adults with learning disabilities The local occupational therapists reviewed the available assessment tools to determine whether there were any existing tools which could meet the criteria identified as important in phase one or if a new tool needed to be developed The lead researcher further explored the literature on the use of assessments by occupational therapists working with adults with learning disabilities
Phase three: Objectives	**Phase three: Actions**
The occupational therapists to agree on an assessment tool that could be piloted in practice that could address the gaps or concerns and meet the requirements that emerged	The local occupational therapists considered if changes to assessment practice were required following the collaborative critical review of the use of assessments The local occupational therapists agreed to engage in an action research study to evaluate current assessment practice and to determine if their assessment practice needed to change or develop. The occupational therapists were recruited as co-researchers (see methodology, Chapter 3). They participated in the co-researcher meetings and activities and completed the OT co-researcher questionnaires on their assessment processes and their experience of the action research process.

4.2 Occupational therapy assessments

A brief exploration of the literature regarding standardised assessments and how they can be used by occupational therapists working with people with learning disabilities was undertaken by the lead researcher at the start of stage one in 2007. A general health definition of assessment: *'the process of evaluating a patient's problems, including recognition and measurement of the problems and determining their cause and extent'* (Wade 1995, p15) focused on measuring particular aspects of body function. Wade (1995) suggested that assessments can be used for a wide range of reasons including: making a diagnosis, quantifying severity or change, determining eligibility for a service, measuring work load and research**.** This definition and set of reasons did not appear to fully encompass the need for occupational therapy assessments to enable people to identify concerns in their daily lives, what motivates them and how they interact with their environment. Law et al (2001) stated that occupational therapy assessments are needed to enable and plan appropriate intervention and to set goals. Unsworth (2000) argued that measures in occupational therapy are important to monitor client progress, increase the focus on the client and facilitate mutual goal setting. She considered that the aim of therapy is a positive change, using the best kind of intervention, at the best time in the most efficient way and emphasised the need for evidence-based practice. Laver Fawcett (2007) proposed a wider definition of occupational therapy assessment that encompasses the use of a variety of tools to collect data from different sources and then using the findings to make decisions throughout the therapy process.

Assessments used by occupational therapists vary according to the field of work, as well as the experience and preference of the individual and team. The assessments are chosen depending on factors such as the time-scale of when the information is needed, the individual's needs and the particular area of concern. Creek (2003) states that assessments need to be *'sensitive to change, be user friendly and provide accurate information from which the therapist can devise therapeutic plans'* (Creek 2003, p40). She suggests that occupational therapists should experiment with different tools in order to use the most appropriate in a given situation.

Standardised assessments need to be valid, reliable and responsive to change. A valid assessment is one that actually measures the underlying attribute (Bowling 2004) and a reliable assessment is one that gives the same responses at a point in

time when administered by different therapists (Laver Fawcett 2007). There are many variations of validity but in behavioural sciences content validity and construct validity are usually considered (Bowling 2004). Content validity refers to if the components of the assessment tool cover all relevant aspects of the attribute, whilst construct validity is '*corroboration that the instrument is measuring the underlying concept it is intending to measure'* (Bowling 2004, p12) and it used if what needs to be measured cannot be observed directly.

McDowell (2006) suggested that seven characteristics of health assessments should be considered by asking the questions that are summarised in Table 4.2. These recommendations were developed to be used by any health professional and in any settings and so the emphasis of each of these aspects would depend on the needs of a specific service. McDowell's list is similar in its emphasis on standardised assessments, to the requirements set out by Bowling (2004) and Unsworth (2000) but provided more detail to support the review of assessment tools being used in the local service.

Table 4.2: Questions to review assessments (McDowell 2006, p8)

1. What is the purpose?
2. Is it broad enough?
3. What is the conceptual approach?
4. How feasible is it to administer?
5. Is the scoring clear?
6. What degree of change can be detected?
7. How strong is the available evidence for reliability and validity?

All the studies accessed by the lead researcher at the start of stage one emphasised the need for professionals to carry out accurate measures using standardised assessments to measure outcome of health interventions. Unsworth (2000) recommended that outcome measures in occupational therapy should be:

- Suitable for the population. This includes age, diagnosis, setting and deadlines.
- Meet the needs of the assessment. The tool needs to be for the correct purpose, sensitive enough to detect change, and able to obtain quality information.
- Standardised. The assessment needs to have a scoring procedure that can easily be measured with norm or criteria referencing.

This concept of measuring a change in a standardised way can be challenging in occupational therapy. Unsworth (2000) suggests that measuring at the start and end

of intervention, when the client is still in contact with the service, is the usual practice, however, acknowledges gains may continue after leaving the service. It is also difficult to separate occupational therapy intervention from other factors that may have influenced any outcomes or changes. People with learning disabilities usually have a stable condition and so the expectation of intervention is not usually to change an underlying condition. It was acknowledged that occupational therapists provide intervention to address wider needs in relation to maintaining quality of life, restriction of social roles and to enable full participation in all aspects of daily life. However, these complex constructs are difficult to measure (Unsworth 2000).

Services for people with learning disabilities in England are based on the four key principles that people with learning disabilities should have legal and civil rights, independence, choice and inclusion (Department of Health 2001). Making choices is seen as *'an expression of autonomy, and a basic human right'* (Baldwin and Thirkettle 1999, p167). However, adults with learning disabilities may not be offered the opportunities as set out by these principles *'because of their very real difficulty in coping with everyday life'*. (Sellars 2002, p2) and some may not have the capacity to make fully informed choices. Bowey et al (2005) reported that community learning disability team members felt justified in over-riding the views of people with learning disabilities whom they considered lacked the capability of knowing what they needed. Bowey et al (2005) suggested that professionals underestimate the abilities of people with learning disabilities and this can lead to over protection and denial of opportunities to take risks. The balance between allowing choice and independence and protecting people from risk is, therefore an on-going concern of services for people with learning disabilities. McGlaughin et al (2004) suggest that any assessment to consider a person's skills and support needs should empower the person with learning disabilities to make choices as far as this is possible.

At the start of stage one there were only limited studies describing occupational therapy assessments when working with adults with learning disabilities. Swee Hong et al (2000) reported that although some assessments were available for people with mild to moderate learning disabilities, there was little information in the literature on assessments for people with severe learning disabilities (see glossary for definitions). Tannous et al (1999) concluded that to measure the effectiveness of occupational therapy with people with learning disabilities and high support needs there needed to be a more inclusive perspective than just considering how goals were met. Success indicators needed to include *'the indirect outcomes of the hands-*

on intervention, namely empowerment and changing perceptions, and the nature of the therapy relationship' (Tannous et al 1999, p33). Tannous et al (1999) concluded that the occupational therapists saw their role as supporting individual client rights and creating a balance between duty of care and dignity of risk. Kottorp et al (2003a) stated that occupational therapists identify that enabling people with learning disabilities to perform daily living skills is important for them to develop independence, empowerment and control over their lives. The study concluded that 'adaptation' or problem solving is the most difficult skill area for this group. Therefore, an assessment tool would need to address these areas of independence and empowerment.

The published standardised assessments, that the local occupational therapists working with people with learning disabilities had access to prior to the start of stage one of the fieldwork, were often either non-profession-specific but developed for people with learning disabilities, or occupational therapy specific but not designed for people with learning disabilities. Often standardised assessments were adapted by occupational therapists to meet the needs of adults with learning disabilities. For example, Law et al (1994) suggested that the Canadian Occupational Performance Measure can be used with caregivers if the person's cognitive impairment meant that they could not answer the questions for themselves. However, this would appear to make the concept that the measure is of *'the client's self-perception of occupational performance'* (Law et al 1994, p1) meaningless, as only the carer's perspective would be obtained. Other practices such as the use of children's standardised assessments for adults or changing parts of the assessment to meet individual needs would affect the validity of the tools. The assessment tools available at this time were, therefore not always meeting the needs of occupational therapists working in this field. This resulted in many of the assessments used by occupational therapists being 'home-made', adapted or out-dated and therefore, non-standardised (Swee Hong et al 2000). Laver Fawcett (2007) stated that the use of inaccurate and unreliable measures could affect professional credibility and may be detrimental to clients. It was identified that occupational therapists working with adults with learning disabilities need to develop a *'user-friendly assessment tool that provides accurate and meaningful information from which the therapist can devise meaningful plans based on the needs of the client's occupation'* (Swee Hong et al 2000, p84).

There was a perception by the occupational therapy profession, researchers and the local occupational therapists that standardised assessments were important when working as an occupational therapist with adults with learning disabilities to ensure that practice was evidence-based and valued. The literature reported that there was a lack of suitable assessment tools published that were useful for this client group and this had also been the conclusion of delegates at the 2006 UK National Annual Conference of the specialist section of the College of Occupational Therapists on working with people with learning disabilities that the lead researcher had attended. This perceived gap was a 'driver for change' during the initial meetings of the lead researcher with the local occupational therapists.

4.3 Stage one: phase one

4.3.1 Method stage one: phase one

In March 2007 the lead researcher met with the local occupational therapists working with adults with learning disabilities as part of their usual practice development meetings. The preliminary exploration of the literature about standardised assessments was presented by the lead researcher to ascertain if the local team of occupational therapists shared this concern regarding their assessment tools and if they would be motivated to participate in research to develop their practice. The group was asked to identify the assessment tools that they most commonly used and a discussion was initiated as to how these were used and if they met the needs of the service. A follow up session in April 2007 considered the three most commonly used assessments by the local occupational therapist and compared how well each addressed McDowell (2006)'s seven questions for review of an assessment (Table 4.2). Notes of the discussions were made by the lead researcher and shared at the following meeting to check for agreement and allow for any concerns to be raised.

4.3.2 Stage one: phase one. Review of local assessment practice

During the first meeting of the local occupational therapists with the lead researcher in March 2007, a variety of assessments were identified that were currently in use. These were a combination of standardised and informal tools, observation and

interviews to meet the wide range of needs of the adults with learning disabilities with whom they were working. The local occupational therapists shared the lead researcher's concerns that there was a lack of published standardised assessments that they could use in their practice. However, they believed that the assessments that they completed were useful and well received. Therefore, a plan was agreed to review the evidence base and standardisation of three assessment tools that were identified as being the most commonly used by the local occupational therapists at this time (see Table 4.3).

Table 4.3: The assessment tools used most commonly by the local occupational therapists at the start of stage one

Tool	Abbreviation	Author
Activities of daily living checklist	ADL	Developed by the local occupational therapy service.
Hampshire assessment for living with others	HALO	Shackleton Bailey and Pidock (1983).
Assessment of motor and process skills	AMPS	Fisher (2003) 5th edition

The local occupational therapists met again In April 2007 to review the ADL checklist, HALO and AMPS using McDowell's (2006) seven questions (see Table 4.2). The reviews for the three tools in Table 4.3 are presented.

(i) The activities of daily living (ADL) checklist

The ADL checklist was the most commonly used assessment by all the occupational therapists in the local service and was constructed as a non-standardised assessment tool. It had been in existence for more than twelve years and it was assumed that it had been developed within the occupational therapy team although its exact origins and concepts on which it had originally been based were unknown. The occupational therapists had collectively agreed changes to the format over time. The ADL checklist consisted of a list of personal care, domestic and community living activities that were considered by the occupational therapists to be required by most people to look after themselves and their home. The person with learning disabilities was scored on each item as: "independent", "needing support" or "dependent on other people" to complete that activity. There was space beside each item for comments to be added if required. The complete form was presented in the occupational therapy reports as the result of the assessment as there was no

process for summarising the scores. The occupational therapists used this information to highlight areas where the person performed well and areas where skill development or support was required. The ADL checklist had an occupational therapy conceptual approach as the focus was on tasks and roles that were meaningful for the person with learning disabilities and his or her carer.

However, the review of the ADL check list highlighted that the local occupational therapists each had different interpretations of the ADL grading categories and did not consistently score the ADL checklist in the same way.

The occupational therapists agreed that the ADL checklist was useful to address the needs of people with learning disabilities and appeared to cover the areas that the occupational therapists considered to be priorities. The locally developed ADL checklist could be adapted by the local occupational therapists to meet the needs of each adult with learning disabilities in the specific situation. The local occupational therapists saw this as an advantage. Their view was that only the ADL checklist was able to meet the scope of all of their assessments and interventions for all the people referred to their service.

The occupational therapists considered that the ADL checklist was the most acceptable assessment to use with people with learning disabilities and their carers as the length of time to complete it could be flexible to meet the concerns and needs that are to be addressed.

The disadvantage of the ADL checklist was that it was non-standardised and there was no evidence of reliability of the grading categories. The ADL checklist could not, therefore, be used to measure change in the client's performance or circumstances.

(ii) The Hampshire Assessment for Living with Others (HALO)

The HALO is an assessment for adults with learning disabilities and was designed to help service providers in the United Kingdom plan the type of residential service that could meet an individual's needs. The first version of the HALO was piloted in 1979 and the final version 5 developed in 1983 (Shackleton Bailey and Pidock 1983). The HALO covers ten categories of personal, domestic and community living skills and consists of 276 items over 10 sections. When the HALO is completed, the scores indicate how well the person's current level of skills could be met in each of three profiles: fully staffed home where staff are available all the time, medium service

where staff are not there all the time but provide support on a daily basis and low level service, where the support is available on a weekly basis.

The scope of the HALO is extensive and all of the questions need to be scored in order to complete the profile. Although these questions are all related to a person's ability to manage daily living skills and so could be within the remit of the occupational therapists, many of the questions were not always directly relevant to the current needs and concerns presented.

The HALO usually was completed over a period of three months, as several interviews and observations were required. The language used could be difficult for people with learning disabilities and their carers to understand. The HALO was not designed so that people with learning disabilities could be involved in their own assessment.

The local occupational therapists had been using the HALO over an extensive period of time to make judgements about a person's skills and support needs. However, the HALO was not designed by occupational therapists and was produced at a time when many people with learning disabilities lived in institutional settings and the assumption was that not everyone could live in the community. The three profiles that the HALO produces did not reflect the variation of living and support arrangements that were currently on offer to people with learning disabilities in the local communities. The conceptual approach was, therefore, considered to be no longer compatible with present day expectations.

Shackleton Bailey and Pidock (1983) reported high test-retest and inter-rater reliability of the HALO. No validity studies were completed so it is not clear if the recommendations as to where someone should live were successful. The HALO had not been updated since 1983 and so the occupational therapists reported that they needed to adapt the tool to take into consideration new technology that had been developed since this time and how services were now provided. Unfortunately, the adaptations they had made, over the years, to the HALO in order for it to be meaningful in their local setting meant that it was no longer standardised. This meant that the HALO could no longer be used to measure change in the client's circumstances over time.

(iii) The assessment of motor and process skills (AMPS)

The AMPS is a standardised assessment based on OTIPM (see Section 2.3) and validated for use with adults with learning disabilities (Kottorp et al 2003b). The AMPS covers the areas of self-care, home management and meal preparation. It could be used to provide information on a person's strengths and needs in relation to their motor and process skills and can give some insight into how best to support skills development. It was developed by Fisher and it was described as an observational evaluation for use by occupational therapists (Fisher and Bray Jones 2014).

The AMPS assessment considers if a person has *'the ability to carry out ADL tasks independently, safely, efficiently, and with minimal effort'* (Kottorp et al 2003a, p203). Kottorp et al (2003a) state that the AMPS is more useful than assessments that evaluate if a person is able to complete a list of tasks independently, which would be similar to the HALO or ADL checklist, as they do not consider which occupational tasks are important for the person to complete and *'rarely provide information about why the client experiences difficulties in the tasks he or she finds meaningful and purposeful'* (Kottorp et al 2003a, p196).

Occupational therapists using the AMPS have to complete intensive training and this is followed up by completing ten assessments and having these scores ratified. The occupational therapist's level of severity when making judgements is then calibrated. The calibration code is used when future assessments are scored using the AMPS software. The reliability is maintained by ensuring that the occupational therapists attend refresher scoring sessions, check with colleagues and learn how to interpret the scores into meaningful reports using professional reasoning. However, only three of the local occupational therapists had been trained in its use so the AMPS was not available as an option for the rest of the team.

Fisher and Bray Jones (2010) described studies used to consider the reliability and validity of the AMPS and concluded that the assessment could reliably measure changes in activities of daily living task performance. A study by Kottorp et al (2003b) concluded that the AMPS is valid when used with adults with learning disabilities apart from those with the most severe cognitive disabilities. Fisher and Bray Jones (2010) reported that parallel forms of reliability tests in which the same person was tested using different AMPS tasks also demonstrated high reliability. However, the AMPS assessor needed to ensure that the selected tasks were of

sufficient difficulty to enable accurate results. It is recommended that if there are concerns about accuracy a third task is observed. This may be difficult to judge for occupational therapists in their everyday practice. Unsworth (2000) acknowledged that there are problems with measuring activity limitation due to *'poor scale construction and other psychometric problems'* (Unsworth 2000 p150). However, she considered that the Rasch analysis used by Fisher and Bray Jones (2010) in the AMPS, had addressed some of these issues.

The AMPS is completed by first discussing with the person their occupational performance concerns and then observing them complete two familiar tasks chosen by them from the manual. The focus of the AMPS is quite narrow in that it is restricted to personal care, domestic and cooking tasks. It does not address budgeting, social interaction or travel skills. Kottorp et al (2003b) argue that the AMPS is based on client choice. However, the experience of the local occupational therapists was that the occupational performance concerns that the person with learning disabilities may identify as meaningful for them may not be one of the tasks that are calibrated for use with the AMPS. Moreover, the tasks available for selection in the AMPS may not relate to the reason why they were referred to the service. The AMPS could not usually be used with people with severe learning disabilities as they would not be able to understand the instructions and may not be able to complete any of the tasks.

Conclusions of the review

The conclusions of the review of the three most commonly used assessments are summarised in Table 4.4. These are followed by a more detailed comparison of the three assessments in terms of their ability to detect change and the evidence of their reliability and validity.

Table 4.4: Summary table comparing the three assessment tools using McDowell's questions (McDowell 2006, p8)

Tool	ADL	HALO	AMPS
Purpose compatible with local occupational therapy service.	✓	Only when adapted	✓
Scope covered the needs of the local service	✓	Too broad	Too specific
Occupational therapy conceptual approach	✓	X	✓
Feasible to administer	✓	X	Only by 3 OTs
Scoring was clear	X	✓	✓
A change could be detected	X	X	? Just specific circumstance
Evidence of reliability and validity	X	✓	✓
Total number of characteristics met	**4/7**	**2/7**	**4/7**

Use of the tools to detect change

None of the three assessment tools reviewed were likely to be useful in detecting change in specific occupational performance concerns. Assessments were conducted by the local occupational therapists by first observing the person completing the specific task that they had chosen to learn in the place where they needed to carry this out, and recording this observation as a baseline. Following intervention such as skills development or adapting the environment, the observation would be repeated to ascertain if the occupational performance issue had been addressed. As the only standardised assessment in local use, the AMPS could be used to measure the effectiveness of occupational therapy intervention but only if the person wanted to develop one of the AMPS tasks as stated in the manual. This, in practice, rarely occurred as most occupational therapy interventions were more holistic than an acquisition of one skill. Interventions may include training carers, or working with the person with learning disabilities on various aspects that could be affecting occupational performance. The outcomes of these interventions could not all be as easily measured with any of the three tools. The assessment tools were usually used by the occupational therapists to support them in gaining insights and detailed information regarding a person's occupational performance skills rather than detecting change, so this criterion may not be of relevance for tools that occupational therapists use.

All of the three assessment tools focused on the person's occupational performance rather than their cognitive or physical abilities. When working with adults with

learning disabilities, it would not usually be expected that there would be a change in the person's underlying condition. However, an exception to this in the local occupational therapy service, was when it was suspected that someone with Down's syndrome may be in the early stages of dementia. The AMPS was used by the local occupational therapists to record a baseline of a person's abilities which could be repeated three to six months later. The local occupational therapists were able to use the AMPS to detect subtle changes that could be used in combination with the other multi-disciplinary team's assessments to identify if someone may be developing dementia and to support the person and his or her carers in managing any changes in occupational performance.

Evidence of reliability and validity

The occupational therapists learned from the reviews that only standardised assessments could be used to reliably detect change. However, even with the standardised assessments, the occupational therapists struggled at times to interpret how to score their observations and the responses that they had received, often on multiple occasions and from different informants. They acknowledged that professional judgement was required to interpret the findings of any of the assessment tools. The discussions highlighted the need for on-going critical reflection of assessment findings and the challenging of assumptions to ensure that the occupational therapy assessments used in the service were correctly administered and produced valid and reliable findings.

The conclusions of the discussion about validity with the local occupational therapists were that a combination of the ADL checklist and the AMPS covered all the areas that they considered important in their usual assessments and so would provide content validity (as defined by Bowling, 2004). The ADL checklist and the AMPS were compatible with the OTIPM and so they were considered to have construct validity. However, Bowling (2004) recommended that the people who will be assessed are asked about their views on the validity of the assessment tools. During the local occupational therapy group discussions it was identified as a gap in knowledge that adults with learning disabilities and their carers had not been formally asked about their perceptions of their experiences of undergoing assessments.

4.3.3 Stage one: phase one. Practice based knowledge - the essential criteria of an occupational therapy assessment.

The use of McDowell's (2006) seven characteristics helped the occupational therapists to focus their thinking and to consider what aspects of the occupational therapy assessment were priorities for the local service. The three assessments were found to have varying strengths but none were considered to meet all the requirements of the local occupational therapy service and the relative importance of each of the characteristics was not clear (see Table 4.3). The local occupational therapists used the assessment tools available to them in a flexible way during their practice and often used a combination of these to address the client need. A combination of both, quantitative and more qualitative data were found to be useful by the local occupational therapists to make occupational therapy decisions. The ADL checklist appeared at times to be used as a short cut for the HALO by some of the occupational therapists, using many of the principles learnt from the experience of completing the more extensive format over many cases.

The lead researcher summarised the discussions with the local occupational therapists regarding the seven characteristics of health assessments (McDowell 2006) and conducted a thematic analysis based on Braun and Clarke (2006) (see Section 3.4.5.1). Sub-themes of interesting statements from the discussions regarding the requirements of an assessment tool that would meet the needs of the local service were grouped into themes. Some of these were directly related and appeared to have been influenced by the seven characteristics but were expanded upon and related to the local practice. Other sub-themes were identified as important by the occupational therapists from their practice experience of working with people with learning disabilities and included concerns regarding the need for flexible, person-centred approaches. The sub-themes were used to develop themes that were the first draft of the essential criteria for an occupational therapy assessment. These were shared with two senior occupational therapists and the team manager in June 2007 to consider if these were meaningful to the occupational therapists. The views of the team manager were ascertained to consider if this was useful for the team as a whole and to ensure that the manager, as a key sponsor for the study, was engaged in the process. The essential criteria were refined by the lead researcher following these discussions and the second draft shared and reviewed with the local occupational therapists in July 2007 where more feedback was obtained. Following these extensive discussions eleven

essential criteria were identified and agreed by the local occupational therapists as essential components of this assessment tool (see summary in Table 4.5).

Table 4.5: The essential criteria for occupational therapy assessment in the local service for adults with learning disabilities

The essential criteria
Assess occupational performance
Global skills rather than just one aspect
Highlight skills and support needs in order to make meaningful and useful recommendations
Client centred/choice and empowerment
Accessible easy to use and understand
Designed for people with learning disabilities
Fit for purpose
Practical/good use of resources
Observation
Incorporate views of all people involved with the person with learning disabilities
Fits with other local, national, international development

Assess occupational performance

The occupational therapy assessment needed to be compatible with the local occupational therapists' values and how they work with people with learning disabilities to meet occupational performance goals in the environment where they need to do these tasks. Kottorp et al (2003b) criticise general adaptive behaviour scales if they do not take into account the person's choice of tasks, or why the person is having difficulties. Assessments that are concerned with measuring specific physical or cognitive abilities not related to occupational performance are also not appropriate.

Global skills rather than just one aspect

The assessment tool has to be flexible enough to address any aspect of occupational performance that is important to the individual and others involved. For example, a person may not have any issues with managing self-care, but may be vulnerable when accessing the community. Another person may need to move away from living with his family and so a full assessment of his skills would be required in order to inform the decisions about what support package would be put in place. It may not be possible to develop one assessment tool that is flexible enough to meet

the wide range of needs of all adults with learning disabilities. The assessment may, therefore need to be in the form of a battery of stand-alone tools that could be used in any combination, allowing the occupational therapists to make professional judgements as to which areas would require a fuller assessment.

Highlight skills and support needs in order to make meaningful and useful recommendations

A large part of the remit of the local occupational therapists was to assess and develop the person's independent living skills, aiming to encourage people with learning disabilities to participate fully in society. The assessment tool needs to be able to format the information gathered in a way that the therapist can use it to formulate recommendations using professional knowledge and expertise about a person's support needs. This needs to take into account both the potential to develop skills and risk/duty of care. The assessment process therefore needs a way of organising the information in order to be able to make a conclusion or recommendations about a person's skills and support needs rather than just providing a list of skills and deficits. Ideally the assessment should be able to provide a profile or indication of level of support required for that person. Fisher and Bray Jones (2010) suggest that occupational therapists assess activities of daily living in terms of effort required, efficiency, safety and independence.

Client centred/choice and empowerment

Adults with learning disabilities need to be enabled to take the lead in expressing their perception of their occupational performance concerns and setting goals in partnership with the occupational therapists. The assessment tool needs to be flexible to allow this process to happen rather than the agenda being set by the requirements of the assessment tool. The assessment, therefore, needs to enable the person being assessed to be at the centre, with his/her views fully taken into account.

Accessible easy to use and understand

In order for the assessment to incorporate the views and involvement of the person with learning disabilities, the assessment needs to be adaptable to meet the individual's particular communication needs. This may mean making the form more accessible with pictures, symbols or simplified language. However, for some people any symbolic communication may be too difficult and so observations of the person participating in occupations and noting the person's reactions to different situations

may be the only way to ensure the assessment process is accessible. The assessment tool needs to be adaptable to meet individual communication needs taking into account reliability and validity issues.

Designed for people with learning disabilities

The assessment tool needs to be specifically designed for adults with learning disabilities. This can be either at the initial design stage of a tool or there could be subsequent studies that have demonstrated that the assessment can reliably be used with people with learning disabilities. If adaptations are made to standardised assessment tools so that they can be more easily used by this client group, evidence is required to ensure that these changes have not affected the reliability or validity of the assessment.

Fit for purpose

The assessment needs to be reliable in that similar results will be found by whoever is assessing the person. This may mean that the assessment has a clear manual or instructions and/or assessors may need to attend a training course. The assessment tool needs to have clear evidence of its validity and reliability when used to assess people with learning disabilities. For example an observation assessment of a person completing a daily living task may be valid in relation to that task, but using this information to make general recommendations about the person's ability in other tasks would need a careful review of the evidence to ensure that these statements were valid. Adults with learning disabilities will often have difficulties generalising skills from one setting to another and so to ensure validity, it is important to assess them doing the skills they need or want to do in their own familiar setting.

Practical/ good use of resources

Assessment of the skills and support needs of a person with learning disabilities may take longer than for other client groups for a number of reasons. Time is required to ensure the person understands the purpose for the assessment and how it will be carried out and this explanation may need to be repeated at each visit. The input from others involved in a person's life need to be taken into account and may involve interviews. The cost of assessment tools and any training that is required before being able to use them may restrict the use of an assessment if resources are limited. It is also important that occupational therapists ensure they keep up to

date with the most recently published assessments tools and upgrade when necessary.

Observation

It was identified from the discussions with the local occupational therapists that observing the person with learning disabilities was considered an essential part of the occupational therapy assessment in the local service. Many assessment tools rely on interview formats to gather information but this was not always found to be useful even if the person with learning disabilities was able to verbally communicate. The occupational therapist assessment needed to be based on observations of a person carrying out the occupational performance skills that the person wants or needs to perform. Adults with learning disabilities may have difficulties understanding the concepts required for self-rating their performance and reliance solely on carer ratings may result in reflecting the carer's view rather than that of the client's. The carer may not have allowed the person with learning disabilities to have completed the task for themselves so their report may not provide a full understanding of the person's abilities.

Incorporate views of all people involved with the person with learning disabilities

A theme from the discussions with the local occupational therapist was the importance of gathering the views of the multiple people involved as part of the assessment process. The occupational therapists acknowledged that there were often different views and perspectives on a person with learning disabilities' abilities but standardised assessment tools often need one specific answer taking into account one person's view. In practice, the occupational therapists had often needed to record a variety of findings as the occupational performance of individuals could vary on different days due to factors such as health, mood, motivation, environment, and their relationships with the people supporting them. Many people and agencies are often involved in the lives of people with learning disabilities. These stakeholders include the person with learning disabilities, carers, friends, advocates, statutory health and social care workers, other support agencies, college staff, employers etc. The balance between the person's choice, and concerns raised by carers and others in the client constellation, needs to be addressed in the assessment process.

Developing skills to cope with the risks of living in the community appears to be a substantial remit for occupational therapists working with people with learning disabilities. Occupational therapy assessments need to address the complex issues of balancing supporting someone to become more independent with managing risks. The decision to allow a person to be exposed to a risk may raise differing concerns in the various parties involved. A number of issues and potential conflicts can arise in practice when occupational therapists complete assessments of a person's skills and support needs and risks are involved. The assessment needs to encourage positive risk taking and enable the person to meet their occupational performance goals taking into account the concerns raised. Occupational therapists need to be able to use the assessment to justify their decision making and to enhance collaboration with others so that their recommendations can be appropriate and followed so that people with learning disabilities can benefit from the assessment process.

Fits with other local, national and international assessment development.
The assessment needs to be suitable for use by the occupational therapists in the local service. It needs to fit with other multi-agency assessment processes for adults with learning disabilities and meet the service remit. This is in order to ensure there is clear communication across agencies and that services are provided in a joined up way. The occupational therapists need to be able to adapt their practice and assessment tools to meet service demands and changes.

4.3.4 Summary of stage one: phase one

The local occupational therapists in stage one: phase one reviewed the assessment tools that they were using in their practice and concluded that none met all of the needs of their service. The themes from the discussions were explored with the local occupational therapists to reach a consensus on what were the essential criteria for an assessment that could be used with adults with learning disabilities in their practice. These criteria were based on the collective practice knowledge and experience of the local occupational therapists. Creek (2003) recommended that occupational therapists need to be familiar with different assessment tools so that they can ensure that they were using the most appropriate ones in practice. Therefore, the lead researcher agreed to search for existing published assessment

tools that could meet these essential criteria so that these could be considered for use in the local occupational therapy service.

4.4 Stage one: phase two - a review of the literature on the assessments of adults with learning disabilities

4.4.1 Method stage one: phase two

A systematic search of potential assessment tools that could be used by the local occupational therapists was found to be challenging due to the large number of published assessments available. In order to narrow down the search to select relevant assessment tools the lead researcher considered the following three areas as recommended by Unsworth (2000) and adapted them to the need of the local occupational therapy service:

- **Suitability for population.**
  Assessment tools needed to be designed or useful for adults with learning disabilities and appropriate to be completed in a community setting. The search needed to include tools that could meet the needs of the diverse levels of ability of the adults with learning disabilities and so several different types of assessment may be required. Many assessments tools may not be suitable for adults with learning disabilities due to the need to be interviewed using complex language or concepts. Even if these assessments could be adapted to be more accessible there would still be some people with learning disabilities who would not be able to be interviewed.
- **Meets needs**
  The tools need to be able to assess occupational performance and community participation. They need to be sensitive to the needs of people with learning disabilities in that they are able to detect small changes in skills. The assessment tool needs to be easily obtained and be able to be conducted by the local occupational therapists.
- **Standardised**
  Only published standardised assessments were included in the search. This was because the occupational therapists had identified that they required a valid and reliable measure that would provide evidence for the occupational therapy intervention in the local service.

These criteria were used in order to exclude assessments that would not be suitable and to reduce the list of potentially useful assessments to a more manageable list that could be reviewed in detail.

4.4.2 Stage one: phase two - review of published standardised assessments

The lead researcher identified published assessments from the following sources:

- Those known by the lead researcher or local occupational therapists as being practised in occupational therapy services for people with learning disabilities.
- Assessments sourced from a preliminary review of the literature on occupational therapy and learning disability specific assessments.
- Clinical Assessments compiled by the College of Occupational Therapists (COT 2007)

There were 230 assessments on the College of Occupational Therapists' list. Five additional assessments were identified from the other sources. A review of the 235 assessment tools was made to exclude all assessments that were designed for children, not related to assessment of occupational performance or were an assessment of a specific condition other than learning disability. See Appendix G for the full list of the identified published assessment tools and Table 4.6 summarises the reasons why assessments were excluded.

Table 4.6: Summary of the categories of assessment tools

Type of assessment tool	**Number of tools**
Assessment tools that potentially could be used by occupational therapists working with adults with learning disabilities.	**39**
Not known: Assessment tools description did not provide enough information to identify if they were potentially useful or could be excluded.	**54**
Assessment tools excluded	**142**
Reason for exclusion of the assessment tools:	
Children specific	**13**
Specific condition (Not learning disability)	**98**
General physical health	**11**
Falls	**6**
Work	**14**
Total of all assessments identified	**235**

From the initial review of the assessments available in 2007, 142 were eliminated using the exclusion criteria and 54 did not have enough information to categorise them. This left 39 assessment tools that were identified as potentially appropriate for the local occupational therapists to use when working with adults with learning disabilities. The local occupational therapists had been previously aware of only 17 of the tools identified. Some of these had been purchased for use in the team and trialled before deciding that they were not useful. Only 4 of this list of 17 tools were currently in use by the local service and listed in Table 4.7. The local occupational therapists also reported using four locally produced assessments at this time.

Table 4.7: Published assessment tools used in the local occupational therapy service

Tool	Author
Hampshire assessment for living with others (HALO)	Shackleton Bailey and Pidock (1983).
Assessment of motor and process skills (AMPS)	Fisher (2003) 5th edition
Adolescent/Adult Sensory Profile	(Brown and Dunn 2002)
Interest checklist (Model of Human Occupation (MOHO))	(Heasman and Salhotra 2008)

The assessments that were already known were reviewed to consider how well they met the essential criteria and none were found to meet all of them. The search for published assessment tools that could meet the needs of the occupational therapists working in the local service with adults with learning disabilities revealed a much larger list than was first anticipated by the lead researcher and the occupational therapists in the group discussions in 2007. It was revealed that there were 22 assessment tools that were not known but looked as though they could be appropriate for use by the local service and an additional 54 that did not have enough information available to eliminate them. The findings of this preliminary review indicated that there could be an assessment already available that could meet the needs of the occupational therapy service. However, the task of reviewing if any of these 76 existing tools met the essential criteria for assessment that were identified in stage one: phase one, would be time-consuming as each of the assessments would need to be obtained and reviewed. This exercise was completed for one of the identified tools; 'The Support Intensity Assessment'

(Thompson et al 2004). The information available about the assessment indicated that it could meet the essential criteria. It was ordered and shipped from the USA as it was not possible to review the assessment without purchasing it. However, on receipt of the assessment, it was not found to meet the needs of the local service as it was intended for use by care managers to decide on costs of care packages rather than having an occupational performance perspective. The cost of purchasing the other 75 assessment tools and the resources of staff time in reviewing each manual to decide whether or not each could be used in practice could not be justified in the local service. The enormity of the task of accessing all the identified assessments and further investigating if there were other tools that could also be appropriate was exposed by this exercise.

The initial expectation that a new assessment tool could be developed to meet the needs of the local service was questioned at this time, as so many published assessments already existed that were not known or used by the local occupational therapists. It, therefore, did not appear from this search that another new assessment tool needed to be developed. However, there appeared to be a problem for the local occupational therapists in accessing the assessments that had been published and utilising them in their work.

One of the original objectives for stage one of the action research fieldwork was to agree an assessment tool that could be piloted in practice. However, the review of the assessment tools did not identify an assessment tool to pilot or to rule out all of the existing assessments available so that the development of a new tool would be justified. None of the known tools were identified as being able to meet all the essential criteria identified in phase one. It was not known if all these criteria for an occupational therapy assessment tool could be addressed by just one tool.

4.4.3 Stage one: phase two - review of the literature on occupational therapy assessment.

The review of published standardised assessments presented in Section 4.4.2 revealed the problems for occupational therapists in accessing and using standardised assessments with people with learning disabilities. Throughout stage one, the lead researcher continued to explore and review the literature on occupational therapy assessment to see if other approaches to assessment could

be identified which were more amenable to work with adults with learning disabilities. This second part of the literature review is presented in a separate section so it is distinct from the literature and policy that was available to the local occupational therapists when they initially developed the essential criteria for assessments (Table 4.5).

At a similar time to the commencement of stage one, Blount (2007) sent questionnaires to occupational therapists working with adults with learning disabilities in the United Kingdom (which included some of the local occupational therapists from this research study) to ascertain what assessment tools they were currently using. Ninety-two, out of the one hundred occupational therapists who responded, reported that they used occupationally focused assessment tools. Just over half of these, (fifty-five) used a combination of standardised and non-standardised assessments. Blount (2007) concluded that, although standardised assessments were used by many occupational therapists with adults with learning disabilities this was not a universal practice. Blount's findings were similar to the local occupational therapists' experiences which would appear to indicate that the local occupational therapists were using assessments in a similar way to those working with the same client group in other services within the same country.

Blount (2007) reported that non-standardised assessments could be used flexibly to meet individual needs but had concerns about their use as they could not be easily replicated to produce outcome measures. She found that it was common practice to modify assessment tools by simplifying the language, using photographs, pictures and symbols to enhance communication with the clients. However, Blount (2007) suggested that this practice of modifying standardised assessments rendered them invalid. The perceptions of the occupational therapists about these assessment tools and whether or not they, or the people with learning disabilities who they worked with, were satisfied with them was not addressed in her study. Blount (2007) recommended that '*further research on the need for specific assessment tools for this complex client group would be beneficial to aid the development of suitable standardised occupationally focused assessment tools'* (Blount 2007, p1).

Goodman and Locke (2009) recommend using measurement tools because *'standardised and well validated outcome measures can, and do, provide objective data to ensure a service is establishing results in line with clinical governance and evidence based practice'* (Goodman and Locke 2009, p 52). However, they also

reported that this could be problematic in practice as assessments are often *'not standardised nor validated for people with a learning disability'* (Goodman and Locke 2009, p 53). Just as the local occupational therapists had experienced in this research study, the authors reported that many standardised assessments require the person to answer questions and so can exclude people with communication difficulties. They may also require the person to be able to focus their attention on occupational performance areas that they had not chosen as important for them or to do things in an unfamiliar way or setting. As in the study by Blount (2007) and discussed with the local occupational therapists (see Section 4.3.2), there was a concern that if the occupational therapist adapts the assessment to meet the needs of an individual with learning disabilities, more useful information may be collected but this change is likely to affect the standardisation of the measure. The practice of the local occupational therapists of using the ADL checklist and the AMPS (Fisher and Bray Jones 2014) together was an example of the suggestion that some occupational therapists may use *'a non standardised assessment to supplement the results of a standardised tool'* (Goodman and Locke 2009, p53).

Section 2.4 describes how Lillywhite and Haines (2010) used focus groups of occupational therapists working with people with learning disabilities in the United Kingdom to explore to what extent the Practice Principles (COT 2003) (see Table 1.1) were being met. Lillywhite and Haines (2010) had similar findings to Blount (2007) and Goodman and Locke (2009) in that the majority of the assessments used by occupational therapists working with adults with learning disabilities were not standardised. Goodman and Locke argued that non standardised assessments could provide useful information in the absence of appropriate standardised tools. They suggested that *'people with learning disabilities may feel more comfortable with a less formal and systematic approach to assessment'* (Goodman and Locke 2009, p54). This statement that people with learning disabilities may prefer one type of assessment over another did not appear to have been investigated by the authors.

The essential criteria developed by the local occupational therapists (Table 4.4 and Section 4.3.3) acknowledged the need for a valid and reliable assessment tool in the criteria: 'fit for purpose' and the need to meet service and occupational therapy professional standards in 'fits with other local, national, international developments'. However, meeting the need for standardisation often appears to be in contradiction to the three criteria: 'client centred/choice and empowerment', 'accessible easy to

use and understand', and 'designed for people with learning disabilities'. The occupational therapists who were adapting assessments would appear to be motivated by meeting this second set of concerns.

There are similar findings regarding the limited use of standardised assessment in some studies of occupational therapists working in other fields. Koh et al (2009) surveyed Australian occupational therapists working with people with cognitive impairments following a stroke. The occupational therapists reported that they used standardised assessments when measuring the person's cognitive impairments but '*relied more on clinical observations or assessments developed by their own workplace'* (Koh et al 2009, p330) to assess activities of daily living. This emphasis on 'observation' was one of the essential criteria for assessment that was developed in the local service. Holmqvist et al (2009) interviewed Swedish occupational therapists assessing people with cognitive impairments following an acquired brain injury. The findings were that the occupational therapists preferred not to use standardised assessments and suggested that this could be due to their collaborative client centred approach. They were not sure how to explain the assessments to the clients and were reluctant to expose their clients to the negative experience of being tested. Many of the standardised assessments available to this group of occupational therapists were focused on function and impairments and so were not considered useful as the occupational therapists were focusing on activity. The occupational therapist described using unstructured observations and how they '*developed their knowledge by learning from every client'* (Holmqvist et al 2009, p21). They suggested that the occupational therapists' use of observations was demonstrating their tacit knowledge in action. The occupational therapists' knowledge, built up from reflecting on their experiences, did not appear to have been acknowledged by them as appropriate evidence on which to base their practice. Holmqvist et al argued that the occupational therapists were using '*both clinical reasoning and clinical judgement*… [but stated that] *empirical research on the concept is scarce'* (Holmqvist 2009, p21). This example of occupational therapists relying on their practice knowledge but not considering this as evidence based practice was similar to the literature explored in Section 2.5 about the importance of occupational therapists reporting on what they are doing in real practice situations and acknowledging this as practice based evidence.

White et al (2014) used semi-structured interviews of nine occupational therapists in New Zealand to explore how they engaged people in assessments with cognitive

impairments acquired as adults due to conditions such as having dementia, multiple sclerosis or a traumatic brain injury. The occupational therapists emphasised the importance of developing a rapport with the person with a cognitive impairment above the rigid use of standardised assessments. The decision to use a standardised assessment was based on the relevance of the questions for that person and how the occupational therapists perceived that the assessment process was affecting the person's level of anxiety. Difficult questions would often be omitted by the occupational therapists due to these reasons and so the standardisation of the tool was compromised. This was similar to the reports by the local occupational therapists in this research study (Section 4.3.2.1). Another finding in the study by White et al (2014) was that there were concerns that the occupational therapists did not always obtain the informed consent of people with cognitive impairments to undergo the assessments. The ethical issues of occupational therapists completing standardised cognitive assessments that were not based on meaningful and familiar occupations and had not obtained the person's consent were questioned in this study. It was concluded that '*therapists experienced increased difficulty engaging clients in assessments that were not specific to occupational therapy, and greater success when using occupation-based assessments'* (White et al 2014, p5).

Jang et al (2009) completed a study of the Loewenstein occupational therapy cognitive assessment, which had been developed for use with people with acquired cognitive impairments, to consider its validity when used with people with learning disabilities. Jang et al (2009) completed validity tests with 111 people with learning disabilities living in Taiwan aged 16-28. The use of the assessment tool in this context was to assess the cognitive function of people with moderate or severe learning disabilities in order to plan vocational rehabilitation and work programmes often in institutional settings such as colleges and sheltered workshops. The assessment was not occupation focused as it consisted of a series of cognitive and visual tests. Although the conclusion of the study was that the Loewenstein assessment was considered valid when measuring the cognitive abilities of young people with learning disabilities, the authors acknowledged that further research was required to investigate '*the association of test performance with employment status or community function*' (Jang et al 2009, p 421). Assessments that just measure cognitive abilities would not meet the essential criteria of the assessment tool identified by the local occupational therapists as they do not meet the three criteria: 'assess occupational performance', 'global skills rather than just one aspect' and 'highlight skills and support needs in order to make meaningful and useful

recommendations'. The occupational therapists in the studies cited (White et al 2014, Holmqvist et al 2009 and Koh et al 2009) had reservations regarding the use of assessments of cognitive function rather than those related to occupation. Assessment of underlying impairments is not usually relevant when working with adults with learning disabilities as a change in the underlying condition is not usually expected and would not be the reason for the intervention (see eight core principles COT 2013a, Table 1.2). If the assessment is related to the occupational performance goals that the adult with learning disabilities has chosen, then they are more likely to be able to understand the purpose of the assessment and to make an informed choice about participating.

White et al (2014) suggested that occupational therapists need to be skilled at providing standardised assessments to people with cognitive impairments ensuring that their approach is enabling and client-centred, includes clear processes for obtaining consent, and is occupation-based. This study emphasised the need for occupational therapists to use standardised assessments whilst acknowledging that '*navigating this challenge is an issue requiring the urgent attention of the profession'* (White et al 2014, p8). Mortenson and Dyck (2006) carried out an insider study where they explored concepts of client centred practice with ten Canadian occupational therapists working in physical medicine. The study explored perceived barriers to occupational therapy client centred practice and issues of power relationships. They concluded that although the quality of the client-therapist relationship was important, *'practice is also shaped by complex interactions between professional discourses, institutional policies and practices and health care resources within a particular setting'* (Mortenson and Dyck 2006, p 269). They recommended that occupational therapists need to critically evaluate their processes, documentation and policies to ensure that they are working in empowering collaborative partnerships with their clients. The examples from the studies on occupational therapy practice with people with acquired cognitive impairments suggests that a rigid adherence to the use of standardised assessments to meet professional or service demands for evidence based practice may be a barrier to client-centred practice.

Mitchell and Unsworth (2004) analysed responses to questionnaires from thirty-six occupational therapists in Australia in relation to their clinical reasoning on home visits. The occupational therapists worked across a variety of specialities although working with adults with learning disabilities was not specifically mentioned. None of

the occupational therapists reported that they used standardised assessments as they were not suitable, had no access to them, no training or experience in using them, they were too general for their purposes, time consuming and a problem if the person could not speak English. The studies reviewed in this literature section suggest that the limited use of standardised assessments by occupational therapists is a wider issue than just within the field of adults with learning disabilities.

Section 2.3 described the model of practice adopted by the local occupational therapists based on OTIPM (Fisher 2009) due to the process driven occupation-centred practice approach. Hawes and Houlder (2010) reported that occupational therapists working with adults with learning disabilities in the community in the United Kingdom need to demonstrate evidence based practice and provide services in a standardised way but also acknowledged that this could then hinder the ability of the occupational therapist to be flexible. To address this concern, Hawes and Houlder (2010) recommended that occupational therapists working with adults with learning disabilities need to have flexibility to decide on a wide range of assessment tools. The authors proposed that *'a potential solution may be to adopt a model of practice that uses consistent and evidence-based occupational concepts to structure the way in which therapists think about their assessments, interventions and reports, while allowing clinical freedom to use the widest possible range of practical assessment and intervention methods'* (Hawes and Houlder 2010, p 564). This was similar to the reason why the local occupational therapists adopted the use of the OTIPM (Fisher 2009). However, Hawes and Houlder (2010) instead adopted a theory-driven model of practice based on the model of human occupation. The MOHOST screening tool (Parkinson et al 2006) was piloted in services for adults with learning disabilities by eleven staff for a six month period and was found to be useful. However, the approach was found not to be suitable for people with profound learning disabilities so excluded a portion of the client group that the occupational therapy service needed to address. The authors also reported the concern that the MOHOST (Parkinson et al 2006) did not meet with the philosophy of occupational therapy for adults with learning disabilities in that '*learning disabilities services prefer to focus on what people can do rather than what they cannot, yet the MOHOST, as an ordinal and objective measure of occupational performance, necessarily highlights deficits'* (Hawes and Houlder 2010, p 566). The MOHOST covered areas that were not the focus of the referral or the goals of the person with learning disabilities but a wider view of occupational performance. This tool appeared to have been devised to ensure that it was standardised from the occupational therapists'

perspective. However, this could mean that the focus for the occupational therapist was filtered by the MOHOST (Parkinson et al 2006) tool rather than the concerns of the people with learning disabilities or the expectations of the organisation, such as being responsive to specific referral issues. This appears to suggest that the use of standardised assessments, such as MOHOST (Parkinson et al 2006), which are based on theory-driven models may not be person-centred or flexible enough to meet the needs of the whole population of adults with learning disabilities with whom the occupational therapists work.

Evaluation studies of the use of AMPS with adults with learning disabilities have been completed by the same group of authors based in Sweden (Kottorp et al 2003a, b and c and Hällgren and Kottorp 2005 see Sections 2.4.2 and 4.3.2.). Dwyer and Reep (2008) published an 'opinion piece' describing their experiences of occupational therapy assessments in the local service and recommended the use of the AMPs to assess people with learning disabilities and mental health needs within the local occupational therapy service. The study reported anecdotal evidence that the AMPS was favourably viewed by people with learning disabilities and their carers but did not have evidence to substantiate these claims. Mesa et al (2014) explored the use of the AMPS within a community service working with adults with learning disabilities in London which was similar to the local service in this research study. They used the AMPS, as part of the generic team role to support the decision making process to establish if someone met the criteria of having a learning disability and so would be eligible to receive a service. The AMPS was not being used to support an individual to meet his or her occupational performance goals but as a justification to allow or restrict access to a service. The study did however suggest that the AMPS assessments could be useful at a future date as a baseline for comparison if the person's skills deteriorated or as an outcome measure to demonstrate evidence based practice. These two studies gave some evidence that the AMPS was being used by occupational therapists working in community services with adults with learning disabilities in London. However, the AMPS was used in the study by Mesa et al (2014) to manage eligibility to access the service rather than the focus on the individual's occupational goals. The AMPS did not appear to be used as an outcome measure of occupational therapy but in both studies it was proposed that it was useful in recording a baseline that was usually only repeated to consider if a person's skills were deteriorating.

The AMPS appeared to meet many of the essential criteria for assessments developed by the local service. It is standardised and has some published evidence as to its validity and use with adults with learning disabilities. It is based on OTIPM and uses observation of occupational performance on specific skills and the findings can be used to make intervention plans and recommendations for support needs. However, some limitations with the use of the AMPS in this field were noted and have been described in Section 4.3.2. Not all the occupation performance concerns that a person may identify can be assessed using the AMPS tasks and so it may not always be client-centred. There were some reservations as to its use with adults with severe learning disabilities. The AMPS may not meet the essential criteria: 'practical good use of resources', as the time required to train each occupational therapists and to purchase the training courses, software and manuals each time they are upgraded would need to be justified in the local services. The AMPS was not designed to incorporate the views of others involved with the person with learning disabilities as it just observes the person completing two tasks. It was not known what adults with learning disabilities or their carers thought about the AMPS.

The initial perception that the use of standardised assessments by the local occupational therapists would support them in their ability to measure the outcomes of their interventions and justify the effectiveness of the service did not appear to be supported by the review of the assessment tools and the literature. The essential criteria for assessments developed in stage one: phase one of the action research fieldwork do not mention the need for the assessment tool to be an outcome measure to demonstrate change as a result of occupational therapy intervention as defined by Unsworth (2000). The criteria: 'highlight skills in order to make meaningful and useful recommendations' more closely matches the wider purpose of assessment defined by Laver Fawcett (2007) which is to use the findings to make decisions throughout the therapy process (see Section 4.2).

4.5 Stage one: phase three - consideration of changes to the local therapists' practice following the review of the assessment tools

Throughout stage one: phases one and two, the local occupational therapists engaged in the discussions as part of their usual service development meetings and the lack of information on what people with learning disabilities and others in the

client constellation considered important in an occupational therapy assessment was highlighted as a concern. It was agreed that, before deciding on any actions in regard to developing a new assessment tool or making any further changes to the occupational therapy assessment process, it would be important to understand how the occupational therapy assessment was currently perceived by all who had an interest in it and to what extent the essential criteria for the assessment were already being met in practice. The local occupational therapists supported the lead researcher's plan to apply for ethical approval to complete an action research study. The two main ethical challenges identified at this time were recruiting the OT co-researchers for an open-ended and unpredictable study and the plan to interview people who may not have the capacity to consent to this. The ethical issues are explored in Section 3.8 and briefly in Chapter 10. Stage one: phase two was completed at the beginning of 2008 and stage one: phase three did not start until April 2010 see time line (Appendix A). This delay was due to the need for ethical approval (see Section 3.6) and also due to the local service undergoing a management restructure.

At this time, the local occupational therapy service continued to be employed by a primary care trust but now, the team working in one borough was managed by the local authority whilst the half of the service continued to be managed by health. These changes resulted in the expectation of the occupational therapists under the local authority arrangements to be more involved in generic working and taking on more social care concerns. There appeared to be little support for retaining senior occupational therapy posts or the need for research under the new management structure. The need to make savings and the possibility of making staff redundant were emphasised. These changes in the expectations of the team moved the focus away from this research study which was temporarily stalled.

The lead researcher's work role was changed to a wider remit which resulted in less direct involvement with the occupational therapy service. The lead researcher, therefore, became less of an 'insider researcher' for this stage of the research study than she had been in stage one, as she had no supervisory or direct occupational therapy delivery responsibilities within the service but did continue to have a clinical leadership role for the wider multi-disciplinary team within the primary care trust. There was concern that the division of the two teams would adversely affect the motivation of the local occupational therapists to be involved in a joint research study as the expectations of them differed under the new structures. However, the

two learning disabilities teams remained as one service and the occupational therapists, including the lead researcher, continued to regularly meet to share and develop their practice. When the ethical approval was granted (December 2009 see Appendix F) for the research study, there was agreement from the new service managers in the local authority for this research study to go ahead.

Section 3.4.3 outlines how the OT co-researchers were engaged in the action research fieldwork. Table 3.2 summarises the demographic details of the nine OT co-researchers who were recruited at the start of stage one phase three. The first set of OT co-researcher questionnaires described in Section 3.4.4.2 were completed before the first OT co-researchers met in April 2010 to ascertain the demographics and perceptions of the OT co-researchers and the lead researcher (see Appendix E for the full version of the questionnaire).

4.5.1 The OT co-researchers use of assessments at stage one: phase three

The OT co-researcher questionnaires (see Appendix E) asked the OT co-researchers and the lead researcher to list the essential requirements of an occupational therapy assessment. The responses were matched by the lead researcher to the essential criteria for the occupational therapy assessment (see Table 4.5), and are summarised in Table 4.8 with some examples of the responses. All of the essential criteria were covered by at least two of the responders except for 'Fits with other local, national, international developments'. However, none of the responders mentioned all of the essential criteria.

At the first OT co-researchers' meeting in April 2010 how the lead researcher had matched the responses (see Table 4.8) was presented and it was agreed that all of the essential criteria for an occupational therapy assessment for adults with learning disabilities were still relevant to their practice. There had been a period of two years and new team members had joined the service since the previous review of the assessment tools in stage one: phase two (see Table 4.7). The OT co-researchers and lead researcher listed the assessments that they had used in their practice in the previous three to six months (see Table 4.9). Although, nineteen different assessments were listed by the nine group members, seven of these had only been used by one of them.

Table 4.8: OT Co-researchers and lead researcher's questionnaire responses at the end of stage one April 2010

Essential Criteria of an assessment tool	**OTs***	**Examples of statements made by the OT co-researchers and lead researcher.**
Assess occupational performance	5	*"Focused on occupational performance".* *"Gaining a clear view of how activity/occupation fits into the person's world".*
Global skills	2	*"ADL tasks".*
Highlight skills in order to make meaningful and useful recommendations	3	*"The assessment identifies impact of diagnosis and environment on function and OT can develop clear recommendations".*
Client centred/choice and empowerment	9	*"Service user is at the centre of the process".* *"Explaining to the client how the assessment fits into their needs/wishes and ensuring they understand what they are being asked to do and why".* *"Client feels that his/her life has improved as a result".*
Accessible easy to use and understand	6	*"User friendly".* *"Appropriate communication techniques are used".*
Designed for people with learning disabilities	5	*"Assessment is completed in the best possible environment".* *"Provided at a time that is relevant". "Being flexible".*
Fit for purpose	8	*"Gathering reliable information of purpose of assessment from all parties".* *"Gaining accurate information".* *"Therapist's own competence in completing the assessment".* *"Standardised".* *"Objective view of the circumstances".*
Practical/ good use of resources	2	*"Resources being available".* *"Preparation".*
Observation	4	*"Observation in different environments and times".* *"Ensuring that you actually see the person doing whatever is relevant to the assessment".*
Incorporate views of all people involved	5	*"Getting the views of significant carers".* *"Have as many opinions from others who know the client as possible".* *"Good background information including access to assessments by other members of the MDT".*
Fits with other local, national, international developments.	0	

**Number of OT co-researchers who mentioned each criteria. (N=10)*

The ADL checklist, AMPS and HALO, continued to be reported to be frequently used in practice but the HALO was now being referred to as an ‘adapted version’. The local occupational therapists had noted that the HALO was not possible to use as a standardised assessment following their reflections and discussions in phase one. They now described using specific sections only as relevant to the issues of the individual being assessed. Four of the occupational therapists were now trained in the use of the AMPS.

The locally produced assessment forms were based on the local occupational therapists’ knowledge built up from their experiences in practice and were used for three different purposes. The eligibility and screening assessments were used to establish if the referrals made was appropriate and to consider prioritisation. The initial assessment form was used to support the occupational therapists to use the OTIPM (Fisher 2009) to assess and plan intervention. Occupational performance was assessed using the ADL checklist as a general review and the travel training, time telling and eating and drinking assessments were used to address the more specific needs. A greater emphasis was on the use of informal observations of the person completing the tasks they wanted to do.

Eleven published standardised assessments were identified as having been recently used by the local occupational therapists. Five of these were reported to be used as specified and are highlighted in green. However, only the AMPS was reported to have been used as standardised by more than one of the OT co-researchers. The remaining six of the standardised assessments had been modified in some way by the local occupational therapists so that they could be used with the people they were working with and are highlighted in yellow. All the locally produced assessment forms, highlighted in pink were used by at least two of the OT co-researchers.

Table 4.9: Assessments reported to be used by the OT co-researchers and lead researcher in April 2010

Most commonly used assessments	Number of OTs who used it	Less commonly used assessments	Number of OTs who used it
HALO (adapted version) (Shackleton Bailey and Pidock 1983)	8	Time telling assessment	2
Observation of task (informal)	8	Sensory profile (Dunn 1999)	1
ADL checklist	7	Role checklist (MOHO Oakley 1984) role checklist adapted with pictures	1
Screening assessment	5	Sensory Integration Inventory Revised for Individuals with Developmental Disabilities (Reisman and Hanschu 1999)	1
Adolescent / Adult Sensory Profile (Brown and Dunn 2002)	5	Occupation Screening Tool version 2.0 MOHOST (Parkinson et al 2006).	1
AMPS (Fisher and Bray Jones 2014)	4	ACIS Assessment of Communication and Interaction Skills – version 4. (Forsyth et al 1998).	1
Eligibility assessment	4	Capacity assessment for paying rent based on the Mental Capacity Act 2005 code of Practice (Department for Constitutional Affairs 2007)	1
Eating and drinking assessment	4	Adaptive Behavior Assessment System – Second Edition ABAS-II (Harrison and Oakland 2003)	1
Travel training questionnaire	4	***Key to colours:***	
Initial assessment based on OTIPM (Fisher 2009)	4	Locally produced tool	
Interest checklist (MOHO Heasman and Salhotra 2008) adapted locally to include pictures.	4	Published assessment	
		Published assessment locally adapted	
Total assessments used by the team			**19**

Number of OT co-researchers.(N=9)

The OT co-researchers shared their experiences of what was going well with the occupational therapy assessments over the last three to six months (see Table 4.10). The occupational therapists reported that they had not been previously aware of most of the individual examples presented by their colleagues and expressed an interest in considering how to apply these different ways of working into their own practice. Many examples included how the person with learning disabilities was supported to take a more active part in their own assessment process.

Table 4.10: Responses to the question "What was going well with occupational therapy assessments?" in April 2010

- *Pictorial Interest checklist- using accessible information, person in control.*
- *AMPS: Clients very happy to take part*
  Doing is better than talking- prevents us making assumptions
  Works well as dementia baseline
  Even if not able to do AMPS can help to structure observations.
- *Sensory Integration Inventory really useful to be able to observe and make recommendations for environment as part of discharge planning.*
- *Interviewing a carer and client separately so that they can talk about their perceptions and fears e.g. travel or moving away from home. Then assessment report allows for the evidence from both to be recorded and to help the parties agree/compromise.*
- *Essential to observe in own environment- home, day centre to build rapport, less threatening, flexibility.*
- *Take time to plan, as this results in fewer cancellations.*
- *Doing*
- *Holistic*
- *Get carer to watch you to model not being over- supporting.*
- *Using a HALO to assess accommodation needs- if this is described well can be good and comprehensive.*
- *An example of producing an accessible report so client could present it himself at the review meeting.*
- *OT assessment gives client opinion in a format they understand and feel valued.*
- *Able to record both strengths and needs.*

The OT co-researchers and lead researcher agreed that, before further changes were made to the occupational therapy assessment process, there was still a need to understand how the occupational therapy assessment was currently perceived by all who have an interest in it and to what extent the essential criteria for the assessment were already being met in practice.

4.6 Reflections on stage one

The responses from the OT co-researchers questionnaires (Appendix E) regarding their expectations of participating in the action research fieldwork were positive and optimistic at this stage. Some comments indicated an understanding of the purpose of action research in trying to improve practice. An example was:

> *'I think if everyone gets involved and contributes fully then we will get a useful outcome that benefits us all and our clients' (Q1)*

All the OT co-researchers who commented indicated that they would fully participate in the study and reported that they were supported by the service to be involved. One suggested that:

> *"open communication will be key. It will be important to get the views of the co-researchers to ensure their on-going commitment to the project (Q1)"*

This suggested that the OT co-researchers were expressing their motivation and commitment to the project and willing to be challenged to collectively critically reflect on and improve their practice. The initial enthusiasm and engagement of the local occupational therapists in phases one and two of stage one influenced the plan for this research study to be a participative methodology using the existing community of practising occupational therapists. The responses at phase three supported the decision of recruiting the OT co-researchers to participate in the action research fieldwork. This met the reflexivity principles of collaboration and creating plural structures set out by Winter (1996), see Section 3.4.1.

Section 3.4.1 describes the use of dialectic critique (Winter 1996, see Section 3.4.1) in which the lead researcher worked to understand the relationships between phenomena in the context of occupational therapy local practice. The local occupational therapists' professional reasoning were explored based on the aspects of occupational therapy professional reasoning as proposed by Boyt Schell and Schell (2008) (see Section 2.5.1. and Table 2.2).

At the start of stage one: phase one, the local occupational therapists were encouraged to review their current use of assessment tools focusing on standardisation of assessments and externally developed evidence and theory. The critical reflections of practice were, therefore initially dominated by *scientific* and *diagnostic* reasoning. This process of critically reviewing the evidence base, reliability and validity of the assessments resulted in the occupational therapists questioning the assessments they were using and realising that none could meet all

of the seven requirements set out by McDowell (2006) (see Table 4.2). This was an example of using reflexive critique (Winter 2006, see Section 3.4.1) in that assumptions about evidence based practice were being challenged and other interpretations were being made.

If the occupational therapists had continued to apply pure scientific and diagnostic reasoning, it would have been expected that the discussions would have proceeded towards attempting to resolve the variables in practice so that the standardised assessments could be applied. However, from the group discussions it appeared that the local occupational therapists considered that the strict application of a standardised assessment reduced their ability to use other aspects of their professional reasoning that did not appear to be covered by the seven requirements of McDowell (2006). Although the local occupational therapists were motivated to adhere to evidence practice, they did not use standardised assessments if they had concerns in regards to other aspects of their professional reasoning. For example: they omitted questions due to concern of causing distress due to the sensitive topic or being too hard to understand. They did not use an assessment if they considered it may not be fair or acceptable for adults with learning disabilities. At these times their *ethical reasoning* appeared to be prioritised over the need to rigidly adhere to a standardised process. *Narrative* and *Interactive reasoning* were explored in the group discussions as the local occupational therapists considered that their assessments needed to focus on their work with adults with learning disabilities to identify their occupational performance concerns and collaboratively work together to achieve a change.

As problems were identified in the discussions, the occupational therapists immediately worked together to consider what would be required to improve each of the assessment tools so that they would meet the need of the local service. *Procedural reasoning* was used to clarify the existing assessment processes. The local occupational therapists revised the categories and the scoring for the ADL checklist as soon as they realised that there were various interpretations of these within the team. *Pragmatic reasoning* was used to make practical changes to address problems that had been revealed. The HALO assessment was updated so that the categories of environments and levels of support would more easily match the options for community living currently available. The technology that had not been available when the HALO was developed such as mobile telephones, the internet, cashpoint machines etc. could be included. However, the local occupational

therapists were aware, using their *scientific reasoning* that these practical changes affected the standardisation of the tool.

The essential criteria for an assessment were developed from the local occupational therapists' engagement in the critical enquiry in regards to their assessment practices. The essential criteria were initially considered by the lead researcher as quite 'obvious' and dismissed as not of significant interest. However, on reflection and following the further review of literature in Section 4.4.3, the essential criteria could be considered as an example of practice based knowledge being articulated, as described by Higgs and Titchen (2001) in Section 2.5. The criteria were accepted by the local occupational therapists as 'tacit' knowledge which had been built up from their collective reflections on their experiences in practice using their *conditional reasoning* as all the aspects of professional reasoning were taken into account. This was an example of the sixth principle of reflexivity: theory and practice internalised (Winter 2006) and how this enhanced the collective practice knowledge. This internal review of the local occupational therapists' understanding of their assessments could now be critically reviewed in the next stages of the action research fieldwork by those who have experienced an occupational therapy assessment. This was planned to challenge the local occupational therapists' practices and assumptions and to consider to what extent the occupational therapy assessments actually met the essential criteria in the local practice.

The lead researcher used a reflexive critique (Winter 1996) when she was facilitating the action research fieldwork so she could be aware of any assumptions and how she was influencing the study. She had envisaged that the action research was going to be a democratic process working in collaboration and partnership with the OT co-researchers. This was planned to be a naturalistic process led by occupational therapy practice. However, she was aware that her role of leading the research study created barriers to this process. At the start of stage one: phase two, the lead researcher reflections in the OT co-researcher questionnaire (Appendix E) indicated that she had a sense of responsibility to the OT co-researchers in that she was encouraging them to commence a process with her that had an unknown outcome or completion date.

> *"I am not certain which direction this project is heading…how my current job role and the service will change, and if this project will be supported for the next three years" (Q1LR).*

This was an example of the principle set out by Winter (1996) of risking disturbance which is an essential component of the action research process. She was aware of the time and resources spent on the action research fieldwork and could not be certain that any changes would be made and sustained and if these would be of a benefit to practice. However, this needed to be balanced with enabling the fieldwork to reflect the real world uncertainties of the local occupational therapy practice.

The lead researcher reflected on the constant need to balance her agenda to complete a research study and the need for occupational therapy practice to lead the direction of the study. The lead researcher's pre-conceived idea to develop a new assessment tool to meet the essential criteria needed to be re-considered and the lead researcher had to move on with uncertainty which was stressful.

During the discussions in stage one: phase one, the local occupational therapists noted problems with the assessment tools that they were using and instantly made plans as to what they could do to resolve them. Individuals were reflecting on their practice in the group discussions and making changes as a result. In stage one: phase three many changes to the assessment process and model of practice had taken place outside of the action research fieldwork. The lead researcher could not identify and record these numerous, continuous and subtle changes for the purpose of the action research fieldwork. She initially wanted to stop any changes to the assessment process so that a clear baseline starting point could be compared with a future change. However, on reflection this would have meant that the action research fieldwork would have been disrupting the natural practice development in the messy real world situations. The lead researcher needed to accept the uncertainty of the action research fieldwork and how this was reflective of the reality of practice. This was an example of how the research study met the principle of Winter (1996) of creating plural structures.

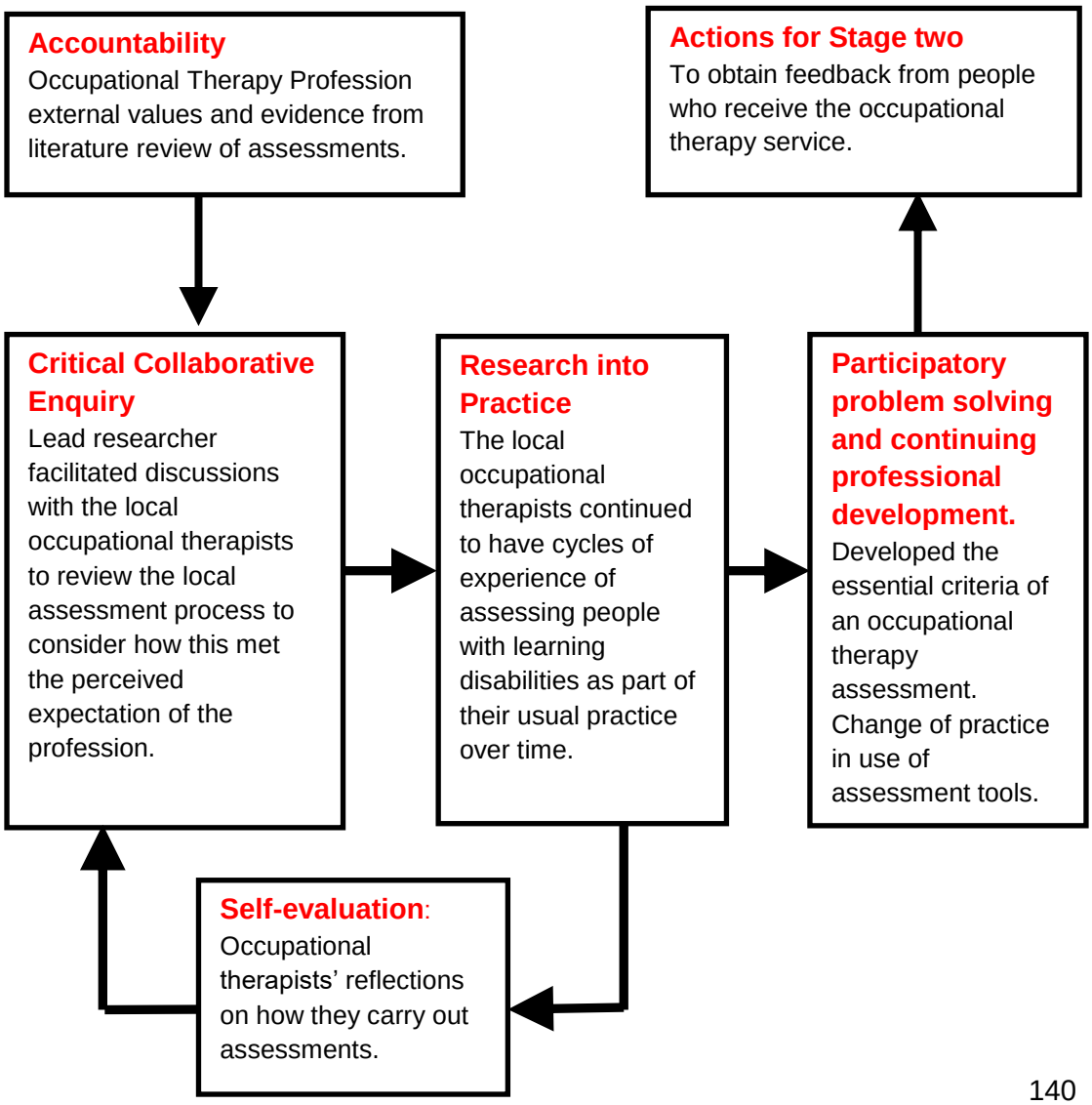
The lead researcher developed the essential criteria from the themes of the discussions of the local occupational therapists in stage one: phase one. As an insider researcher, these reflected her own as well as the other local occupational therapists' perceptions of their practice knowledge. The lead researcher needed to be aware that she could have had undue influence on the development of the criteria and her views could have dominated. In order to counteract this, the lead researcher discussed the draft criteria with the occupational therapy group and her academic supervisors. The OT co-researcher questionnaire sent out at stage one:

phase three was designed so that the local occupational therapists were asked to list what was important in the occupational therapy assessment without reminding them of the essential criteria so that these would not influence their responses. The new literature review and the discussions in stage one: phase three confirmed that these were still considered relevant to practice by the newly recruited OT co-researchers.

4.7 Summary of stage one

Stage one is illustrated in Figure 4.2 using the CRASP model as described in Section 3.3 to illustrate how the action research fieldwork described in Chapter three could be explained within this framework.

Figure 4.2: Stage one illustrated using the CRASP Model of Action Research (Zuber-Skerritt 1996)



In stage one the local occupational therapists were influenced by the dominant discourse in the occupational therapy literature for the need to demonstrate the effectiveness of their intervention by using standardised assessments. They engaged in a critical collaborative enquiry in which they reflected on their current assessment processes. The lack of suitable assessment tools was considered to be a problem by the local occupational therapists in their practice. They reviewed the assessment tools that they were using and concluded that none could meet their needs when assessing people with learning disabilities.

From these discussions, the practice based knowledge of the occupational therapists were gathered by the lead researcher to develop the essential criteria for an assessment tool to be used by occupational therapists working with adults with learning disabilities. A preliminary search of published occupational therapy assessments that could be used with this client group revealed that many tools existed. However, none were considered to meet the essential criteria for assessment developed by the local occupational therapists. It was decided that the original plan to select an assessment tool that could be piloted would not be appropriate at this time.

A further review of the literature that had subsequently been published on occupational therapy assessments still emphasised the use of standardised outcome measures. The professional body for occupational therapists recommended standardised assessments to ensure clinical governance and evidence based practice. However, there was now a suggestion that non-standardised assessments could be appropriate in some circumstances when working with adults with learning disabilities.

Some more recent studies regarding the use of assessments by occupational therapists working with adults with learning disabilities and those working with people with acquired cognitive impairments were reviewed and indicated that the use of standardised assessments was still limited. The assumption that the use of standardised assessments provides good clinical governance was questioned in the findings of some of the studies cited. The local occupational therapists concluded that standardised assessments could present a potential barrier to other essential criteria for the assessment such as being client centred and accessible. There were ethical concerns raised regarding the challenges of using standardised assessments with people with cognitive impairments in relation to ensuring that informed consent

was obtained and that the assessment process would not cause distress. There were also concerns that a standardised outcome measure would be unlikely to encompass the holistic nature of occupational therapy intervention.
None of the studies of assessments reviewed in this section of the thesis sought the opinion of adults with learning disabilities, carer or others involved in the assessment process as to their perceptions of the occupational therapy assessments provided.

At the end of stage one, the newly recruited OT co-researchers reported that they had made some changes to their practice following the review of assessments described in Section 4.3. The OTIPM (Fisher 2009) model of practice had been adopted by the service as well as the initial assessment format that was based on this. The local occupational therapists had increased their awareness of published standardised assessments and had attempted to use some in these in practice. They also understood that adapting an assessment affected its reliability and validity but they continued to develop and use locally produced assessment formats in their practice.

The essential criteria developed by the local occupational therapists in phase one were still considered to meet the OT co-researchers' understanding of their practice-based knowledge. However there were concerns that an assessment tool would not be able to meet all eleven of the essential criteria as some appeared to be incompatible with each other.

At the end of stage one of the research study, it was still the plan to continue the investigation to identify an appropriate assessment tool was planned to be continued. However, this exercise was put 'on-hold' until the findings of the views of the people with learning disabilities and their carers and other people interested in the occupational therapy assessment could be gathered and analysed. It was then envisaged that the aspects of the occupational therapy assessment that needed to change could be prioritised. The perceptions of the occupational therapy assessments provided by the local team are explored in stage two of the research study described in Chapters five and six.

Chapter five: Methods for stage two - an exploration of how existing local occupational therapy practice was perceived by adults with learning disabilities, carers and other stakeholders

5.1 Introduction and objectives of stage two

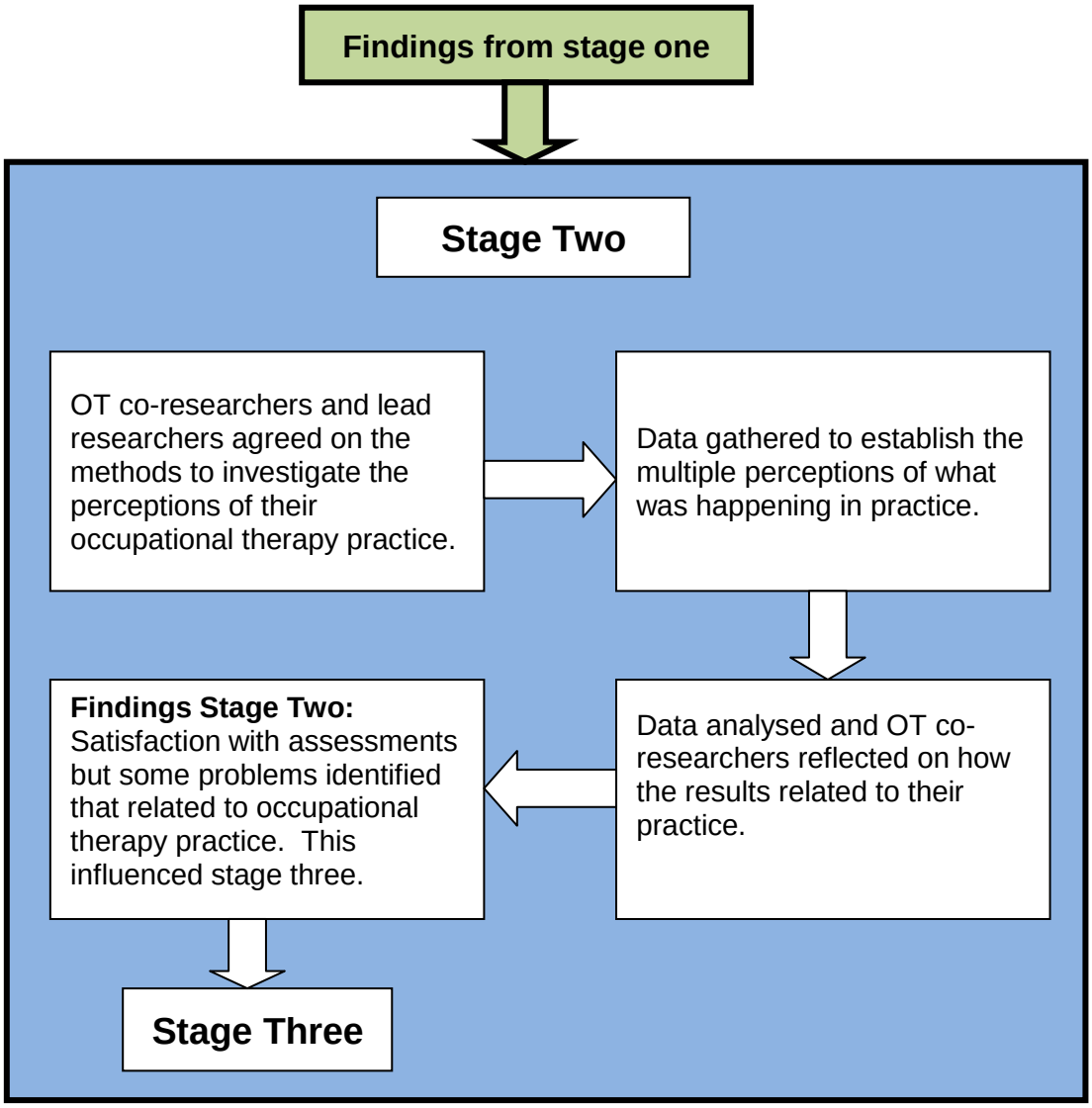
The overall purpose of this study was to evaluate the current occupational therapy practice conducted by a local community health team working with adults with learning disabilities and to further develop and improve practice based on the evidence generated**.** The objectives of stage two are set out in Table 5.1.

Stage two commenced in April 2010 (see Appendix A for timeline). The establishment of the occupational therapy co-researcher group occurred in stage one phase three. The methods of recruitment to the co-researcher group and the research process that the group engaged in were described in detail in Chapter 3. Figure 5.1 illustrates the action research fieldwork of stage two which is set out in Chapters five and six.

Table 5.1: Objectives of stage two

Stage two objectives	Actions
Chapter five Objectives	**Actions**
To engage the occupational therapists in the local team as co-researchers so that they can be agents of change of their own practice development	The OT co-researchers collaborated with the lead researcher in developing the interviews and questionnaires. The OT co-researchers participated in identifying and recruited the adults with learning disabilities as participants in the research study.
Chapter six Objectives	**Actions**
To explore the perceptions of a sample group of people with learning disabilities, their carers and other people involved regarding occupational therapy assessments that had recently been undertaken	The lead researcher conducted semi-structured interviews with a sample of adults with learning disabilities about their experience of occupational therapy assessments. The lead researcher conducted semi-structured interviews with the carers of the participants with learning disabilities. The lead researcher administered questionnaires to other professionals (stakeholders) who were involved with the participants with learning disabilities. The lead researcher administered questionnaires to the occupational therapists who were involved with the participants with learning disabilities.
To ascertain how the occupational therapy assessment process was perceived in order to identify any areas for improvement. To explore any other themes that may have emerged regarding occupational therapy practice development.	The occupational therapists completed questionnaires on the assessments they conducted with the participants with learning disabilities and provided their assessment reports on each participant with learning disabilities. The occupational therapy co-researchers collaborated with the lead researcher in the analysis of the data from the interviews and questionnaires.

Figure 5.1: Diagrammatical representation of stage two of the research study



5.2 Validity and reliability when involving adults with learning disabilities in research

Section 2.4.1 highlighted the importance of gaining the perspectives of adults with learning disabilities on the occupational therapy services that they receive but only one study had been identified that had done this. Many authors, including Cambridge and Forrester-Jones (2003) and Gilbert (2004), suggested that interviewing people with learning disabilities can be challenging in relation to validity and reliability due to a number of reasons. As has previously been stated, occupational therapists work with adults with learning disabilities whose communication skills can range from a very limited 'pre-linguistic' level to people who have quite well developed verbal and written skills. Communication by people with more severe learning disabilities *'tends to consist mainly of non-verbal behaviours such as facial expression, gestures, body movements and vocalisations, and is frequently idiosyncratic'* (Golbart and Caton 2010, p8). Therefore, it is recommended that the support of *'familiar, responsive partners who care about the person they are communicating with'* (Golbart and Caton 2010, p3) should be sought to successfully gather the views of people who have the most complex communication needs. However, *'interviewing of adults with intellectual disability is potentially fraught with problems of bias and interpretation'* (Cambridge and Forrester-Jones 2003, p14). Having someone present in an interview to support a person with his or her communication can result in the person not being able to express their views due to a lack of confidentiality. If a carer is present to interpret what the person had said or give the answer they think the person would give, there is the potential for the carer's view to be provided rather than that of the client.

Even when people with learning disabilities have relatively good verbal skills they are still more likely to have some difficulties when being interviewed. These difficulties are reported by Cambridge and Forrester-Jones (2003) and Gilbert (2004) but more clearly summarised by Gudjonsson and Joyce (2011) who state that the research evidence is that people with learning disabilities may be more likely to have the following vulnerabilities:

- **Suggestibility**, which is when their report is influenced by what other people say.
- **Acquiescence** which is when people *'are significantly more likely than persons of normal intellectual abilities to give affirmative answers to questions'* (Gudjonsson and Joyce 2011, p17).

- **Compliance** is described as when people *'at times have a desire to please others perceived to be in power, including, possibly, interviewers. They may not answer truthfully, but they may respond to questions in a certain manner or direction because they think that is the "expected" or "desired" response'* (Tassé, et al 2005, p5).
- **Memory capacity and confabulation** can occur when people with learning disabilities have difficulties with remembering an event and so may invent information in order to answer the question.
- **Impaired decision making** is when the respondent may give replies without always being aware of the consequences of what has been said.

Tassé et al (2005) also added:

- ***'Recognition that disability is often associated with stigma'*** (Tassé et al 2005 p5)**.** This is when the person may say they understand because they are embarrassed to admit that they are having difficulties.
- ***'Processing time'*. *'***People *… may require additional time to process the question and formulate their response'.* (Tassé et al 2005, p5).

For this research study, the lead researcher needed to be aware of the above potential limitations when interviewing participants with learning disabilities, but that this should not necessarily exclude people from participating in research. Gudjonsson and Joyce (2011) reported that these tendencies are not present in all people with learning disabilities and that *'a careful and humane approach to interviews …. with relevant support may overcome many of the problems associated with potentially unreliable or misleading accounts being obtained'* (Gudjonsson and Joyce 2011, p18).

Various researchers have devised methods to address the difficulties of enabling people with learning disabilities to participate in research. Cambridge and Forrester-Jones (2003) suggest that some researchers have only interviewed respondents who have good verbal communication skills but reported that *'the inability to interview people without or with poor verbal communication has resulted in skewed sampling and subsequently unrepresentative outcome data, as only those who can speak tend to be interviewed and their views or experiences represented'* (Cambridge and Forrester-Jones 2003, p14). They suggest that using other forms of communication such as pictures, photographs and signs can be used to avoid people being excluded. Cambridge and Forrester-Jones (2003) worked with local

speech and language therapists to plan their interviews with people with learning disabilities so that they could benefit from their expertise on how to support each individual to understand and communicate. They reported that working with speech and language therapists provided *'a methodologically sound and effective device for maximising user involvement and participation in research'* (Cambridge and Forrester-Jones 2003, p9).

Gilbert (2004) also acknowledged that it is a challenge to enable people with severe communication difficulties to participate in research. There cannot be a standardised way of interviewing people with learning disabilities as the interviewer needs to adapt the approach to meet each person's communication needs. The standard practice of using open ended questions is not always helpful as *'participants have restricted language skills overlaid by a lack of self-esteem, which produces an apparent unresponsiveness'* (Gilbert 2004, p305). Gilbert recommended that interviewers need to be *'progressively focusing the questions and responses while, at the same time, reading the silences'* (Gilbert 2004, p305). Questions should be asked in different ways to test if consistent responses have been made. Gilbert suggests that using *'the triangulation of multiple sources of evidence'* may be useful but that *'caution must remain around the levels of interpretation used'* (Gilbert 2004, p304).

There are challenges to interviewing people with learning disabilities however it was considered by the OT co-researchers and lead researcher to be an essential part of this research study. The literature suggests that interviewing people with learning disabilities provides the researcher with their unique perspectives and expertise. The challenge was to ensure that, as far as possible, the views and opinions of the people who have the most limited ability to understand and communicate were highlighted and recognized. The lead researcher was experienced in working with adults with learning disabilities and, as an insider researcher, had access to speech and language therapists and other people who knew the communication needs of the potential participants. The OT co-researchers' list of what was working well in the occupational therapy assessment given in Table 4.10 consisted of several adaptations that they had found to be useful in engaging people with learning disabilities in their usual practice such as: using pictures, interviewing the person with learning disabilities and his or her carer separately, working at the person's own pace and going to the person's own environments. It was, therefore, planned to incorporate the existing knowledge and experience of the local occupational

therapists when considering how to collect data on the perceptions of people with learning disabilities on their experiences of being assessed by occupational therapists.

5.3 Method for reviewing how occupational therapy practice was perceived in the local service

At the first OT co-researchers' meeting in stage two it was agreed that it would be important to ascertain the perceptions of a small sample of adults with learning disabilities of their recent experience of occupational therapy. The OT co-researchers expressed similar concerns regarding the ability of adults with learning disabilities to be able to give appropriate feedback on their experiences as in the findings in the study by Ball and Shanks (2012), described in Section 2.4.1. They raised questions about what information would be generated from this exercise. For example:

> *"are we looking at the process or the outcome of the assessment?"* (G April 2010)

The OT co-researchers were concerned that the people with learning disabilities may be unable to distinguish what they had received from occupational therapy and what had been provided by another profession. There was an expectation that the occupational therapy assessment reports were not read. It was agreed that whilst undertaking the data gathering process there would be a need to be aware of these issues to ensure that the questions could be made as clear as possible and that these assumptions could be tested. It was agreed that the following data items would be requested for each participant with learning disabilities to make up each data set:

- A semi structured interview of the participant with learning disabilities.
- A semi structured interview of the carer of the participant with learning disabilities.
- Questionnaires completed by any stakeholders who had been sent a copy of the occupational therapy report for the selected participant with learning disabilities or who were identified by the participant with learning disabilities or the carer as being involved in the occupational therapy assessment.
- Questionnaires completed by the occupational therapist who had worked with the selected participant with learning disabilities.

- The occupational therapy assessment report written about the participant with learning disabilities.

5.3.1 Development of interview guides and questionnaires

Semi-structured interviews were chosen as the method of data collection for the sample group of participants with learning disabilities and their carers. As the purpose of the occupational therapy intervention was to meet the needs of adults with learning disabilities, gathering rich data on their perceptions of this experience, and the perceptions of their carers, was considered to be a priority. Semi-structured interviews were regarded as the best method to use with the participants with learning disabilities, taking into account the recommendations outlined in Section 5.2. Semi-structured interviews were also chosen for the informal carers as they were likely to be less familiar with questionnaires than professional staff. This was also considered to be practical and time-effective as the carers would usually be with the person they care for and so could complete the interviews on the same visit.

Two draft semi-structured interview guides were devised by the lead researcher with questions based on the essential criteria (Table 4.5) for an occupational therapy assessment for adults with learning disabilities (see Table 5.2). One guide was for carers and the other version was adapted to reduce some questions and the more complex concepts so it would be more accessible for participants with learning disabilities but still retain as much as possible of the original.

Questionnaires were chosen for the other stakeholders as it was assumed that this group would be more familiar with the service offered by the local occupational therapists as they were likely to be health or social care professional colleagues and so would be able to complete the questions without needing someone to be present to provide clarification. Section 3.4.4.2 describes some of the advantages and disadvantages of questionnaires set out by Gillham (2000) which applied to the OT co-researcher questionnaires that also applied to the stakeholders. An advantage of using questionnaires for this group was that it was envisaged that stakeholders would be more likely to engage in the quicker exercise of completing a questionnaire than the more time-consuming interview. They could complete this in a time that suits them and their views would not be influenced by the presence of the interviewer. However, it was acknowledged that the information provided by a

questionnaire would be more limited and less flexible. The responses could not be checked with the stakeholders if they were ambiguous and it would not be possible to know why answers were selected. Therefore, a space for comments was added to the questionnaires to encourage the stakeholders to expand on their answers. A stamped addressed envelope was provided with the questionnaire to encourage the return but it was expected that the response rate would be likely to be lower than if an interview had been arranged. A draft questionnaire for the stakeholders was also designed based on the semi structured interview questions see Table 5.2.

The interview guides and questionnaires were designed, as recommended by Gray (2014), to capture *'the values, perceptions and interests of the respondents'* (Gray 2014, p354). The expected responders ranged from people with learning disabilities, informal carers and health and social care professionals and so the challenge was to obtain information on the experience of a specific occupational therapy assessment and intervention but meeting the anticipated needs of each group.

The questions were designed, taking into account the concerns outlined in Section 5.2 and recommendations suggested by Gray (2014). Prejudicial and ambiguous language was avoided. Care was made to consider if the questions could be leading the person to making a particular response. The questions for all the interviews and questionnaires needed to be asking for similar information but needed to be tailored for each to ensure that they are relevant to each participant's experience and to ensure that they will be able to recall it. The lead researcher presented the draft interview guides and questionnaires to the OT co-researchers and asked them to consider if the design of the interview guides and questionnaires would elicit useful information taking into account these factors. They were asked: to estimate the length of time it would take to complete each; if the right questions were being asked and if these were clear; and if there was the right balance of asking specific questions and being open to obtaining new insights and views.

Table 5.2: How the interview guides and questionnaires related to the essential criteria of the occupational therapy assessment

Essential Criteria of an assessment tool that will identify strengths and needs of community living skills of people with learning disabilities	**Questions related to the criteria in carer interview, OT and stakeholder questionnaires**	**Questions related to the criteria asked during participant with learning disability interview**
Assess occupational performance	Do you think that the assessment addressed all the community living skills that are important to the individual?	Did the assessment look at the living skills that are important to you?
Global skills rather than just one particular skill	Or did the assessment concentrate on one particular skill.	Or just one skill?
Highlight skills and support needs in order to make meaningful and useful recommendations:	Did the assessment highlight the person's skills and support needs and from this made meaningful and useful recommendations?	Did the occupational therapist (insert name) say/do anything that made your skills better? Did the assessment look at how you learn?
Client centred/choice and empowerment	Did the assessment take into account client centred choice and empowerment?	Did you have a chance to say what you thought? Did the OT spend the right amount of time with you?
Accessible easy to use and understand	Do you think the assessment process for the client was accessible and easy for him/her to understand?	Did you understand what occupational therapist (insert name) was saying and asking you to do?
Designed for people with learning disabilities	Do you think the type of assessment used worked well for people with learning disabilities?	Did you find the assessment helpful/useful?
Fit for purpose	Do you think the assessment was fit for purpose and do you agree with the results?	Did you agree with what the occupational therapist (insert name) said?

Essential Criteria of an assessment tool that will identify strengths and needs of community living skills of people with learning disabilities	Questions related to the criteria in carer interview, OT and stakeholder questionnaires	Questions related to the criteria asked during participant with learning disability interview
Practical/ good use of resources	Do you think that undertaking the assessment was a good use of resources? Was the assessment completed in an appropriate time frame?	No question asked.
Observation	Did the occupational therapist observe the person carrying out activities of daily living?	Did the occupational therapist (insert name) watch you do things?
Incorporate views of all people involved with the person with learning disabilities	Did the assessment incorporate the views of other key people involved with the person? Did the assessment incorporate your views?	Did the occupational therapist (insert name) talk to the people that you wanted her to talk to? Did the occupational therapist (insert name) listen to your views? Did other people talk about the OT assessment?
Fits with other local, national, international assessment development.	Does the assessment fit with the way you think learning disability services should be working? Does the assessment fit with other policies within your setting (Not asked to family carers)	No question chosen.

The OT co-researchers reviewed the forms and agreed that the questions would need to be individually adapted to meet the communication needs of each of the participants with learning disabilities. There were concerns as to how the questions may be interpreted due to the imprecise language of the draft forms. For example: the question 'what was good about the occupational therapy assessment?' was considered. One comment was:

> *"I'm thinking they might say the occupational therapist was really good rather than the actual occupational therapy…..how to separate the two? It would be difficult to pick out people who are able to do this. Clients and carers will both find this difficult"* (E April 2010).

It was agreed that it may be difficult to distinguish between the person and what the person does and so to address this it was suggested that the lead researcher would need to follow up the answers with more probing questions to clarify the responses received. The semi-structured interviews needed to be flexible enough to adjust for individual needs and to clarify responses with follow-up probes and checking for understanding. Spaces for general comments were added to the questionnaires but it was acknowledged that this method of data gathering would have limitations in being able to clarify any of the information provided.

Each OT co-researcher was asked to pilot the stakeholder questionnaire in order *'to identify errors, weaknesses or ambiguities'* (Gray 2014, p354). They did this by completing it in relation to a recent person whom they had worked with and who had been discharged from their own caseload. They were asked to make comments about the questions and if they thought that anything needed to be changed. The questionnaires and comments were returned to the lead researcher and discussed at the follow up OT co-researcher meeting in June 2010. This feedback resulted in some of the questions on the interview schedules and the questionnaires being changed. For example: a question was added: 'did you read the occupational therapy report before today?' as the OT co-researchers wanted to know if their assessment reports were routinely read when they distributed to them or if the report had only been reviewed as a result of receiving the invitation to complete the questionnaire. There was a concern, from the group, that asking specific questions, in relation to the essential criteria of an occupational therapy assessment tool, at the start of the interview or questionnaire may bias the responses. This was because the responders would be asked to think about the assessments from the

occupational therapists' agenda and could prevent the interviewees from talking about their own perceptions of what was important about their experience of occupational therapy.

Following this feedback from the OT co-researchers, and on reflection with the academic supervisors, the interview schedule formats were adjusted by the lead researcher and shared with the OT co-researchers for comments. The first part was changed to consist of open-ended questions encouraging the respondents to talk about their experience of occupational therapy and what was important to them before being asked more specific questions about the essential criteria.

The stakeholder questionnaire had similar questions to the interview guides for the carers and the participants with learning disabilities. It was 'structured' with short unvarying specific questions, with the option of yes, no or don't know responses. Some open questions were put at the beginning and the end of the questionnaire and there was space for comments after each yes/no response so that the respondents could expand on their answers if they wished. The questions in the stakeholder questionnaire for the occupational therapist who had worked with the participant with learning disabilities were also adapted following the findings of the pilot.

The semi-structured interviews were not piloted as they needed to be individually tailored for each participant. However, the lead researcher reviewed the interviews in each data set when transcribing the recordings prior to the subsequent interview so if any of the questions had needed to be reviewed so any identified changes could have been incorporated. (See Appendices J and K for copies of all the final versions of the interview guides and questionnaires).

5.3.2 Sample selection and recruitment of participants with learning disabilities

Non-probability purposive sampling was undertaken to *select 'information rich cases*…[where] *the researcher exercises a degree of judgement about who will provide the best perspectives on the phenomenon of interest'* (Gray 2014, p217) Bellman (2003) states that action research uses non-probability sampling which means that although the sample is relevant to the local context, it is not known if the

population is well represented. The need to generalise from the findings would not be relevant in this context. The OT co-researchers were asked to consider what type of information they wanted to obtain from the selected sample of adults with learning disabilities who had recently experienced occupational therapy. One asked:

> *"What's the purpose? Do they need to communicate verbally?"* (D April 2010)

The OT co-researchers agreed that the sample group needed to be chosen to provide rich, in depth cases that covered the range of adults, with different levels of learning disabilities and circumstances, to reflect the population with which they work. Adults whose level of learning disability would mean that they would be unable to participate in an interview, no matter how many adjustments were made to support their understanding, would, therefore, not be excluded. In these situations, the carer and other people involved in the occupational therapy assessment could still be asked about the assessment provided.

The OT co-researchers considered if the sample needed to be people who had all experienced the same occupational therapy assessment tool so a specific assessment could be evaluated. A list of potential participants with learning disabilities and the assessment tools used with them was generated. This revealed that a combination of different assessments tools, many of which had been individually adapted by the occupational therapists, had been used. Many of the occupational therapy cases listed had addressed more than one referral issue and sometimes several reports were generated by the occupational therapist on the same person during the time they were open to them on their caseload. The OT co-researchers concluded that it would not be possible to select a sample of people who had used a specific assessment tool. It was agreed that the sample would be selected to consider the perceptions of people who had experienced the existing occupational therapy practice in which a flexible approach was used in selecting and adapting assessment tools. However, to ensure that the focus was on occupational therapy and not generic team roles, the OT co-researchers agreed that the sample of people selected would have all had an assessment of their skills and support needs as the main reason for referral.

During the generation of the list of potential people with learning disabilities who could be approached for interview, several people were excluded by the OT co-researchers. Exclusion criteria included circumstances such as:

- Cases that were currently involved in legal issues due to multiple concerns from the person's family. Even though these issues were not related to the occupational therapy assessment, it was decided that it would not be appropriate to approach the person with learning disabilities and family at such times.
- People experiencing major health needs so would not be well enough to be interviewed and it was envisaged that the carers may be feeling stressed due to caring for someone in these circumstances. However, as working with people who have Down's syndrome and dementia was a significant part of the occupational therapy caseload, it was agreed that having a diagnosis of dementia would not necessarily exclude someone.
- Practical reasons that may make the interview difficult, for example, if a person had moved to a new area or if the carer that had been involved when the occupational therapist was working with the person with learning disabilities but had since left.
- People who did not complete the planned assessment and intervention as they would not be able to comment on the occupational therapy input.

When the exclusion criteria were reviewed it appeared that people who had not engaged or disagreed with the occupational therapist would be likely to be excluded. The group raised the concern that the sample may be biased toward people who had a positive experience of occupational therapy as only people who had agreed to work with the occupational therapist throughout the agreed period of intervention would be selected. Gray (2014) stated that a disadvantage of purposive sampling could be *'that the researcher inadvertently omit a vital characteristic…or may be subconsciously biased'* (Gray2014, p217). The OT co-researcher discussion helped to ensure that potential biases or omissions could be highlighted. In recognition of this, the OT co-researchers agreed to consider the names that they had suggested to be approached to be interviewed to ensure that the final sample would be a fair reflection of their caseload. They agreed to include people with learning disabilities and carers who may not have positive views but may be willing to be approached for interview.

In the OT co-researcher group meeting in June 2010, two to three people who had completed an occupational therapy assessment and intervention and had been discharged within the previous six months were identified by each OT co-researcher. The OT co-researchers who had not been present at the meeting were

also asked to identify other potential people to add to this list. The final sample group, therefore, included: a variety of reasons for referral to the occupational therapy service, adults with mild to severe learning disabilities, a mixture of age, gender and culture and people who received support from paid carers as well as those who had informal family support or lived alone. From this process, the group approved the selection of eight participants who had all worked with a different occupational therapist. This was so the research study would take into account their differing experiences and approaches.

Each of the eight selected adults with learning disabilities and their carers were invited to participate in the study by the OT co-researcher who had recently worked with them. The OT co-researcher explained the research project in the most accessible way for their particular participant. This may have been directly with the potential participant with learning disabilities by telephone or in person, or to the carer who would then discuss the proposed study to the person with learning disabilities. In all cases, the verbal conversation was followed by giving or posting the information sheets for the participant with learning disabilities and the carer to read. There was always a period of time of at least a week for the participant with learning disabilities and the carer to consider the research information that had been provided and the interviewer asked if they had read the information and if they had any questions prior to commencing the consent process (see Appendices H and I).

The OT co-researchers, who had worked with each of the participants, made an initial judgement as to if the person they had identified had the capacity to consent to be interviewed for the research study using the Mental Capacity Act (2005) guidance (Department for Constitutional Affairs 2007). The consent process was completed by the interviewer immediately prior to the interview commencing for both the participant with learning disabilities and the carer. The lead researcher conducted all of the interviews except for one participant with learning disabilities and his carer as she had been involved in the assessment. One of the OT co-researchers completed the interviews in this case and took on the lead researcher's role as described below.

As part of the consent process each participant with learning disabilities was asked if they:

• *Understood the research information.* This included what the participant with a learning disability was expected to do and what may happen to the information.

• *Remembered the information.* The interviewer asked the participant with learning disabilities if they knew what was about to happen and if they remembered and recognised the accessible research information that had been provided by the OT co-researcher. However, as some people with learning disabilities have difficulty remembering information it would be expected that this information would need to be repeated. If the person did not state that they remembered the research information this did not automatically mean that they were not able to give consent. Some who initially said that they did not remember recognised the accessible information sheet when it was shown to them. Most were expecting the lead researcher and knew that they were going to be interviewed about what they had done with their occupational therapist and that they would be recorded.. The lead researcher always repeated the information again before the participant was asked to sign the consent form just before the interview commenced.

• *Were able to use or weigh-up that information.* Even though the benefits to taking part in the interviews and the possible harm that could occur were not considered significant it was important to ensure that the potential participants were made aware of what could happen. It would be unlikely that any of the participants had been involved in research before and would be unlikely to have been made aware of potential issues that could occur. The accessible information sheet, consent form and verbal information were provided to support the potential participants to consider what the good things about taking part in the assessment would be and what bad things could happen. Each of the OT co-researchers and, later, the lead researcher discussed with each participant with learning disabilities that taking part in the interview may help the occupational therapists do their work better for other people. They would only be asked these questions on this one occasion. The things that they said would be written down and may be shared with other people but nobody would know what they had said. If they did not like answering the questions, they could say that they did not want to take part during the interview and it would stop. The consent form was set out so that the participant would be asked about each section separately. Once they had been given the opportunity for each section to be explained they were then asked to verbally consent or to tick that they understood and agreed to that part. This ensured that each aspect could more easily be considered and was preferable to just being asked to remember and agree to the whole process by signing a form at the end (see Appendix H for copy of the consent form)

• *Were able to communicate their decision.* The lead researcher, just before the interview, read out each of the questions on the consent form to the participant with learning disabilities. The participants answered each question and then signed the form. See Appendix H for the accessible consent form which was individually changed to include the named people that were involved in that person's care. If during the interview, the participant with learning disabilities changed their mind or became distressed, the interview would have been terminated and the recording erased as it would be considered that consent had been withdrawn. This did not occur for any of the interviews. At the end of the interviews, the lead researcher checked again with the participants with learning disabilities that they were asked if they were still happy for the interview to be used for the research.

If the OT co-researcher or the carer considered that the participant with learning disabilities was likely to become distressed or that his or her interests would have been negatively affected then the request to participate in the research was not made. This resulted in the OT co-researchers not recommending some people who they had recently worked with due to these concerns, either for the person with learning disabilities or their carer. One carer initially agreed to participate with her relative with learning disabilities in the research study to the OT co-researcher. However, when reflecting on the research information, she telephoned the lead researcher a few days later to cancel the interview. Another participant with learning disabilities and her carer were not at home on the agreed date of the interview and did not respond to a note requesting them to telephone the lead researcher if they wanted to rearrange the appointment. This appeared to indicate that the strategy of giving the potential participants with learning disabilities, and their carers, at least a week to reflect on the information about the research and decide if they wanted to participate was useful. Two out of the eight participants withdrew after having first indicated that they would be happy to participate. If the information had only been presented just before the planned interviews, there was the potential that participants may have felt pressurised into being interviewed without having been given the opportunity to process the information so that they can give their informed consent (see Section 5.2).

With time and appropriate communication support as described above, most of the participants with learning disabilities were able to consent to be interviewed. However, this research study aimed to improve occupational therapy assessments

for all people with learning disabilities, so including people with learning disabilities who may not have the capacity to consent was, therefore, an essential part of the study. The Mental Capacity Act (2005) states that consent is required for people to be involved in research. If consent is not possible due to a person's lack of capacity to understand the information, research can only take place under strict rules (as discussed in Sections 2.4.1 and 3.6). Researchers need to weigh up the benefits and potential difficulties with involvement of people who lack capacity. Two out of the eight participants with learning disabilities identified did not have the capacity to give their consent. Even though these two people were not able to participate fully in the interviews, they were still included so that the views of their carers and other stakeholders could be obtained. The interview was attempted with one of the participants who had some ability to communicate to see if he was able to indicate some views about the work that the occupational therapist had carried out. The two participants with learning disabilities who were considered as not able to give their full consent lived in homes where they were supported by carers who were paid support staff. They had relatives who were their next of kin, but not their carers, who knew them well but were not involved in the occupational therapy assessment and intervention that had been recently provided and so were not involved in any other aspect of the research. The next of kin of both of the identified people with learning disabilities who did not have the capacity to consent to be involved in this research were approached by the house managers to ask if they would be willing to take on the role of 'personal consultee' to advise about their relative's participation in the project (see Section 3.6). The personal consultees were provided with the 'participant with learning disability research information sheets', the more detailed carer information sheet and specific consultee questions and agreed that their relatives could participate in the research study (see Appendices H and I).

5.3.3 Conducting the interviews

The lead researcher and one OT co-researcher interviewed the participants with learning disabilities and their carers. The lead researcher shared the interview guide (Appendix J) and discussed the strategies used with this OT co-researcher to ensure that there was as much consistency as was possible across all the data sets in the way that the interview was approached and conducted.

5.3.3.1 Interviews with participants with learning disabilities.

The interviews with the participants with learning disabilities were planned taking into account the literature in Section 5.2 and the recommendations for communicating with people with learning disabilities which have been set out by Mencap (2008). These strategies included: meeting in person in a quiet familiar place without distractions, asking open questions where possible, checking that the person understands, using objects, pictures or drawings to aid communication, being aware of body language and facial expressions, and not rushing the conversation. Gudjonsson and Joyce report that these principles are difficult to apply in practice *'especially if the subject matter is either complex or sensitive, or both'* (Gudjonsson and Joyce 2011, p18). In order to address these concerns, the interviews were planned in advance, with one idea presented per sentence and allowing enough time for the person to process the information. The local occupational therapy service already worked closely with speech and language therapy colleagues to ensure that their interactions with people with learning disabilities were adapted to meet individual communication needs and so the interviews were planned with the same approach.

The lead researcher allowed adequate time to prepare and carry out the interviews by not scheduling any other appointments following the interviews and asking the interviewees when and where they would like to meet. Time was required to establish a rapport with the participant and to ensure that the information about the research and the consent process was completed thoroughly. Gudjonsson and Joyce (2011) state that if the interviewee feels uncomfortable he or she may feel under pressure to provide an answer. Tassé et al suggest that *'if a close personal relationship has not been established between the interviewer and the respondent there is a great risk of getting inaccurate information'* (Tassé et al 2005, p5). The information sheet, which had previously been provided by the OT co-researcher who had worked with the participant, was used to support the explanation of the research by the lead researcher. This information and the consent form were individualised using the information provided by the OT co-researcher regarding the person's communication needs and understanding. The explanation was adjusted depending on the communication needs of the person with learning disabilities. Small parts of the form or single pictures, were presented one at a time for some people, where others were able to understand a fuller verbal explanation. The specific list of people that the participant's occupational therapy report had been sent to was read out so that each participant with learning disabilities could say if they agreed that the lead

researcher could send them a questionnaire. The participants with learning disabilities and their carers were asked if there was anyone else that would be appropriate to include in this study and these suggestions were added.

For people who lacked capacity to consent, the use of one photograph such as a picture of the occupational therapist they worked with or the accessible goal plan was more meaningful. In these cases, the aim was not to explain the purpose of the research as it was already established that this was not meaningful for that person but to introduce the topic of discussion and establish if they wanted to talk about this at the time.

The interviews were audio recorded so that the interviewer could be more responsive to the interviewee rather than being distracted by the need to write down the answers. The respondents were offered the choice of being recorded or not. One participant with learning disabilities expressed a fear of hearing his own voice but gave his consent for the recording and for the lead researcher to listen to the recording as long as he did not have to listen to himself.

The time spent with each of the participants was approximately an hour. The length of the actual interviews varied depending on the participants' interest and understanding but lasted between 15 and 20 minutes. The explanations and questions were designed to meet each individual's communication needs and accessible formats such as objects or pictures were used as well repeating information or presenting it in a different way when it became clear that the person had not understood the question. The lead researcher was aware of each participant's concentration levels and adapted the interview in response to verbal and non-verbal cues. This resulted in the interviews being of different durations and some questions being omitted when it was clear that the person did not understand or was losing interest in the conversation.

This research used a participatory approach to seek the perceptions of the participants with learning disabilities of their experience of occupational therapy. The lead researcher aimed to engage with the participants with learning disabilities to openly talk about their views on having worked with the occupational therapist using the communication methods that best suited each individual. The qualitative method had *'the aim of interpreting and explaining the experiences of people with learning disabilities'* (Gilbert 2004, p300). When planning the individual approach, the lead

researcher took into account the best practice recommendations outlined in Section 5.2. She also had the advantage of experience of working with adults with learning disabilities and as an 'insider researcher', access to knowledge and advice from the occupational therapist who had worked with the person and access to reports such as the speech and language therapy communication assessment. The lead researcher acknowledged that as an 'insider researcher' (see Section 3.4.2) she would be able to understand some comments that were made by the interviewees that an independent researcher may have missed. For example, names of local people and services and the significance of these. However, there may have been occasions where the lead researcher made assumptions or did not recognise some issues due to these being the local custom and practice which an 'outsider' researcher may have considered more significant. The participants with learning disabilities and all other respondents were made aware that the lead researcher worked in the occupational therapy service so this may have affected some of the responses as they would be aware that she was a colleague of the occupational therapist whose intervention was being reviewed.

5.3.3.2 Carer interviews

All the carers were given information about the research and asked to sign a consent form prior to being interviewed (see Appendix I). Four interviews were completed out of the six carers approached. Two requested to complete a questionnaire rather than being interviewed and of these only one returned the questionnaire. Two of the carers were interviewed at the same time as the participant with learning disabilities and two were interviewed at a separate location and time. The carers were able to give fuller and lengthier answers than the participants with learning disabilities.

5.3.4 Completion of the questionnaires

5.3.4.1 The stakeholder questionnaires

The questionnaires were sent to the stakeholders identified and agreed by the participants with learning disabilities and, when appropriate, their carers. These were the people who had received a copy of the relevant occupational therapy assessment report and any other people identified by the person with learning disabilities or their carers as important stakeholders to this particular piece of work.

This could include the person who had made the referral, any health or social care professional and any other parties such as day centre worker or advocate.

Some brief information about the purpose of the research was attached to the questionnaires (see Appendix K).The questionnaires were sent in the internal post system to team members and sent to others with a stamped addressed envelope for returning to the lead researcher. Completion and return of the questionnaire indicated that the stakeholders had consented. The questionnaires were coded so that the stakeholders' responses could be compared with all the other responses that had been made about the same case.

5.3.4.2 The occupational therapy stakeholder questionnaire

The occupational therapist who worked with each participant with learning disability completed a similar questionnaire (OT stakeholder, see Appendix K) so that the perceptions of all involved in each case could be compared.

5.4 Data analysis of the responses to the interviews and questionnaires

The data were considered for analysis in two distinct groups:

- The specific questions regarding the essential criteria for an occupational therapy assessment using descriptive analysis.
- The more general responses and comments from the semi-structured interview and open questions and comments on the questionnaires using thematic analysis (Braun and Clarke 2006).

Data analysis across the whole research study has previously been described in Section 3.4.5. An inductive thematic analysis of the data was completed which has been described by Braun and Clarke (2006) as data-driven in that the coding should be reflective of the participants' views without being influenced by the researchers' preconceptions or the specific questions that were asked. The data collected for each participant with learning disabilities were gathered from multiple sources as the issues about occupational therapy practice could only be understood *'within a holistic, complex social system'* (Gray 2014, p328). The analysis of data and subsequence actions were completed in a collaborative way with the OT co-researchers. All interviews, questionnaires and reports about the same participant with a learning disability were compared and linked together as a data set (see

Table 3.3) and were considered as to what issues were consistent across the stakeholders and what varied.

Each occupational therapy assessment report was reviewed to consider what assessment was completed and who it was sent to. The reports were referred to when they were mentioned by the respondents to compare with the comments made. The data were then reviewed from all sources to consider if any common themes emerged.

It was recognised that some participants with learning disabilities were able to provide fuller answers than others. The details of the variations in the participants with learning disabilities' ability to respond were taken into account during the analysis of the data to ensure that the voice of all the participants with learning disabilities could be fully acknowledged. Any non-verbal signs such as facial expressions gestures or behaviours were also noted if relevant to the communication and the lead researcher adjusted the questions in response to these. For example, when a participant pointed at or looked at a picture this was noted. When a participant looked away or was distracted by other things the lead researcher had to adjust the interview to allow for the person to do this, to attempt to re-engage them in the subject or to stop the interview as this was an indication that they had finished. The interviews of the participants with learning disabilities and the carers were transcribed from the audio recordings. Notes were made of any non-verbal communication by the participants with learning disabilities such as when they pointed to a picture, nodded or made a facial expression in response to a question. The lead researcher acknowledged these responses by saying for example: "*you are shaking your head do you mean no?"* She made notes of these responses either during the interview or when transcribing the recording. The interviews were semi structured in nature and were intended to allow the interviewee to respond spontaneously. This resulted in some flexibility in the structure of the interviews with the participants with learning disabilities and with the carers. The lead researcher adapted the wording of the questions and at times, the order, by taking into account the responses received. The participants with learning disabilities occasionally talked about other subjects and needed prompting to return to the question. Some questions were not asked as the lead researcher judged that the participant with learning disability had lost interest or had already answered the question in his or her previous responses. The OT co-researcher who completed the interviews for one of the data sets was noted to have kept more rigidly to the script

of the interview. The interview transcripts were shorter when compared to the other data sets as perhaps there had been less probing from the interviewer to encourage the participants to expand on their answers.

The complex nature of the data collected and the different quantities of data produced, due to the wide range of communication skills of the participants with learning disabilities, resulted in some difficulties in triangulating the data and ensuring that the themes that emerged were trustworthy. The aim of the analysis was to reveal the perceptions of the different responders recognising that each person's view was their reality even if these differed from each other. The lead researcher took the lead in analysing the data but collaborated with the OT co-researchers in this process in the group meetings. She shared some of the raw data in the form of interview transcripts at an early stage in the analysis process so they could reflect on the findings and share their views with their colleagues. Towards the end of the analysis process, the lead researcher shared quotes that she had categorised into themes for the OT co-researchers to review and consider if they would categorise them in this way. The views collated contributed to the data analysis and triangulation of the data. The OT co-researcher group was used to consider the initial themes for the participants with learning disabilities interviews and to check the analysis made by the lead researcher as a way of improving the trustworthiness of the findings.

5.5 Summary

Chapter five has described how the OT co-researchers participated with the lead researcher in planning the review of their practice in the first part of stage two of the research study. Chapter six now considers the findings of the exploration of how the occupational therapy assessments and interventions were perceived in order to meet the objectives set out in Table 5.1.

Chapter six: Findings from stage two - an exploration of how the existing local occupational therapy practice was perceived by adults with learning disabilities, carers and other stakeholders

6.1 Description of the data items gathered

Data collected for the six data sets were collected between August and November 2010 (see Table 6.1). Eight of the nine OT co-researchers were able to identify at least one person with learning disabilities on their caseload who met the criteria to be interviewed as described in Section 5.3.2. Two of these participants declined. The stakeholders were sent the questionnaires with a stamped addressed envelope and a written explanation of the study. Non-return of the questionnaire was regarded as a decline of the invitation to participate. The interviews were completed between August and September 2010 and the questionnaires were received between July and November 2010.

Table 6.1: The number of responses for each data set

Data Items	Data Set C	Data Set D	Data Set E	Data Set G	Data Set H	Data Set I	Totals Received
Participant with learning disabilities interview	0 (not able)	1	1	1	1	1	5/5
Carer interview	1	1(q)*	0	1	1	1	5/6
Stakeholder Questionnaires	0/3	2/4	2/3	3/5	2/4	5/6	14/25
OT stakeholder questionnaire	1	1	1	1	1	1	6/6
OT Report	1	1	1	1	1	1	6/6
Total data items	**3**	**6**	**5**	**7**	**6**	**9**	**36**

*** Questionnaire completed as declined interview.**

Five participants with learning disabilities were interviewed (data sets D, E, G, H, I). Participant with a learning disability (C) was not able to be interviewed due to her level of learning disability. Four carers were interviewed. All six occupational therapists (see Section 5.3.4.2) and fourteen stakeholders completed questionnaires (see Tables 6.2 and 6.3).

Table 6.2: Categories of people invited to take part in the review of how occupational therapy was perceived in stage two of the research study

Category	People invited to participate	Respondents who participated
Participant with learning disabilities	8	5
Carer	8	5
OT co-researcher	6	6
Stakeholders:		
Medical doctor	7	3
Social Worker	6	3
Speech and Language Therapist	1	1
Clinical Psychologist	5	5
Day service worker	1	0
Audiologist	1	1
Physiotherapist	2	1
Outreach worker	1	0
Community nurse	1	0
Stakeholders: Totals	25	14

Table 6.3 provides a summary of the participants with learning disabilities in each data set to demonstrate the range of levels of learning disability (see Glossary) and living circumstances within this group.

Table 6.3: Participants with learning disabilities data

Participant with learning disabilities	Gender	Age	Living situation	Level of learning disability	OT assessment
C	Female	52	24 hour support	Severe	AMPS ADL
D	Female	47	Own flat with support staff within building	Mild	ADL AMPS
E	Male	26	Own flat with staff available in building	Mild with autism	AMPS
G	Female	20	Lives with family	Mild and autism	Loose HALO Sexual knowledge
H	Male	21	24 hour support but now moved to own flat with outreach support	Mild	ADL AMPS
I	Male	48	24 hour support	Moderate learning disabilities and dementia	AMPS

Table 6.4 sets out how the data were presented within this research study.

Table 6.4: Stylisation and presentation of the data regarding the perceptions of occupational therapy

Stage	Event and participants	How this is coded
Stage two and three	Interviews of participants with learning disabilities and their carers.	Each data set has a letter that signifies the OT co-researcher who worked with that participant. Stage two: CDEGHI Stage three: ABLMJK
	Participant with learning disabilities	p. followed by the letter code for the OT co-researcher
	Carer	c. followed by the letter code for the OT co-researcher
	Any other stakeholders who have completed the questionnaire about the specific participant with learning disability.	sh. followed by the letter code for the OT co-researcher. If more than one stakeholder is quoted this will be followed by letters a,b etc
	Questionnaire completed by the OT co-researcher who had worked with the participant with learning disabilities	OT followed by the letter code for the OT co-researcher

6.2 Findings of the questions regarding the essential criteria of the occupational therapy assessment.

The lead researcher reviewed all the interview transcripts and the completed questionnaires in order to undertake a descriptive analysis of the responses to the specific questions regarding how well the essential criteria for the occupational therapy assessment were perceived to have been met. (see Appendices J and K). The responses that related to each of the essential criteria were collated by the lead researcher and a decision was made as to whether the responses received indicated ‘yes’ (the criteria had been met); or ‘no’ (the criteria had not been met); or ‘don’t know’ (the responder was not sure if the criteria had been met). Some responses were left blank on the questionnaires and so a new category of ‘blank’ was used. Some criteria had more than one question related to them (see Table 5.2). As the questions were asked at the end of the semi structured interviews for the participants with learning disabilities and the carers, some of the answers had

often already been covered. The lead researcher took into account any previous comments related to the criteria and made the decision that some of the specific questions did not need to be asked again and so, when transcribing the interviews, retrieved these from elsewhere in the discussion. This was considered to be a 'reasonable adjustment' for some of the participants with learning disabilities who may have been losing concentration or have become frustrated if asked to repeat themselves. However, it was also helpful for some of the carer interviews.

Table 6.1 sets out the thirty-six data items collected. The six occupational therapy reports were referred to by the lead researcher so that she could understand the context of the data set but were not used to collect data on the essential criteria of the occupational therapy assessment. The participant with learning disability (I), was able to make some responses in the semi-structured interview, but was not able to understand the more specific questions about the essential criteria. The four participants with learning disabilities who were able to answer the questions in relation to the criteria were not asked about two of the criteria: 'practical, good use of resources' and 'fits with other local, national, international assessment development' as the OT co-researcher group did not consider these questions to be relevant for them.

Table 6.5 summarises the positive responses received for each of the essential criteria of the occupational therapy assessment that were previously agreed by the OT co-researcher group (see Appendix R for more details of the responses). These ranged from 76% to 100% positive responses. Four participants with learning disabilities were able to answer the 'participant with learning disability questions' that covered nine of the eleven criteria and their responses were 100% positive.

Table 6.5: Summary of percentage scores where respondents indicated that the criteria had been met

Essential Criteria of an assessment tool that will identify strengths and needs in community living skills of people with learning disabilities	Percentage of positive responses received.	Number of data sets in which criteria fully met.
Assess occupational performance	93%	4/6
Global skills rather than just one particular skill	90%	4/6
Highlight skills and support needs in order to make meaningful and useful recommendations:	90%	4/6
Client centred/choice and empowerment	93%	5/6
Accessible easy to use and understand	76%	3/6
Designed for people with learning disabilities	97%	5/6
Fit for purpose	100%	6/6
Practical/ good use of resources	84%	3/6
Observation	97%	5/6
Incorporate views of all people involved with the person with learning disabilities	76%	3/6
Fits with other local, national, international assessment development.	96%	5/6

These findings suggested that the occupational therapy assessments, provided in the six data sets, had mostly met the essential criteria of the occupational therapy assessment as developed in stage one. All the responses affirmed that the occupational therapy assessment was fit for purpose and that there was agreement with the occupational therapy conclusions and recommendations. There was a trust from the responders in the occupational therapy findings even though published standardised assessments were not always used. This suggested that the concern of the local occupational therapists identified in stage one that their assessment tools were not appropriate for working with people with learning disabilities and that a new tool needed to be developed did not appear to be an issue for anyone involved in the data sets sampled.

Only three criteria had less than 85% positive responses:

- **'Accessible easy to use and understand'**

  The responses in the data sets involving the participants with learning disabilities who had the most severe communication difficulties (C and I) were the least

positive on the criteria regarding accessible and easy to understand. . For example: data set (I) had the least positive responses (77%). It could be concluded that this low response reflected the ability of the participant rather than a criticism of the occupational therapists' approach.

- **'Incorporate views of all people involved with the person with learning disabilities'**

  All the participants with learning disabilities and the carers perceived that their views had been taken into account by the occupational therapist. The non-positive responses were from five of the professional stakeholders and two of the OT co-researchers. Although not all the responders considered that their views had been taken into account it was not known if this was considered a problem by them or if this would have been expected. For example, a GP or social worker may have been sent a copy of the report for their records without having had any other involvement in the occupational therapy assessment. The two OT co-researchers were aware of people that they did not consider that they had consulted but this did not include the person with learning disabilities or carers.

- **'Practical/ good use of resources'**

  Negative comments were related to having to wait for the referral to be responded to which resulted in the area of concern not being addressed when it was required. This is further explored in Section 6.3.

6.3 Findings from the general responses about occupational therapy practice

The thematic analysis of the data based on Braun and Clarke (2006) (see Section 3.4.5.1) was completed in the six phases outlined in Table 3.4. The thematic analysis aimed to identify patterns of meaning and issues of potential interest in each data item and across the data sets. The analysis of the data was completed by the lead researcher with engagement from the OT co-researchers who contributed their views and checked that there was agreement that the emerging sub-themes and themes were significant.

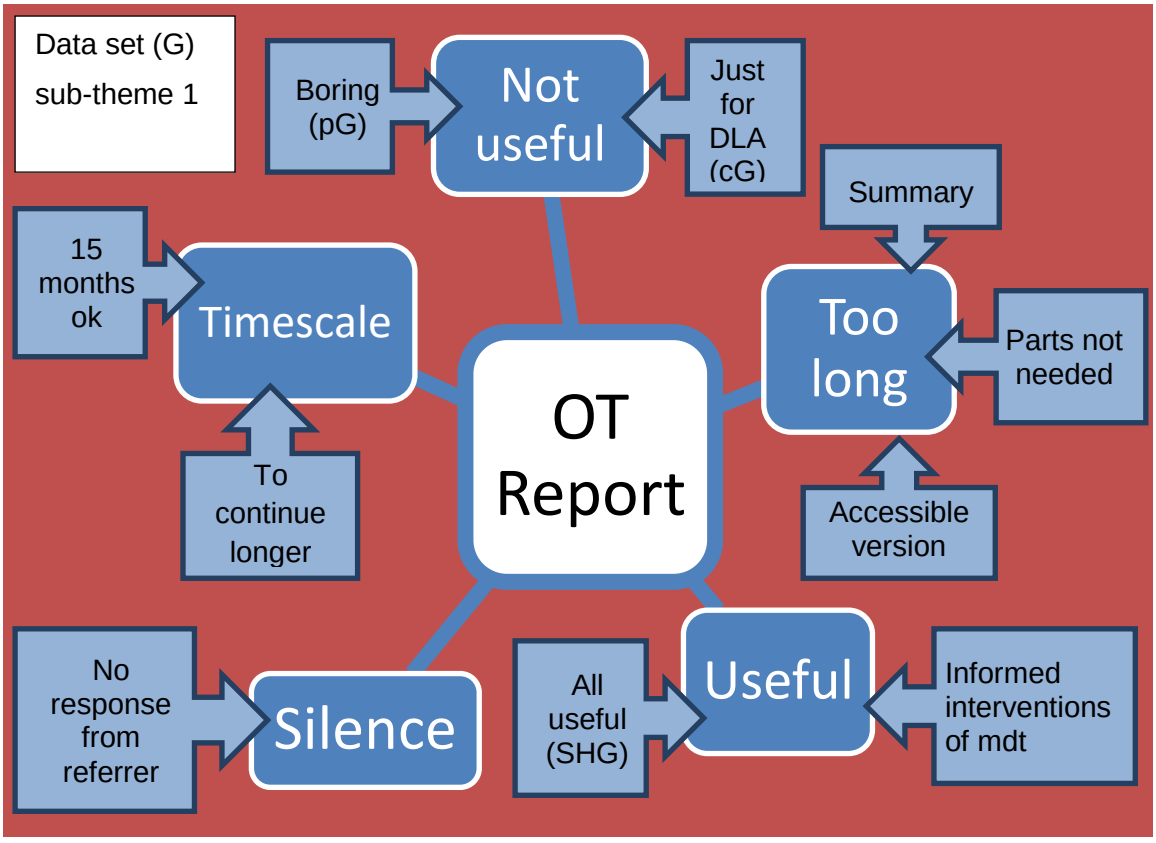
Phase one: Familiarising with the data

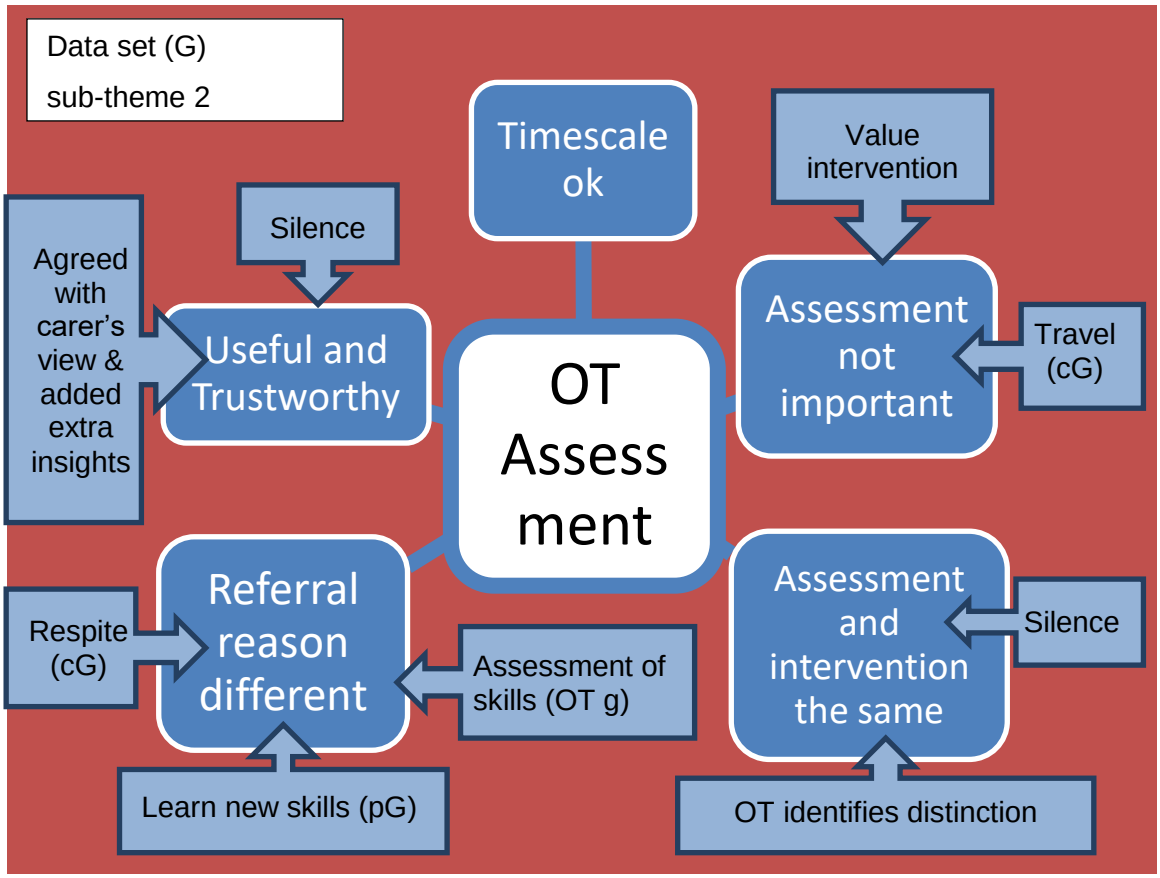
Initially each data item such as the transcript of an interview or a completed questionnaire was read a number of times and data extracts were coded. Interesting ideas were noted as sub-themes. The lead researcher presented a sample of the participants with learning disability interview transcripts for the OT co-researcher group to review in the meeting held in November 2010 and noted their perceptions. Data extracts were first identified from each data item and refined into sub-themes.

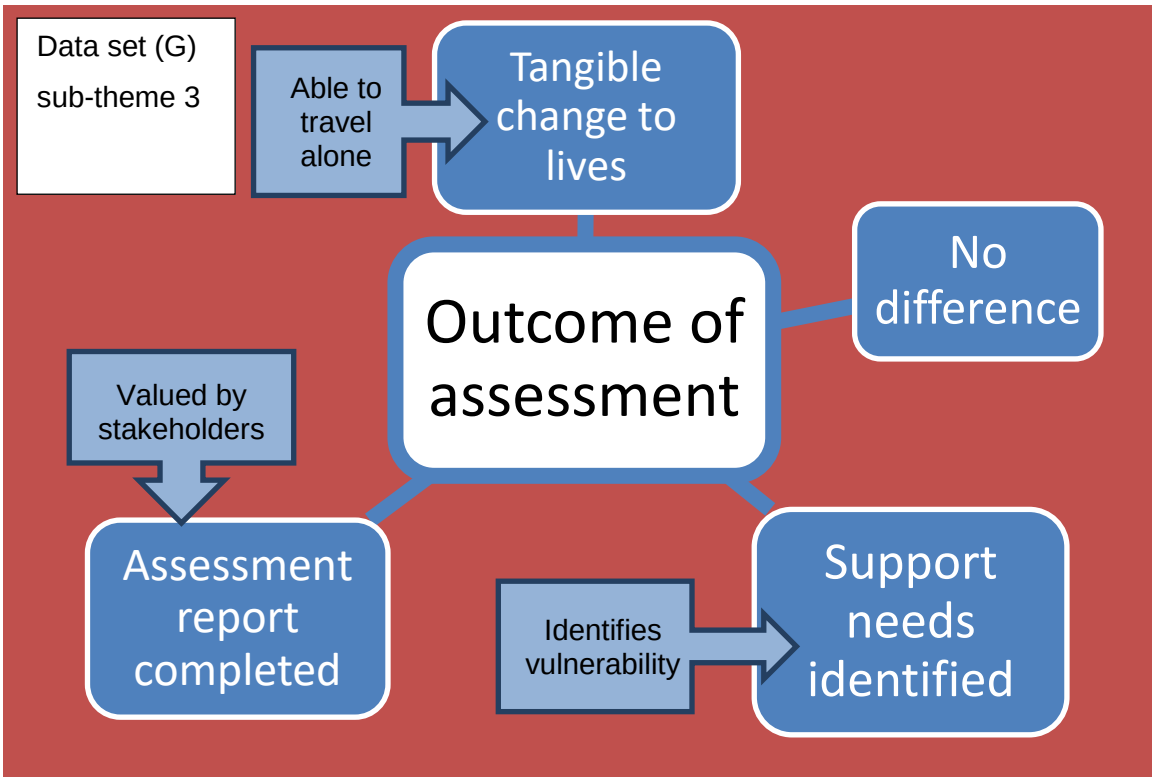
Phase two: Generating sub-themes

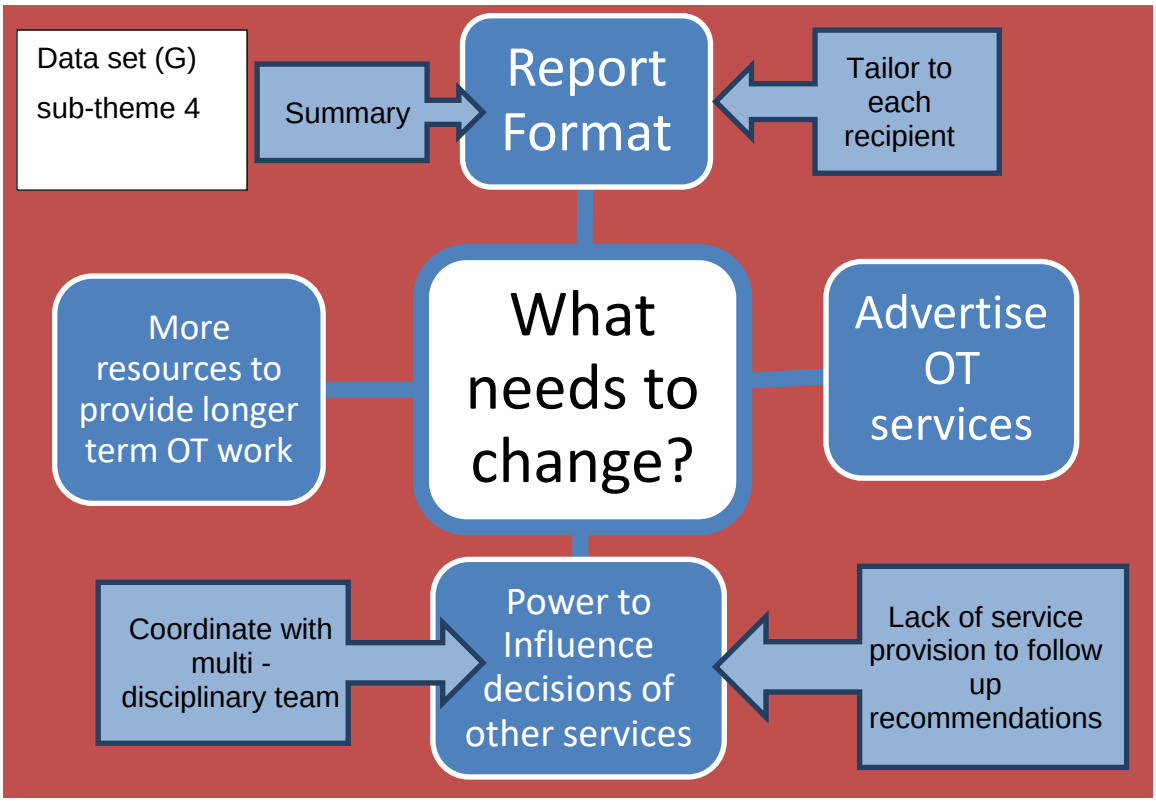
All the data items for each data set (see Table 6.1) were first considered by the lead researcher together so the context of the occupational therapy assessment and intervention for each participant with learning disabilities could be fully explored. Interesting featured were linked and coded across each data set. Figure 6.1 provides an example of how the data features were linked to sub-themes in the data set (G). The six initial sub-themes are featured in the white central boxes.

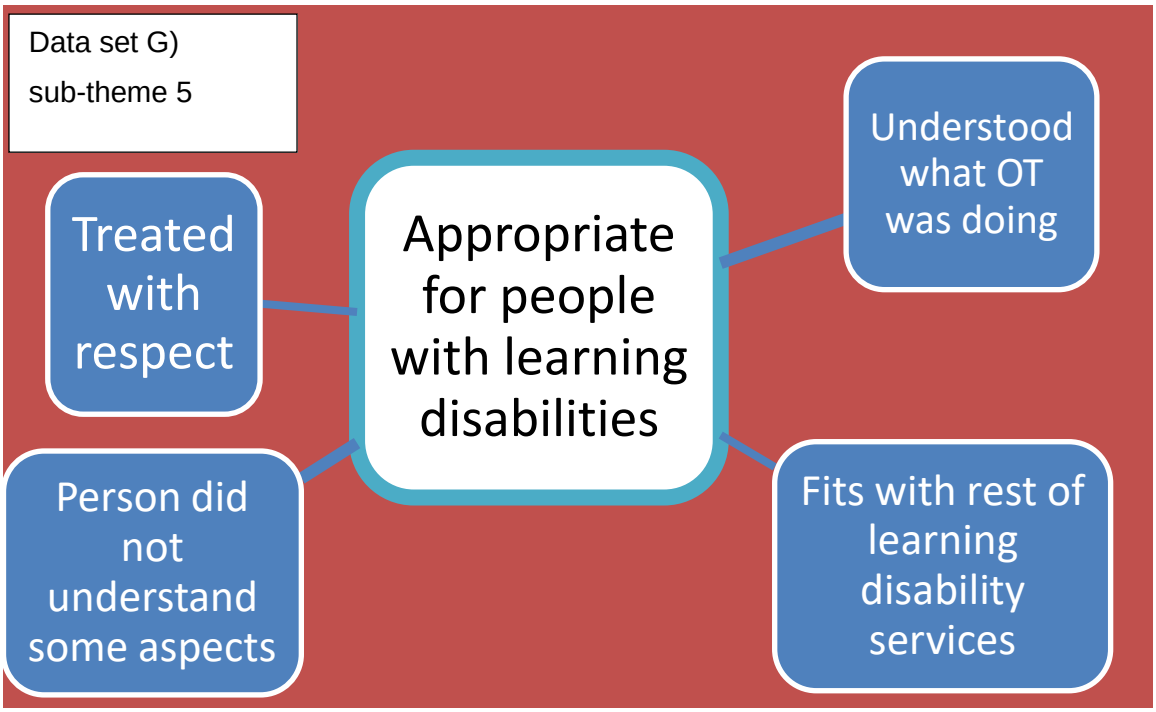
Figure 6.1: Data Set (G), Phase Two - Diagrammatic representation of generating initial sub-themes

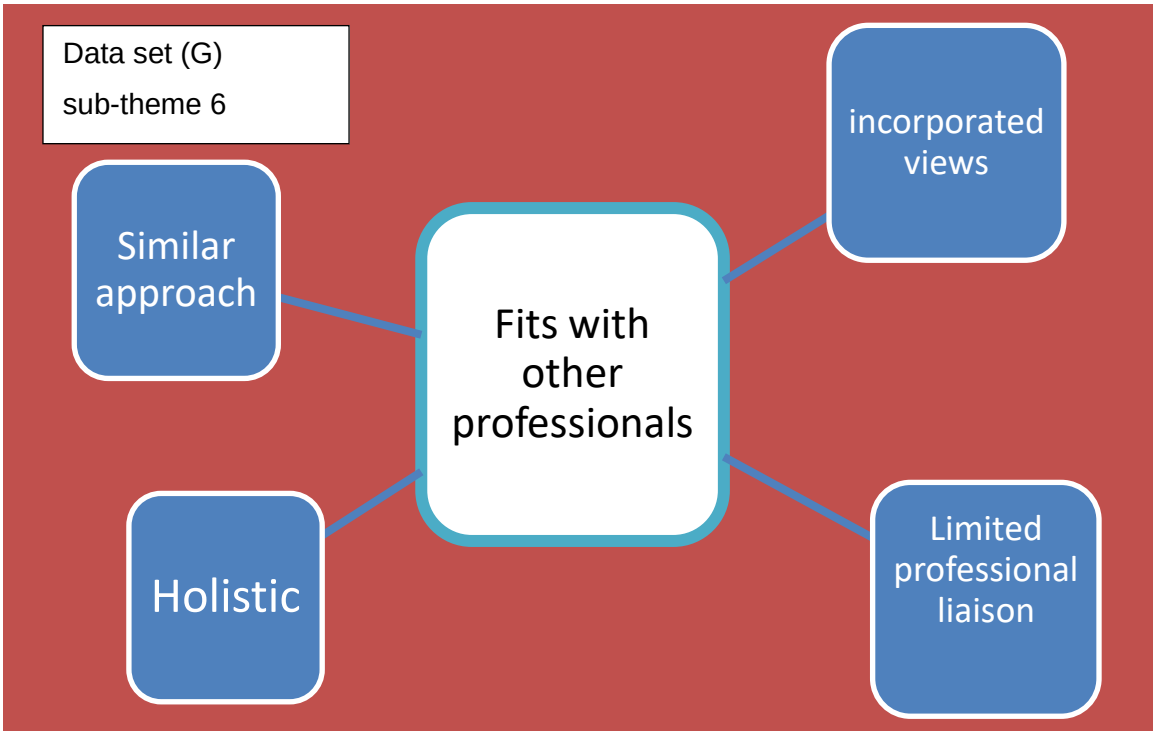



Data set (G)
sub-theme 2
Timescale ok
Value intervention
Silence
Agreed with carer's view & added extra insights
Useful and Trustworthy
OT Assess ment
Assessment not important
Travel (cG)
Referral reason different
Respite (cG)
Assessment of skills (OT g)
Assessment and intervention the same
Silence
Learn new skills (pG)
OT identifies distinction


Data set (G)
sub-theme 3
Able to travel alone
Tangible change to lives
Outcome of assessment
No difference
Valued by stakeholders
Assessment report completed
Identifies vulnerability
Support needs identified


Data set (G)
sub-theme 4
Summary
Report Format
Tailor to each recipient
More resources to provide longer term OT work
What needs to change?
Advertise OT services
Coordinate with multi - disciplinary team
Power to Influence decisions of other services
Lack of service provision to follow up recommendations


Data set G)
sub-theme 5
Understood what OT was doing
Treated with respect
Appropriate for people with learning disabilities
Person did not understand some aspects
Fits with rest of learning disability services



Phase three: Searching for themes

On reflection, the lead researcher became aware that the initial sub-themes being generated may have been unduly influenced by her search for responses that related to the essential criteria. This was the agenda of the lead researcher and the OT co-researchers but the intention, as described in Sections 3.4.5.1 and 5.4, was to use an inductive thematic analysis which was, as far as possible, free of any preconceptions. The lead researcher, therefore, needed to re-examine the data extracts to ensure that the themes were reflecting the views of the participants with learning disabilities, their carers and other people who work with them about the occupational therapy assessment experience. This task was complex and there was a need to ensure that the information from all sources could be successfully triangulated. The data extracts and draft sub-themes from each of the data sets were then considered across all the data sets to start to collate these into potential themes. Table 6.6 offers a simplified version of this process. Some of the sections are left blank when no relevant sub-themes were present in that data set.

Table 6.6: Phase three - initial groupings of draft sub-themes into potential themes across the six data sets

Key for abbreviations in text of table: OT- Occupational therapy, AWLD- services for adults with learning disabilities

Data set C	Data set D	Data set E	Data set G	Data set H	Data set I	Draft themes
OT report long and confusing.	Not a clear understanding of report's message.	Report accessible but still difficult for client to remember	OT report needs to change.	OT report needs to be clearer.	Report needs to change.	OT report too long and confusing.
OT report useful	OT Report important.	Stakeholders not clear about reason for report.	Report provides good evidence and is useful for other services.	Report is useful but needs to be clearer.	OT purpose was understood once assessment completed.	OT report is useful.
Carer confused by MDT roles/ dementia pathway.	Client initially confused social services OT with AWLD OT.		Carer did not know about service or how to refer.		Carer initially confused about MDT and OT roles.	Clients and carers do not have a clear understanding of OT.
	Reason for assessment perceived differently by respondents.		There are different perspectives on the reason for OT assessment.	Service is interested in assessment of skills for moving on to independent living, client and carer interested in actual change in current skills.	Did not meet all needs but concentrated on dementia.	There are different perspectives on purpose of OT
Positive about the OT intervention.	*(Not identified as a theme but client positive about the OT).*	*(Client positive)*	OT is unique and useful.	Useful outcome.	OT seen as positive and useful.	OT seen as positive.

Data set C	Data set D	Data set E	Data set G	Data set H	Data set I	Draft themes
OT assessment appropriate for people with learning disabilities.	Assessment method good for people with learning disabilities	Appropriate for people with learning disabilities.	Appropriate for people with learning disabilities.	Appropriate for people with learning disabilities.	OT meaningful for people with learning disabilities.	OT assessment appropriate for people with learning disabilities.
Timeframe ok.	Use of resources and timeframe good.	Not quick enough to respond to referral. Such a detailed assessment not required.	OT would have been better to have continued longer.		Too long a wait for the reassessment.	Amount of time OT spends is ok but waiting for service too long.
	Client skills changed and improved.	*(Support needs assessed as appropriate)*	Intervention seen by the client/carer as more important than assessment.	Client and carer interested in skills development rather than assessment.		Client and carers interested in skills development. Professionals interested in skills assessment?
OT assessment is trusted despite some inaccuracies.		OT assessment is trusted and respondents agree with the results.	OT is trusted.	Agreed with the OT assessment results.	OT assessment trusted.	OT assessment is trusted.
Complex needs are perceived to be too difficult to assess accurately			OT not able to influence funding for long term change.		Interpretation of assessment results differ.	Not yet categorised.

Phase four: Reviewing the initial themes

In March 2011, the sub-themes from each data set were shared with the OT co-researcher group. The lead researcher prepared flipcharts for each data set with selected data extracts of quotes from the transcripts cut out on strips of paper and grouped into the proposed sub-themes. The OT co-researchers were split into pairs and asked to review one of the flipcharts so that all the six data sets were reviewed within the group. Each pair then shared their views as to whether they considered that the sub-themes reflected the data extracts or not. They were also asked to identify any additional sub-themes from the extracts. The lead researcher reflected on these discussions and continued to develop the sub-themes. From this process the sub-themes were finalised and grouped into the three themes. Table 6.7 illustrates the generation of the thematic map and how this linked with the initial sub-themes.

Table 6.7: Phase four - generation of the themes and how they related to the draft themes and sub-themes

Draft themes from Table 6.6	Sub-themes for Theme 1	Sub-themes for Theme 2	Sub-themes for Theme 3
OT report too long and confusing.		Occupational therapy is unpredictable as it adapts and changes in relation to client need.	Occupational therapy reports need to be improved.
OT report is useful.	Occupational therapy is memorable.		The occupational therapy report recipients have differing needs
Clients and carers do not have a clear understanding of OT.			Explaining occupational therapy to people with learning disabilities is difficult.
There are different perspectives on purpose of OT		There are multiple perspectives of the reason for occupational therapy.	
OT seen as positive.	The outcome of occupational therapy is beneficial.		
OT assessment appropriate for people with learning disabilities.	Occupational therapy is appropriate for people with learning disabilities.		
Amount of time OT spends is ok but waiting for service too long.			Occupational therapy did not always meet other people's timescales
Client and carers interested in skills development. Professionals interested in skills assessment?		Occupational therapy operates within a complex and changing multi-professional and multi-agency system	
OT assessment is trusted.	Occupational therapy is trusted.		
Not yet categorised	Occupational therapy provides a unique contribution.		Occupational therapy did not always make a difference in the longer term.

Phase five: Defining and naming themes

The lead researcher continued an on-going analysis to refine each theme see Table 6.8. Throughout the action research fieldwork, the OT co-researchers were used to consider the emerging themes and to check the analysis made by the lead researcher as a way of improving the trustworthiness of the findings and to check if the themes emerging were meaningful to them as practitioners.

Table 6.8: Phase five - final defining and naming of themes and sub-themes

Themes	Sub-themes
Occupational therapy is valued	Occupational therapy is important and memorable. Occupational therapy is appropriate for people with learning disabilities. The outcome of occupational therapy is beneficial. Occupational therapy is trusted. Occupational therapy provides a unique contribution.
Occupational therapy is provided in a dynamic context	Occupational therapy is unpredictable as it adapts and changes in relation to client need. There are multiple perspectives of the reason for occupational therapy. Occupational therapy operates within a complex and changing multi-professional and multi-agency system
The ability of occupational therapy to influence others to sustain outcomes.	Explaining occupational therapy to people with learning disabilities is difficult. The occupational therapy report recipients have differing needs. Occupational therapy reports need to be improved. Occupational therapy did not always meet other people's timescales Occupational therapy did not always make a difference in the longer term.

Phase six: Producing the report

The findings of the thematic review are presented with samples of data extracts that have been selected to illustrate how the sub-themes emerged and to ensure that all of the participants' views were represented as far as possible. The findings from stage two and from stage three were further analysed in relation to the literature and occupational therapy practice in the discussion Chapter nine to produce the action research thesis.

6.3.1 Theme one: Occupational therapy is valued

The majority of the responders valued the specific occupational therapy assessment and intervention as they considered it to be both important and beneficial. The final pattern sub-themes are summarised in Table 6.8 and all relate to the overall theme.

Sub-theme: Occupational therapy is important and memorable

The participants with learning disabilities appeared to regard the occupational therapy that they had received as something that was significant to them. Even though all of the five participants with learning disabilities who were interviewed had difficulties, to various extents, with understanding, retaining information and communicating, they were able to express something about the occupational therapy assessment and intervention that they had participated in.

All of the interviewees with learning disabilities had some understanding of the areas that had been addressed by occupational therapy. They highlighted what was significant and important to them. Participant with a learning disability (H) reported that:

> *"I remember like going up the shopping to buy some food and when we come back to the house and it was like um she was teaching me how to cook"* (pH).

Participant with a learning disability (G) focused on the things she had learnt to do with her occupational therapist, for example:

> *"We mostly did a lot of travel training… using phone boxes…just in case of emergency if I lose my mobile or anything like that really … um keep myself clean, just learning different new skills and stuff "*(pG).

The AMPS (as described in Section 4.3.2) appeared to be a significant event for the participants with learning disabilities. Three out of the four participants with learning disabilities who had been assessed using the AMPS remembered the assessment and spontaneously discussed it. Participant with a learning disability (E) discussed the AMPS assessment that he had participated in:

> *"She talked to me. She saw me ironing my clothes... and she saw me keeping my flat nice and clean she saw me cleaning my flat"* (pE).

Participant with a learning disability (E)'s occupational therapist commented that the most useful part was the:

"AMPS and other direct observations" (OTE).

She later expanded on this stating:

"as (participant with a learning disability (E)) was able to understand how this related to me assessing what he was good at and what he needed support with" (OTE).

Participant with a learning disability (D) was not aware of the name of the AMPS but recalled her experience of participating in the assessment as:

"She put the things out of the fridge and then put them back in the fridge and I had to remember all the things and do it by myself…Um…. There was Hoovering…She said she is going to give me some things by myself to see if I can manage to do without support…I think she did the same test three different times to see if I remember it" (pD).

The participant with a learning disability (H) did not specifically mention the AMPS, although his carer described this as a significant event:

"Through observation (participant with a learning disability (H)) used to get cleaning materials and take them to his bathroom encouraged to use the right stuff…She took enough time to work with H and get to know his weaknesses. I remembered in the kitchen he used the knife to open the tin but after that he used the right tool. [OTH] taught him all these things" (cH).

Participant with a learning disability (I) has moderate learning disabilities and possible early stage dementia and so there was concern about his ability to meaningfully participate in the interview due to his limited comprehension, communication skills and ability to recall events. However, he was reported to enjoy having visitors and talking to new people, so his nominated consultee agreed to his participation. For most of the interview, participant (I) just answered 'yes' to questions and did not expand on any answers. However, when shown a photograph of the OT he pointed and indicated that he recognised her and then made the only spontaneous statement of the interview:

"'beans on toast" (pI).

The carer of participant with a learning disability (I) was surprised that he remembered that this was what he had cooked with the occupational therapist as part of the AMPS assessment. It is, therefore assumed that as the participation in the AMPS assessment had been a memorable event for participant with a learning disability (I), this had been important for him.

Sub-theme: Occupational therapy is appropriate for people with learning disabilities

All the respondents agreed that the occupational therapy assessment and intervention were appropriate for people with learning disabilities. The previous sub-theme provided examples of how the participants with learning disabilities considered that occupational therapy was important and memorable which could imply that this was, therefore, appropriate for them. Participant with a learning disability (H) indicated that he perceived the assessment to be accessible for him:

> "*Yes it was because I think it was me that chose the food to cook…Yes, and I understood everything"* (pH).

Two carers noted that the occupational therapists had taken time to get to know the participants with learning disabilities so that they could engage with them in activities that were meaningful to them:

> *"to assess whether he can, you know, make beans on toast, I thought was a good kind of gauge… as he likes beans, I like beans, it seems appropriate and these are skills we know he has been able to do"* (cI).

Another carer commented on how the occupational therapist built on the participant with a learning disability's interest in technology to motivate him to find recipes to cook:

> *"Yes: used computer skills to download"* (cH).

Two carers indicated that the occupational therapist and other team members from the specialist learning disability team were able to engage the participants with learning disabilities more effectively than more generic workers. One example was that the assessment took place in the person's home environment as opposed to attending an appointment at a clinic or hospital setting.

> *"Yeah they always visit [participant with a learning disability (I)] here where he lives and a recent example was [the occupational therapist] went to the shops with him so that was appropriate in his natural situation… it seemed that the OT and the psychology were the defining factors for [participant with a learning disability (I)] and the mental health place wasn't … they didn't seem to know very much about [participant with a learning disability (I)] even though he's been there a few times, so in comparison I suppose the OT and psychology have been most beneficial it seems for the outcome."* (cI).

Another praised the way that the occupational therapist and the speech and language therapist from the learning disability service worked with her daughter:

> *"I'm aware that they listened to my daughter, treated her as an individual, treated with respect, asked her if she understood when sometimes she clearly didn't and that was very important"* (cG).

The stakeholders were all positive about the appropriateness of the occupational therapy for the participants with learning disabilities in each data set. One General Practitioner stated that occupational therapy is:

> *"very supportive of patients with learning disabilities"* (sh(a)l).

The social worker and clinical psychologist for participant with a learning disability (H) both agreed that the occupational therapy assessment was appropriate to participant (H)'s needs. This was illustrated by one questionnaire response:

> *"Yes The tasks given in the assessment were relevant to his ability and skills and gave a realistic account of his abilities…The assessment was done over a period of time which was important to the client to gain confidence"* (Sh(a) H).

The occupational therapists who worked with participants with learning disabilities (C) and (E) provided some examples of how they had ensured that the assessment was as client-centred as possible:

> *"Yes assessments in learning disabilities are very client centred, it takes as long as needed to gather the relevant information"* (OTC).
>
> *"When I discussed the assessment process with [participant with a learning disability (E)] we agreed on the type of sessions that we might do together. [He] was able (and did) ask that I did not observe certain activities that he engages in, which was respected…The reasons for OT input were explained to (E) and his consent was obtained before the input and again at the start of each session when the plans for the session were explained. Accessible information was used to support his understanding where possible"* (OTE).

Although attempts were made to be client-centred it was acknowledged by one of the occupational therapists that this was not always possible:

> *"Explanations can be complex. If the task is familiar it's ok"* (OTI).

Sub-theme: The outcome of occupational therapy is beneficial

The participants with learning disabilities were all positive about their occupational therapy experience. For example: participant with a learning disability (D) said:

"Good it was good" (pD)

And participant with a learning disability (E) stated:

"It was good" (pE).

They reported that occupational therapy intervention had supported them to have made various achievements. One participant listed various areas that occupational therapy had addressed and he stated that he was positive about his own abilities:

"Um… doing very well with my money…Keep my money nice and safe…I did very well with my cooking…um…doing very well with my shopping" (pE).

Another participant perceived that the outcome of occupational therapy was that she could now manage more independently:

"She let me get my washing out to show how I can sort colours from whites and wash them for myself without support… I can make a salad without staff helping me I can cook a meal without staff helping me" (pD).

Participant with a learning disability (G) had a clear view that the outcome of occupational therapy was being able to travel more independently:

"Getting to places without always asking my Mum…Before I had [occupational therapist] I didn't really travel on my own um like with mates and stuff, … with [occupational therapist] *I had travel training to … college and back … just been working… at the phone box and bus stops that tell you where it goes*" (pG).

Participant (G)'s carer agreed that her daughter's improved skills in independent travel was a valued outcome despite this not being what she had approached services for help with:

"'it wasn't respite but it was help with travel training, [participant with a learning disability (G)] *can only go to* [two named places] *at the moment, but never the less, that was something we couldn't do a year ago so um I think that* [occupational therapist]*has been great all round"* (cG).

When asked if the occupational therapist had addressed the important issues for her daughter she responded:

"I think so. It was what was most important at that time. There are lots of things that are important but you have to prioritise given the time you've got" (cG).

The carers' perceptions of the outcome of occupational therapy were similar to the participants' views but their comments illustrated why what often appeared to be a simple occupational performance outcome had been important. One carer reported:

"Yes it did make a difference… he understood everything. He did start preparing his own meals, go around the shops and make out his timetable with different meals' (cH).

Another stated:

"I thought she was very professional, she was invaluable for the year we had her, she was a great help to me personally I think and to [participant with a learning disability (G)]*..um because she helped* [her], *therefore that helped me so that's why it was so rewarding for me, it alleviated the stress and strain and also I could talk and share things with her"* (cG).

There appeared to be a distinct difference between the views of the outcome of occupational therapy from the professional stakeholders who were interested in the occupational therapy assessment report and the participants with learning disabilities and their carers who were more concerned with wanting to see a practical change in their lives. For example, the health care professionals who responded for participant with a learning disability (G) considered the outcome of occupational therapy to be the full assessment of skills with responses such as:

"Highlighted the disparity between her presentation and performance in some area…identified her pockets of skills" (OT G).

The GP only mentioned the assessment as an outcome describing it as:

"A very big and detailed written report" (sh(a)G).

Other professionals considered both aspects of the occupational therapy input when asked about the outcome:

"[Participant with a learning disability (G)] was able to travel to some areas independently, including college. Areas where (she) needs support were identified" (sh(b)G).

and

"Direct intervention with [participant with a learning disability (G)] from [the occupational therapist] and a full assessment and intervention report. Identified areas of significant skill and significant support need and vulnerability" (sh(c)G).

All respondents for participant with a learning disability (H) agreed that the occupational therapist assessed relevant skills and made meaningful recommendations. Participant with a learning disability (H) and his carer were specific about the outcome of the intervention in that participant (H) had been

supported by the occupational therapist to develop his cooking skills. The occupational therapist reported the outcome as he:

> *"'gained skills and moved on*" (OTH).

A number of differing but inter-related views on the outcome of occupational therapy were presented by the stakeholders. These were less related to the specific occupational goals but the more general outcome about the support needs:

> *"That [participant with a learning disability (H)] could live more independently but would need on-going support…The message was given that people might overestimate [his] abilities, because of his avoidance and or reluctance to ask/accept support – this is very useful information. This is especially useful for an outreach team to register in their approach"* (sh(b)H).

The social worker reported that the outcome was:

> *"A number of strengths were identified and areas where [participant with a learning disability (H)] could build his skills…the maximisation of a person's independent living skills enabled a move out of residential into his own tenancy"* (sh(a)H).

Beneficial outcomes were reported by two respondents in regards to cases outside of the sample data sets. The carer of participant with a learning disability (C) reported the beneficial outcome of an occupational therapist's recent intervention work with another person with learning disabilities who shared a house with the participant. He reported that the occupational therapist:

> *"gave me some ideas, and since then we have changed things, about walking with service users crossing the road and asking them to take the lead. I never thought of that and now … I give him the money at the library and say pay for it your-self and he does it. When you see him empowered to do things he is much more independent in his life which is exciting".* (cC).

The audiologist reported that occupational therapy has:

> *"In the past have been helpful to inform guidelines for auditory rehabilitation and teaching new skills about using equipment and environmental adaptations"* (sh(c)I).

One occupational therapist explained how she used the combination of informal and standardised assessments to interpret the findings. She stated that the:

> *"AMPS worked well, although doesn't work for all people with learning disabilities. Use of the ADL checklist means that others can contribute their knowledge about a client as well as collecting the client's views…"The AMPS*

supported what was subjectively reported by [participant with a learning disability (E)]and his key worker" (OTE).

Sub-theme: Occupational therapy is trusted

Generally, the respondents stated that they were happy with the occupational therapy assessment and that the findings agreed with their own views, and observations. There appeared to be an implicit trust in what the occupational therapists were reporting. For example when participant with learning disabilities (H) was asked if he agreed with what the occupational therapist had said he responded:

"Yes everything" (pH).

When participant with a learning disability (E) was asked if there was anything about occupational therapy that he did not like he responded:

"I liked her". (pE).

This illustrated that the participants did not always make an obvious distinction between the occupational therapist that they worked with and the occupational therapy that they received but appeared to have established a rapport and trust.

Some of the carers reported that the occupational therapy report agreed with their understanding of the person they supported. For example: the carer for participant with learning disabilities (I) reported:

"'yeah it talked about motor ability not changed and yeah that's what we found that [participant with learning disabilities (I)] has always been quite slow um but it's just his memory skills, picked up as a problem, its remembering to do it, it's not you can't make beans on toast, it's the cognitive skills. Yeah, no surprises really"(cI).

The carer for participant with learning disabilities (G) agreed with the occupational therapy assessment findings:

"*There was no development that I was not aware of, she never, you know, told me anything I didn't know. Um but at the same time it was refreshing to see that somebody was acknowledging my daughter's problems"* (cG).

The same carer reported that she respected the occupational therapist as a professional:

"the important thing was that I felt that [the occupational therapist] was um very capable when I first met up um some people you click with or you don't, that's not a personal thing sometimes you just that know that someone's doing their job really well, you can pick up, you don't have to like them, it's things they say, the way they are" (cG).

Many stakeholders indicated that the occupational therapy assessment was trusted and corresponded with their own findings. For example: a psychiatrist stating:

> *"Yes, this would fit with my assessment"* (sh(b)I)

a clinical psychologist:

> *"Yes. Especially because of what I already know about [participant with learning disabilities (H)] - it fits well with my own 'picture' of him"* (sh(b)H).

an audiologist stated that she:

> *"would rely on the expertise of the occupational therapist"* (sh(c)I).

and a social worker also implied her trust of the assessment as it provided information to support realistic goal planning:

> *"The activities of daily living checklist and observational information given about how the client was able to do the tasks: not just that the tasks were completed. The identification of goals"* (sh(a)H).

Sub-theme: Occupational therapy provides a unique contribution

A unique aspect of the occupational therapy assessment was the observation of the person completing activities of daily living tasks. Participant with a learning disability (E) was asked:

> Did you mind her watching you*? "Just did".* Was it a bad thing or a good thing? *"Good thing".* Ok, is that something that anyone else does or just (the occupational therapist)? *"Oh (occupational therapist) was watching me".* Do other people watch you doing things? *"Not really*" (pE).

The occupational therapist who had worked with this participant with a learning disability suggested that the occupational therapy assessment, which included the AMPS observations, was able to assess skills more accurately than other methods:

> *"Although the psychology report suggests that (participant with a learning disability (E)) is less able than he might first appear based on his psychometric assessments. However, he is limited more by autism and concrete thinking than his learning disability and so his every day skills are generally good"* (OTE).

A social worker commented:

> *"It is very useful to have the observational assessments from an occupational therapy perspective about skills and areas of need for adults with learning disabilities. The assessments can help with planning future input either from existing support networks or in relation to the commissioning of services"* (sh(a)H).

The carer for participant with learning disabilities (G) provided examples of the occupational therapy assessment of her daughter that she valued as unique contributions:

> *"she highlighted and noted things that I have to convince people of and because she was so professional she could just see it and that was good…She looked at areas that I wouldn't have thought of like … sexual knowledge… because she done a complete assessment it opened up the areas I need to work on -holes and gaps"* (cG).

The three carers who worked in supported houses for people with learning disabilities described how the occupational therapists understood the needs of the participants with learning disabilities in a different way from the paid carers. One said about participant with a learning disability (H):

> *"Yes it was a good way 'cause initially when he came to us he was a bit shy shutting the doors and his learning difficulties when she (occupational therapist) came in and identified that and he understood everything like trying to participate in the activities"* (cH).

The carer for participant (C) who was a support worker manager acknowledged that the occupational therapist could provide a more over-arching view than could be provided from his service:

> *"that's what you do comprehensive job: needs others involved. We can't do it. You need our input and day centre"* (cC).

The carer reported for participant with learning disabilities (I):

> *"The OTs are a really great team they are always really informative always try to be as accessible to (participant with a learning disability (I)) as possible and he's always happy to do things"* (cI).

This contrasted with the one respondent who did not value the unique contribution of occupational therapy who considered paid support staff should be expected to complete the occupational therapy role:

> *"Well I think that staff could have been advised how to more systematically teach skills and record outcomes, then this sort of work wouldn't be needed…No I think staff in the house should have been able to do what the OT did"* (sh(d)I).

The social work respondent was dealing with the case on duty and did not have any knowledge of the case prior to completing the questionnaire. It was also noted that this person had been the only respondent to misinterpret the results of the

assessment. This appeared to highlight the difficulty occupational therapy has when relying on the use of assessment reports to explain an assessment and intervention process to people who they have not been directly working with the participant with learning disabilities. In contrast, a carer was clear how the occupational therapist differed from a paid support worker stating that the occupational therapist was:

> *"really helpful, full of suggestions because unlike somebody just being a carer like going out doing travel training or whatever she had the experience that um her training had brought with it so therefore she had an insight into people's special needs. She also, when I explained the situations that might be difficult for the normal person to understand she actually understood as well and she came up with different strategies and things like that you know, even though some may have been tried and tested, others were new which was nice to have that feedback as well"* (cG).

6.3.1.1 Discussion of theme one: Occupational therapy is valued

The findings indicated that undergoing an occupational therapy assessment and intervention appeared to be a valued experience for the participants with learning disabilities and this was also appreciated by the carers.

As was anticipated by the OT co-researchers in Section 5.3.1, it was noted that the participants with learning disabilities did not always differentiate between the occupational therapy that they had received and the occupational therapist. They appeared to find splitting what they thought about the person from what they thought about what the person did, to be a difficult concept. It may be that the participants were just responding positively to having sessions with a professional who was able to build a rapport with them and that the occupational therapy that they received was irrelevant to this relationship. However, this did not appear to be the case as the participants with learning disabilities were able to report the activities that they had participated in during the occupational therapy sessions. Their reported experiences indicated that their participation in occupational therapy had been doing something practical and meaningful which had resulted in being able to do more for themselves and had increased their self-esteem. This dual positivity about the occupational therapists and the outcomes of occupational therapy from the perspectives of the participants with learning disabilities in this research study appears to be a similar finding to that of Roeden et al (2011) who concluded that the

positive working relationship with the therapists was an important factor in achieving positive outcomes (see Section 2.4.1).

The participants with learning disabilities and their carers identified the outcomes of occupational therapy in terms of occupational performance skills that they had improved or developed confidence in. Occupational therapy was delivered in a client-centred way that was accessible for people with learning disabilities. There did not seem to be a distinction made by the participants with learning disabilities between the assessment and intervention of occupational therapy.

The participants with learning disabilities seemed to like being assessed by the occupational therapists using the AMPS and found this to be a significant and memorable experience. They all reported the AMPS as something that they had completed well. There may be a number of factors that have resulted in participating in this particular assessment being perceived as a positive experience. The participants with learning disabilities were given the opportunity to demonstrate something that they were able to achieve and allowed to work at their own pace without interruptions. They were aware that they were being formally assessed but it appeared to be in a format that was not threatening, was understood, relevant to their lives and something they could succeed at. Most people with learning disabilities will have undergone various tests and assessments in their lives, such as a psychometric assessment or school exams. Many of these contain tasks which they may find difficult and there are often parts of the assessment that they may not succeed at which can result in the person feeling that they have failed. The AMPS does assess skills and deficits and produces a score. However, the AMPS is designed so that the person chooses tasks that they find to be a challenge but that they can achieve. This was also an example of using observation as the method of assessment which was one of the essential criteria of the assessment developed by the local occupational therapists.

The significance of the impact of occupational therapy on the participants with learning disabilities and their carers did not always seem to be acknowledged or recognised by the other stakeholders involved including the occupational therapists. This appeared to be because they were more concerned with the results of the assessment of the person's skills rather than what had changed in the person's life. The assessment report was something that all professionals wanted to receive and they considered the occupational therapy assessment provided new information

about the participant with learning disabilities that was useful for their roles. This illustrated that occupational therapy was valued as a contributor to the multi-agency assessment and intervention for adults with learning disabilities. The local occupational therapists' assessment reports appeared to be produced more for the needs of other professionals than to meet the concerns of the adults with learning disabilities and their carers. However, the responses received indicated that the occupational therapy practice had been valued by all the responders.

6.3.2 Theme two: Occupational therapy is provided in a dynamic context

This theme captures the acknowledgement that occupational therapy needs to be adaptable to the person with learning disabilities' needs as well as that of the complex system that surrounds him or her. The sub-themes that illustrate the complexities of the dynamic context that occupational therapy needs to be able to operate within are summarised in Table 6.8.

Sub-theme: Occupational therapy is unpredictable as it adapts and changes in relation to the needs of the person with learning disabilities

The occupational therapists had agreed occupational therapy goals with the participants with learning disabilities and their carers as part of the occupational therapy assessment but the findings from the interviews were that these goals were not always clearly understood and appeared to have evolved over the period of intervention. An example of this was in data set (G) where the occupational therapy assessment and intervention was completed over a period of fifteen months. There was no clear distinction between when the occupational therapy assessment was completed and the intervention started as these occurred concurrently. New referral issues arose during this period of time, for example the occupational therapist reported that the assessment:

> *"Took longer than expected because sexual knowledge assessment became a priority"* (OTG).

The carer for participant with a learning disability (G) explained that:

> *"initially I did not know what the assessment was about and why we were being assessed as I asked for some help with respite. And then [the occupational therapist] explained things which was all new to me"* (cG).

The referral issue for participant with learning disabilities (H) was to assess and develop his daily living skills so that he could be supported to move on to a more independent flat from a staffed group home. However, the stakeholders involved were aware that in order to complete the occupational therapy process successfully, other factors such as the anxiety of the participant with learning disabilities (H) needed to be identified and taken into account. The social worker reported that:

> *"The assessment was done over a period of time which was important to the client to gain confidence"* (sh(a)H).

The carer reported that the occupational therapist needed to be skilled at working in a person centred way with participant (H) in order to be successful:

> *"I think it was really good to be in the home as (participant with learning disabilities (H)) is shy when not used to you he actually opened up to (the occupational therapist)"* (cH).

This ability of the occupational therapists to be flexible to ensure that they were responsive to the needs of the participants with learning disabilities appeared to be appreciated but this affected the clarity of what needs the occupational therapist actually addressed.

Sub-theme: There are multiple perspectives of the reason for occupational therapy

The occupational therapy service had received a referral to address a specific need for each of the participants with learning disabilities. However, the person who originally made the referral was only still involved in working with the case in one of the six data sets (H). None of the referrers in the six data sets were the participants with learning disabilities or their current carers.

The participants with learning disabilities did not always have the same understanding of the needs areas that were addressed by occupational therapy as the occupational therapist. For example, participant with learning disabilities (G) did not mention the sex education that was also covered and participant with learning disabilities (E) reported the domestic and community skills parts of the assessment, but did not mention personal care, communication, relationships and health.

The participants with learning disability focused on the practical things that they did with the occupational therapist rather than the more formal interviews and discussion. Participant with learning disabilities (G) talked about what the

occupational therapist actually did with her and seemed unaware of any assessment of her skills:

> *"We mostly did a lot of travel training and um just learning different new I was going to say skills but it was mainly different skills on how to do different things"* (pG6).

Participant with learning disabilities (D) had some insight as to the reason for the assessment:

> *"to see what I can do without help"* (pD).

However, the occupational therapist for participant with learning disabilities (D) stated that the reason for referral was:

> *"concerns regarding her memory impacting on her skills"* (OTD),

This agreed with the clinical psychologist who reported it was an:

> *"investigation of memory loss"* (sh(a)D).

In data set (E), the occupational therapist stated that the client was:

> *"referred by psychology for skills assessment as there were concerns that participant with learning disabilities (E)'s skills were being overestimated and as such he was not in receipt of an appropriate level of support to manage in the community"* (OTE).

This appeared to match participant with learning disabilities (E)'s understanding of the reason for occupational therapy referral which he reported was:

> *"checking I'm ok…To be safe to be safe"* (pE).

However, in contrast, the social worker believed that the reason for referral was that the:

> *"psychologist referred due to concerns about his behaviour"* (sh(a)E).

In data set (H), the participant with learning disabilities and his carer perceived the occupational therapy referral to be developing practical skills:

> *"going to help me and cooking and something like that"* (pH).
>
> *"I think the whole thing put him through different processes teaching him some skills about cooking"* (cH).

However, the occupational therapist and other stakeholders perceived the occupational therapy addressed a wider remit. For example:

> *"To assess skills in preparation for a possible move to more independent living"* (sh(b)H).

Sub-theme: Occupational therapy operates within a complex and changing multi-professional and multi-agency system

The occupational therapists reported that they saw their role as a partnership with the person, carer and other support systems. For example: one of the occupational therapists reported that what went well was:

> *"Working with staff which enabled them to support (participant with learning disabilities H) to develop his skills"* (OTH).

However, one occupational therapist suggested that there should have been more coordinated:

> *"input with other members of the MDT (multi-disciplinary team)"* (OTG)

Most of the stakeholders agreed that the occupational therapy assessments had taken into account their views and the occupational therapy assessment findings did not conflict with other assessments about the same person. However, the participants with learning disabilities and carers appeared to be less aware of the wider agencies involved and how to link in with them. Most of the participants with learning disabilities did not mention other members of the team. One was aware of some of the people involved but not all. She stated:

> *"I know (OTG) was talking to mum and sometimes I know she was talking to my psychologist as well"* (pG).

The carer for participant with learning disabilities (C), who was a paid support worker was confused between the roles of the different learning disability professionals and expressed feelings of being too busy to manage the information he was receiving from the various team members. Another support worker said that initially the multi-disciplinary team process was confusing as there was no single clearly communicated plan:

> *"as a team we weren't sure of … what was happening ….in fact there were lots of times from the beginning where um we did not know who was speaking to who, and what information was going anywhere. Even though we were probably…given a vague idea we knew it was multidisciplinary and it involves all these people There were times when it did not seem to be going anywhere"* (cI).

However, he went on to say that the involvement of occupational therapy had clarified the process and that the occupational therapist:

> *"was definitely aware of everything else that was going on for client I"* (cI).

The carer of the participant with learning disabilities (G) expressed how much she valued the holistic team work that she had experienced from the local learning

disability team and how positive this was compared to her daughter's experiences of other generic health care workers. She also stated that she had been unaware that an occupational therapy service existed and was available for her daughter. She stated that the service:

> *"is not publicised enough. People don't know it's out there, people don't know what it entails…It needs to be more available...* [to] *everyone" (*cG).

6.3.2.1 Discussion of theme two: Dynamic Context

The reason and purpose for occupational therapy for each of the six data sets was complex and evolved over the course of the intervention. It was assumed that the occupational therapists received a referral, carried out an assessment followed by intervention to address the issue and informed the referrer of the outcome. In this study this did not happen in any of the cases. The intervention was subject to delays and there was a long term nature to much of the work. The referral issue was redefined by the occupational therapist with the participants with learning disabilities and carers and plans were adapted as the participant's needs and interests emerged. The assessment and intervention often appeared to happen simultaneously. The clear distinction between assessment and intervention appeared to be something that only the occupational therapists recognised and were concerned about.

The occupational therapists considered the person with learning disability as their primary concern although it was not always clear if it was the person with learning disabilities' needs or the referrers' needs that were being addressed. Occupational therapy was delivered as a response to a referral but the referrer did not usually remain involved. None of the cases had been a result of a direct referral from the participant with learning disabilities or a carer, but the assessment and intervention plan was negotiated with them. Some of the carers stated that they were unaware of the occupational therapy service or how to make a referral. The participants with learning disabilities appeared unaware that they could request occupational therapy. It would, therefore be expected that there may be a cohort of people with learning disabilities and their carers who may be similarly unaware of services that could be available for them.

The occupational therapists had a wider team role that included providing services to other professionals as well as working with individuals with learning disabilities

and their carers. There can be multiple purposes and needs to be addressed. This complexity of role did not seem to be fully defined by any of the respondents including the occupational therapist involved. Occupational therapists have to be flexible and adaptable so that they can endeavour to meet the needs of the participants with learning disabilities as well as addressing other concerns from referrers and others agencies that may also be involved. Despite the identified complexity there was positivity from the majority of the respondents about how the occupational therapists were able to incorporate the relevant views all people involved. Although the occupational therapists were liaising with other professionals and agencies some participants with learning disabilities seemed unaware that there would be sharing of information with the wider team. It was concerning that information sharing with other professionals was not more explicit.

The data extracts illustrated that the health and social care system within which occupational therapists were working was complex. However, there was a need to be able to explain concepts simply and clearly so that they were accessible for people with learning disabilities. This balance between the occupational therapists having to cope with large amounts of information and being able to provide clear and concise messages to people with learning disabilities needed to be constantly managed. Despite the complexity of the system, the stakeholders were usually positive about the occupational therapy role and how it worked within the system.

The OT co-researchers' stated views of the assessment, intervention and outcome did not always recognise or coincide with the participants with learning disabilities' perspectives of the outcomes. The participants with learning disabilities would often consider the assessment process as intervention which had made a change for them, whilst the occupational therapists considered that they had just provided an assessment. The occupational therapists appeared to be valuing other aspects without always acknowledging what was important to the participant with learning disability. The occupational therapy reports appeared to have been intended for a different audience than the person with learning disabilities.

6.3.3 Theme three: The ability of occupational therapy to influence outcomes varies

The outcome of occupational therapy was affected by the occupational therapists' ability to influence a number of factors that affected how their recommendations were followed. The sub-themes for this theme are summarised in Table 6.8. The first three themes focused on the occupational therapy assessment report which for some of the stakeholders, such as the GP, receiving the report may have been the only contact with the occupational therapy service. The participants with learning disabilities all stated that they had received their report and had either read it, or it had been explained to them. All the other respondents agreed that they had received and read the occupational therapy report, it was relevant for them and they believed that a copy should be sent to them.

Sub-theme: Explaining occupational therapy to people with learning disabilities

There appeared to be difficulties in effectively communicating the occupational therapy assessment findings and recommendations to the participants with learning disabilities. Reports had been sent to all the participants with learning disabilities and there was evidence that the occupational therapist had met with two of the participants with learning disabilities (G) and (H) in person to discuss these. One occupational therapist commented:

> *"The process was accessible but the final report was not"* (OTG).

The occupational therapy report for the participant with learning disabilities (E) had been produced in an accessible version with simplified summaries and clear pictures. The occupational therapist stated that:

> *"It's good to have an accessible version of the report for the client - and sometimes the support staff – to get a clearer understanding of the OT role and recommendations"* (OTE).

Participant with a learning disability (E) was positive about this report although he did not comment on what it said. When asked if he understood the report he said:

> *'Yes I did'* (pE).

This suggested that even if the report has been made to be accessible, it was not necessarily the whole answer as how much participant (E) understood of what the occupational therapist had done, and his ability to recall this, was not clear.

However, one of the stakeholders commented positively about the occupational therapist's attempt to communicate the assessment:

> *"Separate reports: professional AND accessible which was most helpful*" (sh(b)E*).*

Participant with a learning disability (G) was aware of the report but had not been motivated to read it:

> *"She said like she was going to do a report and um and when I get it I can read it and stuff like that but at the moment I didn't have time"* (pG).

She did not make any comments about how it could be improved or whether or not she would ever want to read it. When asked about the occupational therapy reports she said:

> *"They are useful but mostly… I think… boring"* (pG).

This did not appear to be related to specifically the occupational therapy report but her previous experience of assessments:

> *" lot of the reports and stuff are rubbish cos before I had [occupational therapist] and when I was little I used to be going to hospitals and doctors and stuff and they like gave me tons of reports my old speech therapy as well and stuff and it got really boring as well"* (pG).

Although participant with a learning disability (G) had not read the report she had also received a verbal explanation from the occupational therapist. She was able to demonstrate an understanding of what she had achieved when working with the occupational therapist and how she had made the decision that she did not want to develop skills further for the time being as she had other priorities:

> *"I was talking to her before she left and she said…if ever you want more help using the washing machine or something like that or a lot more cooking or something She can always come back and teach me*" (pG).

When asked if she needed more help now participant (G) explained that she did not want to concentrate on learning domestic skills at this time:

> *"Well I can do like some cooking and other stuff but I can't do all of it. And it is good to learn different new skills and stuff but the bad bit is like I'm always out and I like being out. I don't like always being in"* (pG).

This indicated that she had made an informed choice about finishing her occupational therapy intervention and an understanding of when she may need a service in the future.

Participants with learning disabilities (H) and (D) were initially reluctant to say that they could not read and understand the occupational therapy report that they had received. For example, one said:

> *"I think it's fine actually"* (pH)

until this was challenged when he laughed and shook his head saying:

> *"it's not easy to read. There are a lot of words"* (pH).

Participant (D) got the occupational therapy report and read it out during the interview. This demonstrated that she had some understanding of it, for example: she read *'taking exercise and healthy eating',* when asked what this meant she said:

> *"My key worker is helping as she doesn't want me to sit in the house and wants me to go out more"* (pD).

However, at other times she struggled with understanding long words such as: when she read 'clear routine, limit distractions', she said:

> *"I can't get this"* (pD).

When asked if she would like pictures and easier words she enthusiastically exclaimed:

> *"Yes please yes please!"* (pD)

Sub-theme: The recipients of the occupational therapy reports have differing needs

The occupational therapy reports appeared to meet a variety of needs and purposes depending on the recipient. The occupational therapists reported that some of the messages in their reports were not always felt to be appropriate for the person with learning disabilities. This resulted in the participants with learning disabilities sometimes being given a different explanation of the assessment than the other respondents. For example, in data set (D), the assessment of any memory difficulties was not emphasised with participant (D) when this appeared to be the key message for the other professionals. The occupational therapist stated that she:

> *"Tried to explain to [participant with a learning disability (D)] the reason for the assessment, -difficult as there were many sensitive issues around the case"* (OTD).

The occupational therapist's motivation was to protect the person but may have resulted in not being open and clear about the purpose of the assessment. In other data sets there was evidence that the occupational therapy reports did not provide clear messages to the participants with learning disabilities. Comments were made by some of the professional stakeholders regarding this concern for example:

"Report was not accessible" (sh(e)I).

A section of the occupational therapy report was quoted:

"Fair amount of jargon and difficult language e.g. 'some ADL tasks which historically he could undertake independently'" (sh(b)I).

A suggestion to improve this was to provide:

'An abridged/accessible version for the client to have' (sh(c)G):

One carer reported that the report was only important for her to use as evidence of her daughter's disability so that she could receive services and benefit. This was not how the occupational therapist had intended the assessment to be used and was not aware that it had been shared in this way. This indicated that the influence of the occupational therapy assessment for this data set was wider than had been assumed when selecting the stakeholders to be sent questionnaires.

Sub-theme: OT Reports need to be more concise

Some of the professional stakeholders had concerns about the occupational therapy assessment report being too lengthy and complex. For example:

"The most useful part, for me, was the last two paragraphs of background information. In my opinion, these would more usefully have been placed in the summary" (sh(b)I).

"The length of the report is a little unwieldy but this seems unavoidable" (sh(b)G).

'A summary page would have been useful' (sh(a)G).

There were some specific comments about understanding the AMPS assessment reports as these contain computer generated reports that contained 'jargon'. Some commented that they valued the clarity of a graph but wanted more explanation. All the professional stakeholder responses appeared positive about the AMPS assessment with examples such as:

"Know how his skills had changed in a measurable way. Itemised the tasks he was able to do and what he found difficult" (sh(c)I).

"Scores for; comparison of functioning at different time points. Explanation of what the scores mean and how to interpret them" (sh(c)I).

The health professionals, who commented, reported that they found the AMPS assessment results useful and they all interpreted the results as had been intended by the occupational therapist. However, the social workers were not so positive about the AMPS. As previously identified, one appeared to have misunderstood the

outcome that had been presented. This appeared to indicate that even when using a standardised assessment, the same information can be interpreted differently by the recipients of the reports. Another social worker made specific comments about how to present the information clearer:

> *"The graphic report at the back of the assessment… would need some explanations to someone not familiar with the format. The AMPS assessment would be more useful with qualitative information rather than just the tick box as the context of the information assessed is important"* (sh(a)H).

This was just a small sample but there did appear to be a difference in how standardised assessments were perceived by health professionals and others.

Suggestions made as to how the report could be improved included:

> *"Maybe more precise recommendations with details re skill development in identified areas to help staff support service user*"(sh(a)D).

The stakeholders seemed to be interested in the aspects of the report that related to their own role: The general practitioner with a generalist focus stated:

> *"It was all useful"* (sh(a)G)

The speech and language therapist commented that the report was:

> *"a very comprehensive report with practical suggestions for future management…linked in with the Speech and Language Therapy report and assessment well*" (sh(c)G).

The clinical psychologist wrote that the:

> *"Details of (participant (G))'s level of functioning were informative to the approach taken to therapy"* (sh(b)G).

Only one respondent had a negative comment about the occupational therapy report. This came from the carer for participant (C) who reported that he had some concerns when he read the report but did not have the time to respond to the occupational therapist to address these. Despite the reservations with some aspects of the reports all the responders agreed that they appreciated receiving the occupational therapy report and most reported that they had read it prior to being interviewed or completing the questionnaire. The exception to this was one of the social workers as the case was not allocated to a specific person. Examples of comments included:

> *"Yes It is useful to link the information with the assessment which is used to determine the level of support required"* (sh(a)H).

"Yes. Only if OT are aware that we are working with the client and assuming client consents" (sh(b)H).

There were many suggestions from the responders that a summary report would be useful and to provide an accessible version for the participants with learning disabilities. However, there were differing opinions as to what was considered a brief or long report. For example in data set (H) the report was seen by the carer as lengthy:

"It details everything; quite comprehensive" (cH).

However a professional's comment about the same report was:

"Useful also because it is brief – anyone reading an overlong document can have a tendency to skip to the conclusions" (sh(b)H).

Each recipient appeared to have different requirements for the occupational therapy report and it appeared that it would be difficult to meet all potential recipient expectations in one report.

Sub-theme: Meeting other people's timescales

The occupational therapy assessment and intervention was not always commenced in a time scale that was appropriate for the other services involved. The stakeholders for data set (E) were concerned that the delay in commencing the assessment reduced its usefulness. The psychologist stated that the occupational therapy assessment was:

"Very helpful and the reports are clear and valuable" (sh(b)E)

but then went on to say:

"If the assessment was completed sooner the results would have been more helpful". (sh(b)E).

The social worker reported that:

"I think if [the occupational therapist] had met with the psychologist who referred at the time, and had a discussion with the house staff, the full assessment would not have been needed…I think this is an example of a Rolls Royce Service- excellent quality, but slow getting started- when a one off taxi ride would have done the job" (sh(a)E).

However, once the assessment was started, the occupational therapy intervention for data set (E) was completed in the shortest length of time of all the six data sets. The occupational therapist considered that:

"The time frame was nine weeks, which gave time to build rapport, collect information, make observations, undertake AMPS, write it all up and create

an accessible version of the report to go through with participant (E) and his keyworker" (OTE).

There was a similar issue in regards to a delay in the commencement of the service for data set (I). The carer reported:

> *" I don't know if this is resources and you only have so much time to see everyone in the borough so in terms of outcome for [participant (I)] I it felt like we were waiting around for a long time more ….than 2 years*" (cI).

The occupational therapist agreed that there had been a delay but not as long as the carer had perceived it:

> *"Ideally… it should have been carried out 6 months earlier"* (OTI).

Other stakeholders also agreed that the assessment should have been completed sooner:

> *"For dementia assessments, particularly, it would be most helpful for them to be fast-tracked and prioritised to allow for rapid assessment and diagnosis of dementia"* (sh(e)I).
>
> *"Not sure but in someone at high risk of dementia, an earlier repeat would have been helpful especially as there is a three year history of concern about client I's memory"* (sh(b)I).

The length of time the episodes of care were open to occupational therapy in the six data sets varied from nine weeks to three years. Once occupational therapy had commenced, in each case there were no comments received about the length of time it took to complete the assessment. When participant with a learning disability (G) was asked how occupational therapy could be improved she said:

> *"Probably the travel training really. .. Like going to like a little bit more going further or demanding or going different places but go a little more further*" (pG).

This appeared to indicate that participant with a learning disability (G) would have liked to have had the occupational therapist continue to work with her. The carer in this data set also stated that her daughter:

> *"needs lots of help- on-going … in an ideal world if there was funding I would like [the occupational therapist] every week you know once we finish doing the toileting or once we finish doing the travel training or the teeth brushing, we could do the cooking or something… I wish I could have her for ever"* (CG).

All the stakeholders agreed the time frame for completing the assessment and report was appropriate. In data set (D) the occupational therapist suggested that it would have been better to have completed the assessment:

> *"on one visit"* (OTD),

In contrast, the participant with a learning disability (D) seemed happy with the time scale for the assessment:

> *"She spent a good amount of time and then she went to come back was it the second time she said she was going to close my case 'cause I was doing so well"* (pD).

The carer of participant with a learning disability (C) suggested that the occupational therapy assessment needed to be undertaken over time to be effective:

> *"When you shorten time then it's not so comprehensive. If you do it properly it does take time and everyone has to be involved"* (cC).

The perceptions of the majority of the responders appeared to be that there were concerns that the occupational therapy assessment did not always commence in time, but once the assessment and intervention had commenced, there was not a concern that it should be completed to an urgent timescale.

Sub-theme: Able to make a difference

The occupational therapy assessment was only one part of the wider health and social care provision. At times, occupational therapy intervention may have raised expectations that could not be met. In data set (G) the occupational therapy assessment was offered in response to a complaint made by the carer to the social workers as her daughter was found to be not eligible for any support. The assessment was able to highlight participant with a learning disability (G)'s skills and support needs but this has not resulted in any additional funding for the needs identified. The carer commented:

> *"my husband said, …at the end of the report she recommends that I continue to do this and this. He said so really what (is the) benefit … I have got to do it all. I must admit that's not her fault she's done the assessment, and she knows there's no one else, she knows we don't fall into a criteria for any help and support, and that's how she's written it"* (cG).

The occupational therapists only provide a short term assessment and intervention, and then the expectation would be that any on-going support needs identified are

funded from social care but the occupational therapy service are not always able to influence this. The view of carer G about funding of services was:

> *"we have got some great professionals like doctors GPs nurses you know SENCOS teachers OTs, speech therapists but no matter how well trained and how well they do their job it doesn't work if there's no funding and everything's limited because their input is really not enough to make a difference"* (cG).

6.3.3.1 Discussion of theme three: The occupational therapy assessment needs to be able to influence others to ensure effective and long lasting outcomes

The occupational therapists relied on their discharge assessment reports to communicate their findings and recommendations. This was seen as the tangible end of the episode of care and is for some stakeholders the only contact with the occupational therapist. This emphasis of sending out the report at discharge appeared to have resulted in the occupational therapist not always having the opportunity to receive feedback on how their reports were received as they immediately would have closed the case. This limited the occupational therapists' opportunities to follow up recommendations and influence the longer term outcomes. It also did not provide an opportunity for carers to feedback their perceptions of the report and clarify any concerns. Producing one final report encompassing an extensive intervention period covering multiple areas may be one of the reasons why the reports were reported to be lengthy and complex. Waiting to provide this information at the end of all the interventions may not be the most relevant time for information to be provided especially for the person with learning disabilities and for the carers.

The participants with learning disabilities were clear that they liked working in person with the occupational therapist. Most were interested in the content of their occupational therapy report but all struggled with understanding it in the format that it had been produced. Verbal discussion regarding the report was helpful for participant G. Data set (E) was the only example of having a separate, more accessible occupational therapy report produced specifically for the participant with learning disabilities. All the other reports had not been adapted in any way to enable the participant to understand it. Participants with learning disabilities (I) and (C) would not be able to understand any verbal or written reports although there was

evidence that client (I) could recognise photographs indicating that a simple visual record may be useful in enabling the person to recall and communicate his or her views on occupational therapy issues.

6.4 Reflections on stage two

6.4.1 How well the participants were able to provide their views

Four out of the six participants with learning disabilities were considered to be able to consent to take part in the semi-structured interviews. They were enthusiastic about being involved in the research study and were able to participate. They agreed to complete the interviews without the presence of their carers and none expressed a concern about this. They were able to express their views in the semi-structured interviews but some appeared less engaged when asked to respond to the closed questions regarding the essential criteria for the assessment.

The other two participants with learning disabilities were considered not to have the capacity to consent to be part of the research but were included by agreement with their 'personal consultees'. Participant with a learning disability (C) did not have the communication skills or understanding to be interviewed for the research study. Participant with a learning disability (I) was included in the interview as he was reported to enjoy meeting and talking to new people. His carer was present throughout the interview and he remained whilst his carer was also interviewed. There was no expectation that he would be able to contribute in a meaningful way due to his moderate learning disability and dementia. However, Participant with a learning disability (I) was able to recognise the photograph of the occupational therapist and from this recall the activity he had completed with her. He indicated that this was something that he was interested by pointing, nodding, smiling and saying 'baked beans'. This was a valuable contribution in that it revealed that the occupational therapist and what she had supported him to do had been a memorable and significant event for him. The assumption had been that he would not have recalled this event. This also emphasised the importance of using photographs and pictures with people with learning disabilities to enable them to communicate about what they had done and to build on these experiences.

The closed questions regarding the essential criteria were asked at the end of the semi structured interview and required a yes, no or don't know answer. This order

was planned so that the interviewees would not be influenced by the essential criteria questions when first asked to give their perception of the occupational therapy experience. However, this occasionally affected the quality of the answers to the essential criteria questions. The participants with learning disabilities would often appear to be less engaged in the questions than they had earlier in the interview as their ability to maintain attention on the subject often seemed to decrease as the interview continued.

There may have been concerns about acquiescence, however it was also important not to dismiss the responses of the participants with learning disabilities with the assumption that what they were saying would be less valid than other responders. The majority of the responses to the interviews and questionnaires from all the participants were positive but the reliability and validity of the responses from the people without learning disabilities were not scrutinised. The ability of the participants with learning disabilities to recall and demonstrate an understanding of their experiences of occupational therapy surprised the OT co-researchers and lead researcher who had under-estimated their abilities.

The lead researcher was able to change the wording of the questions and give a fuller explanation to clarify any misunderstandings during the semi-structured interviews. However, this was not possible for the questionnaires. Therefore, the data gathered from the questionnaires sometimes lacked clarity as to why a response had been made. Although the options given were: 'yes' 'no' and 'don't know', some questions were left blank or a question mark was provided. The lead researcher needed to make a judgement using other data such as the comments provided to decide how to categorise the response. Negative comments such as 'no' or 'x' did not always have an explanation as to why that was perceived so this was not helpful when analysing the data to understand the concern. A scale of how well the criteria had been met may have made the findings more useful for the OT co-researchers to understand how their work had been perceived.

There were some concerns about the data collection methods however the responses received were useful in understanding the occupational therapy practice in stage two. The participants with learning disabilities were happy to be interviewed and provided valuable insights. This was important to meet the principle of creating plural structures (Winter 1996) taking into account the perceptions of those most affected by the occupational therapy practice.

6.4.2 How the OT co-researchers participated in stage two

During the action research fieldwork the expectation was that the OT co-researchers would be leading on the collaborative process to develop their own practice. The extent to which the OT co-researchers had the time or motivation to be involved in the research related aspects of the fieldwork such as: designing interview schedules or detailed data analysis was less than the lead researcher had initially anticipated. However, on reflection, the lead researcher was aware that much of this activity related to the action research thesis rather than the fieldwork (see Figure 1.2). The lead researcher needed to have time to write up field notes, analyse the data and reflect on the findings and formulate ideas, often left periods of time when the OT co-researchers were not actively involved. This was reflected in some of the responses of the second OT co-researcher questionnaire (see also Section 7.3).

> *"Within sessions I feel it is going well and the themes are useful feedback, but outside of sessions I'm unsure of my role and therefore how well it is working" (Q2).*

This appeared to link with the lead researcher's reflections that the action research fieldwork:

> *"Feels very slow and intermittent" (Q2LR).*

Another response implied that the action research was owned by the lead researcher rather than collectively:

> *"I think you are doing a very important excellent piece of research hard work much needed in the current evidence based climate for our service" (Q2).*

This could imply that the research study had not met the principle of collaboration (Winter 1996) in that the perceptions of the lead researcher were dominating. However, the analysis of the findings of stage two was an on-going process from November 2010 until July 2011. The preliminary raw data and subsequent analysis of these data were shared with the OT co-researcher group as their contributions, insights and reflections were vital to ensure that the emerging themes were meaningful to the practitioners. As the feedback was received and reflections took place, some OT co-researchers reported that their individual practice had changed as a result of the new insights that they had gained. This suggested that theory and practice had been internalised (Winter 1996). The reflections on the perceptions appeared to be supporting many aspects of professional reasoning summarised by Boyt Schell and Schell (2008, Table 2.2) such as: narrative reasoning as they had a

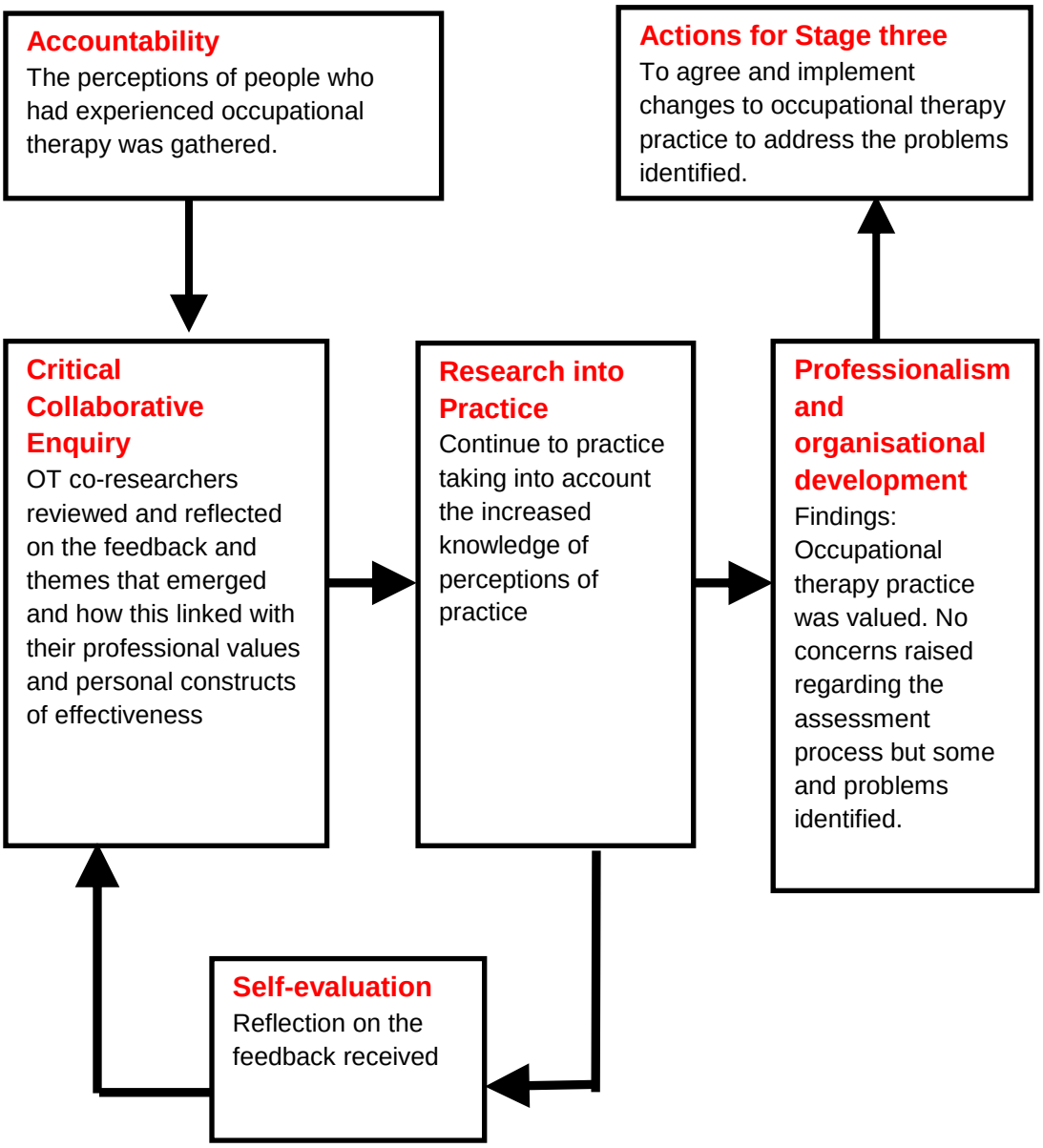
fuller understanding of the effects of their interventions on the participants with learning disabilities lives and pragmatic reasoning as they considered how their expectations of occupational therapy outcomes may have been different in reality to how they had planned. This process of practising as an occupational therapist reflecting on this experience and then using the learning gained to change how they practice with the next person they work with, appeared to be how the occupational therapists were naturally developing their overall professional reasoning.

6.5 Summary

Stage two is illustrated in Figure 6.2 using the CRASP model of action research. The objectives set out in Table 5.1 were met. The OT co-researchers were actively engaged with the lead researcher in developing the interview schedules and questionnaires, selecting the sample group, and the data analysis process. Data were gathered on the perceptions of a sample group of adults with learning disabilities, their carers and other people involved regarding occupational therapy assessments that had recently been undertaken.

The findings from the questions about the essential criteria were mainly positive in that the majority of the respondents stated that each of the criteria had been met in their experience of their recent occupational therapy assessment and intervention. These findings had not been expected by the OT co-researchers and lead researcher who considered that the occupational therapy assessment process was not able to meet all of the essential criteria in their local service. The findings suggested that there was a trust in the occupational therapy assessment, a belief that the criteria had been met and positivity about the experience. All the respondents stated that the occupational therapy assessment report was relevant and useful.

Figure 6.2: Stage two illustrated using the CRASP model of action research Zuber-Skerritt (1996)



The original plan was to develop an assessment tool to meet the gaps identified from the feedback from the people who had experienced the occupational therapy assessment. However, the findings suggested that there were very few concerns. These findings were initially considered by the lead researcher to be disappointing as they were not very revealing. However, this justified the decision to change the data gathering process from the original plan of just asking questions about the essential criteria, to the use of more open questions in order to ascertain more general perceptions of occupational therapy practice in the local service.

The responses from the inductive thematic analysis of the responses were:

- Theme 1: occupational therapy is valued
- Theme 2: occupational therapy is provided in a dynamic context.
- Theme 3: the ability of occupational therapy to influence outcomes varies.

The participants with learning disabilities were able to give insights into their experiences of occupational therapy but had difficulties distinguishing between two concepts:

- The occupational therapist as a person and what he or she did. They valued the positive working relationship which was person-centred and what they did together.
- Occupational therapy assessment and intervention. The participants with learning disabilities and their carers experienced this as a continuous process.

The professional stakeholders valued the occupational therapy assessment as the outcome. They considered that the occupational therapy assessment provided unique information about the participant with learning disabilities that was useful for their roles. Occupational therapy was valued as a contributor to the multi-agency assessment and intervention for adults with learning disabilities. However, problems were identified in theme three that needed to be addressed in stage three to improve the effectiveness of occupational therapy practice and are set out in Table 6.9.

Table 6.9: Problems that emerged from the data stage two

Summary of problems identified in Stage two
Occupational therapy reports were often too long and complex
Occupational therapy reports did not meet all needs.
Intervention was not always provided within an appropriate time-scale
Expectations of occupational therapy were not clear at the start of intervention.

Following the review of the essential criteria and the emerging themes it was clear that there were some areas where occupational therapy practice needed to further develop but these were not in relation to the occupational therapy assessment as had been anticipated by the local occupational therapist at the end of stage one. The focus of the study therefore shifted towards examining occupational therapy practice as a whole rather than just assessment.

The OT co-researchers continued to practise and develop their experiences whilst reflecting on the new insights from the initial findings both individually and within the group settings. These findings did not indicate that there was a need to develop an improved assessment tool but problems were identified that needed to be addressed to improve the effectiveness of occupational therapy practice. How these problems were addressed is explored in stage three which is described in Chapters seven and eight.

Chapter Seven: Stage three - implementing the changes to occupational therapy practice

7.1 Introduction

Stage three is described in two parts:

- Implementation of changes to occupational therapy practice- described in this chapter.
- Exploration of how the local occupational therapy practice was perceived by adults with learning disabilities, carers and other stakeholders after the changes- described in Chapter eight.

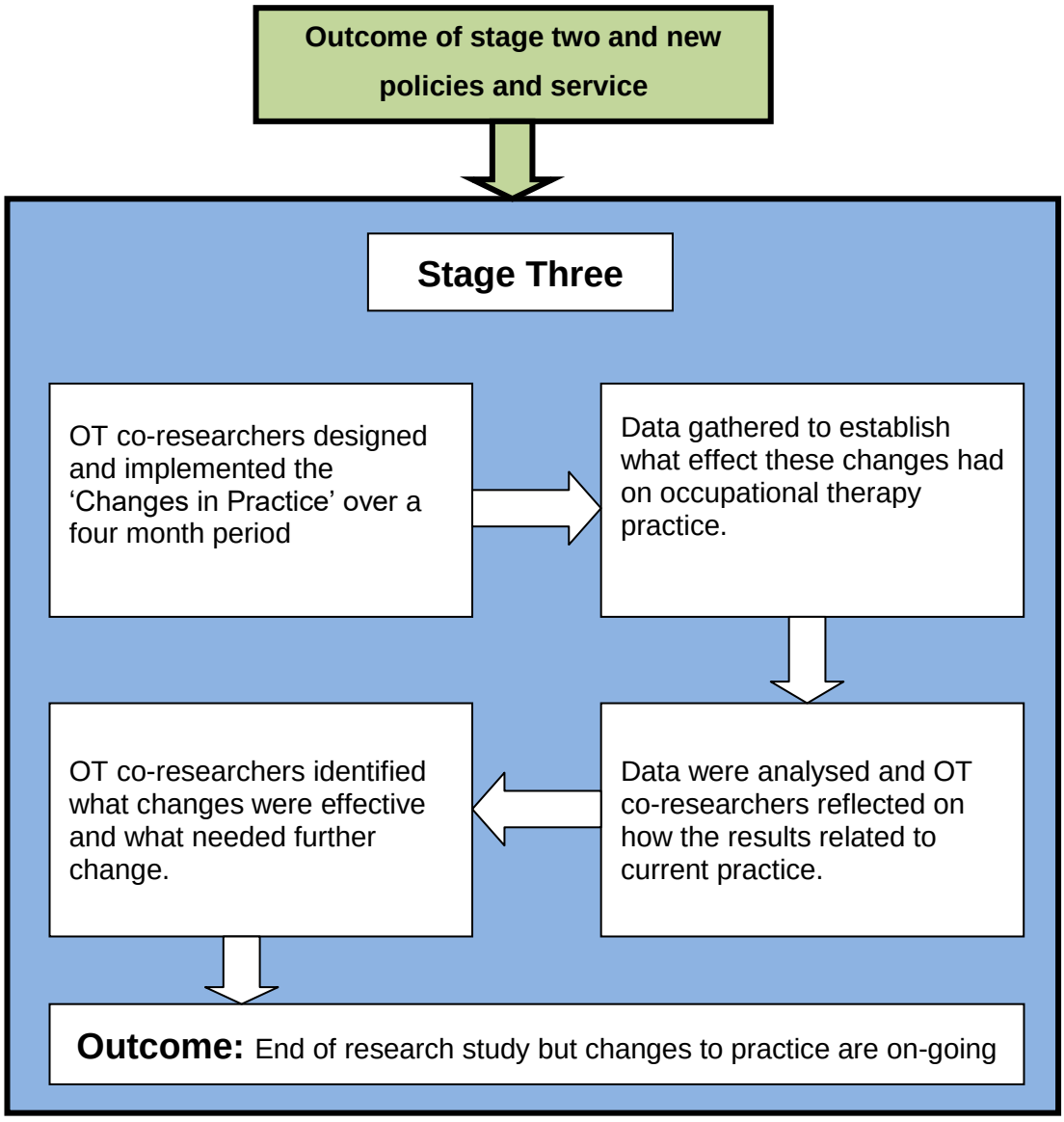
The objectives, which were developed by the lead researcher, with the OT co-researchers, are set out in Tables 7.1 for part one, and 8.1 for part two.

This chapter explores how the OT co-researchers agreed what needed to change in their practice, identified the actions that were required and implemented them. The second part, in Chapter eight, explores how these changes in practice were perceived. The action research field work that took place over the whole of stage three is summarised in Figure 7.1.

Table 7.1: Objectives of stage three (part one)

Stage three objectives for part one	Actions
To continue to engage with the OT Co-researchers as the agents of change of their own practice to identify key areas of concern and how to address these.	The lead researcher and OT co-researchers continued with group meetings to review the findings of stage two. The OT co-researchers completed questionnaires on their Assessment processes and their experience of the action research process. The lead researcher and co-researchers attended a three day action planning meeting
To implement the changes to occupational therapy practice	The lead researcher and OT co-researchers collaborated to generate new forms and processes to address concerns from stage two and meet employer demands for new ways of working (RTT targets). The forms and processes were introduced into OT practice.
To explore how the changes were implemented	The OT co-researchers participated in action learning sets to review and support the implementation of the changes. The OT co-researchers completed questionnaires on their use of the forms and processes.

Figure 7.1: Diagrammatic representation of stage three of the research study



7.2 Context at start of stage three

Stage three commenced in June 2011 (see timeline Appendix A). Two OT co-researchers: F and H had left the service and had not been replaced as these posts had been cut due to financial savings. In April 2011, the adult learning disability team which included the local occupational therapy service transferred from a community health service with some joint management from a local authority to a new employer which was a large acute hospital NHS trust. This resulted in the service having to adjust to some new policies and to review some practices. There was now the expectation that the service considered how to prepare for the implementation of the 'referral to treatment times' (RTT) framework following national guidance that had been published in March 2010 and was expected to be implemented in all services. The framework for allied health professionals (AHP) provided guidance for measuring waiting times for patients accessing National Health Services including occupational therapy. This was '*aimed at improving patients' experiences of NHS AHP services, ensuring they receive high quality care, in the right place, and reducing the time they wait for treatment'* (Transforming Community Services DH 2010, p5). The expectation from the managers of the new organisation was that the OT co-researchers and lead researcher needed to consider how their occupational therapy referral, assessment and intervention process met the RTT rules. This included needing to interpret how the new terminology and definitions from the guidance such as 'starting and stopping the clock' 'active monitoring' and 'first definitive treatment' related to their current practice.

The perceptions of the local occupational therapists in stage one were that the occupational therapy assessment tools that they used needed to be improved. However, the findings of stage two which explored the perceptions of people who received the occupational therapy assessment, and other people involved, did not identify the assessment tools as a concern. It had emerged from stage two that the participants with learning disabilities did not distinguish between occupational therapy assessment and intervention. The findings identified a general satisfaction with the occupational therapy that had been received but some other concerns and issues had emerged. Consequently, at the end of stage two, the focus of the study had changed from assessment to overall occupational therapy practice. However, at the OT co-researcher meeting in June 2011, (start of stage three), it became clear

that the priority for the OT co-researchers was to address the demand from the organisation that they could meet waiting list targets.

The lead researcher reflected on the discussions with the OT co-researchers. The need to address the impact of waiting list targets on the quality of occupational therapy intervention was one of the key areas for research identified by the COT (Lillywhite and Haines 2010) (see Table 2.1) and so was a relevant area for investigation. Occupational therapy intervention not being provided within the most appropriate time scale was also a problem that had been identified in the findings of stage two of the action research fieldwork. The lead researcher, therefore, considered that the new focus on RTT standards was compatible with the action research fieldwork.

7.3 Deciding on changes to occupational therapy practice

Following the review of the findings of stage two, the OT co-researchers' met for the purpose of deciding what changes needed to be made to their occupational therapy practice. The OT co-researchers discussed the expectation for the service to review their practice to ensure that the referral to treatment time could always be within eighteen weeks. Some of the OT co-researchers suggested that as they now had this new priority, the lead researcher could work on developing an assessment tool independently of them. The lead researcher explained that the action research fieldwork could incorporate the need to address RTT. However, the OT co-researchers struggled to connect the two agendas. An extract of this discussion illustrates this conceptual dichotomy:

> *"I'm missing the point entirely your research is about assessments, the assessments are not going to change, just time scales?"* (G).
>
> *"The outcome of stage two was that people were happy with the assessments….. Action research is about what is going on in our group and what we think is important"* (Lead Researcher).
>
> *"It can change?"* (I)

"The nature of action research is that it needs to go where we want it to go. If the outcome of stage two was that no one trusted the assessments…..and this came out as a big problem then that would be the thing to concentrate on" (Lead researcher).

The findings and themes from stage two were discussed and reflected upon with the OT co-researchers in the group meetings. The lead researcher presented the findings and themes (summarised in Section 6.5) for the OT co-researchers to discuss:

The essential criteria for occupational therapy assessments

The findings from stage two were that the essential criteria for assessment had been perceived to have been met. The OT co-researcher questionnaire (see Appendix E) was repeated to consider if the OT co-researchers' views had changed from the end of Stage one. All eight of the remaining OT co-researchers and the lead researcher completed this questionnaire. See Table 7.2 for more details of the responses received.

The OT co-researcher questionnaire responses at the start of stage three compared with those received at the beginning of end of stage one (see Table 4.8) suggested that the OT co-researchers' perspective on the essential aspects of the occupational therapy assessments had changed from the original emphasis on standardised assessments: 'fit for purpose' to more concern about the perception of people with learning disabilities and their carers. At the start of stage two, eight out of the ten respondents made a comment that would relate to the criterion: 'Fit for purpose'. At this stage, none of the OT co-researchers mentioned this as an essential requirement with only the lead researcher indicating this was important. In contrast, the criterion: 'Highlight skills in order to make meaningful and useful recommendations' increased from three out of ten mentions in the previous stage to five out of eight at this time. This appeared to relate to the findings about clarity of recommendations and if these resulted in useful sustained outcomes for people with learning disabilities.

Table 7.2: OT Co-researchers and lead researcher's questionnaire responses at the start of stage three June 2011

Essential Criteria of an assessment tool	OTs*	Unattributed examples of statements made by the OT co-researchers and lead researcher.
Assess occupational performance	1	*"Focusing on "doing"*
Global skills	0	
Highlight skills in order to make meaningful and useful recommendations	5	*"For it to enable the OT to gather as much relevant information in as little time as possible in order to identify functional problems and intervention needs".* *"Clear findings.* *Clear recommendations* *Addressing the referral issue.* *Clear reason for assessment".*
Client centred/choice and empowerment	6	*"Forming a therapeutic bond".* *Empathy for the situation".* *"Openness to help the situation".* *"Client focused".* *"Client /carers aware of and ideally agreeing to OT".* *"Time invested in building a rapport".* *"Motivation of client and carer".*
Accessible easy to use and understand	2	*"For the client to feel comfortable with the assessment process".* *"Clear assessment process"*
Designed for people with learning disabilities	3	*"Assessing in familiar environment".* *"The right assessment for the referral reason".* *"Assessment is completed in the best possible environment".* *"Provided at a time that is relevant".* *"Being flexible".*
Fit for purpose	1	*"Accurate assessment/standardised".*
Practical/ good use of resources	1	*"Able to access the client on a regular basis.* *Knowledge of the assessment tool being used".*
Observation	5	*"Being able to observe the client in their home environment".*
Incorporate views of all people involved	3	*"Writing for the audience".* *"Working in partnership with relevant others".* *"Other people's views (those who know the client)"* *"Good background information, including risk assessment".*
Fits with other assessment developments.	0	

**Number of OT co-researchers who mentioned each criterion. (N=8)*

There was only one comment made that corresponded with the criteria relating to assessing occupational performance and global skills. This had previously been mentioned by half of the responders of the previous questionnaires. This finding,

perhaps reflected the need to consider the RTT (DH 2010) which had focused the occupational therapists on the importance of completing one referral issue at a time, rather than the more holistic consideration of all occupational performance concerns.

The criterion: 'Client centred choice and empowerment' continued to be mentioned by the majority of the OT co-researchers as it was indicated by six out of eight respondents at this stage and previously was indicated by nine out of ten. There were still no responses to the final criterion: 'the assessment needing to fit with wider policies and developments'. This may be because the occupational therapists were considering the needs of the people they worked with rather than the service demands. However, the need to manage waiting lists (RTT) did appear to have influenced the other criteria.

The responses to the questionnaires at this stage suggested that the OT co-researchers had been influenced by their reflections on receiving the feedback on the perceptions of occupational therapy that were collected and analysed in stage two. There was an emphasis on ensuring that occupational therapy met the perceived needs of the people with learning disabilities, carers and other stakeholders and that this was more important than concerns regarding standardisation of assessments. Only the lead researcher was concerned at this stage about the initial plan for the study from stage one which was to ensure that the assessment tools used were valid and standardised.

Theme one: Occupational therapy is valued

The OT co-researchers reflected on the positive responses regarding occupational therapy that had been received. One OT co-researcher asked for clarification as to what was valued:

> *"Is it about the person or occupational therapy?"* (D)

Another responded:

> *"People value 'doing things'. … clients come direct to OT if they want support to do something. People are interested in doing and see what we offer as unique and different".* (E)

The group agreed that the participants with learning disabilities appeared to value the occupational therapists because their focus was on 'doing' activities. It was, therefore, not surprising that there was not a distinction between the person and their role.

Theme two: Occupational therapy is provided in a dynamic context

The OT co-researchers acknowledged that their assessments and interventions were perceived differently by the various respondents and often the perspective of the recipients varied from what they had intended. They discussed that this may demonstrate a lack of clarity of what they provided. The OT co-researchers were challenged to reconsider how they had met referral needs and how they could improve their ability to negotiate the complexities of the various demands of the stakeholders. There was a suggestion that:

"the contracts and 18 weeks rule will make things clearer" (A).

This comment referred to the need to improve RTT. It was suggested that in order to do this the occupational therapy referral pathway needed to be reviewed and that they all should now be using contracts or goal plans to plan their intervention.

Some of the OT co-researchers reported that they had started to review the length of time it took to complete typical episodes of care so that a prediction of how long occupational therapy intervention would take could be made. The group debated if they should all be providing a similar response to referral issues as each other. The group agreed that each occupational therapist uses their own skills, experience and personality when working with a person and so this would inevitably result in differences in approach. However, there needed to be a balance between each occupational therapist adapting their practice to meet individual need and being fair to all. This was illustrated by one OT co-researcher who stated that there needed to be an allowance for the:

"flexibility and personality of the OT but a need to offer the same service" (I).

The OT co-researchers were concerned that they were not as person-centred as they had previously assumed. The practice of addressing multiple referral issues at one time appeared to have resulted in some confusion as to what occupational performance issues were being addressed. The group agreed to changing their occupational therapy practice so that only one referral issue would be addressed at a time. The OT co-researchers agreed that this process should enable occupational therapy to be simpler and easier for people with learning disabilities to understand. It would also help to address the need to meet the RTT expectations.

Theme three: The ability of occupational therapy to influence outcomes varies

The OT co-researchers were concerned that they were not always able to effectively make long term changes and their reports may not be effective at communicating

their assessment findings and recommendations. One OT co-researcher agreed that the occupational therapy reports had been too long and complicated.

> *"50% of the time everything is written in the report but there is a danger it is too long and confusing"* (I),

However, another reported:

> *"I have just completed a report and the mother was upset that it was not detailed enough. She needed it for evidence of her son's disability"* (C).

The OT co-researchers discussed how to make their reports more concise. The consensus was that they need to be clearer about the purpose of the report and who would be receiving it. It was suggested that another profession's reports provided a good example that the occupational therapists could aspire to be like:

> *"Speech and language therapists give specific summaries of need and provide general advice"* (E)

At the end of the discussions, the OT co-researcher group made a preliminary action plan of proposed changes to their practice (see Table 7.3).

Table 7.3 Actions from the OT co-researcher group at start of stage three

OT co-researchers preliminary action plan
• Review the formats of the occupational therapy contracts and reports and when they were used.
• Establish a process to ensure that the occupational therapy service could meet the eighteen week referral to treatment time standards.
• Consider how to make information about the service clearer.
• Review how accessible the information produced by the occupational therapist is for people with learning disabilities.
• Review the occupational therapy assessments used.
• Clarify how to work on one referral issue at a time.
• Review how to respond more quickly to referrers by providing packages of advice.
• To offer specific training to carers such as engagement or skills teaching.

As a result of this discussion, the OT co-researchers agreed that the proposed changes to practice would be part of the action research fieldwork. They took the lead with planning how the changes would be implemented with little direction from the lead researcher. This is illustrated by the following discussions:

> *"We need one day to do RTT, goal planning, stop the clock, and leaflets"* (I).
>
> *"Yes to clarify all these things"* (A).

"We can work on this before the meeting and bring the referral pathway as it stands and how we need to change it. A lot is non-negotiable" (E).

"If we stick strictly within the existing pathway we would see people within 18 weeks" (G).

There was some concern expressed in the group about the proposed changes:

"*lots of rapid changes at the moment … As it is working against how I normally work it makes me unconfident"* (D).

This was responded with reassurance from other OT co-researchers that the proposed changes would not be that different from current practice as:

"We are….still doing our job but in a different manner. There will be changes to time scales, names, we will just manage in a different way" (I).

7.4 Making the changes to occupational therapy practice

Following the discussions in the OT co-researcher groups in June and July 2011 it was agreed that the changes in occupational therapy practice would need to address RTT targets, the problems identified in stage two and the OT co-researchers' on-going concern regarding their occupational therapy assessment tools. The OT co-researchers met for three full days in August 2011 to work together to plan how to change their practice. The agenda for the three days of action planning for changes to occupational therapy practice is set out in Appendix L.

The OT co-researchers and the lead researcher worked together to review the referral to treatment pathway (see Appendix M). Following this, the group split into pairs to work on pathways and packages for specific referral issues. They agreed a process for how specific types of referrals could be addressed and the number of sessions that would be expected to be offered for these episodes of care. Each pair then presented the package that they had devised to the group so that they could add comments and amendments. Individual OT co-researchers and the lead researcher volunteered to complete specific packages and upload them on the shared occupational therapy computer drive so they could be accessed by all.

Even though the findings of stage two and the OT co-researcher questionnaires did not indicate a concern regarding the occupational therapy assessment, this was still an expressed concern for the OT co-researchers. This was also highlighted as one

of the COT (Lillywhite and Haines 2010) key areas for research (see Table 2.1) The lead researcher agreed to present some of the assessment tools that had been identified from the review of the assessment tools (see Section 4.4 and Appendix G) or she had been made aware of subsequently. The group agreed that the locally produced occupational therapy general assessment based on the OTIPM and the AMPS were the main assessments that should be used by all but would also consider using the new assessments.

The final action plan for the changes in occupational therapy practice is set out in Table 7.4. However, this table is a simplification of the process as many of the factors are inter-related and the process was also influenced by the individual reflections and experience of the OT co-researchers. All the new forms developed are listed on the questionnaire on use of the forms and processes (Appendix N).

Table 7.4: Summary of the problems, expectations and planned changes to occupational therapy practice

Problems identified from Stage two	**External Expectation on OT Service (see Table 2.1)**	**Changes in occupational therapy practice. Action Plan**
Occupational therapy reports were often found to be too long and complex.	COT Key Area for Research Number 1 and 2.	To re-structure the referral process so that one referral need could be addressed at a time.
Occupational therapy reports did not always meet the needs of all the recipients.	COT Key Area for Research Number 1 and 2.	To implement an accessible format for making goal planning easier for people with learning disabilities to participate in and understand.
Intervention was not always provided within the most appropriate time-scale.	Need to implement AHP Referral to Treatment times. COT Key Area for Research Number 4.	To develop and implement a new referral to treatment flow chart in order to meet the 18 week target.
		To produce some packages of advice, tips and training that can be offered to carers as a first intervention prior to occupational therapy involvement.
The expectation of occupational therapy was not clearly agreed by relevant stakeholders at the start of intervention.	COT Key Area for Research Number 2.	To agree the expected timescales for each typical referral need, so that the number of sessions could be more easily predicted and expectations could be outlined clearly to people with learning disabilities and their carers.
	COT Key Area for Research Number 3.	To review the assessment packages used to ensure that all occupational therapists are aware of the current best practice.

Key -COT Key Areas for research:

1. Taking into account the perspectives of adults with learning disabilities and others.

2. The effectiveness of occupational therapy interventions.

3. The use of standardised assessments

4. The impact on waiting time targets.

The changes to the occupational therapy practice action planning resulted in the production of 27 new forms and processes which included a new referral to treatment (RTT) care pathway and other forms developed by the OT co-researchers to facilitate the new occupational therapy processes. Some of these processes were new and others were adapted from existing forms (see Table 7.5). The OT co-researchers agreed to use the new forms and process to improve their practice and work in a more consistent way across the service.

Table 7.5: Changes to occupational therapy practice - new forms and processes

Changes in occupational therapy practice: Action Plan	**New form or process developed to support the changes**	
To re-structure the referral process so that one referral need could be addressed at a time.	OT. RTT Pathway Initial assessment form	
To implement an accessible format for making goal planning easier for people with learning disabilities to participate in and understand.	Goal Plan	
To develop and implement a new referral to treatment flow chart in order to meet the 18 week target.	OT. RTT Pathway Initial assessment form	
To produce some packages of advice, tips and training that can be offered to carers as a first intervention prior to occupational therapy involvement.	OT leaflet Participation training form Skills teaching top tips ADL checklist	Cooking skills checklist Carer travel training Top tips when out Housework checklist Personal Care
To agree the expected timescales for each typical referral need, so that the number of sessions could be more easily predicted and expectations could be outlined clearly to people with learning disabilities and their carers.	Care pathway OT assessments. Goal plan	
To review the assessment packages used to ensure that all occupational therapists are aware of the current best practice.	ADL checklist AMPS Activities Specialist OT assessment grid Accommodation support needs Eating and drinking Dementia Budgeting	Client travel training Capacity Interest checklist Equipment Activities Other skills teaching forms Sensory Employment

7.5 Implementing changes to occupational therapy practice

The OT co-researchers initially agreed to implement the changes to occupational therapy practice with any new people who were referred to the occupational therapy service from September 2011.

It was estimated that there would need to be at least a four month period of time to allow the OT co-researchers to implement the changes to occupational therapy practice and complete these new episodes of intervention. During this initial period, the lead researcher facilitated the OT co-researchers to meet in action learning sets to share with each other how the changes were being implemented and to support each other to resolve any difficulties as they emerged. The OT co-researchers were also asked to complete two questionnaires to record how each individual changed their occupational therapy practice.

7.5.1 Methods: Review of the use of the new forms and processes developed for the changes in occupational therapy practice

The Forms and Processes questionnaire (see Appendix N) was sent to the OT co-researchers, at the end of November 2011, three months after starting the launch of the changes in occupational therapy practice action plan. This consisted of a list of the new forms and processes that it had been agreed would be used and the OT co-researchers were asked to indicate how many times they had used each of them and comment where necessary. This questionnaire was then repeated in November 2012 to consider if the changes in occupational therapy practices had been sustained one year later. For both occasions, the OT co-researchers were requested to comment on the occupational therapy intervention they had been undertaking during the previous three months.

All seven of the OT co-researchers completed the questionnaire on both occasions. The lead researcher did not complete the questionnaire as her clinical role was no longer one of practising within the service. The findings were amalgamated so that individual responses were not identifiable by the rest of the group. However, as discussed in Section 3.6, the lead researcher was aware of who had completed each form. A reservation was expressed by one respondent who was happy to

submit the information but requested that some comments made remained anonymous. This request was complied with.

7.5.2 Methods: Action learning sets

Action learning sets were chosen as a method to consider how the OT co-researchers who had devised the changes would now put these into practice. The occupational therapy practice developed by the whole service could be considered rather than just asking the individual occupational therapists to report on their own practice in isolation of each other. This was considered as it has been suggested that *'effective collaboration is fundamental in an action research project'* (Bellman and Webster 2012, p119). Collaboration was seen as a driving force for change and allowed the project to focus on awareness raising and empowerment for the local occupational therapists. The lead researcher endeavoured to facilitate collaboration within the action learning sets by encouraging peer review and learning so that the OT co-researchers could reflect on how they could improve the service and develop professional knowledge through the process of change. The lead researcher role was to consider Bellman and Webster (2012)'s key messages for collaboration which included checking and challenging any assumptions made and recognising that time was needed to learn new skills.

The action learning sets were one hour in duration and took place on the dates set out in Table 6.6. The OT co-researchers were divided into two action learning sets depending on the borough where they worked. In these smaller groups, they were invited to meet to share with each other and the lead researcher as to how the changes were being implemented and to support each other to resolve any difficulties as they emerged. Table 7.6 sets out the action learning set meetings and how these were coded.

Table 7.6: Stylisation and presentation of the data regarding the action learning sets meetings

Event		**Code**
Questionnaires regarding the use of the forms and processes in relation to the changes in occupational therapy practice.		QF&P
Action learning set		ALS:
Distinguish between 2 Boroughs A and B		A. or B.
Combined meeting		AB.
First meetings		1
Second meetings		2
Date meeting took place	**Who attended**	**Code**
27/9/11	Area A Team	ALS:A1
5/10/11	Area B Team	ALS:B1
3/11/11	Combined Teams	ALS:AB1
6/12/11	Area A Team	ALS:A1
13/12/11	Area B Team	ALS:B1
31/01/12	Combined Teams	ALS:AB2

The OT co-researchers were provided with an explanation of the action learning sets and the draft objectives and proposed format (see Appendix O). It was explained that the sessions would be informal but they would be audio recorded. They were asked to comment on the draft proposal and were given the option not to participate in the action learning sets. No comments were received and all the OT co-researchers participated. It was suggested that the OT co-researchers shared with the group their experiences and reflections on whatever they thought was relevant regarding their current cases and how they were attempting to put the new process into practice. The plan was to try to capture the process of implementing the proposed new ways of working. The OT co-researchers agreed with the lead researcher that the sessions would be used to:

- *Develop our understanding of the new occupational therapy changes to practice.*
- *Reflect on the changes to find out; what is going well, and identify the problems.*
- *Share our practice and learn from each other.*

Each OT co-researcher was offered a five to ten minute time slot to share their reflections with the group to ensure that all had the opportunity to participate. This was then followed by a discussion by the wider group. The recordings of the action learning sets were transcribed by the lead researcher and the themes were analysed in relation to the changes in occupational therapy action plan (see Table 6.5) as *'initiating and sustaining collaboration and the resultant learning should be clearly documented in action research studies'* (Bellman and Webster 2012, p123).

7.5.3 Findings: How the changes in occupational therapy practice were implemented

Each of the problems and actions summarised in Tables 7.4 and 7.5 are considered in turn.

Problem 1: Occupational therapy reports were often found to be too long and complex.
Action: To re-structure the referral process so that one referral need could be addressed at a time.
A new process and a new form were developed to address problem one, regarding the complexity of reports and to address problem three, regarding the need for occupational therapy to be more responsive.

The occupational therapy referral to treatment (OT. RTT) pathway is a flow chart devised by the OT co-researchers and lead researcher during the changes in occupational therapy practice meetings (see Appendix M). It describes the occupational therapy pathway for the adult with learning disabilities from when they are referred to the service, offered an initial assessment, specialist occupational therapy assessment and intervention, followed by discharge. The purpose of this process was to ensure that the person referred could be offered a first intervention, defined in the guidance as first definitive treatment, within agreed timescales in line with the referral to treatment targets (Department of Health 2010). The OT co-researchers agreed to a time scale of 12 rather than the required 18 weeks.

The initial assessment form was adapted from an existing occupational therapy screening form that had stopped being regularly used prior to the changes in occupational therapy practice meetings. It had been agreed to change the terminology of occupational therapy screening to initial assessment as this was the

terminology that was used in the RTT Policy (Department of Health 2010). The initial assessment form was designed to be used by the occupational therapist when gathering initial information about the referral in order to start the first definitive treatment. The occupational therapy initial assessment based on OTIPM (see Figure 2.1) was retitled specialist assessment.

During the action learning sets, the OT co-researchers frequently reflected on how they made decisions regarding dealing with referrals using the OT.RTT and initial assessment form. As the action learning sets only continued for four months following the launch of the changes in practice, not many final reports had been completed. Therefore, it was not known if there had been any improvement on the clarity of the occupational therapy report.

The OT co-researchers had to be skilled at managing and prioritising the different referral issues. At times, new referral issues for someone they were currently working with were placed back on the waiting list and at other times the OT co-researcher worked on several referral issues at the same time. The reflections of the OT co-researchers indicated that they considered that their practice would continue to be complex and responsive but that they needed to be clearer when new referral issues arose so that these could be recorded and considered as new pieces of work. A benefit of the new process was described as:

> *"Because we are faster at contacting the referrer, if it is an inappropriate referral, they are less anxious, annoyed, upset than when they waited for three months to be told this".* (ALS:A1.C).

Another OT co-researcher commented:

> *"More pieces of work get opened and closed and a lot go down the fast track route...than before"* (ALS:B1.A).

This suggested that this change in occupational therapy practice had resulted in an improvement in response times.

Other OT co-researchers reflected that it was not always easy to work in such a structured way with one stating that it would not be possible:

> *"to be able to open and close always in complex situations*" (ALS:B1.A).

Another stated that:

> *"When other bits of work come in it makes it slightly more complicated but able to use this as a guide to try and simplify it, but not always that simple, …*

[as it is] difficult to distinguish what is old and new and amalgamate both referrals like we used to do" (ALS:B1.B).

There were discussions about how uncomfortable this change to addressing one referral item at a time was making some of the OT co-researchers feel. One described the experience of explaining the process to someone with learning disabilities and her carers:

> *"It felt a bit tricky,.. It was a challenge for me explaining and not feeling I should do immediate travel training. I think in line with the way we are trying to work, it is fair so other people can be seen who also need input. She should not be prioritised just because it came up at the end of her assessment. In the past we would have carried on working, but this time I'm closing*" (ALS:B1.A).

The discussions within the group questioned if dealing with one referral issue at a time had been positive for the people with learning disabilities who were being seen by occupational therapy. One OT co-researcher stated:

> *"I don't think better or worse. We are just being in line with the organisation. Don't really feel it's better for the clients. Sometimes feels better to give everything now instead of coming back in 6 months' time"* (ALS:B1.B).

This suggested that some of the OT co-researchers were feeling that the needs of the service were in opposition to their professional judgement to meet the holistic needs of the person they were working with. However, others had perceived the new process more flexibly and were still able to recognise and address the adult with learning disabilities' needs but by being more proactive at generating new referrals for these concerns so that they could be addressed by the service in the future.

> *"We are now sharper, slicker and more contained rather than too organic and developing into all sorts of odds and sods that might be good. Our personalities will not allow us to be too prescriptive. There will always be loop holes*" (ALS:A1.G).

During the first action learning sets there were different perceptions of how the OT.RTT process should be completed. Some OT co-researchers reported that they were now doing more extensive information gathering initially and others reported that they were reducing the amount of work they completed prior to opening a case. The discussion in the sets enabled the OT co-researchers to share their different interpretations of the process to check which forms were expected to be used and to

clarify what they should do when unexpected situations arose. Over the course of the action learning sets, the differences in interpretations between the OT co-researchers reduced. By 2012 some commented that it was no longer necessary to refer to the OT.RTT pathway flow chart, as the understanding of the process was now part of practice. For example:

> *"I have not used overtly as system is pretty much established in my mind so I don't have to refer to the form itself…I know and understand the pathway"* (QF&P).

However, others were still referring to the OT.RTT Pathway with one commenting that it was still helpful:

> *"when referral issue was vague, helped focus the questions I asked the referrer"(QF&P).*

During the first four months of the changes in practice, there had been some variations in how individuals had been able to understand and use the new OT.RTT pathway and initial assessment form. It was necessary to achieve a balance between the need to be more responsive to new referrals and still using their professional reasoning to meet the occupational performance needs of the people they were working with. The support of their peers in the action learning sets enabled them to develop these skills. The findings from the action learning sets and questionnaire responses suggest that the new processes to address one referral at a time had been adopted in practice. It was not yet known if this had resulted in an improvement to the clarity of the occupational therapy reports. However, this would be expected as the OT co-researchers reported that they were working in a more structured and focused way.

Problem 2: Occupational therapy reports did not always meet the needs of all the recipients.

Action: To implement an accessible format for making goal planning easier for people with learning disabilities to participate in and understand.

In stage two of this research study, the views of some of the participants with learning disabilities were that they were not able to understand what had been written about them by the occupational therapists. Therefore, the OT co-researchers were motivated to make changes to improve the accessibility of their information.

The OT Goal Plan was a document designed to support the person with learning disabilities to record his occupational performance goals and to agree with the

occupational therapist what each of them is going to do and when this will happen. The format of the plan was designed to be accessible so that each person with learning disabilities would be able to understand it, they would be supported as fully as possible to contribute to goal planning and they would be able to see their progress. This would be adapted to meet the individual needs of each person with learning disabilities, although it was acknowledged that there would still be some people who would not have the ability to understand the concept of a goal plan (see Appendix P).

There were discussions about the use of the accessible goal plans within the action learning sets in each borough. Some of the experiences had been positive, for example:

> *"The goal plan worked well- he needed that approach, did not take to vague plans, liked the concreteness of five sessions and stop and review*" (ALS:A2.C).

However, other OT co-researchers reported why goal plans had not been used such as:

> *"We talked about it, but did not write it as a goal plan because she could read"* (ALS:B2.D).

and:

> *"Goal plans can take a long time and if you want to be quick, sometimes it is not worth it"* (ALS:B2.D).

The action learning set discussion was then used to explore the OT co-researchers' understanding of the goal plans. A consensus was reached that the goal plan should be produced in any format that was accessible to each individual person with learning disabilities. This could be in written form or hand drawn pictures and did not necessarily need follow the template with the use of photographs if this was a barrier to it being produced (see Appendix P).

There were also discussions about if using the goal plan reduces the opportunity for the person with learning disabilities to change his or her mind about what he wants to address with the occupational therapist. There appeared to be a conflict between using the goal plan as a client-centred tool and the new approach (in the changes in occupational therapy practice) of working on one referral issue at a time. An extract of this discussion is set out below:

> *"*D- *takes time with people with learning disabilities to build rapport to work out what they want, more pressing things emerge later, what they want and*

others want. B- *if old system, we would be more open to adding in more things, but now we fill this form and sign it" (*Extract of discussion in ALS:B2).

The OT co-researchers used the action learning set to reflect on their struggle to balance the need to be clear and structured about their plans with the dynamic complexity of their occupational therapy practice. It was agreed that this was a learning process for both the occupational therapists but also for the people with learning disabilities as they may have limited experience in setting realistic goals for themselves. However, the OT co-researchers over time did consider that goal plans were still useful with one stating:

"I think structuring it and letting someone know what you can and can't provide seems to have been quite helpful" (ALS:B2.A).

By 2012, the goal plan was reported to be the third most used form or process following the changes in occupational therapy practice. One OT co-researcher reported that it**:**

'worked very well especially with younger adults who benefited from signed contracts' (QF&P).

However, although the response about the adoption of the goal plan within the local service was positive, there were still some reservations about the practicalities of using the form as the timescale had to be agreed in advance. One OT co-researcher commented that it was:

'difficult to find the time to make goal plans accessible for clients' (QF&P).

Which suggested that barriers to the use of this process still existed for some. There was no discussion regarding how the outcomes of the goal plans could be used to improve the accessibility of the occupational therapy reports for adults with learning disabilities.

Problem 3: Intervention was not always provided within the most appropriate time-scale.

The expectation from the organisation to implement new referral to treatment times standards as a result of RTT (Department of Health 2010) was a driver for change from the local organisation. One of the findings from stage two was that occupational therapy was not always being provided when it was required. The two changes in practice that were made in order to improve response times were: to review the occupational therapy referral pathway (OT.RTT) and to consider if occupational therapy could be delivered in different ways.

Action 1: To develop and implement a new referral to treatment flow chart in order to meet the OT.RTT target.

The RTT and initial referral form have been discussed in problem one. The OT co-researcher discussions suggested that these new processes had been adopted and the referrals were being responded to within twelve weeks of referral with many being 'fast tracked' and seen quicker than this maximum standard. . Examples of these from the OT co researcher actions learning sets included:

> *"The way we work now is more focused on getting the initial assessment done as quickly as possible"* (ALS:B2.B).
>
> *"We are really thinking about how long the work is going to take. We are looking at our guidelines to predict length of time"* (ALS:B2.A).
>
> *" Not getting too caught up in stuff, keep focused on getting the person off the waiting list before getting involved"* (ALS:B2.D).

The occupational therapy service was measured by the local organisation to be meeting the referral to waiting list targets of eighteen weeks on an on-going basis and met their own target of twelve weeks most of the time.

Action 2: To produce some packages of advice, tips and training that can be offered to carers as a first intervention prior to occupational therapy involvement or instead of direct occupational therapy work with the person with learning disabilities.

Table 7.5 lists nine different forms that were developed by the OT co-researchers to address these issues. Some of these were information on how to address typical referral issues that the carers could consider whilst waiting for occupational therapy to commence. These would be selected depending on the nature of the referral issue and then discussed when the case was opened. The two other types of forms that were used most often by the OT co-researchers were:

ADL checklist has previously been described in Section 4.3.2. At the changes to occupational therapy practice three day meetings, the form was reviewed. It was decided that the checklist could continue to be used as an assessment tool but that it would be modified so that it could be sent to support workers or family carers, if appropriate, to be completed by them, prior to the occupational therapy intervention. This would then be used to help focus the occupational therapy process for that individual person with learning disabilities.

The participation training form was introduced as it was proposed that one way of working more efficiently was to provide training to whole staff teams who work with groups of people with learning disabilities in specific services. This would enable a team of support workers to develop skills, rather than an individual occupational therapist providing individual intervention to one person with a learning disability. The OT co-researchers agreed that this greater emphasis on training would be likely to produce more effective and longer term change and to benefit a larger number of people with learning disabilities than responses to individual referrals.

There was speculation from the members of the action learning sets as to how people with learning disabilities and their carers would perceive the changes in practice as there would now be more emphasis on the carers to complete some actions prior to the occupational therapist getting involved. One OT co-researcher wondered if referrers realised that they would be asked to provide more information, they may stop making referrals. However, it was also suggested that:

> *"they might think this is great we are more involved"* (ALS:A1.E).

The OT co-researchers shared their experiences and views within the action learning sets. They reassured those who were concerned and learned from each other's experiences. For example:

> *"My only fear is that we will be waiting on other people bringing back feedback before we start working, I know how it is chasing people to do things… in a time frame. Difficult to get information back"* (ALS:A1.C).

However, another responded that whether or not the carer returned the information was not important as this would be reviewed when the case was opened. Therefore, there was no need to follow up the non-responders.

> *"I'm not worried about getting information back… we will review that when we start,. Do not need to waste time chasing, if not back, it's an indicator of what the work will be like, if straight back, we know they are on the ball and pro-active"* (ALS:A1.E).

The perceptions of carers who had experienced some of this more indirect occupational therapy intervention was not known and was planned to be explored in later in stage three (see Chapter eight).

Problem 4: The expectation of occupational therapy was not clearly understood by relevant stakeholders at the start of intervention.

The OT co-researchers planned some changes to consider if they could be more consistent in regards to how they approached each referral issue. This would be to

estimate the length of time an intervention could take and to ensure that they were sharing their collective knowledge and experiences in order to offer high standard assessment and intervention packages. These two changes are described in turn.

Action 1: The OT co-researchers to agree the expected timescales for each typical referral need, so that the number of sessions could be more easily predicted and expectations could be outlined clearly to people with learning disabilities and their carers.

The care pathway for occupational therapy assessments was a tool which set out the expected number of sessions for each individual assessment and intervention. This was produced by auditing how many sessions occupational therapy pieces of work had taken in the past and comparing these across the occupational therapy team. The expected sessions were agreed by the OT co-researchers and used to inform people with learning disabilities and their carers at the start of an intervention as to how many sessions they should expect to receive. This could then be incorporated into the OT goal plan (discussed in problem two).

The OT co-researchers reflected on some of the difficulties they had experienced in predicting occupational therapy, in the action learning sets. They acknowledged that this could be applied too rigidly. One OT co-researcher reported that the tool was:

> *"useful to be more focused..* [but].., *needs flexibility"* (ALS:B1.D)

as often other people and life events prevented the sessions from being completed as predicted. The OT co-researchers became more flexible with how they used the tool as they became more experienced:

> *"Now we try to plan the sessions and work to time scales set out from the start… this was a big job at the beginning… we now give longer time frames similar number of sessions but longer period of time to allow for cancellations, reviews and meetings. We wised up …as estimating number of session ok but timescale not so easy".* (ALS:B1.B)

Two examples were given where setting the timescales were reported by the OT co-researchers to have been positive. One was seen as a benefit for the carer:

> *"The mum was very pleased, good to know what you are going to do, when and finishing date. That mother, who was knowledgeable and on the ball, was clear about expectations… She was happy"* (ALS:B1.D).

However, the other as a tool to support the occupational therapy service to manage the carer's expectations.

"Good for OT as deadline is being pushed three times as mother will not meet. OT is pleased to have control of the situation can be clear about stage and agreement…and… if expectations can be met" (ALS:A2.C).

The Care pathway of OT assessments tool was reported to be used by all the OT co-researchers and was reported by them to have been fully integrated into practice by 2012. One of the OT co-researchers reported that the care pathway tool was no longer needed to be referred to as:

"I have a good understanding of the number of sessions for OT treatment" (QF&P).

The local occupational therapists developed their practice to have clearer time scales for specific referral issues so that they could address the concerns in stage two that people with learning disabilities and their carers were not clear about what they would be receiving from occupational therapy. However, this OT care pathway was also used as a tool to improve through-put of cases so that the waiting list could be reduced. Some of the OT co-researchers found it easy to interpret the new practice of predicting the number of sessions so that they could continue to work responsively to meet the needs of people with learning disabilities and their carers whilst others found this process restrictive. Over time the occupational therapists appeared to have developed their understanding of the new time scales and found this to be useful tool that improved efficiency and clarified expectations. However, some needed the action learning sets to develop the confidence to trust their professional reasoning to ensure that the quality of the service was not compromised by adhering to the tool too rigidly.

Action 2: To review the assessment packages used to ensure that all the occupational therapists are aware of the current best practice.

Section 7.3 described the specialist occupational therapy assessment grid which summarised the standardised and locally produced assessments that the occupational therapy team had access to. Although, the OT co-researchers continued to express their motivation to use standardised assessments few of these were reported to have been used by them in their practice. Three of the local occupational therapists had been trained in the use of the Evaluation of Social Interaction Skills (ESI) (Fisher and Griswold 2015) but none had been using it in practice. The Supports Intensity Scale (Thompson et al 2004) that was purchased following the review of assessment tools in stage one was also not used (see

Section 4.4.2). Only two of the published standardised assessments presented were in regular use.

All the OT co-researchers were now trained in the use of the AMPS (see Section 4.3.2) and reported that they were using this assessment as well as the specialist occupational therapy assessment based on the OTIPM. These were not listed as a change in the occupational therapy practice as these had already been in use in the team prior to September 2011. However, one of the new forms was the:
AMPS activity list. As part of the changes in practice, the OT co-researchers had agreed that a list of the commonest AMPS tasks used by the team would be produced so that an accessible letter could be sent to people with learning disabilities and their carers to prepare them for the anticipated assessment.

The Financial Decision Making (Suto et al 2007) was one of the published standardised assessments presented and listed as budgeting on Table 7.7 The OT co-researchers adopted this assessment as it met their needs due to there being an increasing number of referrals being made to occupational therapy to address financial issues and it was often an area that led to safeguarding concerns. This assessment was reported to have been used by most of the OT co-researchers in stage three.

The findings were that the OT co-researchers were still using non-standardised assessments for most of their occupational therapy practice. This was even though there were standardised tools available they had received training and support to use them, and had expressed a motivation to do so.

7.5.3.1. Findings of the review of the use of the new forms and processes developed for the changes in occupational therapy practice.

A brief summary of the findings is presented here (see Appendix R for more details of all the responses).

Table 7.7 summarises the OT co-researchers responses regarding how often they used some aspect of the changes in occupational therapy practice when completing an initial assessment during the specified three month periods in 2011 and one year later in 2012. The distinction between these two categories was chosen as it was expected that the initial assessment process would be similar for all clients and so the new processes and forms for this would be used more universally. However, the

on-going caseload work would be more individually planned depending on the referral issue and so there was more likelihood that the new processes and forms may not always be relevant. The number of times that the new processes and forms were used with the people on the occupational therapy total caseload increased from 62% in 2011 to 86% in 2012.

Table 7.7: The number of cases in which the OT co-researchers' used the new forms and processes

September- November	**2011**	**2012**
Number of **initial assessments** where OT co-researchers were using the new forms/processes.	33/41 (80%)	50/54 (93%)
Number of OT co-researchers using the new forms/processes with 100% of clients at **initial assessment.**	2/7	6/7
Total number of clients that the OT co-researchers were working with using the new forms/processes.	61/98 (62%)	109/127 (86%)
Total number of OT co-researchers who were using the new forms/processes with100% of clients.	0/7	3/7

The number of times that the new forms and processes were used by individual OT co-researchers varied. One OT co-researcher reported to have never used any of the new forms or processes in 2011 with people who were on the caseload and another was using them 100% of the time. In 2012 three out of the seven OT co-researchers reported that they were using the new forms with everyone on their caseload. However, the one person who had reported 100% use in 2011 now reported only using an aspect of the new forms and processes for 64% of the cases. In 2012, the lowest reported use by an OT co-researcher of new forms with people on the caseload was for 44%.

Some of the comments gave some insights into the reasons why the OT co-researchers reported that they did not always use the new forms and processes in 2012. Four OT co-researchers commented that they followed the multi-disciplinary team pathway and process for people who had been referred for assessment in regard to potentially having dementia or if they were considered to have a learning disability. These team processes were not considered to have been changed by the new occupational therapy practice processes and forms. Other comments included:

> *"Some clients already known to me, therefore, just needed a review…Their needs do not fit into the pathway".*

The above examples suggested that the OT co-researchers were continuing to adapt their approach to meet individual needs rather than rigidly following the new processes at all times. Other comments appeared to also indicate that the new forms and processes had been assimilated into occupational therapy practice but some shaping of these changes had been on-going:

> *"Always use some aspect of it. I don't find it useful to do the initial assessment normally"*
>
> *"I am cutting corners, going straight to specialist assessment. Using in a broad way, providing more teaching sessions, establishing pathways for eligibility and dementia and complex cases all based some-how in RTT"*
>
> *"I use the forms as relevant to the people that I am working with".*

The findings suggest that the OT co-researchers had been using the new forms and processes in at least some of their occupational therapy practice in 2011 and this use had been sustained and increased one year later. The processes and forms were not used in all cases and this appeared to be due to the need to continue to provide an individualised service and to meet some of the more multi-disciplinary team processes within the wider team.

All twenty seven forms and processes agreed to be adopted by the OT co-researchers as part of the changes in occupational therapy practice are listed in Table 7.8. These are ranked in order of how often they were reported to have been used. The OT co-researchers were asked to report if they had ever used each of the forms since September 2011 and so that forms that had been used outside of the sample time periods were included. However, it was not practicable to ask the OT co-researchers to provide data on the total numbers of times they had ever used each of the forms, due to the time it would take for them to look up all of their records. The number of reported uses of the forms is, therefore, just for the two time periods sampled.

Twenty three out of the twenty seven new forms and processes had been used by at least two of the OT co-researchers by November 2011. Only four had ever been used by all seven of the OT co-researchers: the OT. RTT pathway: initial assessment form: goal plan and the ADL checklist. Four of the forms and processes had never been used by any. This suggests that although some change in occupational therapy practice had occurred they were not all universally adopted by the OT co-researchers. However, some of the forms were developed to only be used for specific referral reasons and so would only be relevant if the OT co-

researcher was working with someone who needed to address that issue. See Appendix R for more details of the OT co-researchers reported use of the new forms and processes.

Table 7.8: Reported use of the new forms and processes by the OT co-researchers between September 2011-November 2012

Form/Process ranked in order of most used	Number of OT co-researchers N=7	Total uses by all the OT co-researchers.
OT. RTT Pathway	7	53
Initial assessment form	7	40
Goal Plan	7	33
Participation training form	6	31
OT leaflet	4	31
Care pathway OT assessments.	6	30
ADL checklist	7	27
Cooking skills checklist	5	11
AMPS Activities	6	13
Eating and drinking	5	8
Dementia	3	8
Budgeting	5	6
Client travel training	3	5
Top tips when out	3	5
Capacity	3	4
Interest checklist	4	4
Housework checklist	2	4
Equipment	3	3
Skills teaching top tips	3	3
Personal Care	2	3
Carer travel training	2	3
Activities	2	3
Sensory	2	2
Specialist OT assessment grid	0	0
Other skills teaching form	0	0
Accommodation support needs	0	0
Employment	0	0

The forms and processes were generated by the OT co-researchers reflecting on their experiences in practice and sharing this learning with their peers. The OT co-researchers appeared to have taken ownership of the new processes which may

have been due to their involvement in generating them. The uptake of these locally developed new forms was greater than the use of the published standardised assessments. This may have been due to the forms being based on the clinical experience of the occupational therapists working in the same local area and so were more easily applicable to their new referrals than tools developed in other settings.

The forms and processes were agreed and generated by the team, however the expectation to remember all the new changes was ambitious. It may, therefore, not be surprising that all the forms were not consistently used. However, the responses in 2012 appeared to show that the OT co-researchers developed their awareness and understanding of the form and processes over time and had not used some of them due to not having any relevant referrals issues.

7.6 Reflections of the OT co-researchers experiences within the action learning sets

The changes in occupational therapy practice that occurred at the start of Stage Three were an example of one of the principles of the action research process of risking disturbance (Winter 1996). The OT co-researchers participated with enthusiasm in changing their practice even though they saw it as something that was imposed on them by the service rather than as a response to problems they had identified in their own practice.

Two initial comments made about the planned changes in practice were:

> *"Quite pleased that we spent those days, although it was not the easiest process - RTT and value for money, but I feel more prepared for it."* (ALS:A1.E)

and:

> *"I had not expected OT to lead it. I am a bit surprised we had done so much work towards it this is quite good. The new working will be tough for some of us to change our style, anyway needs must"* (ALS:A1.G).

This appeared to suggest that the three days planning the changes in occupational therapy practice had been a positive and empowering exercise and that this pro-active planning was perceived to have been something unusual for the service. This also appeared to be an example of how the OT co-researchers were able to critically reflect on a service demand and then had the autonomy to change their practice to

meet the expectations. However, it also illustrated how the demands of the organisation in which the occupational therapists were employed took priority over the expectation of the profession to meet evidence based practice. The OT co-researchers initially abandoned the plans to address the findings of stage two of the action research fieldwork or to continue to address their concerns regarding the occupational therapy assessment process as they considered the new expectation to meet waiting times.

In the first action learning sets the OT co-researchers were asked to reflect on the themes that had emerged from stage two. The OT co-researchers had been surprised by the positive responses regarding how much their interventions were valued. It appeared that some of the OT co-researchers had not previously recognised the value of their own occupational therapy and how this was perceived. The discussions in the action learning sets were often focused on when they had not been able to address all the occupational performance issues that a person with learning disabilities, carers and referrers had raised and how they could improve their practice. However, the OT co-researchers did acknowledge their positive achievements and that the changes in practice action plans would not have affected their fundamental occupational therapy approach. This was summed up by:

> *"what we do always makes a change, don't think the new way of working has affected our quality I think our clients still like what we do, still working on their goals"* (ALS:B1.B).

This focus on the unresolved issues by the OT co-researchers appeared to be due to their use of *narrative* and *interactive reasoning* (see Table 2.2). The OT co-researchers develop an understanding of the individual's occupational performance issues. They then collaboratively work with the individual and his or her carers to address any problems or concerns. They were, therefore, aware that the occupational therapy intervention was just a part of the person's life and that not all of these issues can be addressed by occupational therapy. This suggests that the occupational therapists were focusing on the unresolved problems in people's lives without recognising what had been achieved.

At the end of the three day workshop in August 2011, the OT co-researchers agreed that they would put the agreed occupational therapy referral to treatment (OT.RTT) pathway into practice. Some of the OT co-researchers appeared to be able to use their *conditional reasoning* to blend the changes with their existing occupational therapy practice immediately. Examples of this were:

"Nothing different: Might have worked this way any way as urgent people need more flexible approach- just called it something different". (ALS:AB1.G),

and

"I think I have used this more as an administrative change….. it doesn't change how we think: just prioritise and process in different way" (ALS:AB1. E).

The discussions in the action learning sets revealed that many of the OT co-researchers struggled with the *procedural reasoning* of applying the new forms and processes to their practice. In action learning set (ALS:B1) there was a discussion as to where the actions, that an OT co-researcher had completed with each person, would be labelled and sited on the OT.RTT pathway. This highlighted differences in understanding among the OT co-researchers. Following this discussion, the lead researcher reflected that some of the OT co-researchers were struggling to assimilate the new referral to treatment process with their occupational therapy practice. Some of the OT co-researchers struggled with the use of the newly agreed terminology. For example, the 'initial assessment' was now termed the 'specialist assessment'. The lead researcher discussed with them where the OTIPM process (see Figure 2.1) would be addressed in the RTT.OT flow chart (highlighted in yellow in Appendix M). This was presented and shared in the joint action learning set (ALS:AB1). It is not known if the action learning sets had not been in place if these misunderstandings would have perpetuated or been addressed in the usual practice occupational therapy service development meetings and within professional supervision. The collaborative nature of the action learning sets allowed the OT co-researchers to reflect on their experiences of applying the changes to practice and collaboratively develop new patterns of procedural reasoning regarding their processes.

The changes took longer than expected to embed into practice and were initially quite disruptive. In the joint action learning set (ALS:AB1) that took place two months after they had been initiated, a major theme that emerged from the discussions was that it was too early to be able to consider how the changes were working. There was some expressed anxiety about feeling under pressure to close cases in which the old occupational therapy process was operating so that the waiting list could be reduced. However, despite these concerns, the OT co-

researchers were positive about the new changes and specifically stated that the following were working well:

- having weekly, rather than fortnightly meetings to discuss new referrals,
- all grades of occupational therapists now completing initial assessments, where this had previously been completed by more senior clinicians,
- the more detailed information gathered at the initial assessment,
- the perception that the service was now able to respond to referrals quicker.

The action learning sets appeared to support the OT co-researchers who were feeling challenged by the changes in practice. The following extract of a discussion revealed how the changes in occupational therapy practice were perceived as a different way of working and quite stressful to implement:

> *"The family was wanting an OT skills assessment and I actually sent them information including … my old report. It felt uncomfortable doing that but I did it and explained to them on the phone. They then looked at my report and they decided they did not need OT but the issues were about needing a support service. I closed the referral. It felt alien … and … a little uncomfortable"* (ALS:AB1.D).
>
> *"How did you decide to do it that way?"* (ALS:AB1.G).
>
> *"In the [action learning set] we decided how to do it. It was a learning curve, we learnt from each case. I talked to the social worker who made the referral. … I spoke to the brother and … emailed the form to him…. They all wanted to do the best for him. It did help them focus on what help they wanted and needed. Maybe it did help them"* (ALS:AB1.D).

This suggested that the OT co-researcher had been challenged to use '*pragmatic reasoning'* to clarify that a review of the person's support package was required rather than a repeat occupational therapy assessment, as would previously have been offered. The OT co-researcher may have been feeling uncomfortable due to *ethical reasoning* and feeling that she was denying someone a service. However, she was able to use the action learning sets to reflect on her actions and learn from her colleagues that the changes in practice may be more effective as meeting the need. This enabled her to ensure that her previous occupational therapy recommendations could now be reviewed and the outstanding need for extra support was recognised without the need for unnecessary extra intervention.

Some concerns were raised in the action learning sets that the changes to occupational therapy practice could affect the dynamic and complex working of

occupational therapy that was considered to be a positive aspect of the service. Many of the changes to practice were aimed at ensuring the referrals could be addressed in a more responsive and clearer way and there was a concern that this might result in less multi-disciplinary joint working.

> *"If everyone works to tight deadlines might limit flexibility to hang on and wait for physio or speech… We are usually more flexible to fit in with others"* (ALS:A1.E).

The OT co-researchers recalled instances where they had remained involved in a complex case unnecessarily and the changes in occupational therapy practice had helped to clarify their role in these circumstances. One OT co-researcher reflected on a current complex case:

> *"such huge turmoil in her life hard to see if [occupational therapy] has impacted compared with other factors. Lots of variables, not clear cut"* (ALS:B1.D).

However, there were other examples where the OT co-researchers considered that it was necessary to be more flexible than the changes in practice might imply to ensure that complex multi-agency issues could be addressed. One OT co-researcher reflected on spending time not providing specific occupational therapy but:

> *"contributing to team decision making process…. go to meetings, quite hard to say exactly what I did"* (ALS:B1.A).

The difficulties in sustaining outcomes were discussed in the action learning sets. The sample participants with learning disabilities in stage two had been selected as they had completed an occupational therapy assessment and intervention (see sample selection Section 5.3.2). Therefore, this sample would not include participants with learning disabilities in which the OT co-researchers had not been able to complete their intervention and so may have had more negative perceptions of the outcome. One OT co-researcher talked about the need to work with support workers and carers to enable them to meet the needs of the people with learning disabilities and how:

> *"for half my caseload it feels like they are genuinely interested finding it useful.. making a difference. Others [are] difficult to engage, I could work for the rest of my life, but for reasons not directly related to the client, like family life, lack of funding, you are never going to quite make the impact you want. It's the nature of how we work"* (ALS:A1.E).

The discussions in the action learning sets reflected that the occupational therapy had a valuable role in the collaborative team approach to support a person to move forward in his or her life. Flexibility therefore was needed to ensure that the changes in occupational therapy practice did not restrict the occupational therapists' multi-agency collaboration or prevent them from using their professional judgement to make decisions about the circumstances in which their intervention would be the most useful. It was acknowledged that the outcomes of occupational therapy intervention were difficult to measure due to the complexity of the situations that they were often dealing with.

By the final action learning sets, all the OT co-researchers appeared to be more relaxed about the changes in practice. They reflected that now they were more familiar with using the new processes, their occupational therapy practice had not changed as much as they had expected it to have done. One commented:

> *"We need systems to support our practice, but we may have naively thought it would change everything that we did but it only changed one small part, there will always be people who don't fit that system and the people going on the waiting list, I think this is ok*" (ALS:A2.E).

Another suggested that the changes had resulted in being:

> *"more aware of time, and set some time limits, but it has not influenced my clinical thinking and I think that's alright don't think it's meant to. Now more formalised as we used to be when we had more time*" (ASL:A2.G).

As the OT co-researchers had become more familiar with the new processes, they found that they needed to collect minimal information at initial assessment in order to identify the type of intervention required, leaving the more detailed assessment until the specialist occupational therapy assessment. They had also stopped having weekly referral meetings and returned to the previous pattern of fortnightly meetings. The time to complete parts of the process, such as the RTT.OT had reduced. They were able to understand the new processes and incorporate them more naturally within their occupational therapy practice demonstrating that the changes in practice had been embedded. This would suggest that they were using their *conditional professional reasoning.*

The group discussion in the final action learning set was about wider issues such as whether the emphasis on *procedural reasoning* had reduced their attention on other aspects of professional reasoning such as *ethical reasoning*. The OT co-researchers reflected on the changes made to reduce waiting times. Although the initial response

to referrals was now quicker, this may have resulted in the person receiving a less thorough service or a longer wait elsewhere in the system. Implementing the changes in occupational therapy practice, at least initially, had resulted in a lack of clarity regarding the processes for the occupational therapists. This could have affected the quality of the service provided to people with learning disabilities and their carers. The changes in practice led to carers having to be more involved in completing individual forms and there was a greater emphasis on training staff teams rather than direct work with some people with learning disabilities. How the changes in occupational therapy practice had been perceived by the recipients of the service was explored in Chapter eight.

7.6.1 Lead researcher reflections

The lead researcher was concerned, at this time, as the decisions about the changes in practice did not initially appear to relate to the themes and problems that had emerged from stage two. The plans for the research study appeared to have been superseded as the OT co-researchers reacted to their organisation's demands. However, using the principle of dialectic critique reflexivity (Winter1996), she was able to understand that the OT co-researchers were taking control of their own practice development and that service demands needed to be taken into account for this to occur. The lead researcher was still able to influence the changes in occupational therapy practice by reminding the OT co-researchers of the themes and problems that had emerged from stage two to ensure that these views and concerns were also addressed at this time. The OT co-researchers contributed to the sessions on changing their practice with enthusiasm. They took the lead on deciding what changes were needed and how to action them in order to improve their own practice. The lead researcher was involved in these sessions in the role of a team member as decisions were being made in a collaborative partnership. However, at the same time, she maintained the responsibility for the research study and continued to gather data from the action research fieldwork.

7.7 Summary

The objectives of the first part of stage three set out in Table 7.1 were met. The lead researcher engaged with the OT co-researchers as the agents of change of their own practice to identify key areas of concern and how to address these. They

reflected on the findings of stage two in the OT co-researcher meetings and considered the results of the repeat questionnaires, in order to deduce what was working well in their service and what would be needed to improve practice. The service expectation to meet waiting list targets had become a priority and was assimilated into the action research fieldwork.

The OT co-researchers took the lead in acting as agents of change to develop new forms and processes to address the identified concerns and to implement these into their occupational therapy practice.

The action learning sets helped the OT co-researchers to critically reflect on their experiences of implementing the changes in occupational therapy practice, learn from each other, receive support and develop their professional reasoning skills. This ensured that the occupational therapy practice in the local service was able to meet the demands of the organisation to meet waiting list targets whilst working to maintain the quality of the service provided. The OT co-researchers developed their understanding of the new processes and how these could be more consistently applied but there did appear to be some on-going variations in how the changes in occupational therapy practice were being implemented.

The OT co-researchers reported that those changes which they had adopted were sustained one year later with an increase in the uptake of the new forms and processes over time. It emerged that only four of the twenty seven forms were used by all of the OT co-researchers and even these were often individually interpreted. There were various reasons why the new strategies were not consistently adopted across the group of OT co-researchers. The OT co-researchers worked across two separate boroughs and each of the areas had specific local needs and policies that affected how services were delivered. The OT co-researchers had different levels of experience and varied in their preferred modes of practice so it would not be expected that they would all work in exactly the same way. The needs and referral issues of the people with learning disabilities referred to the service varied widely and the service was committed to responding to individual needs and so there would always be some unique needs that could not be addressed by the use of prepared forms.

Chapter eight explores how occupational therapy practice, following the implementation of these changes, was perceived by a new sample of people with

learning disabilities, and others involved in the process. The perception of the OT co-researchers of the changes into practice, after they have considered how this had been perceived by others, will then be further explored. All the objectives of stage three are reviewed at the end of Chapter eight.

Chapter Eight: Stage three: Exploration of how the occupational therapy practice was perceived after the changes

8.1 Introduction

The second part of stage three commenced after the changes in occupational therapy practice were established by the OT co-researchers. The objectives of the second part of stage three are set out in Table 8.1.

8.2 Methods

A similar method to stage two (see Section 5.3) was undertaken in order to investigate how the local occupational therapy service was now perceived following the implementation of the changes in occupational therapy practice described in Chapter seven. The views of a new sample of people with learning disabilities and/or their closest carer and other stakeholders involved were obtained across six case data sets. The data items requested for each case data set were the same as in stage two. The same questions were asked as in stage two so that the new findings could be compared with the previous ones. One additional question was asked to any responder who had experienced the occupational therapy service before the changes to practice had been implemented to ascertain if they had perceived a difference (see Appendices J and K).

Table 8.1: Objectives of stage three (part two)

Objectives of stage three for part two	Action
To explore the perceptions of a new sample group of adults with learning disabilities, their carers and other people involved regarding the occupational therapy that they have received following the implementation of the changes in occupational therapy practice.	The lead researcher conducted semi-structured interviews with a sample of adults with learning disabilities about their experiences of occupational therapy assessments and interventions. The lead researcher conducted semi-structured interviews with the carers of the participants with learning disabilities. The lead researcher administered questionnaires to other professionals (stakeholders) involved with the participants with learning disabilities. The lead researcher administered questionnaires to the occupational therapists involved with the participants with learning disabilities. The lead researcher analysed the data from the interviews and questionnaires and presented the findings for review by the OT co-researchers.
To explore how the OT co-researchers perceived their practice following the changes, in order to identify what went well and what still needed to change	The lead researcher and OT co-researchers met to review the findings of stage three. The OT co-researchers completed questionnaires on their use of assessments and their experience of the action research process. The lead researcher analysed the data from the OT co-researcher questionnaires on their experience of the action research process.
To explore any other themes that emerged from the data gathering process	The lead researcher and OT co-researchers reviewed the findings of stage three at the final OT group meeting.

8.2.1 Sample selection

As in stage two, participants with learning disabilities were identified and invited to participate in the research study by the OT co-researchers. At this stage, they needed to have completed an episode of occupational therapy assessment and intervention using an aspect of the new changes to occupational therapy practice. There were not as many potential participants identified as there had been in stage two as some were not yet ready for discharge from the service. This resulted in the interviews and subsequent distribution of questionnaires being completed over a longer time period than in stage two so that a sample could be identified that had some similarities in age, level of ability and range of living environments.

The invitation to participate and the consent process was the same as described in stage two (see Section 5.3.2). The six data sets (see Table 8.2) consisted of five participants with learning disabilities who had recently completed an assessment and intervention by an occupational therapist. The sixth data set (L) was in relation to training of a team of support workers who all supported three people with severe learning disabilities who live in one house. The interview with the manager of this house was completed to gain an insight into how one of the changes in occupational therapy practice of providing staff training rather than directly working with the participants with learning disabilities had been perceived. The three people with learning disabilities who lived in this house were not approached for interview due to their lack of direct contact with the occupational therapy service and the nature of their learning disability would mean that they would not be able to contribute to an interview.

Data were collected between April 2012 and March 2013. The occupational therapists who had worked on the selected cases and stakeholders were sent a questionnaire as described in stage three. Tables 8.2, 8.3 and 8.4 set out the data items collected for stage two.

Table 8.2: The number of responses for each case in stage three

Data Items	Data Set J	Data Set K	Data Set L	Data Set M	Data Set B	Data Set A	Totals Received
Participant with learning disabilities interview	1	1	N/A	1	1	1	5/5 (100%)
Carer interview	1	N/A	1	1	N/A	1	4/4 (100%)
Stakeholder Questionnaire	1/4	0/3	N/A	1/2	1/3	0/3	3/15 (20%)
OT stakeholder questionnaire	1	1	1	1	1	1	6/6 (100%)
Occupational therapy report	1	1	1	1	1	1	6/6 (100%)

Table 8.3: Participants with learning disabilities in stage three

	Gender	Age	Living situation	Level of learning disability	OT assessment
Case J	F	27	Lives alone	Mild	Financial ADL
Case K	F	32	Lives alone	Mild	Travel
Case L	2 F 1 M	Various ages	24 hour staffed house	Severe	Initial assessment Training
Case M	M	21	Lives with family	Moderate	Domestic skills
Case B	M	60	Lives alone	Mild	Cooking
Case A	M	54	Lives with partner who also has learning disabilities	Moderate	Financial

Table 8.4: Comparison of the number of data items in stage two and stage three

Data received	Stage two	Stage three
Number of participants with learning disabilities interviews	5	5
Number of carer interviews	5	4
Stakeholder questionnaires	14/25	3/15
OT stakeholder questionnaires	6	6
OT Report	6	6
Total data items	**36**	**24**

8.2.2 Analysis of the data from stage three interviews and questionnaires

The analysis of the data that related to the essential criteria was completed using the same descriptive analysis as set out in Section 5.4. The analysis of the findings of the interviews and questionnaires and the responses of the OT co-researchers within the action learning sets were considered together in order to explore if the themes identified in stage two continued to be significant in the local occupational therapy practice in stage three. The effectiveness of the changes to occupational therapy practice in addressing the problems that were identified in stage two (see Table 6.9) were also considered. As the objective at this stage was to explore how occupational therapy practice was perceived following the changes in practice, a theoretical thematic analysis was completed as opposed to the inductive thematic analysis in stage two. The theoretical thematic analysis was 'analyst-driven' and would be expected to *'provide less a rich description of the data overall, and more a detailed analysis of some aspect of the data'* (Braun and Clarke 2006, p84).

8.3 Findings: how the essential criteria of the occupational therapy assessment were perceived to have been met

The responses to the questions in the interviews and questionnaires regarding the perceptions of the occupational therapy assessments are summarised in Table 8.5 and detailed in Appendix R. The findings from stage two (see Table 6.5) have been included in this table so that a comparison can be made between the responses from before and after the changes had been made to occupational therapy practice. However, caution needs to be taken in comparing and contrasting between the data as the responses are from a different sample of participants with different reasons for requiring occupational therapy. The findings from the data were used to consider if there were general trends and themes that appeared to be emerging that could be triangulated with other findings in the action research fieldwork.

Table 8.5: Comparison of perceptions of the criteria being met at stage two and stage three

Essential Criteria of an assessment tool that will identify strengths and needs in community living skills of people with learning disabilities	**Stage 2 Percentage of positive responses and number of data sets in which the criterion was fully met.**		**Stage 3 Percentage of positive responses and number of data sets in which the criterion was fully met.**	
Assess occupational performance	93%	4/6	94%	5/6
Global skills rather than just one particular skill	90%	4/6	82%	4/6
Highlight skills and support needs in order to make meaningful and useful recommendations:	90%	4/6	94%	5/6
Client centred/choice and empowerment	93%	5/6	94%	5/6
Accessible easy to use and understand	76%	3/6	87%	3/5
Designed for people with learning disabilities	97%	5/6	94%	5/6
Fit for purpose	100%	6/6	100%	6/6
Practical/ good use of resources	84%	3/6	92%	5/6
Observation	97%	5/6	94%	5/6
Incorporate views of all people involved with the person with learning disabilities	76%	3/6	94%	5/6
Fits with other local, national, international assessment development.	96 %	5/6	83%	4/6
Total for data sets Scores of: Yes D/K No Blank **Total responses**	 280 (90%) 21 (7%) 9 (2.89%) 1 (<1%) **311**		 155 (92%) 8 (5%) 4 (2%) 2 (1%) **169**	

As in stage two, the findings in stage three were that the majority of participants agreed that the essential criteria for the occupational therapy assessment had been met in their experience. The overall positive responses for each of the essential

criteria ranged from 82% to 100%, compared with 76%-100% in stage two. The criterion: 'fit for purpose' remained at 100% positive. The three criteria that had scored under 85% in stage two: 'accessible easy to use and understand'; 'incorporate views of all people involved with the person with learning disabilities' and 'practical/ good use of resources', now scored above this level in stage three. These three criteria are discussed in turn:

'Incorporate views of all people involved with the person with learning disabilities' which increased from 76% to 94% positive responses.
All the participants with learning disabilities and carers who responded in stage two and stage three agreed that their views had been taken into account by the occupational therapist with whom they had worked. In stage two, the negative and blank responses for this criterion had been made by the professional stakeholders and the OT co-researchers. In contrast, in stage three, all responses to the questions under this criterion were positive with just one response being left blank. However, as can be seen in Table 8.3, the number of stakeholders identified was 25 in stage two but only 15 in stage three. This suggested that in stage three the occupational therapists liaised with fewer people and were not sharing the assessment reports as widely as they had in stage two.

There could have been many explanations for the reduced number of stakeholders identified in stage three compared with the sample in stage two. For instance, there may have always been a variation in the number of stakeholders involved and that this pattern was not significant in such small sample numbers. However, in discussion in the OT co-researcher meetings, other reasons for this difference were considered. The nature of the work to meet one referral at a time and meet the referral to treatment targets appeared to have affected the joint working within the team. The occupational therapy reports were shorter and more focused and so fewer people may have been involved with the person with learning disabilities during the time period. The use of electronic health records resulted in the reports being uploaded on to a shared system and so the reports no longer needed to be sent to other professions in the same team. However, other health and professional stakeholders such as social workers, clinical psychologists and general practitioners were not on this shared system. Although, using a shared health record was considered to improve team working, it did appear that the reports were not so frequently read as when they were specifically sent to named team members. The OT co-researchers may have been responding to the finding in stage two in which

the participants with learning disabilities had been unaware of their report being shared with other professionals. This may have made the OT co-researchers more aware of ensuring that they had informed the participants with learning disabilities as to who they were sharing their information with and thus reducing the number of recipients. However, a consistent finding across both stages was that all the stakeholders reported that they valued the occupational therapy report.

In stage three, two participants with learning disabilities stated that although they agreed that all the views of the appropriate people had been incorporated they commented that no one had talked to them about the occupational therapy assessment report after they had received it. This suggested that, with the reduced number of stakeholders identified as needing to receive the report, there may have been less people who would be aware of the occupational therapy intervention. Other professionals have a role of reminding and reinforcing any recommendations from the occupational therapy report to ensure sustainability of the outcome.

'Accessible easy to use and understand' which increased from 76% to 87% positive responses.

In stage three, all the responses were positive for this criterion although two of the professional stakeholders for two different data sets responded 'don't know'. These stakeholders were not present when the occupational therapist was working with the participant with learning disabilities and so the responses may have been due to them not having observed this, rather than reporting a concern about the accessibility of the assessment.

'Practical/ good use of resources' which increased from 84% to 92% positive responses.

In stage two, some negative responses indicated that occupational therapy had not always been provided when it was required. In stage three all the responses were positive apart from one professional stakeholder who stated:

> *"don't know"* (ShB).

This may reflect that the changes in occupational therapy practice to ensure that referrals are responded to within a shorter time frame had made a difference to practice.

There were two criteria in which the positive scores had reduced to under 85% in stage three compared with stage two when these had been higher.

‘Fits with other local, national, international assessment development’
In both stages, only the OT co-researchers expressed concerns with this criterion whilst all the other responders were positive that this was addressed. At stage three some OT co-researchers had concerns about how only working on one referral issue at a time may have affected the ability of the occupational therapists to address all the needs of the people with learning disabilities.

‘Global skills rather than just one particular skill’
The changes in occupational therapy practice emphasised addressing one referral issue at a time rather than the previous practice of considering all the concerns of the person with learning disabilities, however the general positive responses received suggested this change had not affected the perception that the occupational therapist was completing a holistic assessment of skills. The exceptions were two occupational therapists and a professional stakeholder who appeared more aware of the change. One commented:

“No. the new way of working means only one skill area at a time” (OTB).

The findings in stage three were similar to stage two and indicated that the majority of the responders considered that the occupational therapy assessment process that they had experienced had met all the essential criteria as defined by the local occupational therapists in stage one (see Table 4.5).
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8.4 Findings: how occupational therapy practice was perceived following the implementation of the changes

8.4.1 Theme one: Occupational therapy is valued

As in stage two, the findings from all the six data sets in stage three were that the occupational therapy that was provided was valued by the respondents. The participants with learning disabilities clearly expressed how occupational therapy had made a difference in their lives. This is illustrated by the following examples:

The partner of participant with a learning disability (A), who also had a learning disability, re-enacted part of the occupational therapy assessment at the interview by getting her purse and asking her partner some of the questions that she reported

that the occupational therapist had asked. This appeared to reveal that this had been a significant event for the couple. When participant with a learning disability (A) was asked if the occupational therapy input on his use of money was important he said:

> *"yes it was as I did not know what to do"* (pA)

His partner added:

> *"He done very well, he knows his money now…at the start he did not know- much better than what he was"* (cA).

Participant with a learning disability (B) reported that the occupational therapist had taught him to:

> *"Wash potato in water. Put it on for 10 minutes"* (pB).

Participant with a learning disability (M) said that the occupational therapist came to see him:

> *"to learn things"* (pM)

His carer agreed:

> *"it was good…like routine…his understanding that always the family…give him breakfast…now he learns to do it by himself"* (cM).

Participant with a learning disability (K) tended to only answer direct questions but was able to expand more on her view of the value of occupational therapy:

> *"My confidence- better… she explained to me what the coloured lines were for and which lines they are for on the Tube map. I remember some of them"* (pK).

Participant with a learning disability (J) was very enthusiastic about her experience of working with the occupational therapist:

> *"I went with her to shopping… (and) cooking… she saw how I….need help. She taught me …and I start understanding…. I could always talk to [OT] really good listener, helped me a lot actually… She is lovely, funny, kind I like work with her .Enjoy. Never said anything bad. She is nice"* (pJ).

The carer was also positive about the impact:

> *"Just absolutely genuinely it is fantastic working with [OT] she has got a really nice enthusiasm and energy and people really like her and she makes really nice links and really supportive to us"* (cJ).

As stated in Section 8.2.1, data set (L) was for a group of people with learning disabilities who live in a shared house and are supported by a staff team. The house manager was asked about the value of the training that the staff had received from occupational therapy. She reported:

> *"We were shown the new approach… We are here to enable people to learn new skills or retain the skills that they have ... It was really good for staff to hear that not just from me or our managers in our organisation good to hear that from people outside our organisation that we need to change. Update their understanding of what this job is about"* (cL).

The overall conclusion was that the occupational therapy that had been received in stage three had been considered memorable and of value by the participants with learning disabilities, carers, other stakeholders and occupational therapists. The participants with learning disabilities were positive about the occupational therapy they had received and were aware of the skills that they had gained.

8.4.2 Theme two: Occupational therapy is provided in a dynamic context

In contrast to the responses in stage two, the participants with learning disabilities, carers, stakeholders and the occupational therapists had similar understandings of the reasons for the occupational therapy referrals and the outcomes achieved, across each data set. The occupational therapist worked with participant with a learning disability (A) just to address concerns about how he managed his finances. The occupational therapist for participant with a learning disability (A) reported that the outcome was:

> *"Report completed to inform care management and care providers with recommendations on how best to support [participant with a learning disability (A)] to plan and make decisions about spending his money"* (OTA).

The occupational therapy intervention for participant with a learning disability (M) was to increase his participation in some household tasks. In stage two, the reports addressed several referral issues that had arisen during the intervention period. The examples appeared to show that focusing on one referral at a time had resulted in more clarity as to the purpose of the occupational therapy provided. The smaller number of stakeholders identified by the occupational therapists, as discussed in Section 8.3 may have also reduced the complexity of the context.

Other findings appeared to reveal that the health and social care system, in which the local occupational therapists were working, was still complex and dynamic. The occupational therapists had been valued as being able to facilitate the participants with learning disabilities and carers to understand and engage with services by being flexible to meet the individual circumstances. The mother of participant with learning disabilities (M) said:

> *"it's good you come back and tell us. You don't know what's out there"* (cM).

It was reported that the staff team had found it difficult to support participant with a learning disability (J) and so the occupational therapy had been helpful to clarify the concerns as to:

> *"if we were … working in the right way. Just having someone external coming in and saying things like: [J] does not want to learn these things. She understands her money and chooses to use it in a certain way, just helped us to feel more confident in what we were doing. It allowed us to take the pressure off and stop hassling [J] about things as it was clear they were not going to change, so, very helpful"* (cJ).

Carer L reported:

> *"I received other referrals from other health professionals at the same time and it was quite complicated"* (cL).

She went on to reflect that the occupational therapist was able to help with clarifying the issues and situation for her:

> *"She explained what they were going to do, and … what the training was about"* (cL).

The participants with learning disabilities and the carers continued to have difficulty understanding and negotiating the complex multi-agency health and social care system. This could prevent referrals being made to the occupational therapy service when needs arise. An example of this was the statement by a service manager for a staff house for people with learning disabilities that:

> *"I was not aware of what the OTs could do... as the team leader…I did not have the chance to learn that about your work"* (cL).

She suggested that other service managers would also not be aware of the service.

In stage three, as in stage two, the occupational therapy practice continued to be provided in a dynamic and complex context. There appeared to have been an

improved clarity by the occupational therapist as to what referral issue they were addressing when working with a person with a learning disability. There was still a need for occupational therapy to contribute to the multi-disciplinary assessment to address complex needs. Some of these roles needed flexibility and may have been affected by a rigid imposition of caseload management processes. The local occupational therapists were seen as people that could clarify some of the processes for the people with learning disabilities who they are working with and their support networks. However, there continued to be a lack of awareness of the occupational therapy service and what it could provide by many of the responders but particularly the participants with learning disabilities and their carers.

The overall conclusion was that the occupational therapy practice was still considered to be complex and dynamic and that the occupational therapists were often seen as people who were skilled at working in complex situations and able to clarify processes. However, there was concern expressed by some of the OT co-researchers that the changes to occupational therapy practice to improve clarity and speed of responsiveness to referrals may have at times compromised the quality and complexity of the practice.

8.4.3 Theme three: Occupational therapy not always able to influence others to sustain outcomes

In stage three, in contrast to stage two, the respondents did not raise any concerns about occupational therapy not being able to influence others to sustain outcomes. As described in theme one (Section 8.4.1), the outcomes of occupational therapy included the following occupational performance areas: travelling on the London Underground, using money and microwaving a baked potato, which the participants with a learning disability reported that they could now do. Occupational therapy was reported to have made a difference to participant with learning disabilities (J) and the support she received and that this was on-going:

> *"the outcome that she had capacity around some financial decisions she was making- particularly food, clothes shopping was very helpful ….This led to a real difference in how support was offered to her and as a result improved her relationship with the outreach staff which was at times at risk of breaking down"* (shJ).

The professional stakeholder concluded by saying:

"Generally I find [OT] useful and can't envisage a learning disability service running without this type of input" (shJ).

Some of the changes in occupational therapy practice had been made to address the problems that had emerged from stage two regarding the sustainability of the outcomes of occupational therapy. The findings from the interviews and questionnaires were that the occupational therapy outcomes were perceived to have made a long term change. However, the action learning sets discussions highlighted that sustaining outcomes involves a number of factors, not all of which could be influenced by the local occupational therapists.

The overall conclusion was that, in stage three, the occupational therapy outcomes were considered to have been successful and sustained by the respondents in the data sets.

8.5 Review of how the changes to practice addressed the problems identified in stage two

The problems raised by the findings in stage two and the solutions that were devised to address them are summarised in Tables 7.4 and 7.5.

8.5.1 Problem 1: Occupational therapy reports were often found to be too long and complex

In stage two (see Section 6.3.3) the occupational therapy reports were perceived to be useful and all respondents reported that they would want to receive a copy. However, they were often reported to be too lengthy as they addressed multiple issues and a summary was requested. The key change in occupational therapy practice planned to address this problem was:

Action: To re-structure the referral process so that one referral need could be addressed at a time

This plan was that shorter simpler reports that only addressed one specific issue at a time could then be produced. There was the expectation that for some people with learning disabilities, a series of reports would be produced as other referrals were subsequently made and addressed.

In contrast to the findings of stage two in which several referral issues were addressed at the same time, the occupational therapists in stage three were only addressing one or two concerns for each of the participants with learning disabilities in the data sets sampled. This appeared to have resulted in the respondents being clearer about the reasons for occupational therapy.

The occupational therapy reports were shorter than those produced in stage two, however, for participant with a learning disability (J), three separate reports were produced that altogether were still long and detailed. When participant with a learning disability (J) was asked about the occupational therapy reports that she had received she responded:

> *"I put it in the files and I gave to people for benefit support... [the occupational therapist] explained me, she talked what she done what she wrote. I think reports are good"* (pJ).

The carer's perception of the same set of reports was:

> *"It was really clear you could understand what it was saying. It's got to be in some detail otherwise it's pointless. Yes really good"* (cJ).

The occupational therapist for data set (L) reported:

> *"The assessments are supporting us to provide a more focussed, targeted service. In some ways I think this is more understandable for the stakeholders, than the on-going input that went from one issues to another that we had offered in the past"* (OTL).

Participant with a learning disability (M)'s carer, when asked what she thought about the report, said:

> *"good"* (cM).

His general practitioner commented that the:

> "*assessment report is detailed giving good insight into his daily living skills"* (ShM).

This suggested that the brief report format in this case had been found useful.

Completing single referral issues was not always perceived as positive. For example, when participant with learning disabilities (K) was interviewed she had been discharged from occupational therapy as the piece of work regarding learning

to use the London Underground had been completed. However, when interviewed she reported:

> *"I still need help with budgeting and stuff"* (pK).

A new referral was generated at the interview as it was clear that participant (K) had not been able to make this referral for herself. Similarly, participant with a learning disability (M)'s carer, was concerned that only a small number of referral issues were addressed before the occupational therapist closed the case stating:

> *"of course it made a difference but … short time"* (cM)

This appeared to indicate that she would have liked the occupational therapist to have been involved for longer. This theme that the occupational therapists had not met all the occupational performance concerns had not emerged as a finding in stage two. Prior to the changes in occupational therapy practice, it may have been expected that the occupational therapist would have explored more thoroughly with the person to check that all their needs had been addressed.

Another example of where considering one referral at a time had not been considered positive was described by the OT co-researcher for participant with a learning disability (B).

> *"Each referral need had been addressed separately such as developing (B)'s cooking skills to improve his diet and making recommendations to improve (B)'s ability to use his bed. The occupational therapist had closed the case each time and this practice of opening and closing multiple pieces of work had been confusing for participant with a learning* disability (B)" (OTB)

The change in practice to address single referral issues had been made to improve clarity of the occupational therapy intervention and to ensure equitability of the service in that newly generated pieces of work could be addressed at a later time if others had been waiting longer. However, the intention was that the occupational therapists would still be following OTIPM (Fisher 2009) in that the person with learning disabilities' identified occupational performance concerns were still expected to be addressed in a holistic way. Some of the OT co-researchers were able to address several referral issues at a time and resolve them separately as in the example of data set (J), others found this more difficult to manage. During the action learning sets (see Chapter seven), it became apparent that some of the OT co-researchers had perhaps initially been applying the changes in occupational therapy practice a little too rigidly. This had resulted in some of the fluidity and multi-

agency practice being lost as they endeavoured to meet the timescales and targets that were being emphasised.

There was evidence from data sets (K) and (M) that the reliance on the person with learning disabilities or their carers to be able to identify their own additional issues and to make a referral to the occupational therapy service had not worked. There was a concern that occupational performance needs could have been missed if the occupational therapists kept to this process too rigidly.

8.5.2 Problem 2: Occupational therapy reports did not always meet the needs of all the recipients

In stage three, the occupational therapy reports had not been sent to as many people as in the previous stage. It was noted that general practitioners had not been sent some of the reports identified in the six data sets despite this being the team policy and that the general practitioners who responded in stage two reported that they valued the reports. The possible reasons for this have been described in Section 8.5.1. Compared to stage two, in stage three the OT co-researchers appeared to have given greater consideration as to who would need to receive their occupational therapy reports. This had resulted in a reduction in the number of people who would receive reports and there was a concern that this may have at times meant that some information may not have been shared when it would have been appropriate to do so and could have affected multi-agency working.

Addressing one referral at a time, as discussed in Section 8.5.1, appeared to have resulted in the reports being perceived as being easy to follow and understand, although they were still not accessible for most of the participants with learning disabilities. Participant with a learning disability (K) did not remember the occupational therapy report but liked the accessible information that she was given when this research study had been explained to her (see Appendix H). (K) commented:

> *"reports need pictures as it helps people understand. She did do pictures which was good"* (pD).

The occupational therapist had used pictures to enable participant with learning disabilities (K) to understand the process during the intervention which had been

appreciated but had not made the occupational therapy report into an accessible summary for her.

The OT co-researchers had been working on making their goal planning and interventions accessible for people with people with learning disabilities and their carers. Two examples of this were: providing skills teaching strategies including photographs. The carer from data set L where the support staff were provided with training from occupational therapy reported that the information in the training was clear and useful for the staff team and that following the training:

> *"[OT] was very helpful she …. gave us interim guidelines to support [the clients] and then she took some photos and those photos are in the guidelines"* (cL).

This highlighted that the information provided to the staff team could be more useful and in a better format than a traditional occupational therapy report. The changes in practices appeared to have resulted in the assessment and intervention information being more accessible for the people who the local occupational therapists were working with. Although some progress appeared to have been made on improving the relevance and accessibility of the occupational therapy reports, there was little evidence that the formal occupational therapy reports had been changed to be more accessible for people with learning disabilities.

Action: To implement an accessible format for making goal planning easier for people with learning disabilities to participate in and understand

Section 7.5.3 describes the accessible goal plans and how the OT co-researchers reported that they were using them. However, an accessible goal plan was only used once across the six data sets sampled in stage three. This was used with participant with learning disabilities (M) who had difficulty engaging in conversations. The occupational therapist reported that he:

> *"initially stated he was not interested, but when presented with the goal plan, he engaged and was prepared for the sessions"* (OTM).

The accessible goal plan was shown to participant with learning disabilities (M) by the lead researcher at the interview. He appeared to recognise the plan and demonstrated an understanding of it by ticking the pictures of 'preparing breakfast' and 'preparing a sandwich' but placed a cross next to the picture 'learn to use the washing machine'. This replicated what the occupational therapist had reported that participant (M) had engaged in the first two pictured tasks with the occupational therapist and still completed these regularly but had never engaged in using the

washing machine. He demonstrated at the interview that he still understood the accessible goal plan and used it to clearly communicate what he liked and wanted to do and what he was not interested in doing.

The occupational therapist who worked with participant with learning disabilities (M) reported having set dates in advance using the goal plan. She reflected that this had appeared to have been helpful for participant (M) who had learning disabilities and autism but she was concerned that perhaps this had resulted in her having less opportunity for flexibility than how she may have previously practised. This comment about having planned set times appeared to be an issue for the mother of participant with a learning disability (M) who suggested that the final plan to use the washing machine did not happen due to the occupational therapist not having enough time:

> *" washing machine, did not work as he is not doing it, yeah he slams, needed little more time… maybe he needed more time"* (cM).

However, participant with learning disabilities (M) had indicated a cross on the goal plan picture of a washing machine which appeared to indicate that this continued to be an activity that he did not want to do. Slamming the washing machine door shut may have also been his communication that he was not interested in this task. This suggested that the goal plan enabled this participant to clearly communicate his wishes even though doing this task was still an expectation of his mother.

The participants with learning disabilities in data sets A, B, J and K were not supported to make a formal goal plan with their occupational therapists however they were able to demonstrate an understanding of the goals that they had worked on. The occupational therapist who worked with participant with learning disabilities (A) did not provide an accessible version of the occupational therapy report and stated that it:

> *"would be useful to develop a budgeting, financial decision making pack with simple explanation of what the OT assessment entails"* (OTA).

However, participant with a learning disability (A) was able to show that he understood the goals he had worked on with the occupational therapist:

> *"How much money I spend… I know what to buy and what to get. I get confused at the shop"* (pP).

The occupational therapist who worked with participant with learning disabilities (B) had supported him to be able to cook a jacket potato in his microwave. The

occupational therapy report had a photograph of the meal cooked by (B). The participant with learning disabilities (B) answered the following questions:

What did [OTB] do? *"Potato tell you the truth"*

Did he watch you cook? *"Yes he watched me"*

Did he help you? (LR) *"He helped me"* (cB).

Participant (K) stated that she appreciated the occupational therapist using pictures to explain what she was doing with her. There was evidence that the occupational therapist had worked with (J) in a person-centred way as her carer reported:

> *"Yes the conclusions really helped clarify what bits we should concentrate supporting (J). We all had to follow (J)'s speed, she made the choice which we all had to go along with which is how it should be"* (cJ).

The OT co-researchers had enabled the people with learning disabilities to express their own views about their wishes which may not have been the same as their carers' views. The accessible goal plan appeared to be a useful tool to enable people with learning disabilities to communicate their views. It was also used to support them to understand what they would need to do to meet their goal so that they were able to make a choice about participating in the occupational therapy intervention. There may be goals that a person with learning disabilities may not want to do but would be important to achieve. In these cases, the accessible goal plan can be a tool to explain the consequences of completing or not completing an action so that an informed choice can be made.

8.5.3. Problem 3: Intervention was not always provided within the most appropriate time-scale

Action 1: To develop and implement a new referral to treatment flow chart in order to meet the OT.RTT target.

An initial assessment and a first definitive treatment within the OT.RTT time scale was completed in all six data sets. The extent of this first intervention and the length of wait from that until they were next seen by the occupational therapist varied. In contrast to stage two, there were no reported concerns regarding how long any of the participants with learning disabilities had waited for their occupational therapy intervention. Carer L reported that:

> *"it happened in the right time".* (cL).

The occupational therapist for participant with a learning disability (M) reported that:

> *"The referral process seems to be working well and so far we are working within the referral to treatment window- RTT"* (OTM).

When carer (J) was asked if the wait to be seen by occupational therapy was the right length of time, she responded:

> *"Yes I don't remember thinking it was outrageous or having any problems with it all seemed fine"* (cJ).

The findings from the sample data sets in stage three were that occupational therapy was perceived to be offered in an appropriate time scale. However, the target only measured how soon occupational therapy was started and did not address the aspect of *'ensuring they receive high quality care'* (Department of Health 2010 p5). As has previously been stated, there were now concerns that the occupational therapy intervention may not have been as holistic in some situations due to the emphasis on closing cases so that new ones could be opened to manage waiting times.

Action 2: To offer carers advice, tips and training as a first intervention prior to occupational therapy involvement or instead of direct occupational therapy work with the person with learning disabilities.

Section 7.5.3 described how the OT co-researchers discussed providing tips and asking carers to complete more information prior to starting to work with people. None of the participants with learning disabilities in the sample group were provided with tips and advice prior to the occupational therapist starting to work. This limited the opportunity to explore how this change of practice had been perceived. However, the emphasis on training groups of staff rather than working directly with individual people with learning disabilities was a marked change in the local occupational therapy team's practice and an example of this was in data set (L). This was described by one of the OT co-researchers:

> *"The team worked together within the session to think about all the residents in the house and develop client focussed plans…, They left the training with a definite plan of how to put the theory into use immediately… Staff had more knowledge regarding engagement…they were confident in what they could do ... They had lots of ideas as to how to broaden opportunities for the other residents. We hope the outcome was that the residents benefited!"* (OTL).

Carer L reported that:

> *"we wanted to move our service on to become a truly supported house and move away from the old fashioned residential setting, identify more what people can do for themselves indoors, do normal things they can participate as much as possible, that happened and the training was at the right time it was good to happen then so the staff found it useful"* (cL).

Offering training for staff teams tailored specifically for the needs of the people with learning disability who they support increased following the changes in practice days. This was done as the OT co-researchers considered that occupational therapy intervention could be more effective if this was targeted to improve the skills of a staff team who support a group of people with learning disabilities and these changes would be more likely to be sustained.

8.5.4 Problem 4: The expectation of occupational therapy was not clearly understood by relevant stakeholders at the start of intervention

Action 1: The OT co-researchers to outline the expected number of sessions planned.

The findings on how the pathway affected practice in stage three overlap with some of the other areas already explored, as the care pathway of OT assessments was used to be able to structure sessions to deal with one referral at a time and to set goal plans. The occupational therapist for participant with learning disabilities (K) reported that the intervention sessions that she provided could not be matched exactly with the existing care pathways but that it was:

> *"good to have clear goal plan and time frame- helped to focus work*" (OTK).

However, the occupational therapist who worked with participant with learning disabilities (B) reported that the time frame was followed rigidly according to the care pathway but it would have been better if there had been the opportunity to have had:

> *"more time with the client"* (OTB) .

The carer of participant with a learning disability (J) reported that the occupational therapist:

> *"was very clear about the process and her role and (J) is the sort of person who wants to blur the role and [the occupational therapist] was very good at keeping it on track. … Very clear about boundaries in the nicest way"* (cJ).

Participant with a learning disability (J) was concerned that the input from the occupational therapist has been completed too soon. However, she appeared to

have understood that although she was sad that the occupational therapy had finished she was aware that she could self-refer for another piece of work in the future:

> *"I don't want her to leave me. Maybe she can come back one day maybe but I want to move out of this house first ….Move out of house, get better cooker and stuff and then ask her to come back and help me with using new cooker"* (pJ).

The structured use of assessment sessions helped to manage participant (J)'s expectations to some extent, but when asked what the occupational therapist could have done better she replied:

> *"stay longer"* (pJ).

Action 2: To review the assessment packages used to ensure that all the occupational therapists are aware of the current best practice.

There were few comments about assessments in the findings of the data sets. As was found in stage two, there did not appear to be a distinction between assessment and intervention within the data sets. (J)'s carer was asked about her understanding of the OT assessment and intervention process. She responded:

> *"I think it probably happens …I'm aware there is a process but I don't have a huge opinion on it…it feels like a natural fluid process"* (cJ).

The Financial Decision Making Assessment (Suto et al 2007) was one of the new standardised assessments introduced in the changes of practice (see Section 7.5.3) and was used with participants with learning disabilities (A) and (J). The description in Section 8.4.1 by participant with learning disability (A)'s partner of this assessment showed, as with the AMPs in stage two, that the process of completing this standardised assessment was a memorable experience and did not appear to have been considered stressful.

The overall conclusions about how the identified problems in stage two were addressed in stage three are presented in Table 8.6.

Table 8.6: Findings of stage three in relation to problems identified in stage two

Problems identified from Stage two	**Changes in occupational therapy practice. Action Plan**	**Outcome: Summary of findings from stage three.**
Occupational therapy reports were often found to be too long and complex	To re-structure the referral process so that one referral need could be addressed at a time.	Occupational therapy reports were of appropriate length and content. One referral issue being addressed at a time ensured reports were clearer. However, there were some concerns that the occupational therapy was less person-centred and holistic.
Occupational therapy reports did not always meet the needs of all the recipients.	To implement an accessible format for making goal planning easier for people with learning disabilities to participate in and understand.	There was satisfaction with the occupational therapy reports. The occupational therapists worked to ensure that information regarding goal planning and interventions were appropriate for the people with learning disabilities and their carers. The reports and goal plans were not always accessible. There were fewer recipients of the occupational therapy reports.
Intervention was not always provided within the most appropriate time-scale.	To develop and implement a new referral to treatment flow chart in order to meet the 18 week target.	Occupational therapy was commenced in an appropriate time scale and the referral to treatment times improved. However, there were some concerns regarding completing occupational therapy too soon.
	To produce some packages of advice, tips and training that can be offered to carers as a first intervention prior to occupational therapy involvement.	The increase in training of support staff was considered positive to make sustainable changes. Tip and packages of advice were useful to provide a more responsive service but could not replace the occupational therapy assessment and intervention.
The expectation of occupational therapy was not clearly agreed by relevant stakeholders at the start of intervention	To agree the expected timescales for each typical referral need, so that the number of sessions could be more easily predicted and expectations could be outlined clearly.	There were some indications that participants with learning disabilities and carers were clearer about what to expect from occupational therapy. The OT co-researchers reported that it was useful to be aware of expectations and learn from each other's practices to set goal plans. However, there was a need to apply these timescales flexibly to ensure that the occupational therapist could respond to individual needs.
	To review the assessment packages used to ensure that all occupational therapists are aware of the current best practice.	The OT co-researchers were more aware of their assessment processes and what affects standardisation. There was an increase in the use of two standardised assessments. The need to adapt assessments to meet individual needs continued to be required. Innovative, flexible practice requires a high degree of skill and sharing of practices with occupational therapy colleagues. It was helpful to learn from peers and to check that any adaptations are appropriate. This flexible approach appeared to be the most acceptable practice for participants with learning disabilities and their carers.

8.6 Findings of the OT co-researcher questionnaires on the essential criteria for occupational therapy assessment

The essential criteria for an occupational therapy assessment for adults with learning disabilities were developed in stage one. At the end of stage one and the start and end of stage three of the action research fieldwork, any changes in the OT co-researchers' views on assessment as the fieldwork progressed were explored by asking the same question in the OT co-researchers questionnaires (see Appendix E). Table 8.7 shows examples of the responses from the three questionnaires and compares them to the essential criteria originally developed in stage one (Chapter 4, Table 4.5).

Two of the original criteria did not relate to any of the responses:

- **'Global skills'**
  Only the responses received in the first OT co-researcher questionnaire emphasised the importance of completing a full assessment of skills with each adults with learning disabilities. Over the course of the action research fieldwork, the local occupational therapists appeared to have become more focused on ensuring that their assessments were addressing the relevant needs.
- **'Fits with other assessment developments'**
  This criterion did not match any of the responses received over all three questionnaires. The local occupational therapists' initial perception that they needed to complete standardised assessments as a requirement of the professional body and to ensure that they were meeting evidence based practice was not indicated as an essential criteria by any of them throughout the action research fieldwork.

There was some variation in responses to the OT co-researcher questionnaires over the course of the action research field work which suggests that the OT co-researchers had been influenced by their reflections on the findings and other service developments in each stage. 'Client centred choice and empowerment' was consistently mentioned in the majority of responses and the comments were similar demonstrating that these appeared to be the criteria that were considered most important throughout the three questionnaires. Two criteria: 'highlight skills in order to make meaningful recommendations' and 'observation' had increased in the second questionnaire and remained high. For the following criteria: 'assess occupational performance', 'accessible, easy to use and understand', 'designed for

people with learning disabilities', 'practical, good use of resources', 'fit for purpose', and 'incorporate views of others', there appeared to be a pattern in which the responses were high for some of the criteria at the end of Stage one (2010), had dipped at the beginning of Stage three (2011) and increased again at the end of Stage three (2013). The process of making changes to practice, assimilating these into the OT co-researchers' work and reflecting on this over time may have resulted in some of the new insights remaining important and being sustained.

The essential criteria for an occupational therapy assessment that were developed in stage one of the action research fieldwork (see Table 4.5) were agreed by the local occupational therapists as their collective practice-based knowledge at the time. The extent to which these essential criteria were being followed in practice and how they were perceived were then explored across stages two and three. The findings were that the perception of the majority of respondents was that these essential criteria for occupational therapy assessment had been met.

Table 8.7: Findings on occupational therapy assessment across all three stages

Essential criteria of an assessment tool	**2010 out of 10**	**Examples of statements made by the OT co-researchers and lead researcher**	**2011 out of 8**	**Examples of statements made by the OT co-researchers and lead researcher**	**2013 out of 5**	**Examples of statements made by the OT co-researchers and lead researcher**
Assess occupational performance	5 50%	*"Focused on occupational performance".* *"Gaining a clear view of how activity/occupation fits into the person's world".*	1 12%	*"Focusing on "doing"*	2 40%	*'Important to focus on the task activity/occupation that is the referral issue but also need to gather information about the context.- holistic .* *Specialist assessments can be used to establish a baseline'.* *'Focusing on activity but also considering, Physical/social and cultural environment and how it impacts on occupation'.*
Global skills	2 20%	*"ADL tasks".*	0 0%		0 0%	
Highlight skills in order to make meaningful and useful recommendations	3 30%	*"The assessment identifies impact of diagnosis and environment on function and OT can develop clear recommendations".*	5 62%	*"For it to enable the OT to gather as much relevant information in as little time as possible in order to identify functional problems and intervention needs".* *"Clear findings.* *Clear recommendations* *Addressing the referral issue.* *Clear reason for assessment".*	3 60%	*'Gathering enough information to understand the impact of the context'.* *'Clear rationale for the assessment and time to complete it'.* *'OT focused, addressing referral need. Able to quickly establish issues and plan intervention.* *Provide clear helpful new knowledge about the person'.*

Essential criteria of an assessment tool	2010 out of 10	Examples of statements made by the OT co-researchers and lead researcher	2011 out of 8	Examples of statements made by the OT co-researchers and lead researcher	2013 out of 5	Examples of statements made by the OT co-researchers and lead researcher
Client centred/choice and empowerment	9 90%	*"Service user is at the centre of the process".* *"Explaining to the client how the assessment fits into their needs/wishes and ensuring they understand what they are being asked to do and why".* *"Client feels that his/her life has improved as a result".*	6 75%	*"Forming a therapeutic bond".* *Empathy for the situation".* *"Openness to help the situation".* *"Client focused".* *"Client /carers aware of and ideally agreeing to OT".* *"Time invested in building a rapport".* *"Motivation of client and carer".*	4 80%	*'Gaining client's consent'.* *'Communication between client /staff/family/carer'.* *'Consent . Working in collaboration with client (Client catered)' .* *'A rapport with client and carer's.*
Accessible easy to use and understand	6 60%	*"User friendly".* *"Appropriate communication techniques are used".*	2 25%	*"For the client to feel comfortable with the assessment process".* *"Clear assessment process"*	2 40%	*'Making assessments as accessible as possible'.* *'Accessible information'.*
Designed for people with learning disabilities	5 50%	*"Assessment is completed in the best possible environment".* *"Provided at a time that is relevant".* *"Being flexible".*	3 37%	*"Assessing in Familiar environment".* *"The right assessment for the referral reason".* *"Assessment is completed in the best possible environment".* *"Provided at a time that is relevant".* *"Being flexible".*	3 60%	*'Time- Finding more and more OT assessments are having to fit into client and carers time schedules which may mean early morning visits or after hours therefore need to be flexible to get relevant information'.* *'Working in a flexible way'.* *'A stable environment in which to undertake the assessment'.*

Essential criteria of an assessment tool	2010 out of 10	Examples of statements made by the OT co-researchers and lead researcher	2011 out of 8	Examples of statements made by the OT co-researchers and lead researcher	2013 out of 5	Examples of statements made by the OT co-researchers and lead researcher
Fit for purpose (reliable/valid)	8 80%	*"Gathering reliable information of purpose of assessment from all parties".* *"Gaining accurate information".* *"Therapist's own competence in completing the assessment".* *"Standardised".* *"Objective view of the circumstances".*	1 12%	*"Accurate assessment/standardised".*	2 40%	*'Gathering reliable information Using standardised assessments where appropriate'* *'Having a good report format to assist writing up/clinical reasoning.* *Using standardised assessment if appropriate'.*
Practical/ good use of resources	2 20%	*"Resources being available".* *"Preparation".*	1 12%	*"Able to access the client on a regular basis.* *Knowledge of the assessment tool being used".*	1 20%	*'Experience of using the assessment tool'.*
Observation	4 40%	*"Observation in different environments and times".* *"Ensuring that you actually see the person doing whatever is relevant to the assessment".*	5 62%	*"Being able to observe the client in their home environment".*	3 60%	*'Observation'.* *'Observational skills'.* *'Observation of a task (Just right challenge or observation of assessment reason)'.*

Essential criteria of an assessment tool	2010 out of 10	Examples of statements made by the OT co-researchers and lead researcher	2011 out of 8	Examples of statements made by the OT co-researchers and lead researcher	2013 out of 5	Examples of statements made by the OT co-researchers and lead researcher
Incorporate views of all people involved	5 50%	*"Getting the views of significant carers".* *"Have as many opinions from others who know the client as possible".* *"Good background information including access to assessments by other members of the MDT".*	3 37%	*"Writing for the audience".* *"Working in partnership with relevant others".* *"Other people's views (those who know the client)"* *"Good background information, including risk assessment".*	3 60%	*'Environment where the person being interviewed knows about the client's key needs'.* *'Gathering background information from different sources'.* *'Detailed background information – diagnosis, risk, previous input/assessments from OT and other professions'.*
Fits with other assessment developments.	0		0		0	

8.7 Review of the findings of stage three by the OT co-researchers

The initial findings from stage three were presented by the lead researcher to the OT co-researchers meeting in May 2013. The context of the local occupational therapy service had changed again in that the team had merged with a third borough and so the occupational therapists were adjusting to working with new colleagues who had developed their own processes for working.

The OT co-researchers all agreed that the changes to practice had been implemented. They questioned some of the findings about their use of the forms and processes (Tables 7.7 and 7.8) as they considered that they were using the new processes all of the time. One reflected:

> *"I wonder if we are not recognising, as we have been doing it so long, it's not new ways it's just <u>the</u> way?* (G) *Yes I agree"* (B).

This appeared to suggest that the changes to occupational therapy practice, one year later were now considered by the OT co-researchers to be their usual practice and met the principle of action research process that theory and practice had been internalised (Winter1996).

The OT co-researchers reflected on their experience of changing their practice (see Chapter seven). One reported that the need to use the RTT process initially felt like:

> *"It was breaking everything we do- traumatic- nobody wanted that scrutiny, no one wanted to change, we were comfortable, without doing" (I).*

This suggested that the action research had caused disturbance to practice which is a risk in this methodology (see Section 3.4.1). However, by this final stage the changes were perceived as having been positive. See Table 8.8 for some examples.

Table 8.8: Examples of the OT co-researchers' perceptions of the changes in practice at the end of the action research fieldwork

Change	*Examples of responses*
More responsive to referrals.	*"The main change is that we are more focused, don't look at all the other things in their life…. If they want something else, open a new referral for that"* (C).
	"we will do lots of things but set time scales for each piece of work" (G)
	"I think overall it worked how it should. Waiting list turn-around times have improved" (Q3).
Improved process of practice	*"Still provide good service but more effective" (I).*
	Actual client work has not changed massively but the process has" (G).
Changed practice	*"Financial assessments and doing more training of support staff"* (A).
	"I feel more confident going to clients knowing what I can realistically offer them" (C).

All the OT co-researchers agreed that they had changed their practice however they perceived that there continued to be inconsistencies across the team. Some of these were due to:

> *"differences in the boroughs, different types of clients and the reasons for referral are different"* (I).

Some of the findings from the perceptions of the participants with learning disabilities, carers and stakeholders were discussed. The positive responses regarding the use of the accessible goal plans were discussed but many of the OT co-researchers reported that they were not using these on a regular basis.

The collaborative critical review highlighted a split between some of the OT co-researchers who were feeling restricted in their practice by the need to keep to time scales and single referral issues, and the others who considered that they could still work flexibly within the structure of the new processes. This was illustrated by the following discussion:

> *"I think RTT makes us not as dynamic as we were before"* (B)… *"In the past we spent more time* [working with people] *as we lost track….I think we continue to be dynamic. If the reason for referral does not reflect what the client needs, we can still change this"* (I).

The OT co-researchers acknowledged an on-going struggle to meet the occupational performance needs of people with learning disabilities within limited resources whilst also having to demonstrate equity and consistency across the service to all clients. There was a discussion about how being more responsive to new referrals may have resulted in the OT co-researchers sometimes rushing to close cases without checking that they had met all the occupational performance needs. The subsequent discussion revealed that some of the OT co-researchers had been interpreting the RTT more rigidly than others.

At the end of the final OT co-researchers' meeting the local occupational therapy team made plans to review the timescales that they had agreed in 2011 for how long episodes of occupational therapy would take and to review the use of the accessible goal plans so that they could be used more frequently. The expectations regarding sharing occupational therapy reports were reviewed by the OT co-researchers to ensure that they were consistent and that the service policies were being followed. The occupational therapy changes had been sustained but practice was continuing to be reviewed and developed beyond the end of the action research fieldwork.

8.8 Reflections during stage three

The local occupational therapists had participated in the action research with enthusiasm across all three stages and reported positively about their involvement. The responses across all three OT co-researcher questionnaires suggested that their engagement was highest in stage two, when they were involved in the data analysis and the emerging themes, and in stage three, when they were taking the lead to decide on and implement changes to their practice.

At the start of stage three (Chapter seven), when the action research fieldwork was related to developing their own occupational therapy practice, the OT co-researchers were all keen to meet regularly and be fully engaged. Some commented on how the action research fieldwork had helped them to reflect on their own practice:

> *"I think it is feeding in well to the OT service development plans as it is focused on what the therapists are actually doing. It enables individuals to reflect on their practice and consider the findings and themes fed back to us from the research" (Q2)*

and:

> *"Makes me think about the work I'm providing in terms of speed, content, clarity of purpose, others' views, benefit for client and most of all what is important for the client. Every time we meet it gives me new ideas on how to improve" (Q2).*

The process of critically reflecting on the feedback, in the OT co-researcher sessions was perceived to have resulted in changes in individual practice. This indicated that the local occupational therapists were motivated to adapt and develop their practice taking into account the multiple demands and expectations on them. However, one response was more cautious:

> *"I think so. It's just that there is so much going on we've got commitments to do many projects" (Q2),*

This suggested that the demands on real world practice can sometimes prevent occupational therapists having the time to develop their practice.

The third set of OT co-researcher questionnaires was completed after the final meeting in which the findings of stage three had been discussed (Section 8.8). The OT co-researchers listed what they considered had supported their practice to develop during the action research fieldwork (see Table 8.9).

Table 8.9: Factors that supported the local occupational therapy practice development

Reflections on the perceptions of participants with learning disabilities, carers and stakeholders about occupational therapy practice.
Autonomy to make own decisions about practice changes.
The whole team working together.
Agreeing actions towards shared agreed goals.
Support from service managers that time could be allocated,
The structure of the meetings enabled discussion and reflections
Being allowed enough time to implement the actions and reflect on these.
The service demand to meet targets (RTT)
Having a stable staff team.

All except one of the respondents identified some areas that had been barriers to their occupational therapy practice development. The main one was the other service demands and commitments which limited the time to change occupational therapy practice. The need to meet targets (RTT) was seen by two of the OT co-

researchers as having prevented the focus of change to be on the occupational therapy concerns. This contrasted with most of the OT co-researchers who had considered RTT to be a positive driver for change.

All of the OT co-researchers stated that they were supported by the service to be involved in the action research. The changes to practice had been developed and owned by them collectively:

> *"We were given time for co-researcher sessions. We were encouraged to make the adaptations to our current practice to develop our "new ways of working" (Q3).*
>
> *"The research seemed to follow changes imposed on the team, for example… the use of RTT, and how we managed these. It allowed for time to think and reflect on our clients' experience of these changes and developments, through sharing the information gathered from the client and stakeholder interviews"* (Q3).

The collaborative critical review of practice had supported the occupational therapists to develop their practice-based skills and knowledge. This suggested that the principles of reflexivity (Winter 1996) had been met in this research study (see section 3.4.1).

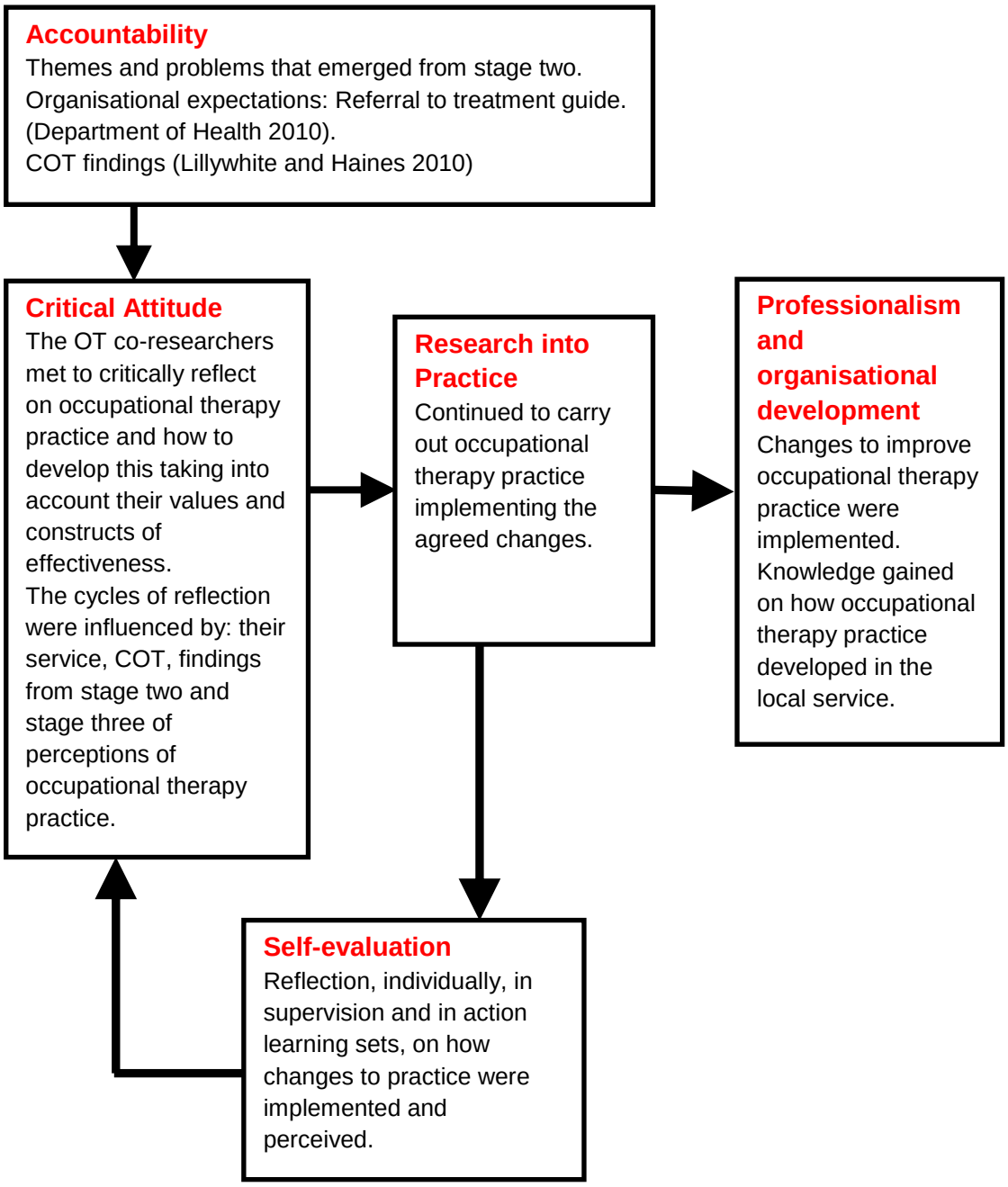
8.9 Summary

Stage three, (described in Chapters seven and eight) is summarised based on the CRASP model in Figure 8.1.

Chapter seven explored how the initial objectives of stage three were met. The OT co-researchers and lead researcher critically evaluated how the drivers for change (see Figure 8.1, box labelled Accountability) could be taken into account when considering their own professional reasoning and understanding of the needs of the local client group and context. The drivers for change were: the problems that emerged from stage two; the expectations from the organisation to rationalise waiting times; and the recommendations of the occupational therapy professional body recommendations about working with people with learning disabilities. The local occupational therapists identified the problems and used the three day workshop on changes in practice to plan how to address these. The process of putting these plans into action was monitored and reflected upon in the action learning sets and via the questionnaires about the forms and processes. The

adoption of the changes varied and there was, initially, some disruption to the service. The OT co-researchers expressed some anxiety as the new processes were assimilated into practice. After one year the responses from the OT co-researchers indicated that many of the changes to occupational therapy practice had been sustained and some of the forms and processes that initially caused them confusion had become familiar and were used as part of their normal practice.

Figure 8.1: Stage three illustrated using the CRASP Model of Action Research Zuber-Skerritt (1996)



Chapter eight has described how the second set of objectives for stage three had been achieved. Following the implementation of the changes in occupational therapy practice, the perceptions were sought from a new sample group of people with learning disabilities, their carers and others involved. The findings were that the occupational therapy assessments continued to be perceived as having met the essential criteria developed in stage one. Responses at stage three again indicated that occupational therapy practice was valued, it was provided in a dynamic context and the changes to occupational therapy practice were able to address the problems that had been identified in stage two.

At the final group meeting in May 2013, the OT co-researchers indicated that the changes were still being sustained. Some of the new processes that were not being carried out consistently across the team were identified and a plan was made to review these. This was to include a review of the format of the accessible goal plan and the number of sessions that would normally be required to address typical referral issues. Occupational therapy practice was therefore continuing to develop beyond the end of the action research fieldwork.

The findings of the action research fieldwork across all three stages are discussed in Chapter nine.

Chapter nine: Discussion

9.1 Introduction

This chapter critically explores to what extent the findings that emerged from all three stages of the action research fieldwork related to previous published research. Chapter One set out the thematic concern which underpinned this study which was the quest of the local occupational therapists to seek and generate evidence on which to evaluate and improve their local practice with adults with learning disabilities (Section 1.7). Chapter Two identified gaps in the literature in relation to the thematic concern and the research question (Section 2.6) and this study was formulated to address some of these. The research question arose from the thematic concern and was as follows:

What is the evidence that the local community occupational therapy service for adults with learning disabilities is:

(i) meeting the needs of adults with learning disabilities;

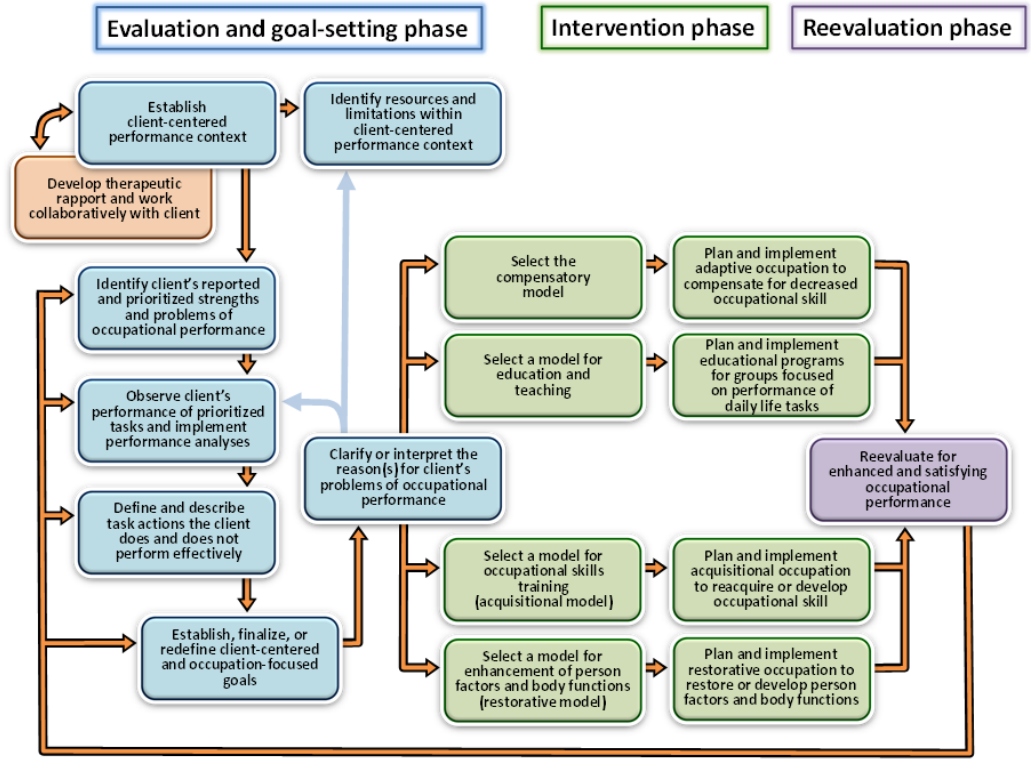
(ii) achieving the service objectives of the employer; and

(iii) meeting the expectations of the professional body (the College of Occupational Therapists) for evidence-based practice in line with the core principles for occupational therapists working with people with learning disabilities (COT 2003 and 2013a).

This chapter will consider the findings of this research study in the light of existing literature in the field (explored in the literature review [Chapter 2], validity and reliability when involving adults with learning disabilities in research [Section 5.2] and the literature on assessments [Sections 4.2 and 4.4.3]) in the context of each component of the research question.

The local occupational therapists adopted OTIPM (Fisher 2009) (see Figure 9.1 repeated from Section 2.3) as their conceptual model of practice following the discussions in stage one regarding the essential criteria for an occupational therapy assessment and the use of the AMPS (Fisher and Bray Jones 2010) (see Section 4.5). The extent to which the use of OTIPM as a client-centred occupation-focused conceptual model supported the local occupational therapists to articulate their professional thinking and influence practice decisions, as proposed by Duncan (2008) and Seymour (2011) is discussed in this chapter.

Figure 9.1: The occupational therapy intervention and process model (OTIPM) Fisher (2009)



Adapted from: Fisher, A. G. (2009). *Occupational Therapy Intervention Process Model: A model for planning and implementing top-down, client-centered, and occupation-based interventions.* Fort Collins CO: Three Star Press. (Revised June 2013)

9.2 Evidence on the extent to which the occupational therapy service was meeting the needs of adults with learning disabilities

The literature review (Chapter 2) revealed a lack of research on occupational therapy with adults with learning disabilities. In particular, there were very few studies which directly sought the views of adults with learning disabilities who had received an occupational therapy service. Chapters six and eight detail the findings on the perceptions of adults with learning disabilities and their carers across twelve data sets, in regards to their perceptions of their experiences of occupational therapy. As the thematic concern of the study was for the local occupational therapists to seek and generate evidence on which to evaluate and improve their practice, gathering these views was a central part of this research study. This was important as Kinsella and Whiteford (2009), Samuel and Wressle (2015) and Dougherty et al (2016) recommended that occupational therapy practice knowledge and evidence need to include the reports of clients, their carers and others involved

as to the effectiveness of the interventions they received. The National Learning Disability Professional Senate (2015), as described in Section 2.4.4, recommended that practitioners need to have personal contact with adults with learning disabilities so that their assumptions can be constantly challenged to ensure that their services are being inclusive. Obtaining the perceptions of adults with learning disabilities and that of their carers on the local occupational therapy service was an achievement in this study. The absence of data on the views of those who used the occupational therapy services was highlighted as a limitation in other studies in this field (Llewelyn 1991, Tannous et al 1999 Adams 2000 and Lillywhite and Atwell 2003).

9.2.1 The quality and trustworthiness of the data collected from adults with learning disabilities

There are challenges to obtaining the perceptions of adults with learning disabilities and in ensuring that this data are trustworthy in order to be able to use these as evidence of practice. Section 2.4.1 highlighted that, although adults with learning disabilities have the right to be invited to participate in research (DH 2013), historically they had been excluded from research due to concerns that they would not be able to contribute or would find the experience difficult or distressing. Most of the studies on occupational therapy and adults with learning disabilities described in Section 2.4.2 such as Francisco and Carlson (2002), Kottorp et al (2003a,b and c) and Hällgren and Kottorp (2005) omit the views of the clients. Even when adults with learning disabilities were interviewed, this was often limited to those with mild to moderate learning disabilities who were able to give consent (Melton 1998, Roeden et al 2011 and White and Mackenzie 2015) or they were jointly interviewed with carers (Urwin and Ballinger 2005, Finlayson et al 2014 and Ineson 2015) and so their unique perspective could have been missed.

This research study included participants with mild, moderate and severe learning disabilities as this reflected the levels of needs of the adults with whom the local occupational therapists worked in all of the twelve data sets. However, for two of the data sets the participants with learning disabilities could not be interviewed due to being at a pre-linguistic communication level. Unlike the assumptions cited in Section 2.4.1, all the participants with learning disabilities who were interviewed reported that they were positive about contributing to the research study and were ready and available at the planned time. None were observed to indicate being

distressed by the experience. As adults with learning disabilities have the right to be invited to participate in research (DH 2013), and in this research study the findings were that this was a positive experience, it would have seemed to be unethical to continue the practice of excluding them.

Prior to this research study, the local occupational therapists had not formally sought the perceptions of people who had experienced their service. In Stage Two of the action research fieldwork the local occupational therapists expressed reservations as to the ability of adults with learning disabilities to give appropriate feedback on their experiences of occupational therapy or even to distinguish between the interventions of different professionals involved (Section 5.3). This was similar to the findings in the study by Ball and Shanks (2012) who identified that occupational therapists are challenged to obtain meaningful feedback from adults with learning disabilities and suggested that this was due to the occupational therapists' lack of time, resources and skills (see Section 2.4.1).

The process of inviting participants to be interviewed and explaining the reason for the research and how it may affect them needed careful planning. However, the time to complete each interview process was under an hour and so not onerous. The use of face-to-face, semi-structured, interviews was found to be a useful method of gathering the data. The lead researcher was flexible during the interviews to respond to the participants if they were losing interest or needing to stop (see Section 6.4.1). With individual adaptations of the interview guide, all the participants with learning disabilities were able to provide at least one insight that was incorporated into this research study. This was a similar process to that recommended by Rogers et al 1998, see Section 2.4.1). Even though all the participants with learning disabilities who were interviewed had difficulties with understanding, retaining information and communicating, to various extents, they were all able to demonstrate that they had some understanding of the areas that had been addressed by occupational therapy. This finding that adults with significant learning disabilities can indicate preferences was also found by Mahoney et al 2016.

The concerns of the local occupational therapists and the wider national group surveyed in the study by Ball and Shanks (2012), that adults with learning disabilities may not be able to provide meaningful data, and that it was difficult to obtain data due to limited time, resources and skills, were not apparent in this study. It could be argued that the level of skills required to complete the semi-structured

interviews would be equivalent to those required by occupational therapists working with adults with learning disabilities using OTIPM to *'identify the client's reported and prioritised strength and problems of occupational performance'* (see Figure 9.1). Perhaps, the challenges in applying for ethical approval for studies that involve adults who may lack mental capacity, as described in this research study (see Section 3.6), may be a barrier to occupational therapists feeling enabled to complete research. When occupational therapists carry out research that relates to adults with learning disabilities, they therefore have a duty to ensure that they use methods that are accessible and to strive to remove barriers that might prevent the participation of people with learning disabilities.

There were some reservations regarding the validity of the responses of the participants with learning disabilities, particularly because they were all so positive (see Sections 6.2. 6.3, 8. 3 and 8.4) There were concerns that the responses were not valid as they could have been influenced by factors described by Gudjonsson and Joyce (2011) such as: suggestibility, acquiescence, compliance, or memory impairment as (see Section 5.2). However, in this research study, the interviews were conducted as described in Section 5.3.3.1 to, as far as possible, take these potential difficulties into account and to minimise the likelihood of these affecting the responses. The lead researcher and the OT co-researchers critically reflected on each interview during the OT co-researcher meetings to consider if any responses had been influenced by any of the factors and there was agreement that this was not likely to have been the case (see Section 6.4.1).

The study by Gudjonsson and Joyce (2011), for example, identified that adults with learning disabilities can provide unreliable information in situations, such as when they are being questioned by a police officer, in circumstances that are unfamiliar or uncomfortable and in which the questioning may be delivered to elicit specific responses. In contrast, the interviews in this research study took place in the participants' own homes at a time that they had agreed. Similar unpressurised settings and questioning were used in the studies by White and MacKenzie (2015), Finlayson et al (2014), and Ineson (2015) for example, in which adults with learning disabilities were interviewed using semi-structured interview techniques. There were no concerns raised in these studies in regard to unreliable responses. In this research study, the open questions at the start of the interviews elicited spontaneous positive responses about the occupational therapy experiences that

could not have been influenced by factors such as suggestibility and acquiescence as no leading questions were used (see interview schedule Appendix J).

There was potentially a concern that the responses may have been affected by the perceived need to be compliant (see Section 5.2) as the participants with learning disabilities were aware that the interviewer was from the same service as the occupational therapist with whom they had worked. This assumed that the participant would have understood that there was a connection and been concerned about giving negative feedback about someone that they no longer had any contact with as they were discharged from the service. Although, the majority of the responses were positive, participants were able to freely provide negative response without any apparent concern about how these might be received. For example: Client G describing the occupational therapy reports as 'boring' (see Section 6.3.3) and participant M placing a large cross next to the washing machine on his goal plan (see Section 8.5.2).

The responses to the closed questions, in regard to the essential criteria, were more of a concern as the majority of the answers to these questions were affirmative and so may have been influenced by a desire to be compliant (see Sections 6.2 and 8.3). A limitation of the design of the questions in regard to the essential criteria was that 'yes' was the desirable response. However if the wording had been changed so that a negative answer would be have been the desirable response, this would have potentially made the language too complex to be accessible for the participants with learning disabilities. The lead researcher did not ask all the questions due to the complexity of the concepts and because she judged that there was a lack of interest. The responses of the participants with learning disabilities were included in these findings but with some concerns regarding the trustworthiness of these. The concerns about memory impairment affecting responses (see Section 5.2) were not apparent in this research study as all the participants who were interviewed could recall their occupational therapy experience including the participant (I) who had a diagnosis of dementia and so was not expected to have been able to do so (see Section 6.3.1). These findings would suggest that semi-structured interviews, in which the questions are asked flexibly taking into account the concerns by Tassé et al (2005) and Gudjonsson and Joyce (2011) outlined in Section 5.2, were appropriate for eliciting the perceptions of adults with learning disabilities.

The OT co-researchers, at times, questioned the reliability of the findings due to their concerns regarding the communication difficulties of the participants with learning disabilities (as described in Section 6.4.1) but at the same time accepted the similar positive perceptions of occupational therapy from the carers and other stakeholders without such scrutiny. This appeared to be similar to the findings of Ball and Shanks (2012) (see Section 2.4.1) in which the occupational therapists they surveyed reported that they did not obtain feedback from the people they worked with due to concerns that the responses would be biased and not meaningful. However, the participants with learning disabilities in the studies by Mahoney et al (2016) and Ineson (2015) (see Section 2.4.1) were considered to have provided trustworthy responses. In this research study, although there were concerns regarding the trustworthiness of the responses to the questions regarding the essential criteria of the assessment, the responses in the semi-structured interviews were considered to be free from bias and clearly identified as related to their personal occupational therapy experience. It is, therefore, concluded that the views of the participants with learning disabilities offered in this research study were as trustworthy and meaningful as the views of the carers, stakeholders and occupational therapists. Dismissing these views could be considered discriminatory and the valuable insights obtained about occupational therapy would have been lost. Historically, people with learning disabilities have been excluded from participating in research studies but the findings from this research study were that all of the participants with learning disabilities who were interviewed were motivated to participate and their contributions were valued by the local occupational therapists. These contributions are discussed in Section 9.2.2.

9.2.2 How the adults with learning disabilities and their carers perceived the occupational therapy that they had received.

A key finding from this research study was that the participants with learning disabilities and carers, who were interviewed across the twelve data sets, were all able to identify the positive effect of occupational therapy on their occupational performance (Theme one: occupational therapy is valued, see Section 8.4.1). Occupational therapy was perceived to have made a difference to the lives of the participants with learning disabilities and had met their individual occupation-focused goals in a meaningful way (see Sections 6.3.1, 6.3.3, 8.4.1, and 8.5.2 for examples). As the responses of the participants with learning disabilities in the semi-structured

interviews were considered to be trustworthy as discussed in Section 9.2.1 this would appear to be evidence that the local occupational therapy service had addressed client-centred occupation-focused needs. The outcomes were perceived as *'enhanced and satisfying occupational performance'* which is the outcome expected when following OTIPM (see Evaluation phase in Figure 9.1).

Another finding in this research study was that the responses of the participants with learning disabilities clearly demonstrated that they were talking about their occupational therapy experiences. They were all able to recall what they had done with the occupational therapist and the lead researcher and OT co-researchers were often surprised by their understanding and insights (see Sections 6.3 and 8.4). The participants with learning disabilities perceived the role of the occupational therapists as distinct from the roles of other professionals or carers (see Section 6.3.1). However, some of the perceptions of the participants with learning disabilities were different from those of the occupational therapists. These included the following five examples:

Example 1: Participants with learning disabilities did not distinguish between the occupational therapist as a person and what he or she did.
When the participants with learning disabilities were asked about their perceptions of occupational therapy practice, many, instead, responded that they liked the occupational therapist (see Section 6.3.1). This could have been considered evidence that confirmed the local occupational therapists' concerns at the start of stage two that the participants with learning disabilities would not understand what had been provided by occupational therapy (see Section 5.3.1) as suggested in the study by Ball and Shanks (2012). However, the lack of distinction between the occupational therapists and their role does not necessarily indicate a lack of understanding of their occupational therapy experience. Rather that the participants with learning disabilities may have been identifying that the occupational therapists had uniquely enabled them to improve their satisfaction in completing the tasks and roles that they had chosen and that they wanted to do. It would appear that the participants with learning disabilities had valued the positive working relationship with their occupational therapists. This suggested that occupational therapy provided was person-centred and that being enabled to focus on occupational performance was something that they valued. In the study by Roeden et al (2011) (Section 2.4.1) it was found that a positive working relationship was a strong indicator of a positive outcome for intervention. The collaborative therapeutic

relationship is critical to OTIPM (Fisher 2009). This finding therefore, appeared to be evidence that the local occupational therapists had met the OTIPM expectation of 'developing therapeutic rapport and work collaboratively with the client' (see Figure 9.1). The primary outcome for occupational therapy as described by Fisher (2009) is achieving engagement in meaningful and purposeful occupation. Outcomes need to be considered in terms of satisfaction, engagement and occupational performance (COT 2015a). Tannous et al (1999), (see Section 2.2), recommended that outcomes should be related to the achievement of the person's goals but that it was also necessary to consider the quality of the therapeutic relationship, the person being empowered by the process and changes made to others' perceptions about the person with learning disabilities. Therefore, the findings that the participants with learning disabilities, and also their carers who were part of the client constellation, were positive about the occupational therapists, would suggest that their occupational–focused outcomes had been achieved.

Example 2: Participants with learning disabilities did not distinguish between occupational therapy assessment and intervention.

The findings suggested that the participants with learning disabilities and also their carers did not distinguish between assessment and intervention but instead considered this to be a continuous process (see Sections 6.3.1, 6.3.1 and 8.5.4). On some occasions, the local occupational therapist reported that they had not completed any intervention but had only provided an assessment such as an AMPS (Fisher and Bray Jones 2014) or the Financial Decision Making Assessment (Suto et al 2007). However, the participants with learning in the same data sets had reported how engaging with the occupational therapist in occupations in order to complete these assessments had improved their skills and enabled them to gain confidence in their abilities (see Sections- section 6.3.1 and 8.4.1). On these occasions, the occupational therapy assessment and intervention appeared to be occurring simultaneously. Perhaps the emphasis from the professional body on the importance of using standardised assessments (COT 2013b) meant that the focus of the occupational therapists had been on the assessment process and meeting the professional expectations, rather than reflecting on how the engagement in occupation had also been therapeutic. This may be an example of how professionals are not always able to articulate what they do and that the descriptions of practice do not fully encompass the multiple perceptions and tacit processes that are simultaneously being undertaken, as suggested by Schön (1991).

The joined up assessment and intervention across all twelve data sets was perceived by all the participants with learning disabilities and carers as a client-centred and relevant experience. The findings in this research study could imply that the act of engaging in occupations with the occupational therapist was perceived to make a difference to the participants' occupational performance skills and confidence. This finding appears to fit with the wider definition of occupational therapy assessment described by Laver Fawcett (2007) in Section 4.2 in which data are collected from different sources throughout the therapy process. Fisher (2009) also advocated that the assessment process in OTIPM (see Section 2.3) should use natural conversation and observation of occupation, rather than a rigid interview format.

The finding in stage two (Chapter six) that occupational therapy practice was not perceived by the participants with learning disabilities and their carers to be clearly delineated between assessment and intervention was considered as a turning point of the research study. It shifted the local occupational therapists' focus on assessment tools in stages one and two of the action research fieldwork (Chapter 4-6) to the wider review of the whole of their practice (encompassing assessment and intervention) in stage three (Chapter 7-8).

Example 3: Participants with learning disabilities did not consider reports to be important or relevant

The participants with learning disability had little interest in the occupational therapy assessment reports although some wanted these to be made more accessible for them to understand. The carers acknowledged that they were happy with the reports but did not consider they were as important as the occupational therapy intervention (see Sections 6.3.1). These findings influenced some of the changes in occupational therapy practice at the start of stage three (see Table 7.4) to have more emphasis on the use of accessible goal plans and reports in order to improve the collaborative, occupation-focused partnership. Following the changes there was evidence in Stage three that the local occupational therapists were sharing their reports and liaising with the adults with learning disabilities, their carers and other people involved in the client constellation (Section 8.4). However, out of the six data sets in stage three, the findings were that more work was required to make the reports accessible to the participants with learning disabilities and only one goal plan had been used (Section 8.5.2).

The lack of interest by participants with learning disabilities in the assessment reports may have indicated that they were unaware of the purpose of the assessment. White et al (2014) noted that obtaining informed consent of adults with cognitive impairments for using standardised assessments is a challenge (see Section 4.3.3). Section 5.3.2 has discussed the Mental Capacity Act (2005) and the challenges of gaining consent from adults with learning disabilities in relation to participating in research but these also apply to consent to assessment and intervention. However, the findings in this research study were that each of the participants with learning disabilities who had undergone a standardised assessment had actively participated implying that they had consented by their actions. They were able to recall their experience to some extent during the interviews although the level of detail varied (see Sections 6.3.1 and 8.4.1). This finding suggested that, unlike the occupational therapists, the participants with learning disabilities and their carers did not considered the report to be an intrinsic part of the assessment process.

The examples illustrate how the meaning of the occupational therapy process for some of the participants with learning disabilities had differed from the understanding of the occupational therapists who were working with them. The full extent of influence and outcome of the occupational therapy report may not be known by the occupational therapists who produced it and could continue to have an influence on the life of the adult with learning disabilities after the person had been discharged from occupational therapy. An example of this was that one family carer revealed that the occupational therapy report which had been intended to be useful for her daughter and wider family, was only important to her because it provided evidence of her daughter's disability to a benefits agency (see Section 6.3.3).The occupational therapists had not been aware of the clients' and carers' perspectives on the reports, They were completed as a professional and service requirement but provided an example of the need for professionals to have a collaborative and reflective relationship with the adults with learning disabilities and to make the professional experience meaningful and accessible as suggested by Roeden et al (2011)(Section 2.4.1).

Example 4: Participants with learning disabilities and their carers did not know how to access the occupational therapy service

In the twelve data sets none of the participants with learning disabilities and family carers had been aware of the occupational therapy service before they had received

it (see Section 6.3.2). Examples of this were: *"it's good you come back and tell us. You don't know what's out there"* (cM) and *"I did not know what the assessment was about and why we were being assessed"* (cG) (see Section 6.3.2). In stage three, two of the participants with learning disabilities needed to be re-referred to the service but had not done so prior to being interviewed for this research study (see Section 8.5.1). One of the key elements of this research study was the inclusion of the views of carers as recommended in the studies by Bowey et al (2005) and McDougall et al (2014). The carers' views provided a new perspective for the local occupational therapists on the accessibility of the service to adults with learning disabilities. In the study by Bowey (2005) carers felt excluded by professionals. In this research study the findings suggested that the local occupational therapy service could have been denying access to adults with learning disabilities and carers because making a referral depended on having a knowledge of the service, the ability to identify occupational performance related needs and the ability and confidence to be able to make a request for it. This would suggest that the local occupational therapy processes had been set up for access by other professionals rather than for participants with learning disabilities and their carers. This is further discussed in Section 9.3.2.2.

Example 5: The participants with learning disabilities and their carers had different perceptions of occupational therapy.

In this research study valuable insights were gathered from nine family and paid carers (see Tables 6.2 and 8.2). Carers were interviewed separately from the participants with learning disabilities, whenever possible, in order to ensure that the responses were not influenced by each other's presence (see Section 5.3.3). Two participants with learning disabilities were interviewed in the presence of their carers (I see Chapter 6 and M see Chapter 8) due to their difficulties with understanding and communication but even in these circumstances separate interviews were conducted. The findings were that all the participants with learning disabilities contributed different insights to those of their carers (see Section 6.3.1.1 and 8.4). This was in contrast to the studies by Urwin and Ballinger (2005), Finlayson et al (2014) and Ineson (2015) where joint interviews were conducted and there was no distinction made between responses of each interviewee.

The suggestion by Law et al (1994) that carers can complete the Canadian Occupational Performance Measure (COPM [Law et al 1994]) on behalf of people with cognitive impairments (see Section 4.2) implied that both parties would have

the same perspectives of their occupational performance needs. The findings of this research study were that there were differences in the understanding and the perspectives between the client and the carers on what was important to them. Examples of these were Participants with learning disabilities (G) and (M) who stated their occupation performance goals which were contrary to their mothers' expectations (see Sections 6.3.1 and 8.5.2). Therefore, clearly distinguishing between the perceptions of the participants with learning disabilities and their carers in regards to their goals was important as it enabled the occupational therapists to understand the motivators and barriers to occupation. This strengthens the case for occupational therapists to directly obtain the views of adults with learning disabilities on their occupational performance goals rather than solely listening to carers or making assumptions. Despite some differences, findings showed that the responses from the participants with learning disabilities and their carers were more similar to each other than they were to the responses from the professional stakeholders and the occupational therapists within each of the data sets (see Section 6.3.1).

Section 2.4.1 identified the limited studies on the perceptions of carers of adults with learning disabilities. The study by McDougall et al (2014) explored the impact of the caring role and the importance of the carer's needs being met to enable them to continue to meet the needs of the adult with learning disabilities. In this research study, examples of when occupational therapy had direct impact on carers in completing their role include: one family carer implied that she considered herself as having been assessed alongside her daughter (see Section 6.3.2) and a house manager considered that her staff team had benefited from the occupational therapy training and intervention (see Section 8.5.3). This suggests that in this research study the occupational therapists were considering the carers as part of the client constellation and were enabling them to make their own occupational performance changes to enable the person they care for to address his or her needs (see Figure 9.1). Therefore, the perceptions of the carers should be acknowledged as well as the participants with learning disabilities in order to work in collaboration with them, as recommended when using OTIPM (Fisher 2009, see Section 2.3). The occupational therapists appeared to have addressed the different needs of the participants with learning disabilities, carers and also the other professionals as the findings indicated that occupational therapy was valued (Theme 1 Section 8.4.1). This was a similar finding to that of Pawson et al, (2016) (see Section 2.4.4) who identified the need to liaise with various people who had different levels of expertise and remits when addressing referrals. It is, therefore, vital to involve all relevant

stakeholders in the referral chain to ensure that occupational therapy can be adapted to the specific needs of the adult with learning disabilities within the client constellation so that the outcomes can be sustained.

The findings on the perceptions of the participants with learning disabilities were that they all considered that occupational performance needs had been addressed although, for some in stage three, there were some unmet needs identified during the interviews with participants with learning disabilities and carers (this is discussed in Section 9.3.2). The five examples illustrated in this section of how occupational therapy was perceived by the participants with learning disabilities and the carers challenged the occupational therapists' assumptions about their practice. These findings were significant as only one of the published studies reviewed in the literature (see Section 2.4.2 (Melton 1998) obtained the perceptions of adults with learning disabilities and none considered the perceptions of their carers regarding their experiences of occupational therapy practice. The results of the OT co-researchers' questionnaires at this time indicated that there was an increased emphasis on the importance of prioritising the views of their clients and carers when they listed the essential aspects of occupational therapy practice over the expectation to use standardised assessments (see Section 7.3). This meets with expectation of OTIPM (Fisher 2009) to establish the client performance context in a flexible person-centred way (see Section 2.3). This was an example of how the insights from the participants with learning disabilities and their carers affected the local occupational therapists' perceptions of their practice and the direction of the research study. Therefore, the responses of the adults with learning disabilities and their carers (Sections 6.3 and 8.4) challenged the local occupational therapists to ensure that they were focusing on meeting the occupational performance needs that were relevant to each individual and meeting the recommendations of the Learning Disability Professional Senate (2015) to be inclusive (see Section 2.4.4).

9.3 Evidence on the extent to which the occupational therapy service met the employing organisation's objectives

Mortenson and Dyck (2006) suggested that occupational therapy practice is influenced by complexities of the professional interactions, policies and resources of specific settings (see Section 2.4.4). The evidence that the local occupational therapists were meeting the expectations of their employer to provide a multi-agency

service for adults with learning disabilities in the local community is discussed in this section. Establishing this evidence was a challenge during the action research fieldwork as the employing organisation's expectations were constantly changing due to: service reconfigurations; the publication of new legislation and policies; and an increased need to manage resources efficiently (see Section 7.1 and Appendix A).

In this section, the extent to which the local occupational therapy service met the expectations of the professionals in the wider multi-agency services is first discussed. Then how the service met a specific employer expectation in regards to waiting list management. Finally how the occupational therapy practice was affected by the employing organisation's expectations.

9.3.1 The extent to which the local occupational therapy service met the expectation of the wider multi-disciplinary professionals

The findings of the perceptions of the participants with learning disabilities and their carers discussed in Section 9.2, were important in this research study, however, Kinsella and Whiteford (2009), Samuel and Wressle (2015) and Dougherty et al (2016) all recommended that occupational therapy practice based evidence also needs to include the reports of others involved (see Section 2.5). In this research study forty professional stakeholders were identified as being involved in the occupational therapy practice across all twelve data sets but only seventeen of them participated in the research study (see Table 8.4).

Adams (2000) and Atwell and Lillywhite (2003) (see Section 2.4.1), identified that professionals working with adults with learning disabilities have a lack of clarity as to their understanding of the role of occupational therapy in this field. In contrast a finding of this research study was that, like the participants with learning disabilities and their carers (see Section 9.2.2), the professional stakeholders clearly distinguished the role of the occupational therapists from those of others. The professional stakeholders perceived the local occupational therapists to be essential contributors to the multi-agency assessment and intervention for adults with learning disabilities (see Section 6.3.2 and 8. 5.1). These findings provided evidence that within the twelve data sets the local occupational therapist met the COT expectation in that they were perceived to have *'a unique occupational role and perspective'*

(Principle 1 COT 2013a). In this research study all the participants were asked about their perceptions of a specific experience of occupational therapy, rather than in the studies by Adams (2000) and Atwell and Lillywhite (2003), which sought the more general view of the role of occupational therapists working with adults with learning disabilities. In this research study there was an understanding of the occupational therapy role within a specific context. However, as occupational therapy is a complex intervention (Creek 2003) it would not be expected that professional stakeholders would be able to clearly define all the aspects of the role of occupational therapy in general. It should be noted that a limitation of this research study was that the occupational therapy practice in each of the twelve data sets was selected as outlined in Section 5.3.2 to ensure that the focus was on occupational therapy and not generic team roles. Therefore, the unique occupational role may have been more prominent in the twelve sample data sets than another sample selection which may have included more examples of occupational therapists carrying out more generic team roles

In contrast to the participants with learning disabilities and their carers (see Section 9.2.2), the professional stakeholders did distinguish between assessment and intervention. They valued the occupational therapy report as it provided unique information about the participants with learning disabilities. All of the professional stakeholders stated that the occupational therapy reports of assessment findings and recommendations were trusted, relevant and useful (see Table 8.5). The local occupational therapists appeared to have focused their formal reports to address the referral issue which was often the concern and expected outcome of occupational therapy for many of the professionals, whilst the actual occupational therapy intervention of engaging in activities were more important for the clients and carers (as discussed in Section 9.2.2). This met with the expectation of OTIPM that the therapeutic occupation is the primary means of occupational therapy and engagement in meaningful and purposeful occupation is the primary outcome (Fisher 2009 Section 2.3).

As discussed in Section 9.2.2, the main sources of referrals to the local occupational therapy service in the twelve data sets were health and social care professionals rather than the person with learning disability and his or her carer. The local occupational therapists' professional practice was based on OTIPM (Fisher 2009) and addressed the occupational-focused goals of the adult with learning disabilities but also needed to address the referrers' agendas (see Sections 6.3.2.1 and 8.4.2).

An example of this was in data set E when the referral had been triggered because two of the professional stakeholders had different understandings of participant (E)'s skills and abilities and how much support he required. The occupational therapy assessment and intervention that had been perceived to have addressed both the participant with learning disabilities' occupation-focused goals and also clarified his support needs for the two professional stakeholders although this was more positively received by one than the other (see Section 6.3.3). The findings in this research study were that the local occupational therapists were able to meet the majority of the perceived needs of the multiple professional stakeholders who responded in each data set. This seemed to be a similar finding to the study by Pawson et al, (2016) (see Section 2.4.4) which identified the complexities of managing referrals when there are different motivations and expectations and motivations.

The findings of Theme 2 (Occupational therapy was provided in a dynamic context, see Section 8.4.2), suggested that the local occupational therapists collaborated across complex health and social care systems. The local occupational therapists were seen as being skilled at working in complex situations and able to clarify processes (see Section 6.3.2). In stage three, following the changes in practice, there had been some reduction in complexity of the occupational therapy intervention. However, the findings revealed that the occupational therapists had continued to be valued as being able to facilitate the participants with learning disabilities and carers to understand and engage with health and social care services. This met the National Learning Disability Professional Senate (2015) recommendation that multi-agency community learning disability teams across health and social care should be seamless and joined up and demonstrate effectiveness of the team for individuals with learning disabilities and their families (see Section 2.4.4). The local occupational therapists as members of the multi-agency services for adults with learning disabilities therefore, met the expectation that *'occupational therapists should work collaboratively with others to meet the needs of people with learning disabilities'* (Principle four: COT 2013a) (see Table 1.2). However, as not all the professional stakeholders responded it is not known if they would have had a different perspective than those who were motivated to respond.

9.3.2 The extent to which the local occupational therapy service met the employing organisation's expectation to improve waiting times to access the service

One of the key areas for research recommended by the COT review (Lillywhite and Haines 2010) was the need to gather evidence of the impact of service expectations on the quality of occupational therapy interventions in learning disability services (see Table 2.1). This was identified as a gap in the literature (see Section 2.4.4).

In stage three (Chapter 7), the changes to occupational therapy practice were implemented to meet the demands imposed by the employer to meet 'referral to treatment' targets RTT AHP (DH 2010) and also to address the problems identified from the findings in stage two. Following the changes to practice, the findings were that the local occupational therapists met their employer's objectives to improve waiting times for their service (see Section 8.5.3).

The aim of RTT AHP (DH 2010) was to improve clients' experiences and quality of care, although in the local service, the employing organisation did not ask for any feedback as to how the change had impacted on the adults with learning disabilities, their carers or other aspects of the inter-agency pathway and system. There were no expectations to report on the length of wait for subsequent appointments or how long clients remained open even though these aspects had also been made more efficient as a result of the changes in occupational therapy practice. It, therefore, appeared that the employing organisation was satisfied that the objective of satisfying a national requirement had been met but otherwise did not closely monitor the local occupational therapy practice.

The review of the implementation of RTT AHP (DH 2011) recommended that decisions about implementing waiting list management systems should be based on professional judgement and consultation with all involved. The findings of stage two were that the adults with learning disabilities and the carers did not indicate any concerns about how long they had waited for occupational therapy services. Most were satisfied with the duration of the occupational therapy intervention, although some would have preferred this to have been longer. The concerns raised in regards to the response time to referrals in stage two of the action research fieldwork were from professional stakeholders or the occupational therapists themselves (see Sections 6.3.3). Following the changes in practice, the findings in stage three were that no concerns were expressed by any of the respondents about

the speed of the response of occupational therapy to referrals (see Section 8.5.3 and Table 8.6). It was therefore, assumed that professional stakeholders' concerns about the time to respond to referrals had been addressed by the new process.

The expectation that improving the speed of response to the referrals would support the delivery of high quality care (Transforming Community Services DH 2010) was not always reflected in the findings in stage three of the action research fieldwork (see Section 8.5.3). The study by Pawson et al (2016) in relation to waiting list management in primary care health services for the general population, had similar findings to this research study in that changing the response times had unintended consequences and affected other parts of the inter-agency system that were not always beneficial (see Section 2.3.4). Achieving a balance between occupational therapy principles and employer targets was a major challenge for the occupational therapists. McSherry and Warr (2006) (see Section 2.4.4) stated that practice development provides a challenge to ensure the maintenance of equity, quality and effectiveness, rather than just improving efficiency (see Section 2.4.4). The following findings highlighted some negative impacts of applying RTT AHP (DH 2010) in the local occupational therapy service:

9.3.2.1 Improved efficiency of referral pathway became a barrier to client-centred practice and resulted in some occupation performance needs not being met

One of the problems identified in the findings of stage two was that the expectations of occupational therapy were not always clear at the start of intervention (see Table 6.9). The occupational therapy assessment and intervention often addressed complex and multiple needs at the same time, as the local occupational therapists continuously addressed each new concern as it arose (see Table 7.5). This was a general finding across all responders in the data sets in stage two and could have been due to the different expectations from the referrers and the participants with learning disabilities as discussed in Section 9.3.1.

In stage three, the local occupational therapists met AHP RTT (DH 2010) requirements and worked to improve the efficiency of their interventions by focusing on one referral issue at a time. Clarifying each referral pathway was helpful in explaining the process to the adults with learning disabilities, carers and other stakeholders. This resulted in reducing the length of the occupational therapy intervention and the reports and freed up time for the occupational therapists to

address new referrals. However, by addressing each issue separately, holistic, person centred practice appeared to have been missed. Two of the participants with learning disabilities and carers in stage three identified unmet occupational performance needs following their discharge from the service (participants M and K Section 8.5.1). This had not previously been noted as a finding in stage two. The lack of clarity of expectations identified in stage two was not reported as a negative by the participants with learning disabilities and their carers, as they perceived that the occupational therapists had addressed appropriate concerns. This could be an indication of client centred working.

By focusing on single referral issues, it seems that the occupational therapists' person-centred occupation-focused practice using OTIPM (Fisher 2009) had been affected by the demands of the employing organisation to provide evidence of meeting RTT AHP (2010). This tension between the need to reduce costs but also to provide a person-centred service was a similar finding to that of the study by Pawson et al (2016) (see Section 2.4.4). Although the OTIPM (see Figure 9.1) does acknowledge the need to *'identify resources and limitations within the client-centred performance context'* (Fisher 2009, p92) working to time limits and on single issues appeared to restrict the occupational therapists' flexible, holistic and person-centred approach.

The OT co-researchers reflected, within the action learning sets in stage three (see Section 7.5.3), that not all of their work could fit neatly within a planned pathway for a single occupation-focused concern, as there would always be a need to provide multi-agency, flexible support to meet complex needs. The focus on just one aspect of occupational performance in isolation was similar to the studies on occupational interventions such as those completed by Wennberg and Kjellberg (2010), Applegate et al (2008) Green et al (2003) and Urwin and Ballinger (2005) (see Section 2.4.2). The conclusion of Section 2.4.2 was that many of the studies described were restricted to a narrow aspect of occupational therapy and did not take into account the perceptions of adults with learning disabilities who had experienced this. The holistic quality of occupational therapy and the messy real world of practice (Schön 1991) were not fully acknowledged.

9.3.2.2 Waiting list management did not increase accessibility to the service for adults with learning disabilities or their family carers

A finding from stage two in the action research fieldwork was that the local occupational therapists continued to work with adults with learning disabilities for long periods of time, addressing new referral issues as they arose. This appeared to prioritise the needs of the adults with learning disabilities with whom they were currently working rather than the unmet need of others who are waiting for a service. In stage three, the changes to occupational therapy practice to meet RTT AHP (DH 2010) were made to reduce the duration of occupational therapy interventions so that resources could be made available to address the needs of the people on the waiting list (see Section 7.5).

One of the reasons for waiting list management systems was to provide an equitable service for all. McSherry and Warr (2006) and Pawson et al (2016) suggested that the demand for health services in the United Kingdom has increased as patients became more knowledgeable about what interventions were available and their expectation to be offered choice. RTT AHP (DH 2010) was a national initiative for all allied health professionals working with any client group within the NHS. However, the findings in this research study, were that the participants with learning disabilities and their family carers had not been aware of the local occupational therapy service prior to the referral being made on their behalf and so none had requested a service. In stage three it was found that even after having a positive experience of occupational therapy, the participants with learning disabilities and their carers did not refer themselves for a service when new needs arose (see Sections 8.5.1 and 9.2.2). The finding in this research study that some occupation performance needs had not been met was only discovered when the participants with learning disabilities were interviewed. This lack of initiative to seek support was similar to the findings by Mencap (2014) (see Section 2.4.1) that adults with learning disabilities are unlikely to complain about their service. However, two participants with learning disabilities (G) and (J) were able to say that they knew how and when they could request an occupational therapy service if they needed to in the future (see Sections 6.3.3 And 8.5.4). This suggests that supporting adults with learning disabilities and their carers to be empowered to be able to re-refer to the service is possible and important to meet the COT practice principle to promote recognition of occupational therapy (COT 2013a Principle 6).

These findings indicated that waiting list management designed for efficiency and rationalisation of services could become a barrier for adults with learning disabilities and their family carers and challenged the assumption that the service was person-centred. This suggested that there was a need for the local occupational therapists to support people with learning disabilities to identify their occupational performance concerns, to generate new referrals for them and to explain clearly to them and their carers how they could ask for help in the future. The local occupational therapists were seen as people who could clarify the complexity of the multi-agency system and facilitate connections with others who may be a helpful resource for the person with learning disabilities (Theme 2 see Section 8.4). This appeared to be similar to the 'advocacy' role that was suggested as a key role of occupational therapists working with adults with learning disabilities in the study by Llewellin (1991). This role is required to ensure that adults with learning disabilities are able to access services in a fair and equitable way.

If the employing organisation's expectation is that the occupational therapists need to rationalise their resources by managing their waiting lists, the role of supporting new referrals could be considered to be in opposition to this expectation. However, whilst not providing a timely service may have resulted in some short term saving of resources, it could have resulted in costing services more if placements had broken down or other crises had occurred. The concern was that too rigid an adherence to the organisational demand to meet a waiting list target, could potentially exclude some of the most vulnerable people. This appeared to be an example of a concern raised by the National Learning Disability Professional Senate (2015) which was the need to be aware of service-led practices that may be creating 'problems' (see Section 2.4.4).

There was an expectation, on the part of the employer, that responding to referrals in a shorter time scale would promote excellence in practice. McSherry and Warr (2008) stated that excellence in practice is rarely achieved due to ever-changing factors (see Section 2.4.4). An improvement in quality was not apparent in the findings from this study. On the contrary, the change in practice appeared to be detrimental with regard to enabling access to the service for the most vulnerable people. The outcomes of implementing RTT AHP in the local occupational therapy service appeared to contradict the recommendations of the National Learning Disability Professional Senate (2015) which were that professionals working with adults with learning disabilities needed to critically review their practice and take into

account the feedback of people who access the service to ensure that their practices are inclusive (see Section 2.4.4) so that *'Person-Centred Practice and individual service design should be at the heart of the commissioned and provided specialist community learning disability health team practice'* (National Learning Disability Professional Senate 2015, p7). Although the focus of RTT AHP (DH 2010) may have been person-centred in its original intention (DH 2010), the local implementation had focused more on how to address an expectation of the organisation. Therefore, the person-centred care had not been the primary focus of this practice development as recommended by McSherry and Warr (2006) (see Section 2.4.4).

9.3.2.3 Increase in speed of response to the referrals made by professional colleagues resulted in a reduction in collaborative working

As the local occupational therapists were striving to complete their interventions more efficiently so that they could respond to new referrals their interactions with other professionals reduced. In stage three of the action research fieldwork, fifteen professional stakeholders were identified as being involved in the client constellation as compared to the twenty-five identified in stage two (see Table 8.4). Although the data in the two stages cannot be directly compared and may have been a naturally occurring variance, the size of the reduction was unexpected as the sample selection had been similar in both stages. This finding could have been for a number of reasons. The changes made to occupational therapy practice resulted in less time and flexibility to complete multi-disciplinary or multi-agency work. This was because multi-disciplinary work increased the complexity of the intervention and would have prevented meeting RTT targets. The local occupational therapists were no longer keeping clients' cases open long enough for other professionals to be able to complete collaborative work. Only working on one specific issue at a time resulted in the occupational therapists producing short summary reports. The issues addressed were not relevant to as wide a group of professionals as the previous complex reports and the occupational therapists did not share them as widely. The reduced sharing of reports was noted despite the findings in all data sets of stage two that the professional stakeholders valued and expected to receive the occupational therapy report. This diminished the occupational therapists' compliance with the COT practice principle four that occupational therapists should collaboratively work with others (COT 2013a, Table 1.2). The local occupational therapists changed from using profession specific hard copies of notes (in stage two) to a shared electronic health records in stage three (see Section 8.3). Although

shared records, in theory support collaborative working, in this research study, the individual health professionals within the same employer were no longer receiving a copy of the report as they were expected to read it on the system. However, this did not make a difference to other professional stakeholders such as social workers, clinical psychologists, psychiatrists or General Practitioners as there were not shared records across the different agencies. The local occupational therapists took note of the findings from the data sets and reviewed their practices to improve their collaborative working, but as this was beyond the end of the action research fieldwork, there are no data as to the effect of these changes (see Section 8.7).

The focus on waiting list management in this study, imposed by the employer, appeared to have meant that the local occupational therapists did not take into account the whole multi-agency service as would be expected in practice development (McSherry and Warr (2006) see Section 2.4.4). The local occupational therapists reflected on their initial experience of implementing the changes in practice in the action learning sets (described in chapter 7). They then met in the final OT co-researcher meeting (see Section 8.7) to reflect on the findings from the data sets in stage three and made plans to ensure that their future practice is client-centred and there is effective communication and collaboration with all stakeholders involved.

9.3.3 How meeting employer objectives impacted the local occupational therapists' practice

During stage three of the action research fieldwork the local occupational therapists implemented RTT AHP (DH 2010) which improved the clarity and efficiency of their response to referrals and more parity of what was offered by the individual occupational therapists. However, the findings that the needs of some of the participants with learning disabilities had not always been fully met and there had been a reduction in collaborative working with other professionals, would suggest that health service emphasis on establishing clear care pathways was not always compatible with the occupational therapy person-centred approach.

In the action learning sets the local occupational therapists collectively reflected on their experiences of changing their practice to be more focused on single referral issues and following standard pathways of practice in order to meet the RTT AHP

(DH 2010) expectation. Some were confident that they could do this whilst continuing to base their practice on OTIPM (Fisher 2009). However it was initially challenging for others (see Section 7.5.3). The latter occupational therapists were supported by others in the action learning groups to understand how to apply RTT AHP (DH 2010) more flexibly so that their practice met the principles of OTIPM (Fisher 2009) principles. Following this reflective discussion, the OT RTT flow chart was adapted to include how the OTIPM process could be implemented at each stage (see Appendix M). However, even though these discussions and reflections took place in the action learning sets prior to the selection of the six data sets in Stage three, the findings from the data sets suggested that, at times, the focus on RTT AHP had adversely affected the occupational therapy practice.

At the end of the action research fieldwork, the local occupational therapists again reflected on whether their practice and professional reasoning had been too focused on the need to meet RTT AHP rather than being directed by OTIPM (Fisher 2009) (see Section 8.7). This was an example of how the employing organisation's emphasis on RTT AHP (DH 2010) had affected the quality of the occupational therapy practice. Through these discussions, the occupational therapists developed their understanding of how multiple referral issues could still be addressed but needed to be identified as separate referrals. The occupational therapists then needed to make judgements about whether referrals should be addressed simultaneously or at a later date. Some occupational therapists were able to manage this new approach more easily than others. The local occupational therapists continued to critically review and reflect on their practice individually and with each other. At the final OT co-researcher meeting when the findings of stage three were discussed the occupational therapists reflected on how the changes in practice had been initially disruptive but now they had become assimilated into their practice and they were now able to manage the various referral issues as separate goals but were more able to manage multiple issues at the same time (see Section 8.7).

The findings that emerged across the action learning fieldwork suggested that occupational therapy practice could not all be captured in structured processes. The local occupational therapists would reflect on an experience or a new insight and immediately apply this to their practice in a reactive, innovative and creative way. The complexities of occupational therapy practice to address individual occupation-focused needs in partnerships within a multi-disciplinary agency could not always be

addressed in set timescales or by addressing referral issues one at a time. The occupational therapists needed to be skilled at managing the complexity of the wider system whilst ensuring that the people with learning disabilities and their carers were supported to understand what this meant for their specific situation. Despite the identified complexity there was almost universal positivity from the respondents about how the occupational therapists were able to incorporate the relevant views of all people involved and be effective: 76% in Stage Two and 94% in Stage three (see Table 8.5).

At the final OT co-researcher meeting the service employer expectation to complete AHP RTT (DH 2010) was noted as a significant event in the action research fieldwork. However, the local occupational therapists were split as whether this had been a driver or a barrier to developing their practice (see Section 8.8). It was considered by the local occupational therapists as a barrier to the development of their practice as initially, it took precedence over the need to address the problems that had been identified by the action research fieldwork (see Sections 7.2 and 7.3). Even though the local occupational therapists had the findings from stage two of the action research fieldwork which indicated that the existing way of delivering the service was valued (theme 1) and no concerns had been expressed from the participants with learning disabilities as to the speed of their response to referrals, they were not able to use this information at the time to prevent these changes being imposed. This could imply that the local occupational therapists were not able to remain autonomous and make their own professional decisions as they needed to react to management-led directives. This could be an example of how, as suggested by Upton et al (2014) described in Section 2.4, the demands of real-world occupational therapy practice can be a barrier to maintaining a focus on evidence-based practice.

However, when the local occupational therapists met at the end of the action research fieldwork (Section 8.8) they acknowledged that the expectation to apply AHP RTT (DH 2010) was an opportunity to also address the problems raised in stage two of the action research fieldwork (see Table 6.9). Although the expectation to complete RTT was imposed by the employing organisation, the local occupational therapists had the autonomy to decide how this would be done in practice. The AHP RTT expectation was a driver for practice development as it provided an opportunity for the local occupational therapists to take time out of their practice to plan how to meet their employer organisation's directive. This would suggest that demands

made by the employing organisation although challenging and initially disruptive were also useful in promoting critical reflection on practice. The action research methodology based on CRASP (Zuber-Skerritt 1996) used in this research study was adaptable enough to enable the research study to incorporate the complexity of the real world practice.

The study by Kinsella and Whiteford (2009) (see Section 2.4.4) suggested that, if service expectations are different from the values of the occupational therapists, they find subtle ways to maintain their professional autonomy without direct confrontation and so service policies are either accommodated into occupational therapy practice or actively resisted. In this research study, the local occupational therapists were motivated to change their practice to meet the expectation of the employer. However, as the local occupational therapists reflected on the impact of introducing RTT AHP (DH 2010) they adjusted their practices using their professional judgement to ensure that they could continue to meet the occupational-focused needs of their clients. It could be argued that the local occupational therapists provided the employing organisation with enough information on RTT AHP (DH 2010) that meant that they had fulfilled the expectation but perhaps were less open about the subtle adjustments and multiple referral issues that had been used to enable practice to remain occupation focused. This may have been due to the complexities and constant changes in the services and the time it took to fully embed changes into practice, there was limited opportunity for the local occupational therapists to feedback to managers as to how their expectations had affected adults with learning disabilities. By the time the change had been implemented, new demands for change were already being requested and so the agenda had often moved on.

The findings of this research study were that organisational changes and demands did affect the local occupational therapy practice. As recommended by Lillywhite and Haines (2010) (Section 2.3.4), the occupational therapists took responsibility to lead on developing their practice rather than accept and follow the demands. The local occupational therapists were able to respond to the need to provide a service within a shorter time scale. However, during the initial implementation process of the changes to their practice, the local occupational therapists needed to ensure that their primary focus was client and occupation centred guided by OTIPM (Fisher 2009), rather than being led by organisational or professional agendas.

9.4 Evidence on the extent to which the occupational therapy service met the COT expectations for evidence based practice in line with the core principles of practice for people with learning disabilities (COT 2013a)

This section discusses the extent to which the local occupational therapy practice met the expectations of their professional body. The findings that relate to the COT eight core principles for occupational therapists working with people with learning disabilities (COT 2013a) as described in Table 1.2 and repeated here as Table 9.1 are discussed throughout this chapter. Principles 1, 3, 4, 6 and 7 have been discussed in Sections 9.2 and 9.3 in which the local occupational therapists were found to be meeting these principles from the perspective of the participants with learning disabilities, carers and professionals. The remaining core principles: assessment (Principle 2) and outcome measurement (Principle 5) are discussed in this section. Professional skills (Principle 8) are discussed in Section 9.5.

Table 9.1: Eight core principles for occupational therapists working with people with learning disabilities (COT 2013a)

Principle 1	Occupational therapists should provide a unique occupational role and perspective
Principle 2	Occupational therapists should assess the impact of the person's learning disability on their occupational performance.
Principle 3	Occupational therapists should offer interventions to people with learning disabilities that focus on engagement in occupation and enabling independence.
Principle 4	Occupational therapists should work collaboratively with others to meet the needs of people with learning disabilities.
Principle 5	Occupational therapists should measure the outcomes of occupational therapy interventions for people with learning disabilities.
Principle 6	Occupational therapists should promote recognition of occupational therapy with people with learning disabilities.
Principle 7	Occupational therapists need to creatively respond to the impact of health and social care policy on occupational therapy with people with learning disabilities.
Principle 8	Occupational therapists need to develop skills to work with adults with learning disabilities.

9.4.1. The extent to which the local occupational therapy service met the COT Core Principle 2 on assessment

The initial driver for this research study was the expectation from the occupational therapy professional body that *'standardised assessments should be used wherever possible'* (COT 2003, p3) by occupational therapists working with adults with learning disabilities. The occupational therapists in the local community practice wished to find, or develop, a standardised assessment which they could use to assess the needs of people with learning disabilities and evaluate the effect of occupational therapy intervention. Stage one of the action research constituted this search for a suitable standardised assessment (Chapter 4). During stage one, the occupational therapists reflected on their experience of using assessments in practice and from this developed the essential criteria for occupational therapy assessment when working with adults with learning disabilities in the local service (Table 4.5). Although many published occupational therapy assessment tools were subsequently identified that could be used with this client group (see Appendix G) no single assessment was considered to meet all of these essential criteria. The findings from stage one were that the flexible and person-centred nature of occupational therapy with adults with learning disabilities was not very amenable to standardisation.

The literature on occupational therapy assessments explored in Sections 4.2 and 4.4.3 revealed that it was predominantly the perspectives of occupational therapists that were considered. Consequently, this research study broadened the focus to include the perspectives of adults with learning disabilities, their carers and other professional stakeholders in regard to their experiences of the local occupational therapy assessments. The initial intention of the research study was to develop a new assessment but, as discussed in Section 9.2.2 and 9.3.3, the findings did not indicate that participants, other than the occupational therapists, had concerns with the existing assessment process.

The findings of this research study were that the local occupational therapists used non-standardised assessments in all of the twelve data sets. These consisted of an initial assessment based on OTIPM (Fisher 2009) and other non-standardised assessments. Two standardised assessments were used in stage two: AMPS (Fisher and Bray Jones 2014) was completed in five out of the six data sets; and in stage three: the Financial Decision Making Assessment (Suto et al 2007) was used

in only two out of the six data sets (see Tables 6.3 and 8.3). The reason for this reduction in standardised assessment in the data sets in stage three could have been because the local occupational therapists were asked to identify participants with learning disabilities with whom they had used the changes in occupational therapy practice (see Table 7.5). The AMPS (Fisher and Bray Jones 2014) was not considered to have been one of these changes and so the absence of these in stage three was not considered to be a significant finding.

A finding discussed in Section 9.2.2 was that the participants with learning disabilities and their carers did not appear to distinguish between assessment and intervention within the overall occupational therapy interaction. Even when completing a standardised assessment, participants with learning disabilities reported that they perceived this process as developing their skills. These findings raise the question as to whether or not the theoretical distinction between assessment and intervention actually existed in the reality of the local occupational therapists' practice. Unsworth (2000) as well as much of the occupational therapy literature on assessments set out in stage one (Section 4.2) highlighted that assessments are distinct entities from intervention and are used to measure performance at the start and end of intervention. OTIPM (Fisher 2009), as illustrated in Figure 9.1, clearly describes the distinct phases of evaluation, intervention and re-evaluation. Findings showed that in contrast the participants with learning disabilities and their carers, the professional stakeholders and occupational therapists themselves clearly distinguished between assessments and interventions. The professional stakeholders appeared to value the assessment findings within the reports but had little comment in regards to the occupational therapy intervention when this was described (see Sections 6.3.3, 8.5.1, 9.3.1). The assessment findings presented in the reports appeared to be for the benefit of other professionals rather than of benefit or interest to the participants with learning disabilities (see Sections 9.2.2 and 9.3.1). The need for reports to be accessible to adults with learning disabilities had been highlighted in the findings of stage two but the situation had not significantly changed in the data sets in stage three (see Section 8.5.2). This may have been due to the occupational therapists still considering that the assessment findings were more relevant to the professionals who usually triggered the referrals for the service, than the participants with learning disabilities. However, the expectations of meeting the requirements of RTT AHP (DH 2010) to reduce waiting times, may have meant that the local occupational therapists did not prioritise the time to also produce an accessible version of the report (see Section 8.7). Although

the occupational therapy assessment reports were not directly accessible to people with learning disabilities, sharing of these with other professionals was intended to support collaborative working for the benefit for the adults with learning disabilities.

The local occupational therapists' awareness and knowledge of published standardised assessments developed over the period of the action research fieldwork. The variety of assessment tools available to the local occupational therapists increased but the adoption of these tools in practice continued to be low, with the exception of the AMPS (Fisher and Bray Jones 2014) and the Financial Decision Making Assessment (Suto et al 2007) (see Sections 4.5.1, Stage one and 7.5.3, Stage three). The responses from the final OT co-researchers' questionnaires suggested that the local occupational therapists' perception was that standardised assessments were only used when appropriate (see Table 8.1). New standardised assessment tools were used by the local occupational therapists only if they were perceived to be useful in assessing and addressing the occupational performance needs of the person with learning disabilities with whom the occupational therapist was working. It was also important that there was support from occupational therapy colleagues when learning to apply new assessment tools to the local practice and to reflect collaboratively on the feasibility of using them. Developing their understanding of assessment tools supported the local occupational therapists to review their practice even when they decided that a tool could not be adopted within the team.

The essential criteria for occupational therapy assessment developed by the local occupational therapists were perceived by the majority of respondents to have been met across all twelve data sets (see Sections 6.2 and 8.3 and Table 8.5). These findings were that the local occupational therapy assessment processes were occupation-focused and person centred which would be expected if the conceptual model of practice, OTIPM (Fisher 2009), was being used. This would suggest that there is some evidence that OTIPM was influencing the local occupational therapists' practice decisions. The occupational therapy assessments fitted with the findings of Parkinson et al (2009) in that the occupational therapists working with adults with learning disabilities were found to be occupation-focused (see Section 2.3.1). This was in contrast with the study by O'Neal et al (2007) which found that occupational therapists working in the field in the United States of America were not basing their practice on theories.

The assessments were trusted and clarified the impact of the participant's learning disabilities on his or her occupational performance (see Table 8.5). Although the majority of the occupational therapy assessment findings were from non-standardised assessments, none of the responders were interested in a detailed explanation of the process or justification of how these conclusions were made. They just wanted to be informed of the outcome of the assessment which they accepted and valued as they found this information to be useful and relevant to the lives of the participants with learning disabilities. The majority of respondents agreed that the occupational therapy assessments met the essential criteria for assessment: 'highlight skills in order to make meaningful and useful recommendations' (see Table 8.5). As stated in Section 4.4.3, this closely matches the broad purpose of assessment defined by Laver Fawcett (2007) which is to use the findings to make decisions throughout the therapy process (see Section 4.4.3). This would suggest that rather than using standardised outcome measures of performance before and after specific intervention to demonstrate change as set out Unsworth (2000), the responses from the participants with learning disabilities and their carers were that the occupational therapy assessments, using this flexible non-standardised assessment approach, were appreciated (see Sections 6.3.1 and 8.5.1). The initial view that a single standardised assessment tool could be developed for occupational therapists to use when working with adults with learning disabilities was questioned by the local occupational therapists at stage one (Section 4.4.2) and not found to be important from the feedback from the participants who had experienced occupational therapy in stages two and three.

The essential criteria for assessment developed in stage one (Table 4.5) were found to be consistently identified by the OT co-researchers in each of the OT co-researchers questionnaires which were completed three times during the action research fieldwork (see Section 8.6). The OT co-researcher questionnaires indicated that providing person–centred choice and empowerment was consistently scored the highest of the essential criteria for assessment by the local occupational therapists (see Table 8.7). The expectation of the profession that occupational therapists use standardised assessments (COT 2013b) appeared to conflict with the local occupational therapists' positive experiences in practice when they were working in a person centred, flexible way to support the achievement of the individual's occupation focused goals. Occupational therapists, therefore, need to have the expertise and skills to address complex issues, by prioritising their professional reasoning skills when applying and considering the findings of a range

of assessment tools including both standardised and non-standardised, to meet individual need. The exploration of the literature in Section 4.3.3 and the findings from this research study would suggest that person-centred occupational therapy working with adults with learning disabilities across a wide range of needs on their own occupation-focused goals could not be addressed by a single standardised assessment tool. This flexible approach to understand the client-centred performance context, from client led conversation and observations, is advocated by the author of OTIPM (Fisher 2009) (see Section 2.4.1).

The findings of this research study were that the use of standardised assessments could not encompass the complete holistic nature of occupational therapy intervention or all the assessment needs within the local service. The recommendation by Laver Fawcett (2007) (see Section 4.2), reproduced in the COT position statement on standardised outcome measures (COT 2013b), is that non-standardised measures can have a potentially negative impact on clients and the credibility of the professional. However, it could also be argued that this would be the case if occupational therapists used standardised assessment inappropriately. Standardised assessments should only be used with adults with learning disabilities if they are easily understood, made accessible to meet the individual's communication needs, person centred, directly relevant to the person's occupational performance goals and do not restrict occupational therapy professional reasoning using OTIPM (Fisher 2009). A single standardised assessment tool for all adults with learning disabilities cannot meet all of these requirements.

Fisher (2009) does advocate the use of occupational therapy standardised assessments such as the AMPS (Fisher and Bray Jones 2014). Fisher (2009) and Hawes and Houlder (2010) recommend that occupational therapists working with adults with learning disabilities need to have flexibility to decide on a wide range of assessment tools (see Section 4.4.3). The College of Occupational Therapists regularly updates the list of published tools (COT 2014) as new assessments are developed (see Section 4.4.2). The occupational therapy profession therefore appears to continue to search for the perfect assessment. This constant need for new assessment tools appears to be a result of the continuous development of practice and is perhaps an acknowledgement that tools will never fully meet the needs of all the diverse client groups that occupational therapists work with. The occupational therapy profession continues to emphasise the need to use standardised assessments (COT 2013b) and the lack of standardised assessments

accessible to adults with learning disabilities was identified as a research gap (Lillywhite and Haines 2010) (see Table 2.1). However, it is unclear how the evidence based practice agenda that appears to be privileged by the professions can be aligned with the individualised care agenda promoted by the Learning Disability Professional Senate (2015) building on the expectations of 'Valuing People' (Department of Health 2001).

This finding that non-standardised assessments could be appropriate in some circumstances when working with adults with learning disabilities agreed with other studies cited in Section 4.4.3 (Blount 2007, Goodman and Locke 2009 and Lillywhite and Haines 2010). Goodman and Locke 2009, Holmqvist et al (2009) Koh et al 2009 were concerned that a standardised outcome measure would be unlikely to encompass the holistic nature of occupational therapy intervention or provide good clinical governance. Non standardised assessments will always be used, as the local occupational therapists continually assess throughout their practice. The most commonly used assessment tools in the local service were locally produced such as the specialist assessment adapted to follow OTIPM (Fisher 2009).

9.4.2 The extent to which the local occupational therapy service met COT Principle 5 (outcome measurement)

The COT Core Principle 5 concerned the need to demonstrate the effectiveness of occupational therapy interventions with people with learning disabilities (COT 2013a Principle 5 see Table 9.1). The expectation of the professional body was that occupational therapists should measure the outcome of their interventions using standardised assessments (COT 2013b). This research study explored different ways, both quantitative and qualitative, of evaluating the effect of occupational therapy interventions with adults with learning disabilities. The findings were that standardised assessments to measure the outcomes of intervention were of limited use in this field and that qualitative, non-standardised approaches were often more relevant and useful in practice.

Much of the literature on occupational therapy interventions (see Section 2.4.2) focused on the effectiveness of a specific occupational therapy intervention for example: Applegate (2008), Kottorp et al (2003c) and Unwin and Ballinger (2005). In these studies, a baseline measure of the person's abilities was completed and this

was compared following occupational therapy intervention. These studies only considered a narrow aspect of the occupational therapy intervention and only considered outcomes from the perspectives of the occupational therapists. In contrast, in this research study, as recommended by the studies by Kinsella and Whiteford (2009), Samuel and Wressle (2015) and Dougherty et al (2016) feedback was collected from all those involved to evaluate all aspects of occupational therapy practice.

The responses in all the data sets suggested that occupational therapy practice and its outcomes were valued. However, there were some indications that the participants with learning disabilities and their carers often had differing perspectives of their experience of occupational therapy practice which would only partly match the occupational therapists' understanding of their practice and its outcome. These findings challenged the assumptions that the occupational therapists involved in each data set were aware of all that had been achieved by their interventions and may also imply that the positive outcomes were not as a direct result of occupational therapy. There could have been many reasons why the feedback provided in the interviews were different from the local occupational therapists' understanding. The participants with learning disabilities and their carers may not have been asked these specific questions, they may not have been able to express themselves to the occupational therapists that they had been working with. However, as discussed in Section 9.2.2, the participants with learning disabilities indicated that they had good relationships with the occupational therapists. As the occupational therapists were not contacting the adults with learning disabilities, carers or other stakeholders after the person had been discharged, they may not have fully understood how their practice had been perceived or the long-term sustainability of their intervention. This would appear to agree with Unsworth (2000) who suggested that gains may continue after leaving the service (see Section 4.2).

The occupational therapists, using OTIPM (Fisher 2009), were working in a collaborative partnership with adults with learning disabilities to develop their skills. Therefore, the occupational therapist was not in a control but rather in a facilitator position, empowering the person to be confident to develop skills. Although some of the outcomes reported as being achieved as a result of the intervention had not been directly intended by the occupational therapists, this does not mean that they were not a result of the collaborative enabling partnership between the adult with learning disabilities, the occupational therapist and others involved.

The occupational therapy professional focus on assessment and intervention as distinct entities (see Section 9.4.1) may have been to meet the evidence based practice agenda of demonstrating a difference between the assessed baseline and the status at the end of intervention. However, as discussed in Section 9.2.2 the act of engaging the participants with learning disabilities in occupations during an assessment appeared to alter the perceptions of the participants with learning disabilities' confidence in their skills, and possibly their abilities. Therefore an occupation-focused assessment perhaps can never be considered as a 'true' baseline assessment as the act of doing changes the person (Creek 2003 and Yerxa 2014 see Section 2.2).

Another finding of this research study was the challenge in setting occupational therapy goals with the participants with learning disabilities in an accessible way. It was noted, in stage three, that although one of the changes in practice was to use accessible goals plans, the local occupational therapists were not always using them (Section 7.5.3 and, 8.5.2). It was often not possible to set goals at the initial stage due to the need to first, fully assess the situation and the context. The participants with learning disabilities were not always clear at the start of the intervention as to what goals they wanted to achieve. Often it would be only after experiencing working towards a goal and being encouraged to persevere at this, would they know if they wanted to do that activity. At the early stages of intervention, there would often be adjustments and changes in plans before the goals could be agreed. Some goals were designed to be worked on over time, beyond when the occupational therapy sessions were completed. Others were achieved immediately for example the provision of a simple strategy or advice. In stage three of the action research fieldwork, when the occupational therapists focused on one referral issue at a time, it increased the clarity of what could be expected from their intervention, and these goals were identified and achieved more easily. However, as has been discussed in Section 9.3.2, there were also concerns that too much focus on one specific referral issue can mean that other needs were not always met. Therefore, measuring if occupational performance goals have been met is not a straightforward process.

The findings in this research study agreed with those of Unsworth (2000) as described in Section 4.2. She suggested that occupational therapy outcomes cannot be easily separated from what was provided by others in the multi-agency service. It

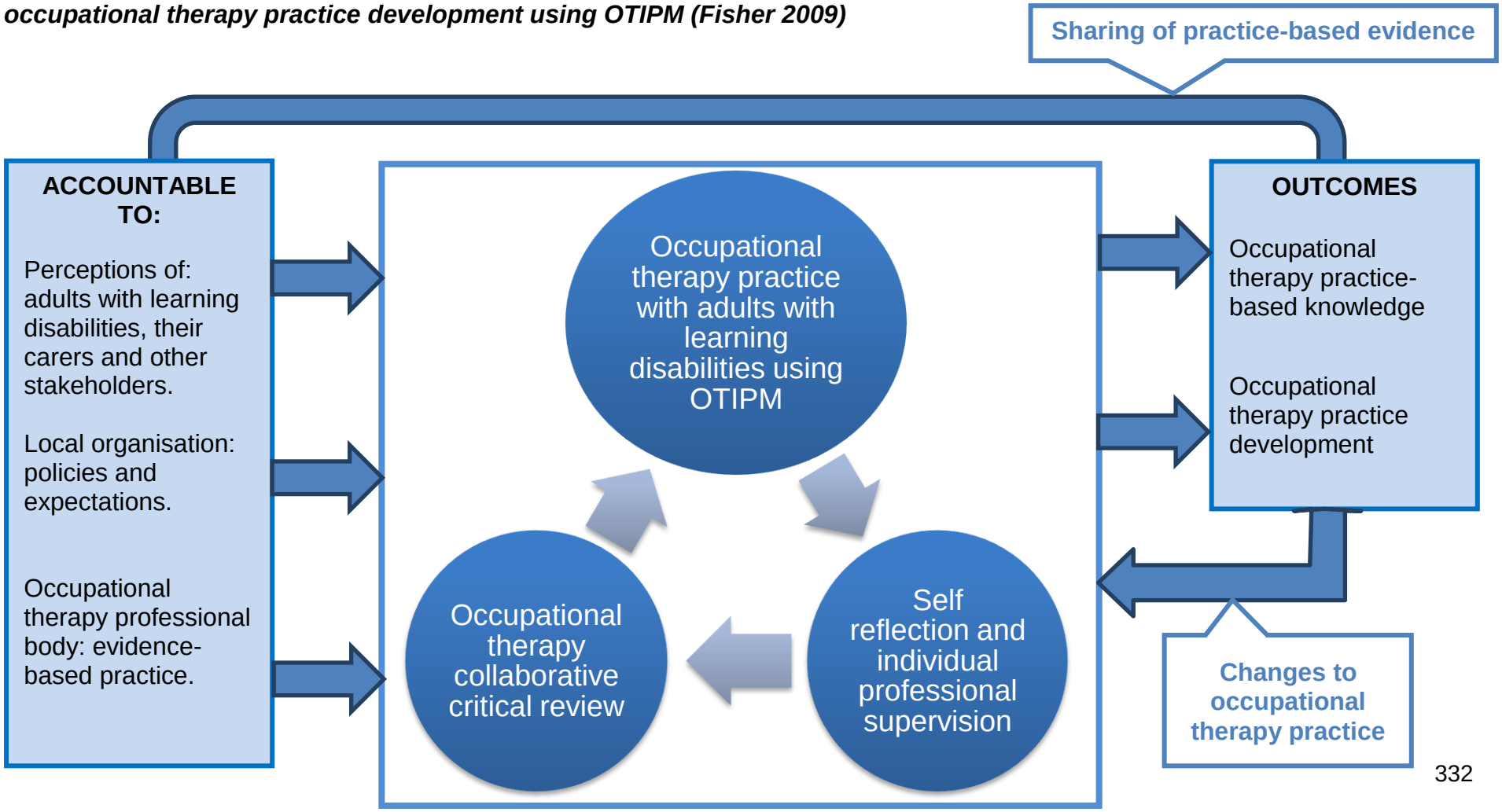
is also difficult to separate occupational therapy intervention from other factors that may have influenced any outcomes or changes. It was acknowledged that occupational therapists provide intervention to address wider needs in relation to maintaining quality of life, restriction of social roles and to enable full participation in all aspects of daily life. However, these complex constructs are difficult to measure.

In the local service, the multiple perceptions, on-going and collaborative nature of the occupational therapy outcomes could not be measured by quantitative methods (as discussed in Chapter three) that solely considered improvement of one specific occupation performance aspect. Instead, the CRASP (Zuber-Skerritt 1996) methodology was used in this research study to gather a wider, more holistic and encompassing multiple perspective of occupational therapy outcomes.

9.5 Managing change and developing practice

In Chapter one, Figure 1.2 listed the factors that were assumed at the start of this research study to influence the local occupational therapy practice. At the start of the research study, it was not known if this list was complete, how significant each of the factors would be and how each interlinked to affect practice. The action research methodology based on the CRASP (Zuber-Skerritt 1996) model has been used to explore how the various factors influenced the development of occupational therapy practice during the action research fieldwork and is summarised in Figure 9.2. This chapter has discussed how the local occupational therapists were accountable to adults with learning disabilities and their carers (Section 9.2), the employing organisation and wider multi-agency team (Section 9.3) and the expectations of the occupational therapy profession (Section 9.4) in the action research fieldwork. The local occupational therapists responded to these expectations and demands whilst continuing to develop their practice individually and as a group. This process is represented by the central square in, Figure 9.2, which contains three circles representing the continuous cycles of occupational therapy practice development in the action research fieldwork.

Figure 9.2: The whole action research study illustrated by the CRASP Model of Action Research (Zuber-Skerritt 1996) and occupational therapy practice development using OTIPM (Fisher 2009)



The three processes of: occupational therapy practice; self-reflection and collaborative, critical review were constant cycles completed by each of the local occupational therapists throughout the action research fieldwork (see Chapters four to eight). New learning, from these critical collaborative reflections, was then applied by the local occupational therapists directly when working with the adults with learning disabilities. However, the dynamic nature of the local occupational therapy practice and how it developed was a challenge to observe and record in the action research fieldwork. These findings agreed with those of Creek (2003), Reagon et al (2010) and Boyt Schell and Schell (2008) regarding the complexity and uncertainty of occupational therapy practice due to the need for multiple decisions and actions. The local occupational therapists' direct practice was not observed as this was not the remit of this study, but even if this had been attempted, it would still be expected that much of their professional reasoning would still be difficult to recognise due to its intuitive and spontaneous nature. However, some examples of reflecting on practice using professional reasoning based on the aspects of reasoning described by Boyt-Schell and Schell (2008)(see Table 2.2) have been suggested in the reflective summaries at the end of each of the action research fieldwork stages (see Sections 4.6, 6.4, 7.6 and 8.8).

Titchen and Ersser (2001) and Blair and Robertson (2005) (see Section 2.5) claim that practice based knowledge can be validated by a process of engaging in critical reflection that includes reflexivity, introspection, collaboration, problem solving and transformation with colleagues to reach a consensus. During the action research fieldwork, the local occupational therapists were able to make explicit some of their tacit knowledge and professional reasoning processes, based on OTIPM (Fisher 2009), that they had developed during their practice. These were explored within the OT co-researcher group meetings and agreed as shared practice-based knowledge. Examples of these were: the development of the essential criteria for assessment in stage one (see Table 4.5) and the new forms and processes developed by the occupational therapists as part of the changes in occupational therapy practice at the start of stage three (Chapter seven).

The local occupational therapists' new forms and processes that were developed as part of the changes to occupational therapy practice appeared to be more easily adopted by the local occupational therapists than published standardised assessments. The new forms and processes were not considered to be assessments but strategies that had been developed from practice as they had

been found to be useful. These usually encompassed the whole occupational therapy process of assessment and intervention guided by the principles of OTIPM (Fisher 2009). They provided guidance for approaching a typical occupation focused goal including how many sessions an intervention would be expected to take. The local occupational therapists used these as a tool to support their own clinical reasoning. These were used flexibly so they could be adapted to meet each individual's unique occupational performance concerns and circumstances.

The occupational therapy practice-based knowledge then underwent multiple cycles of action, reflection, listening to the perspectives of others and modifying their practice over time. New experiences were reflected on by the local occupational therapists in order to consider how these related to their existing practice-based knowledge and values. . Being reflexive, using the six principles of Winter (1996), enabled the local occupational therapist to address conflicting perspectives and lack of clarity in order for practice to change. The essential criteria for assessment and the new forms and processes could, therefore, be considered as examples of the professional reasoning processes that had been developed in the local service as a result of years of practice, and critical collaborative reflection now made explicit as their collective practice-based knowledge. Theory and practice could be seen as having been internalised (Winter 1996 see Section 3.4.1) in that the local occupational therapists practice had been refined into theory and then transformed practice in a continuous process. The findings of this research study were that the local occupational therapy practice, using the essential criteria for assessment and the forms and processes, was considered to be effective by people with learning disabilities, carers and others in the client constellation as well as by the occupational therapists.

The perceived emphasis from the occupational therapy profession on the need to use published research evidence may have resulted in some of the local occupational therapists not valuing the expertise within their own service. However, even though the evidence-base for using the locally devised forms was not considered to be robust by the local occupational therapists, they used them within practice without expressing any concerns and the take up of these was greater than more formal published assessment tools. It could be argued that the forms and processes are supported by robust practice-based evidence which had been built up by repeated experiences of occupational therapists addressing similar occupational performance concerns and critically reflecting on these within the occupational

therapy team. This was similar to the process of developing practice based evidence as described by Dougherty et al (2016) (see Section 2.4.2) These were then shared, assimilated into practice and collectively critically reflected upon by the local occupational therapists.

Hitch et al (2014) proposed that occupational therapists need to have a wider view of sources of evidence on which to base practice. Both the new forms and processes and the essential criteria for occupational therapy assessment, could be considered practice based knowledge that has been validated as proposed by Titchen and Ersser (2001) (see Section 2.5) in that the local occupational therapists reached a consensus from engaging in critical reflection and discussion. The evidence was synthesised from multiple perspectives and applied by the occupational therapists, using professional reasoning as suggested by Kinsella and Whiteford (2009). There was a continuous process which used both internalised evidence from the occupational therapists' collective knowledge base and evidence gathered from each specific intervention as suggested by Dougherty et al (2016). The local occupational therapy practice-based knowledge developed from the on-going action-reflection cycles is not a static entity. Instead, this knowledge continues to be shaped and modified by the local occupational therapists with each individual adult with learning disabilities with whom they worked.

Some traditional researchers would appear to dismiss evidence generated in this way as not being a legitimate base for practice. For example, concerns were expressed in regards to occupational therapists developing 'home-made' assessment tools (Swee Hong et al 2000), or relying on colleagues as sources for decision making (Upton et al 2014). However, other researchers recommend that occupational therapy practice-based evidence can be generated from rigorous and relevant reflective practice (Blair and Robertson 2005, Higgs and Titchen 2001, Kinsella and Whiteford 2009 and Dougherty et al 2016).

The occupational therapists in the local service appeared to be sharing their practice knowledge and learning together continuously within the professional development meetings, OT co-researcher meetings, action learning sets but also in other informal settings as practice experiences were shared. This was a continuous process of dynamic knowledge creation in which all the local occupational therapists contributed and supported each other's development to ensure that the quality of practice in the whole service could be maintained. This was similar to how McSherry

and Kell (2007) suggested that practice development is used to generate evidence from practice which is then used to continually add innovations (see Section 2.5).

The eighth core principle for occupational therapists working with people with learning disabilities (COT 2013a Table 9.1.) is that occupational therapists need to develop the skills to work with adults with learning disabilities. The local occupational therapists supported the development and sharing of practice-based knowledge and skills to benefit each other throughout the action research fieldwork (described in Chapters four to eight). This process of informal learning based on practice experience was proposed by Bezzant (2008) as being effective at sustaining change. The findings in stage three also influenced practice (see Section 8.4) that continued beyond the end of the action research fieldwork. This research study, therefore generated evidence on how the local occupational therapy practice developed over time. Like the study by Morley (2007)(see Section 2.5.1), the local occupational therapists benefited from critical reflection from their colleagues for their professional development, although in this research study this was considered beneficial for occupational therapists of all levels of experience, rather than just those who were newly qualified.

The action research fieldwork was not initially intended to be an in-depth exploration of professional reasoning but these findings emerged due to the inductive nature of the action research methodology. Therefore, the data collected on how the local occupational therapists were using and developing their professional reasoning during the action research fieldwork were not explicitly sought or recorded and so there were limitations in how data collection was completed. It has been acknowledged that it is a challenge to identify evidence for how occupational therapists link their professional reasoning to their actions due to the often tacit processes involved (Boyt Schell and Schell 2009, Turner and Alsop 2015). However, the choice of action research as the methodology for the study led to insights into how practice and practice based knowledge developed within the local occupational therapy service.

9.6 Discussion conclusion

The action research study was triggered by the professional body's requirement for evidence-based practice. The COT recommendations were that the occupational

therapists should use standardised assessments, where possible, in order to measure the outcomes of occupational therapy with adults with learning disabilities and thereby produce evidence that occupational therapy was effective. Stage one of this action research study revealed that occupational therapy with adults with learning disabilities was not amenable to a quantitative, scientific approach and no existing standardised assessment was found which met all the criteria for occupational therapy assessment in this field. The action research therefore explored other ways of evaluating occupational therapy with this client group and the focus moved from a quantitative to a qualitative approach. Through the use of an action research methodology, the emphasis of the study changed from 'evidence-based practice' to 'practice-based evidence'.

The views of the participants with learning disabilities and their carers indicated that the occupational therapy they had received was relevant to their needs, was occupation focused and had a positive effect. The participants with learning disabilities appreciated the therapeutic relationship that they had developed with the occupational therapists and gained satisfaction from doing activities that they had identified as important. The insights of the participants with learning disabilities and their carers influenced the direction of the research study as the focus changed from assessment to occupational therapy practice.

The expectation of the employer was that the occupational therapists should provide their service as part of a multi-professional agency. The local occupational therapists met the expectations of other professionals. The professional stakeholders valued the unique contribution of occupational therapy but were more concerned with assessments than intervention. The changes to occupational therapy practice that arose from the findings of stage two related to: the format of the occupational therapy report; intervention not always being provided within an appropriate timescale; and a lack of clarity of expectations at the start of intervention. These were mainly concerns of the professionals rather than the participants with learning disabilities and their carers. In stage three, the local occupational therapists addressed the problems identified in stage two and also met the expectation of their employer to meet waiting list targets. The changes had unintended consequences which affected the quality of the occupational therapy practice. The local occupational therapists reflected on the changes at the end of the action research fieldwork and made plans to continue to develop their practice to

ensure that their primary focus was client and occupation centred, guided by OTIPM (Fisher 2009), rather than being led by, organisational agendas.

The findings of the research study were that the occupational therapy practice broadly met the expectations of the professional body (Eight core practice principles COT 2013a). The local occupational therapists delivering a service to adults with learning disabilities worked flexibly, relying on their professional reasoning and judgement rather than always using standardised assessment processes. The expectation that they should use outcome measures for specific interventions was questioned due to the findings that the occupational therapy outcomes were perceived differently by those involved. The outcomes are multiple and the timescales for when these are expected to be achieved are variable. The evidence from this research study has contributed to the occupational therapy body of knowledge on four of the COT key area for research for occupational therapist working with people with learning disabilities (Lillywhite and Haines 2010 [Table 2.1]): the perspectives of key stakeholders on occupational therapy practice; the use of standardised assessments; measuring outcomes and the impact of waiting time targets on the quality of occupational therapy intervention.

Action research methodology based on the CRASP (Zuber-Skerrit 1996) was useful in exploring practice based evidence on the effectiveness of occupational therapy that is relevant to adults with learning disabilities. The practice-led process enabled the OT co-researchers and participants to engage in the research without undue disruption to service delivery. The reflections of the OT co-researchers and lead researcher on their practice as they synthesised their experiences with their chosen model of occupational therapy, OTIPM (Fisher 2009), their theoretical knowledge and professional reasoning were central to the study. The methodology allowed the flexibility for occupational therapy practice development to be investigated in the complexity of the real world. This methodology was used to generate evidence as to how the local service was perceived from multiple perspectives. The insights were related to the specific local service at a specific time but new knowledge could be relevant to other occupational therapy services working with adults with learning disabilities.

Chapter ten: New knowledge, quality, recommendations and conclusion

10.1 Introduction

The purpose of the research study, as outlined in Section 1.6, was to evaluate the current occupational therapy practice conducted by a local community health team working with adults with learning disabilities and to further develop and improve practice based on the evidence generated. The thematic concern of the study was the quest of the local occupational therapists to seek and to *generate evidence* on which to evaluate and improve their practice with adults with learning disabilities. The goals of the occupational therapists were:

(i) to demonstrate that they could meet the needs of adults with learning disabilities.

(ii) to demonstrate to their employers that the service they provided to people with learning disabilities was effective and achieving the service objectives

(iii) to meet the demands of the professional body (the College of Occupational Therapists) for evidence based practice in line with the core principles for occupational therapists working with people with learning disabilities (COT 2003 and 2013a).

This action research study achieved all three of these goals to some extent. Key findings in relation to these goals were:

- the responses of participants with learning disabilities and those of their carers, in the interviews, indicated that the occupational therapy they had received was relevant to their needs, was occupation focused and had a positive effect;
- the local occupational therapists were able to meet the employing organisation's service objectives of: providing a multi-professional and multi-agency service for adults with learning disabilities; and meeting the targets for referral to treatment times, by making changes to their occupational therapy processes. However, this did restrict the occupational therapists' holistic approach.
- the local occupational therapists were able to mostly meet the core principles for working with people with learning disabilities (COT 2013a). The extent to which the principles were addressed by the local occupational therapy practice at the

conclusion of the study is considered as part of the new knowledge set out in Section 10.2.

Lillywhite and Haines (2010), in a COT review, identified key areas in which there were gaps in the research evidence on occupational therapy for adults with learning disabilities (see Table 2.1). Four of these research gaps were:

(i) occupational therapy practice from the perspective of adults with learning disabilities and other key stakeholders;
(ii) the effectiveness of occupational therapy interventions;
(iii) assessments that are appropriate for adults with learning disabilities;
(iv) the impact of service expectations on the quality of occupational therapy interventions.

These areas were all explored within the remit of this research study. The practice-based evidence developed through the action research provides some new understanding and knowledge that could be added to the occupational therapy body of evidence within this speciality.

10.2 New understanding and knowledge arising from the action research study

This action research study was conducted by a local, community based team of occupational therapists providing a service to adults with learning disabilities. New understanding and knowledge arose from this research study which influenced the practice of the participating occupational therapists. This new understanding and knowledge may be applicable to other occupational therapists working with this client group and includes the following:

(i) Adults even with moderate to severe learning disabilities can be active participants in research if interview techniques are adapted to their needs and a creative approach to research is employed.
(ii) Adults with learning disabilities can, and do, provide valuable and valid data about their experiences which indicate the value of occupational therapy and can influence occupational therapy practice development;
(iii) Carers of adults with learning disabilities and other health and social care professionals understand and value the unique role of occupational therapy.

(iv) Occupational therapists do provide occupation focussed assessments and interventions which have a positive effect on the occupational performance of adults with learning disabilities;

(v) Occupational therapists use professional reasoning in their assessments and interventions with adults with learning disabilities rather than a standardised, formulaic approach. This ensures a flexible, holistic and person-centred approach which works in a dynamic community context;

(vi) Standardised occupational therapy assessments which generate quantitative data are not suitable for universal use with adults with learning disabilities;

(vii) Occupational therapists face continual changes in organisational systems and imposed ways of working. They respond to these challenges pro-actively and are creative and innovative in adapting their practice in order to maintain occupational therapy principles whilst also meeting employer demands.

10.2.1 New knowledge about engaging adults with learning disabilities as active participants in research about occupational therapy practice

A major achievement of this research study was to obtain the perceptions of a sample group of adults with learning disabilities who had experienced occupational therapy practice. Section 2.4.1 highlighted that, although adults with learning disabilities have the right to be invited to participate in research (DH 2013), there was limited evidence in the literature that any had been asked to participate in research or to relate their experiences of occupational therapy practice. In this research study the perceptions of people with learning disabilities about their experiences of occupational therapy have been heard for the first time and were influential. Section 5.2, explored the factors that needed to be considered in order to enable adults with learning disabilities to be able to fully contribute their views. Many of the studies cited in Section 2.4.1 of the literature review only invited participants with learning disabilities who had mild learning disabilities or who were able to verbally communicate. In this research study, ten adults with learning disabilities were interviewed out of the twelve data sets. The participants who had limited communication abilities were enabled to express their views via pictures, gestures and facial expressions. The participants with learning disabilities who were

interviewed were motivated to engage and appeared to be empowered by the process.

10.2.2 New knowledge about the positive effect of occupational therapy as perceived by adults with learning disabilities

The responses in the interviews with participants with learning disabilities indicated that the occupational therapy assessments and interventions were person-centred and occupation focused. A finding of the action research fieldwork was that the participants with learning disabilities had an understanding of what they had done and achieved during their occupational therapy sessions. They reported that they had been involved in planning their own goals and that these had been relevant to their lives, suggesting that they had been fully involved in this partnership. The participants with learning disabilities' understanding of occupational therapy and its significance, was underestimated by the occupational therapists. The findings from the participants with learning disabilities supported occupational therapy practice development. They influenced practice of the local occupational therapists who focused more on each individual's specific occupational performance goals and on ensuring that clear plans were made with the person that were accessible and meaningful. The findings from this research study identified that occupational therapy practice in the local service was valued and that it enabled the participants with learning disabilities to engage in occupation-focused goals with which they expressed satisfaction. The local occupational therapists' practice met the COT (2013a) Principles 1 and 3, in that occupational therapy was considered to offer a unique role and the focus was on occupation and engagement.

10.2.3 New knowledge about the positive effect of occupational therapy as perceived by carers and health and social care professionals.

The findings of the action research fieldwork were that occupational therapists were seen as having a unique role that was valued by carers and professionals. The occupational therapy assessments were trusted and clarified the impact of the participant's learning disabilities on his or her occupational performance. Carers gained insights and changed their perceptions on how to enable the person they supported to engage in occupational performance tasks and roles and develop

skills. The local occupational therapists were seen as people who could clarify the complexity of the multi-agency system and facilitate connections with others who may be a helpful resource for the person with learning disabilities.

Occupational therapists were perceived as an essential part of the multi-agency community services for adults with learning disabilities. They contributed to the wider remit of the services and the outcome of occupational therapy intervention could often not be separated from the inputs of other professionals.

Carers, and other stakeholders with whom the local occupational therapists worked appreciated their collaborative approach (COT 2013a, Principle 4). Also, referrals were made by other professionals demonstrating that the occupational therapy role was recognised by them (Principle 6). The local occupational therapists promoted their own and other services to adults with learning disabilities, carers and others in contact with services. However, there were some concerns that recognition of the occupational therapy service was more limited for those who had not previously been in contact with adult learning disability services.

10.2.4 New understanding about occupational therapists' use of professional reasoning to provide a flexible, holistic approach to assessment and intervention with adults with learning disabilities

Occupational therapy was provided using a flexible approach incorporating occupational therapy professional reasoning built up from practice based experience and continual critical reflection. During the action research fieldwork, the local occupational therapists were able to make explicit some of their tacit knowledge and professional reasoning processes that they had developed during their practice. These were explored within the OT co-researcher group meetings and agreed as shared practice-based knowledge. The occupational therapy practice-based knowledge then underwent cycles of action, reflection, listening to the perspectives of others and modification of practice over time. New expectations and experiences were reflected on by the local occupational therapists in order to consider how this related to their existing practice-based knowledge and values. The essential criteria for assessment, developed in stage one, and the new forms and processes that were developed in stage three are examples of the professional reasoning

processes that occurred in the local service which, together with critical, collaborative reflection made explicit their collective practice-based knowledge.

This research study showed that occupational therapists in the local service were able to develop their skills to work with adults with learning disabilities through their engagement in the action research process. It enabled them to share skills and experiences with each other and to develop their collective practice to ensure the quality of the service to adults with learning disabilities (COT 2013a, Principle 8).

10.2.5 New understanding about occupational therapy assessments of adults with learning disabilities

At the start of the action research process the local occupational therapists were concerned that their practice was not meeting the expectations of the professional body which had recommended the use of standardised assessments to demonstrate evidence-based practice. However, the findings from the action research fieldwork revealed that occupational therapy was valued but the evidence of its effectiveness had evolved through practice and had not been acknowledged. Practice based evidence about occupational therapy was developed from the insights provided by the participants with learning disabilities, their carers and other health and social care professionals and the local occupational therapists themselves.

The occupational therapists did not fully meet the COT (2013a) recommendation on the measurement of specific outcomes of intervention (Principle 5) or the use of standardised assessments when appropriate to do this (Principle 2). The local occupational therapists initially sought standardised assessments in order to provide evidence to support their practice but they were unable to find any which met all their essential criteria for assessment (see Sections 4.4.2). Measuring a baseline, setting goals and measuring the outcome of interventions were not always possible as this did not encompass the holistic and longer term nature of the occupational therapy interventions in which others were often enabled to continue the work.

As opposed to ‘evidence based practice’ based on standardised assessment, the findings of this action research study provided ‘practice-based evidence’ which supported the local occupational therapists on the journey from stage one where they were seeking an ideal standardised single assessment tool towards the shift in

understanding that assessment and intervention with each adult with learning disabilities is an application of the occupational therapists' collective practice-based knowledge, using professional reasoning, and may require multiple approaches. This seems to reflect the conclusions of Blair and Robertson (2005) (see Section 2.5) who considered that an understanding of occupational therapy is not a search for elusive facts, rather an exploration of meaning and understanding.

10.2.6 New understanding of the ways in which occupational therapists adapt and develop their practice in response to changes imposed by employers

The action research also showed how the local occupational therapists were able to creatively adapt their practice to respond to the impact of organisational change and service demands whilst continuing to provide a person-centred, occupational performance focused practice with adults with learning disabilities (COT 2013a, Principle 7). The employing organisation influenced the direction of the research study in stage three when they imposed new policies and processes on the local service, including waiting list targets. The local occupational therapists had the knowledge and skills to take into account the multiple needs of adults with learning disabilities, carers and other stakeholders, whilst meeting the expectations of the employing organisation and the occupational therapy professional body. They reflected on their experiences and critically and collaboratively reviewed their practice as a community of occupational therapists. This enabled the local occupational therapists to identify if the changes were compromising person centred practice and allowed them the autonomy to adapt the processes to ensure that a quality occupational therapy service continued to be delivered.

10.3 The quality of the action research

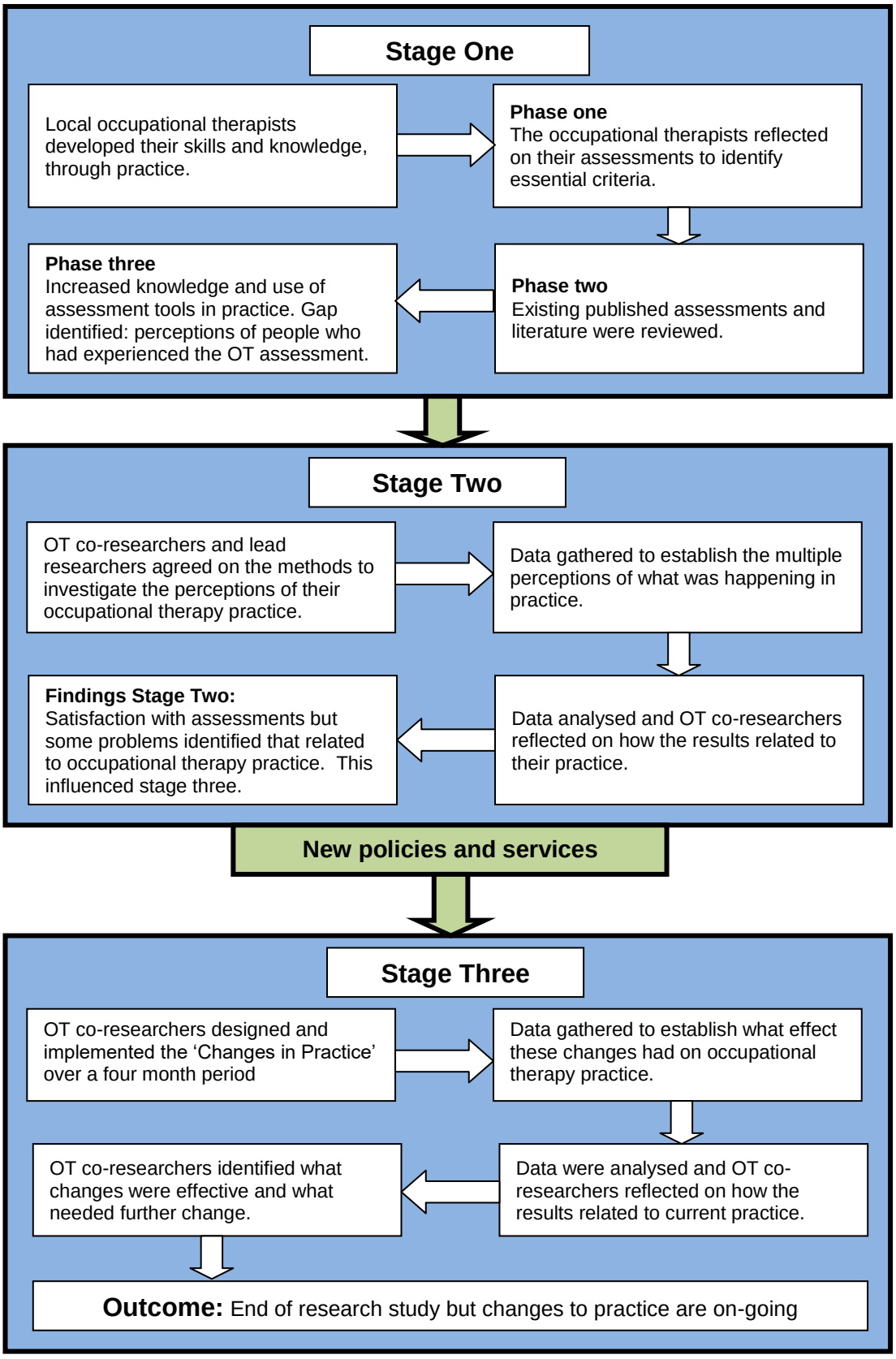
Action research was selected as the methodology for this study because it reflected the natural way of collaborative working that the local occupational therapists already engaged in. This methodology enabled the local occupational therapists to actively engage in the action research fieldwork using the CRASP (Zuber-Skerritt 1996) model. This methodology was found to be useful to gain insights into, and enable understanding of how practice-based knowledge and expertise were

acquired and the complexities of developing occupational therapy practice in the local service.

This research study met the expectations of action research as recommended by Williamson et al (2012) (see Section 2.2) in that it achieved a change in practice and generated new knowledge. The action research fieldwork was completed over the three stages summarised together in Figure 10.1. How the specific objectives of each of the stages (Tables 4.1, 5.1, 7.1 and 8.1) of the action research fieldwork were achieved are summarised in Sections 4.7, 6.5 and 8.9. As has been described in Section 3.2, some occupational therapy action research studies have been collaborations between academic researchers and occupational therapists often with the researcher aiming to impart their academic knowledge to the practitioners. When change is imposed from an external source there can be concerns regarding the sustainability of this once the research study is completed as '*colleagues have to understand and be convinced in order to feel a genuine need for transformation and become motivated'* (Eikeland 2006, p44). In contrast, in this research study, the lead researcher, as an insider researcher, collaborated with the OT co-researchers to enable them to be empowered to generate the changes for themselves. These changes in practice continued to be followed beyond the completion of the study.

The CRASP model of action research, summarised in Figure 9.2, was a useful theoretical framework on which to base the research study. It facilitated and empowered the occupational therapists to make changes and to embed these into practice. Crucially, time was prioritised for this as they were enrolled in a research study. Without the research study, the impetus to follow through the actions may have been lost as other priorities took precedence. The research study generated new knowledge about occupational therapy practice, how it was perceived and valued and the importance of allowing time for the occupational therapists to engage in critical reflection with their peers to support practice development.

Figure 10.1: Summary of all three stages of the research study



Sections 3.5 and 3.6 introduced some of the quality and potential ethical issues in relation to this research study. Table 10.1 summarises the quality issues presented in Table 3.5 and how these were addressed in this research study. The words in the bold type link to the action research fieldwork objectives set out in Table 3.1 and Section 1.5.

Table 10.1: How this research study met the action research quality requirements as set out by Zuber-Skerritt and Fletcher (2007 p418)

Requirements:	**This research study**
Practice orientated- improving practice.	This study met the overall purpose of evaluating and developing the local occupational therapy practice. The action research fieldwork resulted in changes to occupational therapy practice which is continuing to develop.
Participative- including all stakeholders and others affected by the results.	The local occupational therapists were recruited as co-researchers and actively participated throughout the action research fieldwork in partnership with the lead researcher. Views of service recipients and other professionals/stakeholders were sought.
Using multiple perspectives of knowing, triangulation, of appropriate methods and theories and connecting their own judgements to discussion in the current literature	Data were collected on the perspectives of the occupational therapists, selected people with learning disabilities, their carers and others involved in the support network. Data were reviewed in relation to relevant literature and policy.
Focussed on significant issues relevant to selves and community/organisation	The focus of the action research fieldwork changed in response to the feedback from people with learning disabilities, their carers and other stakeholder, the needs of the local organisation and the views of the local occupational therapists.
Explicit about assumptions so that readers and examiners may see appropriate criteria for judging the quality of work reflective, critical, self-critical and ethical.	Quality, ethical issues and limitations are explored throughout the thesis.
New knowledge in theory and practice -Rigour in action research methodology and creative innovation. Contributing something new to knowledge and theory.	This action research thesis contributed to new understanding and knowledge about the effect of occupational therapy on adults with learning disabilities and about how occupational therapy practice is developed and sustained in a multi-disciplinary context.

10.4 Trustworthiness of the research findings

As this action research study was highly contextual and specific to the local occupational therapy service, the lead researcher worked collaboratively with the OT co-researchers to reveal tacit knowledge, gain new understandings and make changes to improve occupational therapy practice. Data were obtained from a variety of different sources including adults with learning disabilities, their carers and others involved in their support network. In addition, longitudinal field observations were made over the course of the study in collaboration with the OT co-researchers.

The data were reviewed taking into account literature and policies that affected the practice. Data from all sources were triangulated to gain a rich perspective on practice. The thematic analysis based on Braun and Clarke (2006) was flexible enough to allow all the variety of responses to contribute to an understanding of the occupational therapy practice.

The lead researcher used a reflexive approach when making judgements as to the relative importance of each source when completing the data analysis. The OT co-researchers reviewed the data analysis and commented on the findings at all stages in the action research fieldwork. Throughout the research study, the lead researcher worked with the OT co-researchers to establish *'internal credibility'* (Williamson 2012b, p39), to ensure that the account was accurate and it had a clear connection to the local situation and the changes that occurred. The account also aimed for 'external consistency' so that others who were not aware of the local service would find the account convincing.

There were some reservations as to what extent the responses provided by the participants with learning disability could be relied upon as most of their responses were positive. The lead researcher used a number of strategies to clarify the responses provided by the participants with learning disabilities during the interviews and reflected on the data when reviewing the recordings and transcribing to consider if the responses had been influenced in any way by her. Open questions were mainly asked due to the concerns of acquiescence. Although the responses had been mainly positive, there were many occasions when the participants did make negative statements for example: one reported that occupational therapy reports are boring and another deliberately placed a large cross by the picture of a washing machine on his goal plan. In fact, the participants with learning disabilities

appeared less likely to modify the message that they were communicating to spare the interviewer's feelings, or to consider other implications, due to their less sophisticated communication abilities.

The lead researcher, as an insider researcher, was not expected to be a neutral observer but fully involved in the fieldwork and one of the agents of change. The lead researcher was aware of the ethical obligation to be self-reflective and to acknowledge the impact of the research on others and to be aware of her own potential for subjectivity. The lead researcher's reflexive review has been presented as part of the reflection sections at the end of each stage of the action research fieldwork and specifically in Sections 4.6 and 7.6.1. These have been shared to '*reveal the tensions and dilemmas inherent in the process'* (Smith 2006, p211) These reflective sections also considered what had been transformative for the OT co-researchers and the lead researcher as they reacted to the changes and findings.

The lead researcher endeavoured to facilitate the OT co-researcher sessions rather than to impose her views. When reviewing the recordings of the group discussions, she was able to develop insights into how much she may have influenced the direction of the discussions and which members of the OT co-researchers were dominant in the discussions. The questionnaires were used to give the OT co-researchers the opportunity to express any views that they had following time for reflection or that they found difficult to say in front of the group. Care was taken throughout the study to reflect on assumptions, checking with the OT co-researchers and discussing issues with the academic supervisors who were not part of the service.

There were some differences in perspectives on the research study between the OT co-researchers and the lead researcher. The multiple perceptions of occupational therapy practice development were not expected to be uniform as the reality of each occupational therapist's experience was unique. Challenges were to be expected as the epistemological stance was one where the knowledge needed to emerge from practice. Although they did not always have the same understanding of the research study as the lead researcher, the OT co-researchers were actively engaged in partnership with the lead researcher to develop practice and the change to practice continued beyond the time scale of the action research fieldwork.

The lead researcher needed to make the decisions as to what could be included in the thesis and what needed to be left out. The lead researcher needed to include enough of the action research to ensure that a faithful, diligent description of the actions that had taken place to provide an accurate and trustworthy record. Therefore, the lead researcher's academic expectations and personal experiences did influence the direction of the research study but trustworthiness was assured by the on-going reflecting and checking with the OT co-researchers throughout the fieldwork.

10.5 Strengths of the research study

Adults with learning disabilities were able to give valuable insights regarding the occupational therapy that they had experienced. These contributed to the themes and problems that were identified in stages two and three and influenced the occupational therapy practice and knowledge development. Creative and flexible techniques were used to adapt each interview to meet the communication needs of each participant as the priority was to give a voice to those people whose needs the occupational therapy service had been set up to address. Multiple perspectives from adults with learning disabilities, carers and other stakeholders as well as from the local occupational therapists provided a full understanding of the local occupational therapy practice within context.

The action research methodology allowed findings and insights to be applied to practice to address problems and improve practice, (see Table 8.6). The lead researcher developed the plan to involve all the occupational therapy staff in the local service in the research study as this was something they were motivated to do following their involvement in the initial discussions in stage one. Throughout the action research fieldwork, the OT co-researchers enthusiastically engaged with, and led, the process of reflection, identification and resolution of problems in their own practice. The local occupational therapists prioritised attending the action research fieldwork meetings, only missing sessions if they were on leave. This was important for the study as they were able to engage in the collaborative critical reflections, decide on and embed the changes so that the occupational therapy practice could develop. Being co-researchers in this study was an empowering experience for the local occupational therapists. This research study would not have been possible

without the sustained motivation of the occupational therapists. (see timeline Appendix A)

Another strength of the research study was that occupational therapy practice could be studied over a six year period so that the sustainability of changes could be reviewed. Although this did require a long term commitment of the OT co-researchers, time spent reflecting and developing practice would have occurred anyway. Service development meetings already occurred prior to the commencement of the study and continued to do so after the fieldwork had been completed. The fieldwork was only completed intermittently as the actual time spent by the OT co-researchers was limited to the specific sessions outlined in Appendix A. The fieldwork was planned so that it did not take place at times where it would have been disruptive to the service. The experience of the local occupational therapy team before, during and beyond the action research fieldwork was one of constant policy and service changes imposed by the employing organisations. The strength of this research study was that it had the flexibility to adapt to fluctuating situations and to the needs of the local occupational therapy service rather than disrupt it by imposing additional changes.

A further advantage was that the lead researcher was an 'insider' researcher which meant that the multiple expectations and demands were understood and could be incorporated into the action research.

At the start of the study, the duration of the action research fieldwork and what would be addressed were all unknown. This was because *'action research is open ended, collaborative, situation specific, methodologically eclectic, and thus not prescriptive in its use of methods, processes or final goals'* (Zuber-Skerritt and Fletcher 2007, p423). This is conceptually problematic when applying for ethical approval, using traditional ethical criteria where the research study plan and expectations of the participants need to be clearly stated. Furthermore, involving people with learning disabilities as research participants, including one who was unable to consent, presented additional ethical problems. Gaining ethical approval for this research study was challenging and time consuming but, ultimately, was one of its major achievements. Many of the creative approaches to data collection that emerged in this study were in direct response to the ethical issues raised.

10.6 Limitations of the study

The research was completed by the local occupational therapists, which included the lead researcher, so a limitation of the study could have been that existing practices were not challenged as much as if there had been an external researcher. However, the occupational therapists were continuously challenged to critically review their practice throughout the action research fieldwork as they considered the findings of each stage and addressed the new demands from the employing organisation and the expectations of the professional body.

The OT co-researchers and lead researcher were a group of staff of different grades and levels of experience and expertise (see Table 2.1). Therefore, a limitation could have been that the OT co-researchers' participation in the group discussions could have been affected by factors such as supervisors and supervisees relationships, the length of time staff had worked together and their personal relationships with each other. Eikeland (2006), states that it is important to address any issues in regards to power imbalances or there could be *'the spontaneous, habitual emergence of subtle power structures on a micro-level, not clearly visible in the beginning, but accumulating and 'petrifying' over time into larger unwanted patterns'* (Eikeland 2006, p39). As described in Section 3.4.3, the OT co-researchers were given the choice to participate in the action research fieldwork. However, on reflection, it may have been difficult for individuals to opt out of the research study as it was being endorsed by more senior staff within the team. The lead researcher did not directly manage anyone in the team but she still had a lead clinical role and was senior to the other occupational therapists. Although the ethos of the local occupational therapy service and the design of this research study were to be democratic and collaborative, this was limited at times due to the context of the organisational policies and the hierarchical structures. A number of strategies were implemented by the lead researcher to try to address any power imbalances but individual occupational therapists could only communicate their concerns to people within the service who were more senior to themselves and so may have felt inhibited.

Within these constraints, the OT co-researchers contributed to the discussions and challenged each other. They were also given the opportunity to express their views in the OT co-researcher questionnaires which were not shared with the group. The research study explored how occupational therapy practice developed and changed

within a real setting so the complexities of working together and managing differences in personalities and relationships could be considered to be part of that on-going process.

Confidentiality was also a potential issue in the study. The research took place in the lead researcher's own work setting which meant that she was often able to identify individual participants from their responses to questionnaires. The lead researcher made every effort to keep this as confidential as possible (see Section 3.4.4.2). The team of OT co-researchers was small and so people who knew the individuals involved may have been able to identify actions or statements and be able to link them with the person described. The lead researcher needed to be aware of this and to be careful in how she presented data so that it could be demonstrated that all the OT co-researchers were involved but to not identify individuals. This was a challenge and resulted in some data not being selected due to concerns about confidentiality. The OT co-researchers were encouraged to share their views within the OT co-researcher sessions and to discuss cases as they would in their usual practice development meetings but not to discuss these outside of the meetings.

A limitation of the research study was that only adults with learning disabilities and carers who had completed their occupational therapy were selected to be interviewed (see Section 5.3.2). This meant that insights from people who had not engaged or withdrew from occupational therapy were not obtained and so their reasons for non-completion could not be explored.

10.7 Implications for future practice and recommendations

Implications for occupational therapy practice with adults with learning disabilities: assessments

The value of practice-based evidence that has evolved from the experiences of different occupational therapists working with people with learning disabilities followed by self-reflection and collaborative critical review, should be recognised. Occupational therapists have access to a range of assessment approaches and tools so that the most appropriate can be used depending on the individual situation. While some standardised assessment is useful it is the process of assessment and consideration of the holistic needs of the individual that determine an effective occupational therapy outcome.

It is recommended that occupational therapy assessments used with adults with learning disabilities need to be flexible and, when standardised assessments are used, they should be supplemented by the occupational therapists' more individualised assessment process using observations and professional reasoning. Occupational therapists should use their practice-based knowledge with confidence and continue to develop and share this with their colleagues within their services.

Working in partnership with adults with learning disabilities

Occupational therapists should ensure that they explain occupational therapy in an accessible way and not underestimate the ability of adults with learning disabilities to work in partnership to meet their occupational performance goals.

Occupation-focused, accessible goal plans developed with two of the adults with learning disabilities were found to be a useful tool to support occupational therapy practice. It is recommended that such goal plans are used, both to review individual goals and to provide accessible reports.

It is recommended that occupational therapists check with each adult with learning disabilities that he or she understands and consents to what has been planned and the reason for this each time they meet. Open sharing of information is recommended, whenever possible, so that any difficult issues can be addressed in partnership to ensure quality, person-centred practices. If there are concerns that an adult with learning disabilities is unable to give informed consent or handle sensitive information, then this needs to be considered with regards to the Mental Capacity Act (2005) and best interest decision making.

Improving access to services

The participants with learning disabilities and many of the carers were unaware of the occupational therapy service prior to the referral or what it could provide. It is recommended that occupational therapists, when working with adults with learning disabilities and their carers, enable them to understand the circumstances under which they may need occupational therapy again and how to make a referral themselves.

It is also recommended that other health and social care professionals be made aware of occupational therapy services for adults with learning disabilities so that

they can support access. Similarly, one of the roles of the occupational therapist is to signpost adults with learning disabilities to other services as appropriate.

Seeking feedback on service users' experiences of occupational therapy

The views of adults with learning disabilities should be sought when evaluating the occupational therapy services that they use. Occupational therapists should consider imaginative ways to gather this feedback which needs to be flexible and allow enough time to meet individual communication needs. This feedback should be sought throughout the occupational therapy period of intervention and also after discharge to ensure that occupational therapy outcomes have been sustained. Seeking regular feedback would also demonstrate that the occupational therapists are accountable to the people who use their service.

Recognising and supporting occupational therapy practice-based knowledge and practice development

The CRASP model of action research used in this study showed how the local occupational therapists were able to develop their collective practice knowledge and skills. They were able to respond to organisational changes and service demands whilst continuing to provide a person-centred, occupational performance focused practice with adults with learning disabilities.

It is recommended that the CRASP model of action research (see Figure 9.2) could be used as a theoretical framework to support a system of ongoing practice development. This could be used by individual occupational therapists or by an occupational therapy service as a whole, as a form of qualitative audit. The CRASP model may continue to be used in the local setting after completion of this research study. It could also be explored by occupational therapists in other settings to help them to develop insights into how various factors may be affecting their practice. Occupational therapists could consider how their experiences relate to each component of the model in order to identify any imbalances or blocks to practice development. The findings from this audit could be used to address any concerns and to demonstrate to others the quality of their service.

Implications for managers or commissioners of occupational therapy services

All occupational therapy practice with adults with learning disabilities has to take into account new external evidence, policy and perspectives and to adapt these into practice. Occupational therapists need to be accountable to their professional body,

comply with health and social care policy and ensure they take into account new evidence and best practice guidance in order for occupational therapy practice to develop. However, vulnerable people such as adults with learning disabilities may be adversely affected by policies that restrict or rationalise services as some are not able to recognise their own needs or access a service. Therefore, service managers need to allow occupational therapists sufficient autonomy and flexibility to decide how to put the new policies into practice so that the needs of the individuals with learning disabilities can still be addressed. Sufficient time should be allowed for them to critically review the expectations with other occupational therapists. Such reviews should include feedback from the people who receive the service.

Occupational therapists should inform their managers as to how any proposed changes may affect the service and identify realistic time scales for implementing changes. Occupational therapists should also be given opportunities to feedback to commissioners, managers or policy makers as to how their expectations had affected occupational therapy services for adults with learning disabilities.

10.8 Implications for future research and recommendations

Adults with learning disabilities have the right to be included in any research that is relevant to them.

The adults with learning disabilities in this study appreciated being invited to participate in this research study and provided valuable insights, including one who was not able to consent but who participated under the agreement of his personal consultee. One of the reasons why there are so few studies involving adults with learning disabilities could be the length of time it takes to ensure appropriate consent.

It is recommended that adults with learning disabilities should be invited to contribute to any research about occupational therapists working with them. Innovative strategies are needed to remove any potential blocks to their participation. Ethics committees should consider reducing the expectation of providing detailed information about research studies to potential participants. Participants with learning disabilities should not be automatically excluded from studies that affect them even if they do not fully understand the whole reason for the research.

In any future studies on occupational therapy for people with learning disabilities it would be important to ascertain the perceptions of people who did not complete their occupational therapy intervention to understand why this had been the case and if the occupational therapists needed to adjust what they were doing to address any concerns raised.

Future research on occupational therapy practice

Lillywhite and Haines (2010) identified key areas for research in occupational therapy with adults with learning disabilities. Four of these were addressed to some extent by this research study. However, much research remains to be done in this field of practice to increase the amount of research literature available and to build up the evidence base for occupational therapy. This study has demonstrated that research is possible in this field of practice and that people with learning disabilities can actively participate in research and make valuable contributions to it.

The choice of action research as the methodology for this study provided the flexibility and breadth of approaches needed to explore the complexity of occupational therapy practice in the field of learning disabilities. Future research should make use of a wide range of methodologies rather than be restricted to traditional scientific approaches. Qualitative methods were used in this study largely because it was locally based and involved small numbers of people. These approaches were shown to work well within this context and should be explored as methodologies for future research.

Further research could be conducted to investigate if the practice–based evidence on the essential criteria for occupational therapy assessment and the new forms and processes could be transferable to other occupational therapists working with adults with learning disabilities in other services.

10.9 Conclusion

Occupational therapy assessment and intervention with each adult with learning disabilities is an application of collective practice-based knowledge using professional reasoning and requires multiple approaches. Assessments and interventions are person-centred, occupational performance focused and therefore

need to be flexible. The views of the participants with learning disabilities indicated that the occupational therapy they had received was relevant to their needs, was occupation focused and had a positive effect. Standardised occupational therapy assessments which generate quantitative data are not suitable for universal use with adults with learning disabilities. Qualitative approaches to assessment better identify the needs of adults with learning disabilities and are consistent with the holistic principles of occupational therapy. Occupational therapists face continual changes in organisational systems and policy. They respond to these challenges pro-actively and are creative and innovative in adapting their practice in order to maintain occupational therapy principles whilst also meeting employer demands.

There is an expectation that the findings and recommendations of this study could be relevant and transferable to other occupational therapy services working with adults with learning disabilities. The perceptions of adults with learning disabilities and carers on occupational therapy practice should be sought in order to ensure that services are meeting needs and to identify areas of improvement. The practice-based evidence developed from this research study adds to the occupational therapy body of evidence within this speciality and could influence future revision of the College of Occupational Therapists' core principles for occupational therapists working with people with learning disabilities.

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Appendices

Appendix A: Time line of action research fieldwork activities

Date and time	Attendees	Event	Stage and Chapter
21/3/2007 Whole day	Local OT team	Team meeting. Review of assessment used and scoring.	Stage one Chapter 4
11/04/2007 2 hours	Local OT team	Team meeting to review assessments used.	
April-July 2007	Lead researcher	Review of literature, discussions : Drafting the essential criteria for assessment.	
23/7/2007 2 hours	Local OT team	Team meeting to discuss and agree the essential criteria for assessment..	
July- Sep 2007	Lead researcher	Finalised essential criteria for assessment.	
October 2007- March 2008	Lead researcher	Reviewed existing assessments to consider if any could meet essential criteria. Agreed with OT co-researchers the need to review how assessments are perceived	
April 2008- Oct 2009	None	Service integrated and managed under social care. Research study initially not supported.	
	Lead researcher	Ethics application writing and submitting.	Chapter 3 Section 3.6
21/12/2009	Ethics committee	Ethics application granted	Stage 1: Phase 3 Chapter 4
March 2010	Lead researcher and OT co-researchers	Recruitment of OT co-researchers. Information sheets and consent process	
April 2010	OT co-researchers	First OT co-researcher questionnaires completed.	
21/04/2010 2 hours	9 OT co-researchers: A BCDEFGH Lead researcher	OT co-researcher meeting part one: Review of essential criteria for assessments and agree plan for stage two.	
21/04/2010 2 hours	A BCDEFGH Lead researcher	OT co-researcher meeting part two: Review and pilot questionnaires.	Stage two Chapter 5
24/6/2010 1 hour	ACDG Lead researcher	Finalise the sample to be approached for interviews	
July-Sep 2010	Lead researcher	Planning interviews, sending out questionnaires and transcribing.	Stage two Chapter 6
3/8/2010	Lead researcher	Interview G and carer G	
17/8/2010	Lead researcher	Interview I and carer I	
20/8/2010	Lead researcher	Interview carer C	
23/8/2010	Lead researcher	Interview D	
26/9/2010	Co-researcher B	Interview H and carer H	
6/9/2010	Lead researcher	Interview E	

Date and time	Attendees	Event	Stage and Chapter
2/9/2010 Half day	AB CEFG I Lead researcher	OT co-researcher meeting. Initial analysis: 3 interview transcripts.	Stage two Chapter 6 continued
Sep 2010 -Sep 2011	Lead researcher	Analysis of data from stage two interviews and questionnaires	
18/11/10 1 day	ABCDEFGHI Lead researcher	OT co-researcher meeting combined with service development day. Reflecting on findings whilst reviewing the OT operational policy considering the assessment process- screening and initial assessments, goal plans.	
3/3/2011 Half day	ABCGI Lead researcher	OT co-researcher meeting. Reviewed data extracts to agree initial themes.	
21/03/2011 30 minutes	ABCDEFGHI Lead researcher	Team Meeting. Presented possible actions from discussions on 3/3/2011.	
30/06/2011 Half day	ABCDEI Lead researcher H ,F left service	OT co-researcher meeting. Discussed the three themes.	Stage three Chapter 7
30/06/2011	ABCDEGI Lead researcher.	Second OT co-researcher questionnaires distributed.	
28/7/2011 2 hours	ABCDEGI Lead researcher	OT co-researcher meeting. Agreed final themes. Planned actions.	
July 2011	ABCDEGI Lead researcher.	OT co-researcher questionnaires returned.	
18/08/2011 1 day	ABCEGI Lead researcher	Workshop: Changes in OT practice day 1	
22/08/2011 day	ABCEGI Lead researcher,	Workshop: Changes in OT practice day 2	
25/08/2011 1 day	ABCDEGI Lead researcher.	Workshop: Changes in OT practice day 3	
01/09/2011 onwards	OT co-researchers	Implementation of changes to OT practice	
27/9/2011 1 hour	CEG Lead researcher	Action learning set team A	
05/10/2011 2 hours	ABD Lead researcher	Action learning set B	
11/10/2011 1 hour	I Lead researcher	Action learning set lead	
3/11/2011 2 hours	ABCDEGI Lead researcher	Action learning set combined	
Nov 2011	ABCDEGI	Questionnaires Forms and Processes	
6/12/2011 1 hour	CEG Lead researcher	Action learning set team A	
13/12/2011 1 hour	ABD Lead researcher	Action learning set team B	
31/01/2012 2 hours	ABDEGI Lead researcher	Action learning set final session.	
31/01/2012 1 hour	ABDEGI Lead researcher	Identified potential sample of participants with learning disabilities for second set of interviews.	Stage three Chapter 8

Date and time	Attendees	Event	Stage and Chapter
March 2012	Lead researcher	Planning interviews and questionnaires	
11/4/2012	Lead researcher	Interviews K	
13/4/2012	Lead researcher	Interviews M and carer M	
20/4/2012	Lead researcher	Interviews J	
12/6/2012	Lead researcher	Interview B	
25/10/2012	Lead researcher	Interviews P and partner P	
May-Nov 2012	Lead researcher	Analysis of data from interviews and questionnaires	
Nov 2012	ABCDEGI	Questionnaires: Forms and Processes	Chapter 7
27/3/2013	Lead researcher	Interview carer L	Stage three Chapter 8
March-April 2013	Lead researcher	Analysis of data	
07/05/2013	ABCDGI Lead researcher	Final OT co-researcher meeting to review themes and findings across all three stages.	
June 2013	ACDGI Lead researcher	Final OT co-researchers questionnaires distributed and returned.	

Appendix B: Literature search : Occupational therapy and adults with learning disabilities

Date of search	Search data base or source	Search terms used	Parameters scope	Results
Through-out fieldwork	All local occupational therapists sharing literature obtained from any source.	Data base searches. Policy documents, COT website, presentations at conferences, general access to professional literature, occupational therapists sharing in practice	Anything considered potentially relevant to the local practice.	15 published papers identified
29/4/2016	EBCOST-and Medline	First search: Intellectual disabilities *and* occupational therapy. Second search: Learning disabilities *And* occupational therapy Full article available only. 1990-2016 All fields	Manually removed not relevant studies such as: Children; Not related to Occupational therapy e.g. cognitive behaviour therapy	36 published papers identified
1/5/2016	EBSCO CINAHL and Medline CINAHL Plus for nursing & allied health journals and Medline for medical, nursing and veterinary sciences and Pscharticles	intellectual disability or mental retardation or learning disability or developmental disability or learning disabilities occupational *and* thera* *not* child *and* community Field Title.	120 articles Manually excluded e.g. • Postural care- physiotherapy service • USA terminology learning disabilities- not British term as specific learning needs • Not learning disabilities • Children studies • Not occupational therapy related	32 published papers identified
1/5/2016	All fields – all data bases EBSCO ticked.	Intellectual disabilities or mental retardation or learning disabilities *and* occupational therap* *and* adults. *Not* Child* Field-abstract	Manually reviewed the 584 articles to add any new articles that were revealed. Reviewed articles if before 1990 and appeared to be relevant.	59 published studies identified 47 published studies cited in this research study.

Appendix C: Permission to reproduce OTIPM figure

Re: Reproduction of the OTIPM

anne.fisher@innovativeotsolutions.com (anne.fisher@innovativeotsolutions.com)

01/06/2016

To: Judith Reep

Hi Judith,
The figure is available as a PDF if you chick on the OTIPM Figures tab index OTIPM on the website. You just need to state the source (website) and say you use it with permission.

On May 30, 2016, at 5:26 AM, Judith Reep <> wrote:

Dear Anne

I am an occupational therapist at the final stage of completing a PhD, part-time, which is an action research study on occupational therapy practice with adults with learning disabilities in the UK.

Our practice is based on OTIPM as a result of attending one of your courses in London several years ago and so this is described within the thesis. I would like to be able to reproduce the OTIPM diagram in full as it is a key part of the thesis. The figure that I have identified is located on the Center for Innovative OT solutions website: http://www.innovativeotsolutions.com/content/otipm/

However, I am not clear how I apply for permission to do this. Please could you let me know if reproducing this is possible and who I need to apply to. I have tried to access Three Star Collins Press but have been unable to find a contact address for this organisation.

Yours sincerely

Judith Reep

Appendix D: OT co-researcher participant information sheet and consent form

Version 1 29/10/09

Information about the Research

Title of study: An action research study to develop an occupational therapy assessment tool to identify the community living skills of adults with learning disabilities.

I would like to invite you to take part in a research study. For the purposes of the study I am referred to as the 'Lead researcher' and am completing this study as part of a PhD at London south Bank University. I want to recruit members of the occupational therapy team as 'OT Co-researchers'.

Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
In 2000, occupational therapists identified the need to develop a 'user-friendly assessment tool that provides accurate and meaningful information from which the therapist can devise meaningful plans based on the needs of the client's occupation' (Swee et al 2000 p84). The literature review identifies that occupational therapists feel that there continues to be a lack of occupational therapy assessments specifically designed for working with people with learning disabilities and that this is a problem in their work. This study plans to address this problem by clarifying what occupational therapists working with people with learning disabilities require in an assessment tool, and by using this new knowledge to develop a tool and implement it in practice.

Why have I been invited?
All the occupational therapy staff working in the teams for adults with learning disabilities in Southwark PCT are invited to participate in this project. The Action Research approach has been chosen so that occupational therapists who use the assessment tool can be fully involved as Co-researchers. Your expertise and experience can be used to clarify the issues and identify what needs to change to meet local needs. You can then be involved in implementing any changes in practice and reflecting on these changes.

Do I have to take part?
Taking part is entirely voluntary. It is up to you to decide. I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time,

without giving a reason. This will not affect your work within the team. The OT Co-researchers will be asked to sign up for the full length of the research project. However, due to the plan that the project will last between 2-3 years, it would be expected that there may be people who wish to leave the project during this time and others who may want to join. The Co-researchers will, therefore, be able to review their participation in the project at any stage but will be formally asked if they want to continue at the end of each of the stages of the project.

What will happen to me if I take part?
The OT Co-researchers will meet with the Lead researcher at appropriate times throughout the action research process. This will usually be for approximately one and a half hours on a monthly basis but frequency and length will be reviewed with the group and will be influenced by the stage of the project and the need for the meeting. See **Outline of the study** attached.

The OT Co-researchers' roles are to be active participants working in partnership with the Lead researcher to define the action research problem that needs to be addressed, to plan the project such as the identification of the participants, interview schedules, questionnaires, data collecting methods, reflecting on findings and planning each action step. The OT Co-researchers will reflect on their on-going experiences of assessing people with learning disabilities throughout the project. However, no patient identifiable information will be shared or individual notes reviewed.

The Lead researcher will encourage the OT Co-researchers to record important discussion points and action plans on flip charts. These will be collated by the Lead researcher and shared with the OT Co-researchers in order to ensure that they agree with the accuracy of the notes and on reflection are committed to each step. The meetings will be audio taped so that the notes can be made of key points and actions. The notes will be shared with the group. If there are any questions about the accuracy of the notes, the group can refer back to the part of the tape where the discussion had taken place.

The level of engagement and collaboration of the Co-researchers, what moved the project forward and what was inhibiting will be recorded and reflected upon. This data will be systematically collected over time to record the process of change.

All the paper or audio records of the meetings will be kept in a locked confidential place. Any transcribed or electronic identifiable information will be kept on NHS encrypted computers and memory sticks. The group discussions will be recorded without identifying individual participants. However, it may be helpful to include individual quotes when describing the change process discussions.

Expenses and payments
Your involvement in the action research project will be considered as part of your role to ensure that people with learning disabilities are provided with assessments that are evidence based and meet best practice. Therefore, meetings and any research activities will take place during your working hours. Any travelling or other expenses incurred will be paid in accordance with the usual PCT policies.

What will I have to do?
Actively participate in the majority of the monthly meetings. The dates and times of the meetings will be planned in advance. It is expected that attendance at all of the meetings

will not be possible due to annual leave, sickness and other commitments. If you cannot attend a meeting you will need to inform the Lead researcher in advance and to provide any feedback as required.

There may be an opportunity to volunteer to take part in some interviews of participants with learning disabilities, carers and stakeholders.

You will be asked to complete a questionnaire about your expectations of the project at the beginning and to repeat this at each stage, at the end of the project or if you decide to leave before the end. This will be used by the Lead researcher to consider how the change process has evolved.

What is the procedure that is being tested?

The occupational therapy assessment process within the learning disability team is being reviewed, reflected upon and developed. This will involve gaining feedback from all people involved in the assessment process including people with learning disabilities. During the project it is planned that new assessment tools will be developed and piloted.

What are the possible benefits and disadvantages of taking part?

Benefits
Is hoped that the occupational therapy assessment will be improved and better meet the needs of people with learning disabilities.
Occupational therapists need to ensure that they are keeping up to date with best practice and will review the assessment process as part of this. Participation in this project will mean that the assessment process will reviewed in joint systematic and coordinated way with shared insights from others with similar roles.
The action research process is a learning opportunity. You will be able to gain an understanding of research methods and benefit from developing an understanding of assessments.
The action research process will offer an opportunity to gain insights from feedback from people with learning disabilities, carers and others affected by occupational therapy assessments, as well as from your own colleagues.
Disadvantages
Involvement in the project will take up time. It is envisaged that meetings will be arranged at times most suited to the team and to try to involve as little travelling as possible.
Involvement in the project may be difficult at times as our practice will be open to scrutiny and criticism. It may be identified that some things that the occupational therapy team do are not appropriate.
Change can be difficult and it may be identified that the group want to so things that you may not be happy about. It may not be possible for the group to agree on a shared way forward and compromises may need to be made.
There is a risk that the project may increase expectations in that all the problems about the assessment can solved. It may not be possible to change the problem or plans may not be completed due to issues such as time, resources or commitment.

What happens when the research study stops?
The research is planned to be on-going for 2-3 years. The assessment tool will have been developed and will be available to use in practice. The findings of the study will be written up as part of the Ph.D. project and submitted for publication.

Will my taking part in the study be kept confidential?
Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. See above under 'what will happen to me if I take part'. However, the action research project is based on the local real setting. The research is being sponsored by [redacted] so it will be possible for people to know that the OT Co-researchers are members of this particular team.

Data will be collected by recording notes taken by the group on flip chart paper. The Lead researcher will also make notes of the group discussion using audio recording of the groups. The transcriptions of these meetings will be shared with the group members so that verification of accuracy can be agreed. You will have the right to check the accuracy of data held about you and correct any errors.

The information from the group discussions will be used to describe how the change process developed. The transcriptions will not identify individual people. Direct quotes may be used when writing up the project. No data that will identify individual occupational therapy staff will be shared. Data collected from the group discussions will be retained for up to10 years.

If any information is disclosed that may affect an individual with learning disabilities, the working of the service, or some other important issue, this will be dealt with in the same way as any issue brought up in a team meeting. Issues may need to be addressed in supervision or shared with others in team. If this occurs the Lead researcher will discuss the disclosure with the group and explain why it will need to be shared.

What will happen if I don't want to carry on with the study?
You have the right to review any data collected from each group and decide if you are happy with how it has been worded and how it will be used. You can withdraw from the project at any time, however, data already agreed and collected will continue to be used as part of the study. You will be invited to complete an exit questionnaire if you withdraw. If you are still working within the service you will informed of any outcomes of the project that may affect the team practice.

What if there is a problem?
If you have a concern about any aspect of this study, you can talk to me who will try to solve the problem. Alternatively, you can bring any issues and problems to the OT Co-researcher group to try to resolve these with the whole group. If you want to discuss issues outside of the action research group or wish to make a more formal complaint you can contact [redacted], Team Manager. If you remain unhappy and wish to complain formally, you can do this through the [redacted] NHS Complaints Procedure.

What will happen to the results of the research study?
Each stage of the action research project will be shared with the OT Co-researchers so that the group can decide what the next action should be. At stages throughout the process

information from that stage will be shared locally with relevant stakeholders. Other parts of the project may be shared nationally in presentations.

The results of the research will be written up as a PhD project by the Lead researcher. It is envisaged that findings from this will then be shared and some parts of the project will be submitted for consideration to be published. The completed Ph.D will be made available to the OT Co-researchers. You will not be identified in any report/publication unless they have given your consent.

Who is organising and funding the research?
I am completing this research as part of a part time PhD at London South Bank University. I am part funded by [redacted] and part self-funded.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the South London and Maudsley Research Ethics Committee.

You will be given a copy of this information sheet and a copy of the signed consent form to keep.

Please contact me if you would like further information about the study. You may wish to discuss your participation with your supervisor.

Completed by

Judith Reep

Consultant Occupational Therapist

OT co-researcher consent form

Title of Project: An action research study to develop an occupational therapy assessment tool to identify the community living skills of adults with learning disabilities.

Name of Researcher: Judith Reep

Please tick √ one box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

   Yes ☐

   No ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected.

   Yes ☐

   No ☐

3. I understand that any data collected during the study will be anoymised but may be shared with the supervisors of Judith Reep at London South Bank university, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these records.

   Yes ☐

   No ☐

4. I agree to take part in the above study.

   Yes ☐

   No ☐

_____	_____	_____
Name of Participant	Date	Signature

Two copies of the form to be completed: 1 for OT Co-researcher; 1 for researcher site file

Appendix E: OT co-researcher questionnaires

[redacted]

Lewisham Team for Adults with Learning Disabilities

[redacted]

[redacted]

[redacted]

OT Co-researcher. Initial Feedback form 7/4/10

Dear

Thank you for agreeing to take part in this project as a co-researcher.

Prior to our first meeting I would like you to complete the following information so I can find out your initial views of the project. The aim of this exercise is to have a quick idea about your current perceptions so please jot down your thoughts and return it to me as soon as possible.

I will amalgamate these responses and feedback to the first OT Co-Researcher group on 22nd April at the OT Away Day, where there will be an opportunity for further discussion. I will not state who made particular comments, although you will have the opportunity to voice your own opinions and expand on these views at the meeting if you wish.

I have coded the feedback form for my records, as the plan is to repeat this feedback exercise at key points in the project. This will allow changes in views and reflections of individual group members to be noted. If you want to keep a copy of your own reflections for your CPD portfolio please do so.

If you have any questions please let me know.

Thanks

Judith Reep

Lead Researcher

Confidential

OT Co-researcher. Initial Feedback form

Code:

What year did you qualify as an OT? _____

What year did you start working in this OT team? _____

1. **What are the essential parts of an OT assessment?**
   Please list the factors that you feel are important, in your experience, when carrying out a successful occupational therapy assessment.

2. **OT Assessment**
   How do you feel about the OT assessments you have undertaken in the past 3 months?

   What are the key areas that are going well?

   What are the key areas that need to change?

5. Action Research Project

Please give feedback on your perception of the action research project plan.

How do you think it will work?

Have you any ideas about how it could be improved?

Do you feel you will be able to participate fully?

Is there support from the service to focus on this work?

Any other comments:

Date form completed: _____

Please return the form in an envelope to Judith or leave in her pigeon hole at [redacted] by 13/4/10

Or [redacted] by 14/4/10

Thanks

Amendments made to second OT co-researcher questionnaire

Additional questions under the following sections:

2. OT Assessment

Has anything you do changed as a result of the action research project?

What would do you see are the priorities to concentrate on for the next stage of the project?

5. Action Research Project

How is the action research project working?

Have you any ideas about how it could be improved?

Amendments to third OT co-researcher questionnaire

Changes in OT Practice ('New Ways of Working').

Please list anything that you do that has changed as a result of the action research project.

What are the key areas that are going well?

What are the key areas that need to change?

The Action Research has now completed but it is hoped that the development of OT practice will continue. What would do you see are the priorities to concentrate on next?

5. Action Research Project

How did the action research project work?

Have you any ideas about how it could have been improved?

In what way were you able to participate?

Was there support from the service to focus on this work?

What things supported change?

What were the blocks to change?

Appendix F: Ethical approval

The Joint South London and Maudsley and The Institute of Psychiatry NHS Research Ethics Committee
South London REC Office (2)
1st Floor, Camberwell Building
94 Denmark Hill
London
SE5 9RS

Telephone: 020 3299 5033
Facsimile: 020 3299 5085

21 December 2009

Ms Judith A Reep
[redacted]

Dear Ms Reep

Study Title:	**An Action Research project to develop an occupational therapy assessment tool to identify the community living skills of people with learning disabilities.**
REC reference number:	**09/H0807/79**
Protocol number:	**1**

Thank you for your letter of 04 December 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 09 December 2009. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005
I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The Committee has not yet been notified of the outcome of any site-specific

assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. I will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents
The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter		27 October 2009
REC application	2.5	27 October 2009
Investigator CV		27 October 2009
Evidence of insurance or indemnity		26 October 2009
Letter from Sponsor		26 October 2009
Referees or other scientific critique report		01 December 2007
CV for Supervisor		27 October 2009
Covering Letter		04 December 2009
Protocol	2	04 December 2009
Participant Information Sheet	2	04 December 2009
Response to Request for Further Information		04 December 2009

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review
Now that you have completed the application process please visit the National

Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/H0807/79	**Please quote this number on all correspondence**

Yours sincerely

Dr Theresa Joyce
Chair

Email: faye.cuffie@nhs.net

Enclosures: "After ethical review – guidance for researchers" *[SL-AR1 for CTIMPs, SL- AR2 for other studies]*

Copy to: *Professor Nicola Crichton, London South bank University, Sponsor*

Appendix G: Published assessments

Potential assessment tools that could be used by occupational therapists in the local service when working with adults with learning disabilities (stage one)

Name of assessment tool	Test	Authors	Already known to local OT team	In use by local OT team
1. Activities Health Assessment		Cynkin and Robinson (1990)	X	
2. Adaptive Behavior Assessment System – Second Edition	ABAS-II	Harrison PL, Oakland T. (2003) The Psychological Corporation, Harcourt Assessment company.	✓	
3. AAMR Adaptive Behavior Scales: Residential and Community Edition	ABS-RC2	Nihira K, Leland H, and Lambert N. (1993) Published by Pro-ed in association with American Association on mental retardation adults LD.	X	
4. Adolescent / Adult Sensory Profile		Brown CE and Dunn W (2002) Pearson Psychological Corporation.	✓	✓
5. Assessment of Communication and Interaction Skills – version 4.	ACIS	Kirsty Forsyth, with: Marclle Salamy, Sandy Simon, and Gary Kielhofner (1998). http://www.moho.uic.edu/assess/acis.html	✓	
6. Assessment of Motor and Process Skills	AMPS	Fisher AG (1990, Revised 2010) Version 5, 7. http://www.ampsintl.com/	✓	✓
7. Brief Praxis Test. Scale for Adults with Down Syndrome.		Dalton A, Fedor B (1997) NYS Institute for Basic Research in Developmental Disabilities. New York.	X	
8. Canadian Occupational Performance Measure 2nd Edition -	COPM	Law M, Baptiste S, Carswell A, McColl MA, Polatajko H, Pollock N (1994). http://www.caot.ca/copm/index.htm	✓	X

Name of assessment tool	Test	Authors	Already known to local OT team	In use by local OT team
9. Cognitive Assessment of Minnesota	CAM	Rustad, RA, DeGroot TL, JungkunzML, Freeberg KS, Borowick LG, Wanttie AM, (1993) The Cognitive Assessment of Minnesota: Examiner's Guide, The Psychological Corp., San Antonio, Texas, USA,	✓	
10. COMPASS: A multi-perspective evaluation of quality in home life.	COMPASS	Cragg R, Look, R (1992) Available from: 302 Station Road, Kings Heath Birmingham B14 7TF UK	X	
11. Comprehensive Occupational Therapy Evaluation	COTE	Brayman, S.J. & Kirby, T.F. (1982) Slack publishers	X	
12. Dementia Questionnaire for people with learning disabilities(DLD)	DLD	Evenhuis, HM, Kengen MMF and Furlings HAL (2007) UK adaptation Harcourt Assessment	X	
13. FACE - Core assessment and outcomes packages	FACE	On-going development since 2001 http://www.face.eu.com/solutions/assessment-tools/learning-disabilities FACE Recording and Measurement Systems, Nottingham	✓	
14. Goal Attainment Scaling (Method)	GAS	Ottenbacher and Cusick (1990). Goal attainment scaling as a method of clinical service evaluation American Journal of Occupational therapy 44(6) p519-525	✓	
15. Hampshire Assessment for Living with Others	HALO	Shackleton Bailey MJ. Pidock BE (1983)The Hampshire assessment of living with others (HALO) 5th version Hampshire Social Services	✓	✓
16. Interest Checklist	MOHO	Heasman D and Salhotra G (2008) http://www.cade.uic.edu/moho/productDetails.aspx?aid=39	✓	✓
17. Katz Index of Independence in Activities of Daily Living scale	Katz ADL	Katz S (1959, Revised 1976). Katz, S., Down, T.D., Cash, H.R.,and Grotz, R.C. (1970) Progress in the development of the index of ADL. The Gerontologist, 10(1), 20-30.	X	

Name of assessment tool	Test	Authors	Already known to local OT team	In use by local OT team
18. Mayers' Lifestyle Questionnaire (1)		Mayers CA (Updated 2004). Developed to enable people with problems related to physical disability or older age to state their quality of life priorities at the beginning of occupational therapy intervention. The Mayers' Lifestyle Questionnaire (1) is recommended by the Department of Health for use within the Single Assessment Process. http://www2.yorksj.ac.uk/Default.asp?Page_ID=1955	X	
19. Model of Human Occupation Screening Tool version 2.0	MOHOST	ParkinsonS, Forsyth K and Kielhofner G (2006) http://www.cade.uic.edu/moho/productDetails.aspx?aid=4	✓	
20. Occupational Circumstances Assessment Interview and Rating Scale (Version 4)	OCAIRS	Forsyth K, Deshpande S, Kielhofner G, Henriksson C, Haglund L, Olson L, Skinner S, and Kulkarni S (2005). http://www.moho.uic.edu/assess/ocairs.html	✓	
21. Occupational Performance History Interview –II (Version 2.1)	OPHI _ II	Kielhofner G, Mallinson T, Crawford C, Nowak M, Rigby M, Henry A, and Walens D (2004). http://www.moho.uic.edu/assess/ophi%202.1.html	X	
22. Occupational Questionnaire		Smith NR, Kielhofner G and Hawkins Watts J (1986) The relationship between volition, activity pattenr, and life satisfaction in the elderly. American Journal of Occupational Therapy 40 278-283 http://www.cade.uic.edu/moho/resources/files/Occupational%20%20Questionnaire.pdf	X	
23. Occupational Self Assessment (Version 2.2)	OSA	Kathi Baron, Gary Kielhofner, Anita Iyenger, Victoria Goldhammer, and Julie Wolenski (2006). http://www.moho.uic.edu/assess/osa.html	✓	
24. Pool Activity Level Instrument for Occupational Profiling	PAL	Pool J. Pool J (2002) The Pool Activity Level (PAL) Instrument for Occupational Profiling: a practical resource for carers of people with cognitive impairment. London, Jessica Kingsley	X	

Name of assessment tool	Test	Authors	Already known to local OT team	In use by local OT team
25. Scale for Assessing Coping Skills		Whelan E and Speake B (1979) Copewell Publishing	✓	
26. Sensory Integration and Praxis Tests	SIPT	Ayres A J (1989). WPS available from USP: http://www.wpspublish.com/store/p/2971/sensory-integration-and-praxis-test-sipt [accessed 6th November 2016]	X	
27. Sensory Integration Inventory Revised for Individuals with Developmental Disabilities	SII	Reisman J, and Hanschu B, (1999) Stillwater, MN: PDP Press.	X	
28. (The) Sensory Integration Model		Fisher AG et al (1991)	X	
29. Sensory Modality Assessment and Rehabilitation Technique	SMART	Gill-Thwaites H (1997) The Sensory Modality Assessment Rehabilitation Technique--a tool for assessment and treatment of patients with severe brain injury in a vegetative state. *Brain Injury*,11(10), pp.723-34.	X	
30. (Long and Short) Sensory Profile		Bhreathnach E (1996) Avaialble from USP: http://www.sensoryattachmentintervention.com/ [accessed 6th November 2016]	X	
31. Six item Cognitive Impairment Test	6CIT	Katzman R, et al (1983). Available from USP : http://patient.info/doctor/six-item-cognitive-impairment-test-6cit [accessed 6th November 2016]	X	
32. Snellen Chart	---	McGraw et al (1995)	X	
33. The star profile social training achievement record. Instruction manual.		Williams, C. (1982) British Institute of Mental Handicap Kidderminster.	✓	

Name of assessment tool	Test	Authors	Already known to local OT team	In use by local OT team
34. Supports Intensity Scale	SIS	American Association on Mental Retardation (2004) Washington, DC USA	X	
35. Teaching Age-Appropriate Purposeful Skills	TAPS	Rona Pogrund, Gene Healy, Kelley Jones, Nancy Levack, Sharon Martin-Curry, Carolina Martinez, Janet Marz, Burnsteen Roberson-Smith, and Anna Vrba (1995).	X	
36. Therapy Outcome Measure	TOM	Enderby P, John A, and Petheram B (2006) *Therapy Outcome Measures for Rehabilitation Professionals.* Wiley, Chichester.	X	
37. The Remotivation Process Version 1.0	---	de las Heras CG, Llerena V, and Kielhofner G (2003) http://www.cade.uic.edu/moho/productDetails.aspx?iid=1	X	
38. Vineland Adaptive behavior scales II second edition		Sparrow SS, Cicchetti DV and Balla DA (2005) http://www.pearsonclinical.co.uk/SearchResults.aspx?keywords=vinelan	✓	
39. Volitional Questionnaire (Version 4.1	VQ	de las Heras CG, Geist R, Kielhofner G, and Li Y (2007) http://www.cade.uic.edu/moho/productDetails.aspx?aid=8	✓	

Appendix H: Participant with learning disability information and consent forms

Version 2 04/12/09

Information leaflet

Making occupational therapy assessments better.
OTs meet with people with learning disabilities to find out what things they can do.

Things like cooking

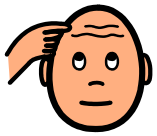
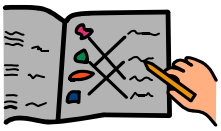
and using money

This is called an assessment.

They want to help you do more for yourself.

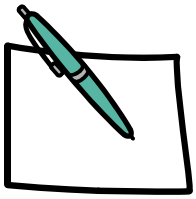
Photo of OT

You have been working with your OT *(Add name)*

<table>
<tr><td> 
  </td><td>I want to ask you what you think about

your assessment</td></tr>
<tr><td colspan="2">If you talk to me I will not tell anyone who you are.

But If you tell me anything that is a big problem, I may need to share this with other people.

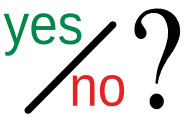
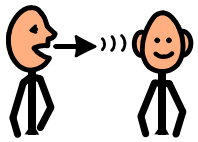
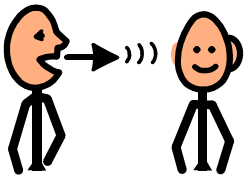
I will tell you if I need to do this.</td></tr>
<tr><td> 
Photo of OTs

 </td><td>I will tape and then write down all the things you say.

All the things that people say will be shared with the group of OTs

so that we can find out what is good…

and what is bad about the assessments.</td></tr>
</table>

We want to make the assessments better to help other people.	
	You can say yes
	You can say no at any time
	It's up to you
	Talk with a friend/carer. They may want to ask questions too
	Take time to think about it.
	If you have any questions you can talk to me again.

(Photograph, name and contact details of lead researcher)

LONDON SOUTH BANK UNIVERSITY

Version 2 04/12/09

More detailed Information about the Research

Making occupational therapy assessments better.

Photo of lead researcher

My name is [Lead Researcher]

I want to ask you what you think about your OT assessment.

Please ask *[name of occupational therapist]* if you do not understand anything.

Take time to decide.

Why is this project being done?

I want occupational therapists to do a good job.

I want to find out how occupational therapists can do their job better.

The reason we are asking you these questions is that we will try to carry on doing the good things and try to change the bad things.

Occupational therapists can use different ways of finding out how well you can do things for your-self. We call these ways, assessments. We want to find out if we are doing the best assessment possible.

Why have I been invited?

We want to talk to 8 people who have seen an occupational therapist.

You have just been assessed by

Photo of OT

[name of occupational therapist]

Do I have to take part?
No. It is up to you.

What will happen to me if I take part?
I will come and see you at your house.
I will ask you some questions.
It will take about 1 hour.

I will record the interview with a voice recorder or video you
I will keep the recording.

I will write down what you say and do.

A copy of what you said will be sent to you if you want.

I will talk about what you said to the other OTs and to my supervisors and write this down in my project.

I will make sure that no one will know the names of people I interview.

But, if you tell me something that I think is a big problem I may need to tell other people. If this happens I will talk to you about it and with someone you are happy for me to talk to.

All the things you say will be kept in a place that no one else can find them.
All the things people say will be put together. I will not say who said what.
Some things you say may be written down like this:

One man/woman said 'I did not like…….'.

Taking part will not change how our service works with you in the future.

If you feel unhappy please tell me or *(Significant carer)*

Other people
I would like to talk to other people about what they thought about your assessment.

These people will be all the people who were given a copy of your report.

People like:

[Name of carer]

[Name] of social worker

[name] of nurse

[name] of psychologist

Dr [name] of GP

[Photo and name] of your occupational therapist

Can you think of anyone else who you would like me to talk to?

Will joining in help me?
The things you tell me are very important.

We hope it will help other people get a better service from occupational therapy.

Will anything upset me?
I hope not.

You might find the questions difficult.

You can have a break when you need one.

You can ask to stop if you need to.

Will anyone else know I'm doing this?
The OTs will know you are taking part.

All the people you say it is ok for me to talk to will know you are taking part.

I will not tell them what you say.

I will not tell you what they say.

All the things you say will be kept private.

No one will know that you said any of the things.

What if something goes wrong?
If you are upset or worried at any time please speak to your Mum or me Judith Reep. My number is 02086986788

Or [name] *Team Manager* telephone number

You can ask your carer to call if you like.

What if I don't want to do this project anymore?
If you do not want to take part that is ok.

You can say stop at any time.

If you do not want to talk to me, you can talk to another OT instead.

If you do not want to take part :

You can tell me.

You can tell *(Significant carer)*

I will not be upset.

What will happen next?
All the things found out will be told to the OTs so they can try to make the assessment better.

I will write everything down and share it with people who might be interested.

This could be:

People like you who helped with the study.

People who work with people with learning disabilities.

Occupational therapists who work with people with learning disabilities in other places.

South Bank University who are teaching me how to do this project.

Who is doing the project?
[name of lead researcher]. I am an occupational therapist and I am a student at London South Bank University.

Who is paying for the project?
[name of trust].

Did anyone else check the study is OK to do?
Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee.

They make sure that the research is ok.

Your project has been checked by the South London and Maudsley Research Ethics Committee.

Please call me or tell *(Significant carer)*if you want to ask any questions.

Thank you

[name of lead researcher, title, work address

Participants with learning disabilities Consent Form

Version 1. 29/10/09

Title of Project:
Making occupational therapy assessments better.

Name of Researcher: Judith Reep

Consent is asking you if you are happy or not happy to take part.

Please tick√ yes or no

Have you read/had read to you the information sheet/leaflet?

□ Yes □ No

Has somebody else explained this project to you?

□ Yes □ No

Do you understand what this project is about?

□ Yes □ No

Have you asked all the questions you want?

□ Yes □ No

Do you understand the answers to your questions?

□ Yes □ No

Do you understand it's OK to stop taking part at any time?

□ Yes □ No

Are you happy to take part?

□ Yes □ No

I would like to talk to other people about what they thought about your assessment.

Will it be ok for me to talk to:

Photo	Name of Carer	□ Yes	□ No
Photo	Name of social worker	□ Yes	□ No

List to include all recipients of the assessment and set out as above *(e.g. GP, speech therapist, psychologist, advocate, day centre worker)*

Photo	Your occupational therapist	□ Yes	□ No

Anyone else? Please tell me their name:

---------- □ Yes □ No

---------- □ Yes □ No

Are you happy to be video recorded when you answer the questions?

□ Yes □ No

If any answers are 'no' or you don't want to take part, don't sign your name.

If you do want to take part, you can write your name below

Your name _____

Date _____

The person who explained this project to you needs to sign too:

Print Name _____ Sign _____

Date _____

Thank you for your help.

Personal consultee consent form

Version 1 17/08/10

Consultee Questions

Please read the information sheets carefully and then advise on the following:

You are not being asked for your own personal view about the project just what you think the view and interests of the participant are.

You are not being asked to consent on behalf of the person who lacks capacity.

Do you think [*name of participant with learning disabilities*] should take part in the project? Yes No

Are you happy that I approach the team of people who have contact with [*name of participant with learning disabilities*] to comment on their perceptions of the occupational therapy assessment?
Yes No

At any stage, you can advise the researcher if you feel that **[*name of participant with learning disabilities*]** would want to withdraw from the project, and your advice will be respected.

I confirm that I am happy for [*name of participant with learning disabilities*] to be involved in this project

Name _____

Signature_____

Relationship to [*name of participant with learning disabilities*] _____

Independent advice about this role can be obtained from [redacted] PCT Mental Capacity Advisor.

Reference: Mental Capacity Act 'Nominated Consultee' Guidance Feb 22 2008

Appendix I: Carer information and consent forms

Carer information sheet

Version 1 29/10/09

Carers' Information about the Research 17/08/10

Study title: An action research study to develop an occupational therapy assessment tool to identify the community living skills of adults with learning disabilities.

Shorter title: Making occupational therapy assessments better.

My name is [lead researcher]. I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to me about the study if you wish.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
The purpose of the study is to try to improve the occupational therapy assessment process for adults with learning disabilities.

Why have I been invited?
You have been chosen for this study as you are the identified carer for XXX who has recently had an assessment from an occupational therapist. I would like to interview you. I would also like to send a questionnaire to other people who had an interest in the assessment.

Do I have to take part?
Taking part in the research is entirely voluntary. It is up to you to decide. When I meet you I will describe the study and go through the information sheets. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This will not affect how anyone in the service will provide care for XXX now or in the future.

What will happen to me if I take part?
I will come and see you at your home. I will ask you some questions. This will take about 30 minutes. The interview will be recorded using an audio recorder and I will also take some notes.

All the things people say will be put together in a final document. Some things you say may be written down as a direct quote although you will not be able to be identified.

When all the interviews have been completed, I will contact everyone to see if you would be interested to see the results of the interviews.

Expenses and payments

There is no payment for taking part in this study. I plan to meet you in a time and place that is best for you. It is not expected that there will be anything that will need to be paid for. If you feel that expenses may incur please discuss this with me to see if any arrangements can be made.

What will I have to do?

I will meet with you to ask some questions about your experience and views of the occupational therapy assessment. Any comments made at this day will also be recorded and shared with the OT Co-researchers.

What is the procedure that is being tested?

Occupational therapists can use different ways of finding out how well people with learning disabilities can do things for themselves.
We want to find out what people think of the way we are assessing people at the moment in order to find out what is working and what may need changing.

You are being interviewed at the beginning of the research project so we can find out how the assessments are working at the moment before any changes have been made.

What are the possible benefits and disadvantages of taking part?

Participation in this project will mean that the OT assessment process will reviewed taking into account views or carers, people with learning disabilities and other relevant stakeholders. This may not benefit you or the person you care for directly as you have just completed an OT assessment. Is hoped that the occupational therapy assessment will be improved and better meet the needs of people with learning disabilities in the future.

Involvement in the project will take up time. It is envisaged that the interviews of you and the person you support will be arranged at the time that most suits you. It is hoped that this will not take longer than one and a half hours for both interviews.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All the things you say will be kept in a confidential place on NHS encrypted computers and memory sticks. Your name will not be used and no one will be able to identify who you are from the written reports. The interview will be confidential and your identity will not be shared. The information will be shared with the occupational therapists in this service who have agreed to be part of the project and my research supervisors. These are called OT Co-researchers. Only myself and the OT Co-researchers will know who said.

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you will have your name and address removed so that you cannot be recognised.

If anything is disclosed in the interview that may need to be reported such as a safeguarding adult issue or a problem with a service, this will be discussed with you if possible. However, there may be occasions where duty of care over rides confidentiality.

The information from the interviews will be stored for up to 10 years in a secure place. It will then be destroyed. Once you have agreed that the information can be used it may be reviewed in a future part of the study when considering if any changes to the OT assessment process have met any of the concerns raised at the beginning of the project.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed.
If you have a concern about any aspect of this study, you should ask to speak to me who will do my best to answer your questions.
[lead researcher tel number
Alternatively you could contact:
[team manager and contact details supplied]
If you remain unhappy and wish to complain formally, you can do this through the XXX Complaints Procedure.

What will happen to the results of the research study?
Findings from the study will be shared with local interested groups throughout the study. They may also be shared more widely, for example with other occupational therapists working with people with learning disabilities. The research is being completed as part of a PhD and so the results will be part of the dissertation. It is expected that some aspects of the project will be written up for publication. You will not be identified in any report/publication unless you have given your consent.

Who is organising and funding the research?
I am completing this research as part of a part time PhD at London South Bank University. I am part funded by [redacted] and part self-funded.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by South London and Maudsley Research Ethics Committee.

You will be given a copy of this information sheet and a copy of the signed consent form to keep. Please contact me if you would like further information about the study.

Completed by

[Lead researcher]

Consent form- Carer

Version 1 29/10/09

Carers' forms. CONSENT FORM

Title of Project: An action research study to develop an occupational therapy assessment tool to identify the community living skills of adults with learning disabilities.

Name of Researcher: [lead researcher]

Please tick √ one box

1. I confirm that I have read and understand the information sheet dated 29/10/09 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

   Yes ☐ No ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being or the care of the person I support being affected.

   Yes ☐ No ☐

3. I understand that any data collected during the study will be anonymous but may be shared with the supervisors of [lead researcher] at London South Bank University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to these records.

   Yes ☐ No ☐

4. I agree to take part in the above study.

   Yes ☐ No ☐

_____ _____ _____

Name of Participant

_____ _____ _____

Name of carer Date Signature

When completed form to be provided to: 1 for Carer; 1 for researcher site file.

Appendix J: Semi-structured Interview Guides

Participant with learning disabilities Client interview guide

Version 1 29/10/09

Adapted 2/8/10

Name:

The interviewer will show the participant a copy of the OT assessment report.

My research is about making the occupational therapy assessment better.

I want to talk to you about the assessment you did with *Name of OT show photo*

Do you remember this person?

Tell me the things you remember doing with *Name of OT*?

How did she assess you?

What went well?

What did not go so well?

Name of OT was the OT who worked with you and wrote down what she/he did in this report.

What things did you talk about or do with *Name of OT*

What did you think about the assessment?

What things were good?

What things were bad?

What did ….OT say you should do?

What did …….OT say other people should do?

Were these important to you?

Was this useful?

Did you understand what the OT did/said?

Do you think what the OT said about you was true?

Was the amount of time spent doing the assessment ok?

Did the OT see you doing any activities?

Did the OT listen to what you said?

Is there anything else you would have liked the OT to have done?

Do you have any other things you want to say?

If the person is able, the questions set out for the carer will be asked as well.

Did the OT assessment meet the following criteria:	**Yes/No/ Don't know (DK)**	**Comments**
Did the assessment look at the living skills that are important to you?		
Or just one thing in particular.		
Did the OT say/do anything that made your skills better?		
Did the assessment look at how you learn?		
Did you have a chance to say what you thought?		
Did you understand what ….was asking you to do and telling you?		
Did you find the assessment helpful/useful?		
Did you agree with what the OT said?		
Did the OT spend the right amount of time with you?		
Did the OT watch you do things?		
Did the OT talk to the people that you wanted her to talk to.		
Did the OT listen to your views		

Was it useful to have an OT assessment?		
Did other people talk about the OT assessment?		
Is there anything else you would have liked the OT to have assessed? Other comments/views…		

What things do you think will make the assessment better/ needs to change?

Thank you

Carer semi-structured interview guide

Version 1 29/10/09

Semi structured interview for carers

I want to talk to you about the OT assessment on …….. carried out by…….

I will be asking some general questions and then some more specific.

What did you think about the assessment?

1.Referral process

How was the OT referral identified?

Did it address the needs you expected?

2. How the assessment was carried out.

Venue

Your understanding of what OT did.

Type of assessment how did the OT find out these things?

3. Validity/value

Did it make sense, feel true, appropriate

4. Outcome

Make any difference

5. Report

Useful. Understanding.

6.What things went well?

7. What things could be better?

Any other comments?

Did the OT assessment meet the following criteria:	Yes/No/ Don't know (DK)	Comments
The focus of the assessment was on how the person's learning disability affects his/her skills.		
The assessment addressed all the community living skills that are important to the individual.		
Or The assessment concentrated on one particular skill.		
The assessment highlighted skills and support needs and from this made meaningful and useful recommendations.		
The assessment took into account client centred/choice and empowerment		
The assessment process for the client was accessible and easy for him/her to use and understand		
The assessment was relevant and designed for people with learning disabilities		
The assessment was fit for purpose and you agreed with the results.		
Undertaking the assessment was a good use of resources.		
The occupational therapist observed the person carrying out activities of daily living rather than solely relying on reports of others.		
The assessment incorporated your views.		

The assessment Incorporated the views of all people involved with the person with learning disabilities List who		
The assessment was useful for you.		
The assessment fits with other assessments carried out on the same person.		
Did the assessment fit with the way you think learning disability services should be working?		
{Not carer question unless they work for an organisation} The assessment fits with other policies within your setting.		
Is there anything else you would have liked the OT to have assessed?		

The research is about changing the OT assessment what things do you think are the most important to change?

Please make any additional comments about occupational therapy assessments in general from the learning disability team.

Thank you for your time.

Appendix K: Questionnaires for stakeholders and occupational therapists

Stakeholder Questionnaire

Version 1.2 23/08/10

ADDRESS and telephone number

Dear

I would like to invite you to take part in a research study. The purpose of the study is to try to improve the occupational therapy assessment process for adults with learning disabilities. The occupational therapists in the learning disability teams in [redacted] have selected a small group of people with learning disabilities who have recently had an OT assessment completed with them.

You have been chosen for this study as you have been identified as someone who has an interest in the occupational therapy assessment recently completed with XXXX.
Even if you feel that you do not have much information, this will still be useful, as the project is considering the perspectives of all the various parties involved.

XXX and/or his carer have already given their consent to be part of this study and have participated in interviews. They have agreed that you should be approached.

If you are happy to participate please complete the enclosed questionnaire and return it in the pre-paid envelope to me as soon as possible.

What will happen to the results of the research study?

The questionnaire is designed so I can link the feedback to the specific OT assessment. However, once the questionnaire is received, the information will be kept securely and made anonymous. No identifiable information will be disclosed to other parties. All the things people say will be put together in a final document. Some things you write may be directly quoted but all responses will be anonymous.

Findings from the study will be shared with local interested groups throughout the study. The research is being completed as part of a PhD and so the results will be part of the dissertation. It is expected that some aspects of the project will be written up for publication. You will not be identified in any report/publication. If you would like to be sent a copy of a summary of the findings please indicate on the questionnaire.

Who is organising and funding the research?

I am completing this research as part of a part time PhD at London South Bank University. I am part funded by [redacted] and part self-funded.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by South London and Maudsley Research Ethics Committee.

Please contact me if there is anything that is not clear or if you would like more information.
Yours sincerely

Judith Reep

Your Profession:

Please answer the following questions specifically about the OT assessment carried out on XXXXX between date and date.

What was the reason for the assessment?

What was the outcome of the assessment?

What parts of the assessment was useful to you?

What aspects were not useful?

Please comment on each of the statements below.

Did the OT assessment meet the following criteria:	**Yes/No/ Don't know (DK)**	**Comments**
Did you receive a copy of the assessment report before today?		
Had you read this assessment report before today?		
Is the assessment relevant to your work with the person?		

Did the OT assessment meet the following criteria:	Yes/No/ Don't know (DK)	Comments
Do you think that the assessment addressed all the community living skills that are important to the individual?		
Did the assessment highlight the person's skills and support needs and from this made meaningful and useful recommendations?		
Did the assessment take into account client centred/choice and empowerment?		
Do you think that the assessment process for the client was accessible and easy for him/her to use and understand?		
Do you think the type of assessment used worked well for people with learning disabilities?		
Do you think the assessment was fit for purpose and you agree with the results?		
Do you think that undertaking the assessment was a good use of resources?		
Was the assessment completed in an appropriate time frame?		
Did the occupational therapist observe the person carrying out activities of daily living?		
Does the assessment incorporated the views of other key people involved with the person?		
Did the assessment incorporate your views?		
Does the assessment fits with other assessments carried out on the same person.		
Did the assessment fit with the way you think learning disability services should be working?		

Did the OT assessment meet the following criteria:	Yes/No/ Don't know (DK)	Comments
Does the assessment fit with other policies within your setting.		
Do you think you should receive occupational therapy assessment reports?		

Please list below any aspects of this occupational therapy assessment that you think could be improved?

Please make any additional comments about occupational therapy assessments in general from the learning disability team.

Thank you for your time.

Occupational therapy stakeholder questionnaire

Version 2 20/08/10

OT Questions

Study title
An action research study to develop an occupational therapy assessment tool to identify the community living skills of adults with learning disabilities.

Name_____

Please answer the following questions specifically about the OT assessment you carried out on

_____

Start date of assessment _____

Discharge date or date report completed if still open. _____

Types of assessments used.

What was the reason for the assessment?

What areas did you cover?

What was the most useful parts of the assessment?

What was the outcome of the assessment?

What things do you think went well?

What things would you like to have changed?

Please comment on each of the statements below.

Did the OT assessment meet the following criteria:	**Yes/No/ Don't know (DK)**	**Comments**
Do you think that the assessment addressed all the community living skills that are important to the individual?		
Did the assessment highlight the person's skills and support needs and from this made meaningful and useful recommendations?		

Did the OT assessment meet the following criteria:	Yes/No/ Don't know (DK)	Comments
Did the assessment take into account client centred/choice and empowerment?		
Do you think that the assessment process for the client was accessible and easy for him/her to use and understand?		
Do you think the type of assessment used works well for people with learning disabilities		
Do you think the assessment was fit for purpose and you agreed with the results.		
Do you think that undertaking the assessment was a good use of resources.		
Was the assessment completed in an appropriate time frame.		
Did the you observe the person carrying out activities of daily living rather than solely relying on reports of others.		
Does the assessment incorporated the views of other key people involved with the person?		
Does the assessment fits with other assessments carried out on the same person.		
Did the assessment fit with the way you think learning disability services should be working?		
Does the assessment fits with other policies within your setting.		

Please list below any aspects of this occupational therapy assessment that you think could be improved?

Please make any additional comments about occupational therapy assessments in general from the learning disability team.

Thank you for your time.

Occupational therapy stakeholder questionnaire: Stage three

This was the same as stage two except for the following amendments:

Version 3

29/11/12

Study title:

An action research study to improve the *occupational therapy practice* provided to adults with learning disabilities in a community health team

Since September 2011 the occupational therapists have changed the way they work taking into account the findings from the first part of this project and other changes that needed to be made within the service.

Did you change how occupational therapy was carried out in this case, taking into account the new ways of working?

☐ Yes

☐ No

If Yes please list all changes and comment on if these were positive, negative or made no difference.

Changes	**Comments**

Please make any additional comments about occupational therapy assessments in general from the learning disability team.

Appendix L: Changes in occupational therapy practice planning days

Occupational Therapy Team Days Agenda

Day 1: Thursday 18th August 2011

9:00 Start
9:15 Presentation of Referral to Treatment Times (RTT) Away Day.
9:45 18 Weeks Referral to Treatment- What we are doing now.
10:00 Ideas on improving RTTs.
Please bring examples of leaflets, pathways eg travel training pack, budgeting, dementia, skills teaching etc.
10:45 Break
11:00 Work on developing packs to address different referrals and interventions.
12:30 Lunch
1:30 Present packs. Agree action plans
2:00 Review OT pathway e.g. Completing Initial assessment rather than screening.
2:30 Review specific issues with the new way of working:
E.g.: Working with Families vs working with support workers
Consider what is our duty of care.
3:00 Break
3:15 How to manage our existing waiting list/caseloads.
4:30 Finish

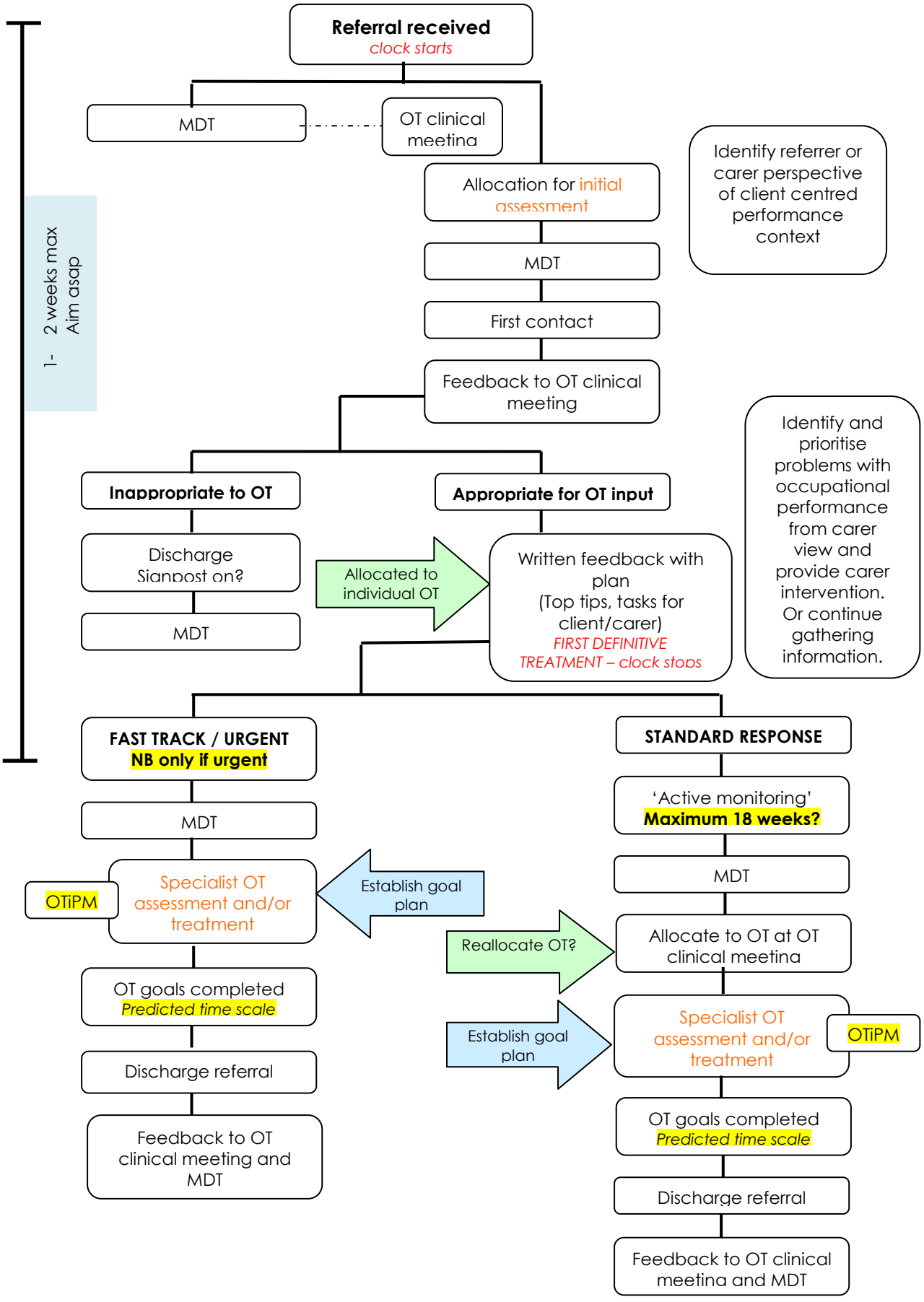
Day 2: Monday 22nd August

9:00 Start
9:30 Assessment process- OTIPM
10:00 Assessment tools-
10:30 Break
10:45 Review of assessments we are using and report formats. Please bring examples of formats.
12:30 Lunch
1:30 Individual OT pathways for assessments and interventions.
– How many sessions do we expect.
_ Outcomes
3:00 Tea
3:30 RIO Issues
4:30 Finish

Day 3: Thursday 25th August

Finalising the new way of working for OT
9:00 Start
9:30 Plan agenda to include:
Finalised packs to address referral issues.
Finalised OT pathway
Agreed assessment and report templates.
RIO Recording
Agree dates for peer supervision.
4:00 New way of working for OT is ready to be put in practice!

Appendix M: Referral to Treatment Pathway



Appendix N: Questionnaire on use of new forms and processes

OT Co-Researcher survey of New Ways of Working.			
Name	Date 3/11/11	Numbers	Comments or brief description
How many new referrals have you completed initial assessments on since 1/9/11?			
How many of these are you using new way of working strategies?			
How many initial assessments are you currently working on?			
How many using new way of working?			
How many people on your case load have you worked with using some aspect of the New Way of Working since 1/9/11?			
How many people on your caseload have you worked with since 1/9/11 without using any New Ways of Working strategies?			
Please indicate in the table below which forms you have used or referred to since 1/9/11			

Form	How many times used?	How many clients used with?	Have you considered or plan to use?	Any suggested changes needed.	Comment on how you used it or why not *Please provide me with examples of completed forms.*
OT RTT Pathway *Flow chart*					
Care Pathway OT assessment *Expected Sessions*					
Goal Plan					
Initial assessment form					
OT leaflet					
Budgeting					
Capacity					

Form	How many times used?	How many clients used with?	Have you considered or plan to use?	Any suggested changes needed.	Comment on how you used it or why not *Please provide me with examples of completed forms.*
Cooking skills checklist					
Housework checklist,					
Equipment					
Full skills ADL					
Interest checklist					
Personal care					
Client travel training					
Top tips when out					

Form	How many times used?	How many clients used with?	Have you considered or plan to use?	Any suggested changes needed.	Comment on how you used it or why not *Please provide me with examples of completed forms.*
Carer Travel Training screening.					
Specialist OT assessment Grid					
Participation training forms					
Skills teaching Top Tips					
Other skills teaching forms					
Accommodation support needs					
Activities					
Dementia					

Form	How many times used?	How many clients used with?	Have you considered or plan to use?	Any suggested changes needed.	Comment on how you used it or why not *Please provide me with examples of completed forms.*
Eating and drinking					
Employment					
Sensory					
AMPS activities list					
Please add any other forms used					

Please add any other comments here or over page.

JR 3/11/11

Appendix O: Invitation letter for action learning sets

Action Learning Sets: OT Co-Researchers

Team A	**10-11am**	**27/9/11**
Team B	**10-11am**	**5/10/11**
Combined	**1:30-2:30pm**	**3/11/11**
Team B	**10-11am**	**30/10/11**
Team A	**10-11am**	**6/12/11**

Aims- To develop our understanding of the new OT process.

To reflect on the changes – what is going well, what are the problems.

To share our practice and learn from each other.

Please can you be prepared to share for 5-10 minutes each about whatever you think is relevant regarding your current cases and how you are attempting to put the new process into practice. We will then have 10-15 minutes for discussion on each person's presentation.

This is an informal session so please don't worry about spending too much time preparing. (You may want to complete a reflective log that could then be added to your cpd portfolio).

I will be taping the sessions. The plan for my research is to try to capture the process of implementing our proposed changes and how this is working in practice.

I also want to identify possible people to approach for interview as we go along. I want to complete 6 more cases by January 2011.

This is my initial plan for these sessions. Please feel free to comment on this draft and let me know if there needs to be any changes by email before the session or at the sessions.

Thanks

XXX

Lead researcher

21/09/11

Appendix P: OT Goal Plan

Photo of OT

Occupational Therapy

Goal Plan

This is an agreement between us.

It says what work we will do together.

We will go through it together.

If we agree with the plan we will sign our

Goal Plan

What?	Who?	When?

We are happy with our goal plan

Photo of client

Photo of OT

Appendix Q: Occupational Therapy Assessment and Intervention Timescales

September 2011 Each session = 3.45hours

Type of Assessment or intervention	How Long?	Discharge Indicators	Who
AMPS	• 1 session to administer • 2 sessions to write • 1 session to feedback Total = 3	AMPS completed in the context of wider assessment	AMPS qualified OT's, currently band 7+
Specific Skills Assessment: Financial/Budgeting Cooking Domestic Self Care Domestic Community Access Travel Training	• 1 session to make observations/goal setting • 1 session to write up • 1 session = feedback and negotiate skills teaching programme Total = 3	Skills assessed, recommendations in place for skills training or identified level of support in place	All OT's
Skills teaching programmes: Financial/Budgeting Skills Cooking or Domestic Skills Self- Care Community Access - within walking distance Travel Training – including use of public transport	• Up to 4 sessions • Up to 6 sessions with a review half way • Up to 8 sessions with a review half way • Up to 8 sessions with a review half way • Up to 12 sessions with a review half way	Goal achieved Goal achieved Goal achieved Goal achieved Goal achieved	All OT's
ADL Checklist	• 3 sessions =gather information and undertake observations • 1 session = write up • 1 session = feedback Total = 5	ADL checklist completed and feedback	All OT's

Type of Assessment or intervention	How Long?	Discharge Indicators	Who
Placement Support Accommodation Profile	• 7 sessions = gather info and observations (may include skills assessment, ADL checklist, sensory profile, HALO) • 2 sessions = write up • 1 session = feedback Total = 10	Assessment completed and recommendations made	All OT's
Interest Checklist	• 1 session = administer • 1 session = write up • 1 session = feedback with information on identified activities Total = 3	Assessment completed with recommendations	All OT's
Role Checklist	• 1 session = administer • 1 session = write up • 1 session = feedback with information on identified activities Total = 3	Assessment completed with recommendations	All OT's
Sensory Assessment and Intervention	• 2 sessions = speaking to carer's (across settings) • 3 sessions = direct observation (across times/activities/environments) • 3 sessions = trial options • 2 sessions = write up recommendations and feedback Total = 10	Assessment completed with recommendations	All OT's under specific supervision of a SI qualified OT

Type of Assessment or intervention	How Long?	Discharge Indicators	Who
Eating and Drinking	• 2 sessions = collecting information and mealtime observations • 1 session = trial solutions • 1 session = write up recommendations and feedback Total = 4	Assessment completed, equipment/guidelines in place Case closed	All OT's
Dementia Training	• 2 sessions to prepare and plan training with other members of the MDT • 1 session to deliver training	Support staff receive bespoke training for the client they are supporting	All OT's
Dementia Co-ordinator	• Up to 6 sessions across the year to liaise with support staff and MDT, to arrange review meetings and co-ordinate referrals	Client and support staff receive input from the MDT in a co-ordinated manner	All OT's
Groups: -Community Safety -Living Together -Moving On -Sex and Relationships -Thinking about Options	• 12 sessions = preparation/pre-post measures/accessible information • 12 sessions = practical sessions with clients • 9 sessions = feedback to carers/report and recommendations Total = 33	Outcomes, recommendations and aims met Community safety portfolio received	1 OT's (any grade) > 8 clients

Type of Assessment or intervention	How Long?	Discharge Indicators	Who
Day structure and activities	• Up to 5 sessions = trying out suggested activities if client does not have support • 1 session write up final recommendations and feedback	Activities recommended and in place for client to use if no support or Activity recommended and staff/carer supporting client to use.	All OT's

OT TEAM 8.09.11

Appendices R: Additional details of findings from Chapters six, seven and eight

Table R.1: The responses from the interview and questionnaires in stage two regarding if each criterion was perceived to have been met when the occupational therapy assessment was completed.

	Data Set C	Data Set D	Data Set E	Data Set G	Data Set H	Data Set I
Number of responders	**2**	**5**	**4**	**6**	**5**	**7**
Assess occupational performance Yes: 27/29 (93.10%) D/K 2 No 0	1/2 Carer d/k	5/5	4/4	6/6	5/5	6/7 SH d/k
Global skills rather than just one particular skill Yes: 26/29 (89.65%) D/K: 2 No: 1	2/2	5/5	3/4 SH no	6/6	5/5	5/7 2 D/K OT and carer
Highlight skills and support needs in order to make meaningful and useful recommendations: Yes: 26/29 (89.65%) D/K: 3 No: 0	1/2 carer D/K	5/5	4/4	6/6	5/5	5/7 Carer D/K as still ongoing. SH D/K
Client centred/choice and empowerment Yes: 27/29 (93.10%) D/K: 2 No: 0	2/2	5/5	4/4	6/6	5/5	5/7 2 D/K OT and SH.
Accessible easy to use and understand Yes: 22/29 (75.86%) D/K: 4 No: 3	2/2	4/5 SH D/K	4/4	5/6 SH D/K	5/5	2/7 2 D/K OT Carer 3 SH no
Designed for people with learning disabilities Yes: 28/29 (96.55%) D/K: 1 No: 0	2/2	5/5	3/4 SH D/K	6/6	5/5	7/7
Fit for purpose/reliable/valid/(standardised) Yes: 29/29 (100%)	2/2	5/5	4/4	6/6	5/5	7/7

	Data Set C	Data Set D	Data Set E	Data Set G	Data Set H	Data Set I
Number of responders	**2**	**5**	**4**	**6**	**5**	**7**
Practical/ good use of resources Yes: 21/25 (84%) D/K: 2 No: 1 Blank 1 (Pwld not asked)	1/2 Carer blank	4/4	1/3 2 SH D/K	5/5	4/4	6/7 SH no
Observation Yes: 28/29 (96.55%) D/K: 1 No: 0	2/2	5/5	4/4	5/6 SH D/K	5/5	7/7
Incorporate views of all people involved with the person with learning disabilities Yes: 22/29 (75.86%), D/K: 3, No: 4	2/2	4/5 SH D/K	4/4	6/6	3/5 2 No OT SH	3/7 2 no OT SH. 2 SH D/K
Fits with other local, national, international assessment development. Yes: 24/25 (96 %) D/K: 1 No: 0 (Pwld not asked).	2/2	4/4	3/3	5/5	4/4	6/7 OT D/K
Total for data sets Scores of : Yes 280 (90.03 %) D/K 21 (6.75 %) No 9 (2.89 %) Blank 1 (0.32 %) Total responses 311	 19/22 2 D/K 0 no 1 blank 86.36%	 51/53 2 D/K 0 no 96.23%	 38/42 3 D/K 1 no 90.48%	 62/64 2 D/K 0 no 96.87%	 51/53 0 D/K 2 no 96.23%	 59/77 12 D/K 6 No 76.62%

Key to abbreviations: D/K –don't know. SH- Stakeholder OT- Occupational therapist Pwld – participant with learning disabilities.

Table R.2 Completed Initial assessments

September- November	**2011**	**2012**
Number of initial assessments completed by OT co-researchers	23	38
Number of completed initial assessments using the changes in occupational therapy practice.	18 78%	34 89%
Number of OT co-researchers using the changes in occupational therapy practice to complete initial assessments 100% of the time.	3/7	6/7

Table R.2 sets out the OT co-researchers responses regarding the initial occupational therapy assessments that each had been completed in the three month time period. In 2011, three out of the seven OT co-researchers used the new initial assessment format. In 2012 this increased to six out of seven OT co-researchers. This respondent who did not use the new form for all initial assessments reported using it for five out of nine referrals.

Table R.3 Current initial assessments

September- November	2011	2012
Number of initial assessments that the OT co-researchers were currently working on.	18	16
Number of initial assessments where OT co-researchers were using the changes in occupational therapy practice.	15 83%	16 100%
Number of OT Co-researchers using the changes in occupational therapy practice with 100% of clients.	4/7	6 (out of 6)

The initial assessments that were still being completed by the OT co-researchers at the time of the survey are reported in Table R.3. In 2011, four out of the seven OT co-researchers were using some aspect of the new ways of working for the current initial assessments that they were working on. In 2012 this increased to six out of the six OT co-researchers. One OT co-researcher was not currently working on initial assessments during the second time period due to having a different role and so this may also explain why the number of initial assessments that were currently being worked on had reduced from 18 in 2011 to 16 in 2012.

Table R.4 Total of all initial assessments

September- November	2011	2012
Total number of initial assessments that the OT co-researchers worked on.	41	54
Number of initial assessments where OT co-researchers were using new format,	33 80%	50 93%
Number of OT co-researchers using the new format with 100% of clients at initial assessment.	2/7	6/7

Table R.5 The reported use of the new individual forms and processes by the OT co-researchers between September 2011- November 2012.

Form/Process	Number of OT Co-Researchers who used the form (OT) and the number of times the form was used in total (Uses) 01/09/2011-30/11/2011		Number of OT Co-researchers who used the form (OT) and the number of times the form was used in total (Uses) 01/09/2012-30/11/2012		Total reported use combined scores. 01/09/2011-30/11/2012		
	OTs	**Uses**	**OTs**	**Uses**	**OTs**	**Uses**	**Rank**
1 OT RTT Pathway	6	22	4	31	7	53	1st
2 Care pathway OT assessments, expected sessions	5	7	4	23	6	30	6th
3 Goal Plan	5	8	6	25	7	33	3rd
4. Initial assessment form	6	12	6	28	7	40	2nd
5. OT leaflet	4	13	4	18	4	31	4th=
6 Budgeting	2	2	4	4	5	6	12th
7 Capacity	0	0	3	4	3	4	15th=
8 Cooking skills checklist	3	3	5	8	5	11	8th
9 Housework checklist	2	3	1	1	2	4	16th=
10 Equipment	3	3	0	0	3	3	18th=
11 Full skills ADL	6	10	6	17	7	27	7th
12 Interest checklist	1	1	2	3	4	4	16th=
13 Personal Care	1	1	2	2	2	3	18th=
14 Client travel training	0	0	3	5	3	5	13th=
15 Top tips when out	1	1	2	4	3	5	13th=
16 Carer travel training	1	1	1	2	2	3	18th=
17 Specialist OT assessment grid	0	0	0	0	0	0	24th=
18 Participation training form	0	0	6	31	6	31	4th=
19 Skills teaching top tips	0	0	3	3	3	3	13th=
20 other skills teaching form	0	0	0	0	0	0	24th=
21Accommodation support needs	0	0	0	0	0	0	24th=

Form/Process	Number of OT Co-Researchers who used the form (OT) and the number of times the form was used in total (Uses) 01/09/2011-30/11/2011		Number of OT Co-researchers who used the form (OT) and the number of times the form was used in total (Uses) 01/09/2012-30/11/2012		Total reported use combined scores. 01/09/2011-30/11/2012		
	OTs	Uses	OTs	Uses	OTs	Uses	Rank
22 Activities	1	1	1	2	2	3	18th=
23 Dementia	2	2	3	6	3	8	10th=
24 Eating and drinking	1	2	4	6	5	8	10th=
25 Employment	0	0	0	0	0	0	24th=
26 Sensory	1	1	1	1	2	2	22nd
27 AMPS Activities	1	1	6	12	6	13	9th
28 other	0	0	1	1	1	1	23rd

The twenty seven forms and processes agreed to be adopted by the OT Co-Researchers as part of the changes in occupational therapy practices are listed in Table R.5. The number of OT Co- Respondents who reported that they had used each individual form or process is indicated in the 'OTs' columns. The number of times the form was reported to have been used is indicated in the 'Uses' column. The time periods: 01/09/2011 and 30/11/2011 and 01/9/2012 and 30/11/2012 are compared and the total combined scores are set out in the third column. The OT Co-Researchers were asked to report if they had ever used each form between 01/09/2011 and 30/11/2012 so that forms that had been used outside of the sample time periods were included. However, it was not practicable to ask the OT Co-Researchers to provide data on the total numbers of times they had ever used each of the forms, due to the time it would take for them to look up all of their client records. The number of reported uses of the forms is, therefore, just for the two time periods sampled.

Table R.6 The number of form Uptake of new forms and processes across the OT Co-Researchers

Number of forms:	01/09/2011-30/11/2011	01/09/2012-30/11/2012	01/09/2011-30/11/2012
Never used by any OT Co-Researcher	8	5	4
Used by 1 OT Co-Researcher	8	4	0
Used by 2 OT Co-Researchers	3	3	5
Used by 3 OT Co-Researchers	2	4	6
Used by 4 OT Co-Researchers	1	5	2
Used by 5 OT Co-Researchers	2	1	3
Used by 6 OT Co-Researchers	3	5	3
Used by 7 OT Co-Researchers	0	0	4
At least 2 OT Co-Researchers	11	18	23
Total forms	**27**		

The OT Co-Researchers reported use of the forms is recorded in Table R.6 to consider how many forms were adopted universally within the team. Twenty three out of the twenty seven new forms that were agreed had been used by two or more OT Co-Researchers at least once between 1/9/2011 and 30/11/2012. Only four of the forms had ever been used by all seven of the OT Co-Researchers at any time and four had never been used by any.

Table R.7 Forms used by all OT Co-researchers

Forms	01/09/2011-30/11/2011			01/09/2012-30/11/2012			01/09/2011-30/11/2012		
	OT	Use	Rank	OT	Use	Rank	OT	Use	Rank
OT RTT Pathway	6	22	1st	4	31	1st=	7	53	1st
Initial assessment Form	6	12	3rd	6	28	3rd	7	40	2nd
Goal Plan	5	8	5th	6	25	4th	7	33	3rd
Full skills ADL	6	10	4th	6	17	7th	7	27	7th

Four forms were reported to have been used by all of the OT Co-researchers at some stage and are listed in Table R.7. Three of these forms, OT RTT Pathway, Initial Assessment Form and Goal Plan were also reported to be the three most often used forms. The other form, Full Skills ADL was ranked as the seventh most used form.

Table R.8: Forms used by Six of the OT Co-researchers

Forms	01/09/2011-30/11/2011			01/09/2012-30/11/2012			01/09/2011-30/11/2012		
	OT	Use	Rank	OT	Use	Rank	OT	Use	Rank
Participation training form	0	0	=Bottom	6	31	1st=	6	31	4th=
Care pathway OT assessments, expected sessions	5	7+	6th	4	23	4th	6	30	6th
AMPS activities list	1	1	2nd to bottom	6	12	9th	6	13	9th

Table R.8 lists the three forms that were reported to have been used by six of the seven OT co-researchers at some point during the assessed period.

Table R.9 Forms used by Five of the OT Co-Researchers

Forms	01/09/2011-30/11/2011			01/09/2012-30/11/2012			01/09/2011-30/11/2012		
	OT	Use	Rank	OT	Use	Rank	OT	Use	Rank
Cooking skills checklist	3	3		5	8		5	11	8th
Eating and drinking	1	2		4	6		5	8	10th=
Budgeting	2	2		4	4		5	6	12th

Table R.9 lists the three forms used by five of the OT co-researchers at some point.

- **Cooking skills checklist**

The cooking skills checklist is a briefer version of the full skills ADL with only the skills specifically related to cooking included. It is designed to send to clients and carers when cooking skills have been identified as a need. This form was developed during the new ways of working strategy meetings when its need was identified.

The cooking skills checklist was used once each by three of the OT co-researchers in 2011. This increased to eight uses by five OT co-researchers in 2012. However, it was only used more than once by one respondent who used it four times in 2012. It appears that the cooking skills checklist has been adopted and used since the change of working was implemented but not frequently. However, the form is only designed for use when there is a specific referral issue around cooking skills and so it would not be expected to be used as frequently as the forms designed for all referrals.

- **Eating and drinking.**

The use of this form was increased from two uses by one OT in 2011 to six uses by four different OT co-researchers in 2012. However, one OT co-researcher reported that the old form was still used.

- **Budgeting**

Budgeting and financial assessment was one of the assessments presented at during the changes in occupational therapy practice days and again at a subsequent occupational therapy meeting. It was agreed by the OT co-researchers that this assessment was required as there were an increasing number of referrals being made to occupational therapy to address this issue.

The assessment was reported to have been used twice by two OT co-researchers in 2011 and four times by four OT Co-researchers in 2012. The form is indicated as only being used once by each respondent. Budgeting and financial assessments would only be used in response to a specific referral issue and so would be expected not to have been used as much as a universally used form. However, the new assessment has been used at some point by five out of the seven OT co-researchers and demonstrates that the service has been able to develop its repertoire to meet changing service needs.

Table R.10: Forms used by Four of the OT co-researchers

Forms	01/09/2011-30/11/2011			01/09/2012-30/11/2012			01/09/2011-30/11/2012		
	OT	Use	Rank	OT	Use	Rank	OT	Use	Rank
5. OT leaflet	4	13	2nd	4	18	6th	4	31	4th=
12 Interest checklist	1	1		2	3		4	4	16th =

Table R.10 lists the two forms that were used by four of the OT co-researchers at some point.

- **OT leaflet**

The OT Leaflet is an accessible leaflet with photographs of the occupational therapists in the team and typical tasks that occupational therapy can help people with. It is designed for people with learning disabilities and their carers. The service already has a leaflet, but it was agreed to ensure that the leaflet was up to date and more proactively used when responding to referrals.

The OT leaflet was reported to have been used thirteen times by four of the OT co-researchers in 2011. The same four OT co-researchers reported that they had used the leaflet eighteen times in the three month period in 2012. The other three OT co-

researchers reported that they had never used it. Three of the four were from the same Borough. The person who reported using the OT leaflet most in 2012 reported that it is a

> *'good source of information to inform referrer, carers, client what AWLD OT can help with'* (QF&P).

This response appears to indicate a difference in practice within the occupational therapy team. The OT Leaflet is a form that can be universally used with all referrals as it does not relate to a specific referral issue. Only half of the team regularly use the leaflet. It is not known if this group use the leaflet as part of the new ways of working change in practice or if this was their usual practice anyway. This demonstrates an inconsistency within the team but no clear information why this is the case.

- **Interest checklist**

The Interest checklist is a form designed to help the client identify activities that he is interested in doing. The format has been adapted to be made accessible. This is a checklist which was used for specific referral issues rather than for all people referred to the team.

This interest checklist was already used prior to the new ways of working strategy meeting but was agreed to be one of the forms to use. It was used once by one respondent in 2011 and three times by two different respondents in 2012. One respondent wrote**:**

> *"initial assessment form has highlighted their interest therefore have not used this"* (QF&P).

This does not appear to be a form that has been consistently adopted by the team.

Table R.11: Forms used by Three of the OT co-researchers

Forms	**01/09/2011-30/11/2011**		**01/09/2012-30/11/2012**		**01/09/2011-30/11/2012**		
	OT	**Use**	**OT**	**Use**	**OT**	**Use**	**Rank**
Dementia	2	2	3	6	3	8	10th=
Client travel training	0	0	3	5	3	5	13th=
Top tips when out	1	1	2	4	3	5	13th=
Skills teaching top tips	0	0	3	3	3	3	13th=
Capacity	0	0	3	4	3	4	15th=
Equipment	3	3	0	0	3	3	18th=

Table R.11 lists the six Forms used by three of the OT Co-researchers at some point. All of these forms were developed to meet specific referral issues and developed from the collective clinical experience of the OT Co-Researchers. Many of the forms were devised in

order to provide some advice and guidance in response to a referral issue whilst waiting for the specialist OT assessment.

- **Dementia**

This form was used twice by one OT in 2011 and six times by three of the OT Co-Researchers in 2012 but did not appear to be universally adopted or understood. The comments demonstrated the lack of clarity:

> *"Dementia screening form to be done by 2 professionals",*
>
> *"No form available"* and *"use AMPS as a standard for informing baseline assessment"* (QF&P).

- **Client Travel Training**

This form was not used at all in 2011 but has been used five times by three of the OT co-researchers in 2012. The respondent who reported using the client travel training form the most wrote**:**

> *"Used to highlight travel routes and also carer vs client perception of ability to learn routes"* (QF&P).

- **Top tips when out**

This form was used once on 2011 and four times by two different OT co-researchers in 2012 with only one using it more than once. It does not appear to have been universally adopted.

- **Skills teaching top tips**

This form was not used in 2011 and then three times by three of the OT co-researchers in 2012. However, one respondent who had not used it during the two specified periods of time reported:

> *"have used every time client is to wait for treatment"* (QF&P).

- **Capacity**

This form was not used in 2011 at all. In 2012 only three OT co-researchers reported having used the capacity form on four occasions and they were all from the same borough. This capacity form, is similar to the budgeting form, in that it is only required for a specific referral issue. One person wrote:

> *"no specific capacity issues in caseload"* (QF&P).

- **Equipment**

The equipment form was used once by three of the OT Co-Researchers in 2011 but was not used at all in 2012. This change to use this form does not appear to have been sustained over the implementation period but this may have been due to a lack of referrals for this issue.

Table R.12: Forms used by two of the OT co-researchers

Forms	01/09/2011-30/11/2011		01/09/2012-30/11/2012		01/09/2011-30/11/2012		
	OT	Use	OT	Use	OT	Use	Rank
Housework checklist	2	3	1	1	2	4	16th=
Personal Care	1	1	2	2	2	3	18th=
Carer travel training	1	1	1	2	2	3	18th=
Activities	1	1	1	2	2	3	18th=
Sensory	1	1	1	1	2	2	22nd

Table R.12 lists the five forms that were only used by two of the OT Co-Researchers during the whole implementation period.

- **Housework checklist**

This form was only used three times by two OT Co-Researchers in 2011 and its use reduced to one use in 2012. It was only used in one borough. One OT Co-Researcher who reported to be planning to use this checklist in 2011 had not used it in 2012 and one respondent explained that it was not used as

> *"found using full ADL checklist more beneficial"* (QF&P).

This may be a form that is only required for a limited number of referral issues or it may be a form that needs to be reviewed to consider if it is still relevant.

- **Personal Care**

This form was only used by two OT co-researchers from the same borough. It was used once in 2011 and twice by two OT co-researchers in 2012.

- **Carer travel training**

The carer travel training form is designed for the carer to complete to record their perspective on the skills of the person they support before a travel training programme can be devised. The form was only used by one OT co-researcher in 2011 and used twice by a different respondent in 2012.

- **Activities**

This was only used by one OT co-researcher in 2011 and twice by a different OT co-researcher in 2012. One respondent reported still using the

> *"old activity checklist used"* (QF&P)

which indicates that this OT did not take on the change of process for this form.

- **Sensory**

The various sensory forms available to the team for use were considered by the OT co-researchers at the changes of occupational therapy practice meetings and it was agreed that a single form for all to use would be provided. However, this task was not completed. Even so, this sensory form was reported to have been used by one OT Co-Researcher in 2011 and a different one in 2012. Only one comment was made that reflected the situation that an agreed form had not been produced:

"no form available" (QF&P).

Another commented:

"no clients" (QF&P).

This may explain why the lack of new form was not noticed as the majority of the OT co-researchers had not needed to use a sensory assessment form due to this referral issue not needing to be addressed.

Forms only used by one of the OT Co-Researchers.

The number of forms only used by one OT Co-researcher which would indicate that the team were not working consistently was eight at the early stages of the launch but none of the forms had only been used by one OT co-researcher since the launch period.

Table R.13 Existing Caseload

September- November	**2011**	**2012**
Number of people on OT co-researchers caseload	57	73
Number on caseload that OT co-researchers were using new strategies.	28 49%	59 81%
Total number of OT Co-Researchers using new strategies with 100% of clients.	1 (Range 0%-100%)	3 (Range 44%-100%)

The reported use of the changes in occupational therapy practice forms by the OT co-researchers for people on their existing caseload was overall less than for the initial assessment process. The results in Table R.13 demonstrate that there was an increase in the use of the new forms by the OT co-researchers with people on their current caseloads from 49% in 2011 to 81% in 2012. The one respondent who was using the new ways of working 100% of the time in 2011 had reduced to 64% of the time in 2012 and only three out of the seven OT co-researchers were using the new forms 100% of the time in 2012. The number of times that the new forms were used by individual OT co-researchers varied. One OT co-researcher reported to have never used any of the new forms in 2011 on people who were on the caseload. In 2012, the lowest reported use by an OT co-researcher of new forms with people on the caseload was for 44% of clients. One explanation for the

reduction in the use of the new format is that all new referrals need to have a similar process to identify the person's needs initially, but the intervention then needs to be tailored to the individual needs.

Table R.14 Total of all cases seen.

September- November	2011	2012
Total Number of people OT Co-Researchers worked with.	98	127
Number of clients that OT Co-Researchers were working with using the changes in occupational therapy practice strategies.	61	109
Percentage of clients that OT Co-Researchers were working with using the changes in occupational therapy practice strategies.	62%	86%
Total number of OT Co-Researchers using the changes in occupational therapy practice with100% of clients.	0/7	3/7 (bdi)

Table R.14 illustrates the combined results of all the initial assessments and existing caseload. All the OT co-researchers reported that they used some aspect of the new action plan in 2011 and in 2012. The overall total of clients, that the OT co-researchers used some aspect of the new ways of working with, increased from 62% in 2011 to 86% in 2012. The number of OT co-researchers who used the new action plan for all clients increased from none in 2011 to three out of the seven in 2012. In 2011, the OT-Co-researchers would have been in a transition stage between the old system and the new system. Therefore, some of the clients on the OT co-researchers' caseloads would have been worked with using the old system, It would be expected, therefore, that the numbers using the new ways of working would have increased in 2012. The reasons why the OT Co-Researchers reported that they did not always use the new ways of working strategies were:

"Training, dementia screening, dementia coordinator"

"Some clients already known to me therefore needed reviews"

"Dementia coordinator"

"1 client dementia coordinator, 4 clients are pre- TT and their needs do not fit into the pathway".

"" always use some aspect of it. I don't find it useful to do the initial assessment normally"

"I am cutting corners, going straight to specialist assessment. Using in a broad way, providing more teaching sessions, establishing pathways for eligibility and dementia and complex cases all based some -how in RTT"

"I use the forms as relevant to the people that I am working with, so when I have not used the forms it is because I have not worked on those referral issues in the time period. I think the forms are useful"

Table R.15 Uptake of new forms and processes across the OT Co-Researchers

Number of forms used by:	**01/09/2011-30/11/2011**	**01/09/2012-30/11/2012**	**01/09/2011-30/11/2012**
Never used by any OT Co-Researcher	8	5	4
1 OT Co-Researcher	8	4	0
2 OT Co-Researchers	3	3	5
3 OT Co-Researchers	2	4	6
4 OT Co-Researchers	1	5	2
5 OT Co-Researchers	2	1	3
6 OT Co-Researchers	3	5	3
7 OT Co-Researchers	0	0	4
At least 2 OT Co-Researchers	11	18	23
Total forms	**27**		

The OT Co-Researchers reported use of the forms is recorded in Table R.15 to consider how many forms were adopted universally within the team. Twenty three out of the twenty seven new forms that were agreed to be used at the end of the new ways of working sessions had been used by two or more OT Co-Researchers at least once between 1/9/2011 and 30/11/2012. This indicates that some change in occupational therapy practice had occurred. However only four of the forms had ever been used by all seven of he OT Co-Researchers at any time and four had never been used by any. This appears to indicate that overall the new ways of working were not universally adopted by the occupational therapy team. However, the forms had different uses, and so the result of how each individual form was adopted and perceived by the OT Co-Researchers was also collected.

Table R.16: The responses from the interview and questionnaires in stage three regarding if the each criteria was perceived to have been met when the occupational therapy assessment was completed.

Data Sets	J	D	L	M	B	A
Number of responders	**4**	**2**	**2**	**4**	**3**	**2**
Assess occupational performance Yes: 16/17(94.12%) D/K: 1 5/5 pwld	4/4	2/2	1 /2 1 D/k	4/4	3/3	2/2
Global skills rather than just one particular skill Yes:14 /17 (82.35%) D/K: 1 No: 2 5/5 pwld	4/4	2/2	1 /2 1 d/K	4/4	1 /3 2 No	2/2
Highlight skills and support needs in order to make meaningful and useful recommendations: Yes: 15/16 (93.75%) No: 1 4/4 pwld (pM blank)	4/4	2/2	1 /2 1 no	3 /3	3/3	2/2
Client centred/choice and empowerment Yes:15 /16 (93.75%) D/K: 1 4/4pwld (pM blank)	4/4	2/2	1/2 1 D/K	3 /3	3/3	2/2
Accessible easy to use and understand Yes: 13/15 (86.67%) D/K: 2 N/A:2 5/5 pwld	3/4 1 D/K	2/2	0/0 2 N/A	4/4	2/3 1 D/K	2/2
Designed for people with learning disabilities Yes:15 /16 (93.75%) Blank 1 4/4 pwld (pM blank)	4/4	2/2	1/2 1 blank	3/3	3/3	2/2
Fit for purpose/reliable /valid/(standardised) Yes:15 /15 (100%) N/A 1 4/4 pwld (pM blank)	4/4	2/2	1 1 N/A	3/3	3/3	2/2
Practical/ good use of resources Yes: 11/12(91.67%) D/K:1 (Pwld not asked)	3/3	1/ 1	2/2	3/3	1/ 2 1D/K	1/1

Data Sets	J	D	L	M	B	A
Number of responders	**4**	**2**	**2**	**4**	**3**	**2**
Observation Yes:16/17 (94.12%) D/K: 1 5/5 pwld	4/4	2/2	2/2	4/4	2/3 1D/K	2/2
Incorporate views of all people involved with the person with learning disabilities Yes: 15/16 (93.75%) Blank 1 4/4 pwld but 2 said that other people did not talk about the report to them. (pM blank)	4/4	2/2	2/2	3/3	2/3 1 blank	2/2
Fits with other local, national, international assessment development. Yes: 10/12 (83.33%) D/K: 1 No: 1 Pwld not asked.	3/3	1/1	2/2	3/3	1/2 1 no	0/1 1 D/K
Total for data sets Scores of yes 155 (91.72%) Scores of D/K 8 (4.73%) Scores of no 4 (2.37%) Scores of blank 2 (1.18%) Total responses 169	41/42 97.62%	20/20 100%	14/19 73.68%	37/37 100% All blank from pwld so 100%	24/31 77.42%	19/20 95%