Shaping Our Lives

Improving Understanding of Service User Involvement and Identity

A Report of Research Findings

January 2017 to November 2017

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Foreword

This report has been produced by Shaping Our Lives in honour and memory of our great friend Patricia Chambers.

Patricia, a prominent member of the black and minority ethnic mental health user/survivor movement and a dear friend and colleague passed away in May 2016. For over 25 years, Patricia worked tirelessly to address issues at the intersections of race/culture and madness, within services, within the wider user/survivor movement and within research and policy.

In 2009 Patricia took over as the Network Manager of Catch-a-Fiya, the only (and now defunct) national network for people from black communities. It is impossible to list all the places and platforms she contributed to/through: BUGS, the Afiya Trust, Shaping Our Lives, Black Women's Mental Health Project, The Forward Project, the DRE Ambassadors programme, NIMHE's Making a Real Difference programme, the Count Me In census, Dancing to Our Own Tunes…. and the many local/informal user groups where she acted as an advocate and friend to people who needed that.

We developed this project from an interest Patricia had in the conflicts for people who use services and who also work to improve them. The project has been funded by the National Lottery through the Big Lottery Fund. All of us at Shaping Our Lives hope it will go some way to keeping the very fond memories we have of Patricia alive as well as bringing about the kind of positive change she worked so hard and wisely to achieve.

Executive Summary

This report aims to improve understanding of good and bad experiences of service user involvement in the commissioning, design, delivery and evaluation of public sector services and the challenges faced by service users in negotiating their dual role of both being a service user representative and recipients of services. This report will be of interest to Disabled people who are service users and for people who design, manage and evaluate services in the public sector.

This was a user-led piece of research designed and carried out by Disabled researchers. It arose directly out of a Disabled person's own concern and was undertaken by a Disabled People's Organisation.

In April and May 2017 twenty-two Disabled women and men from across England were interviewed. All of them had experience of being both service users and service user representatives, some with many years working with services in a representative capacity (for more than twenty years), others newer to the role. Interviewees had been representatives in a wide range of public sector organisations.

A great deal is known about the advantages of service user involvement for services or professionals. In this study we wanted to find out about the impact of being a service user representative for the people who put themselves forward to take on the role, how service providers can make sure they manage service user involvement well and how being a service user representative can be a positive experience for those who give up their time to do it.

The findings reveal a range of conflicts for Disabled people when they use services and are also a service user representative. Most representatives got involved because they wanted to share their experiences of being a disabled person and make services better for others. Although there were some positive experiences more people had had negative experiences of involvement. There were practical access issues, a breadth of communication problems and poor attitudes from professional staff. The research showed that people felt better about being a service user representative than a service user, based on experience of being both. Being a representative was described as being empowering, rewarding and satisfying. Being a service user was described as disappointing and disempowering. However, the word 'frustrating' was used a lot to describe both experiences.

Many participants had experienced more positive relationships with professionals providing services when they were being a service user representative than when they were engaged in a service user/provider relationship, sometimes even within the same institution. Many participants did not experience being regarded as experts in their own conditions and impairments, but for those who did they felt they got better outcomes from their treatment.

Participants reported both advantages and disadvantages to being a representative, and were able to identify a wide range of benefits that they had experienced. These

included; personal development, social activities and new opportunities. Over half said that representatives should receive some form of payment, but a significant minority said they should not; they perceived there were disadvantages to this.

There are clear practice pointers on how to enable the process of service user representation so that that it is a beneficial experience with positive outcomes for all. Interviewees were keen to pass on advice to others considering becoming representatives. They prioritised being prepared to ask questions, listening carefully, thinking before you speak, and respecting others' views. They felt it was important for representatives to work out what they want to achieve and plan how to do that. Finally they felt it was vital to be interested in the service under review, passionate and committed.

Representatives also had advice for professionals to prevent some of the negative experiences they had had. Important ideas are put forward on how professionals can ensure voices are heard to shape services without diminishing service users.

In conclusion it is important to look carefully at the impact on service users of becoming service user representatives. When service user involvement is respectful and inclusive this has a positive and mutually beneficial impact for professionals and service users. When arrangements for user involvement do not pay sufficient attention to dismantling of barriers to participation, representatives experience organisational exclusion; they feel their contribution is neither adequately respected nor properly valued.

When they are treated more respectfully as a representative compared to when they are using services this causes people to question this double standard and query if their knowledge gained through lived experience is really valued in either role.

Strategies need to be in place to make sure representation is positive and beneficial. Conflicts need to be addressed so that service users feel more confident, competent and comfortable as representatives. Training should be provided for service providers. They must understand and meet the access requirements of the people they involve, and they must ensure equal participation; ideally they should co-produce services with service users.

There are four simple steps that service providers can take to improve service user involvement – these are described in the recommendations of the full report.

There are also recommendations for service users; they can be proactive and take steps to ensure their involvement is both beneficial for them and for the services under review. This includes understanding the skills, knowledge and experience required for being an effective representative and asking for training to address gaps.

This research was funded by the Big Lottery Fund from its Awards for All grants. Outputs from this research will be two good practice guides; one for service user representatives (or those considering becoming one) and one for service providers

and practitioners. These help improve participation of disabled people in service user representation in order to promote good service outcomes, value for money provision and improved wellbeing for all service users.

The Research Team

The Research Team was led by Becki Meakin of Shaping Our Lives. The team comprised Dr Colin Cameron from Northumbria University, Professor Michele Moore, Ann Nutt and Charley Bell-Moore.

There are many other Disabled people who have given their time and expertise to the research findings and guides in this series. Shaping Our Lives is very grateful for their invaluable contributions.

This report was written by Becki Meakin, Colin Cameron, Michele Moore and Joanna Matthews.

Acknowledgements

Introduction

Shaping Our Lives is a national organisation and network of user-led groups, service users and disabled people. It is a non-profit company and a user-led organisation committed to inclusive involvement. Shaping Our Lives specialises in the research and practice of involving diverse communities in policy, planning and delivery of services.

Shaping Our Lives' vision is of a society where all people have the same rights, responsibilities, choices and opportunities; a society where people have choice and control over the services they use and how they live their lives.

Shaping Our Lives has twenty years' experience of undertaking research with service users and representing their views. Our inclusive approach enables people from all communities to have an equal say, including people with physical, sensory and cognitive impairments, older people, people in care, homeless people, mental health service users, people with alcohol or drug use issues, people from black and minority ethnic communities and lesbian, gay, bi-sexual and transgender people and their carers. We understand that people have complex identities and recognise that people often face multiple disadvantages and that there is intersection between economic, social, cultural and environmental influences.

Listening to and respecting service users' voices and perspectives is increasingly known to be an essential part of developing quality health and social care services.

This discreet project adds new and different dimensions to this work by looking carefully at the impact on service users of becoming service user representatives.

When done properly, user involvement can have a positive impact on power relations between professionals and service users, disrupting traditional assumptions such as that 'professionals know best, they are the experts, they have the answers'. Indeed, we are pleased many Disabled people nowadays have experience of being asked, as 'service user experts', for their views and are regularly called upon to take part in consultation exercises. Within these, what service users have to say is valued and taken seriously. Yet locally, nationally and internationally we are finding evidence of a paradox in that, back in the context of day-to-day experience as service users, a service user's status or identity as 'expert' is forgotten and less respectful power relations resume. A situation re-emerges in which, within encounters with professionals, service users are reminded that to be identified as Disabled people often means to be regarded as 'less competent' or 'dependent upon professional help'. What is experienced here is role conflict and role ambiguity which can leave service users confused over status and concerned about having been used or exploited.

We have used this grant funding from the National Lottery through the Big Lottery Fund to interview Disabled people who have service user representative roles to develop practical guidance for Disabled people taking on such roles and for professionals seeking to maximise respectful inclusion of service users.

This research study provides a new understanding of the importance of service user involvement for Disabled people, in contrast with a focus which is usually on the advantages of service user involvement for services or professionals.

This research study will provide additional understanding in the following areas:

1. The lack of knowledge about role conflict that Disabled people experience between their everyday existence and being a service user representative.
2. Disabled people's ideas on how this role conflict can be better managed.
3. Professional development needs; how professionals involve service users to ensure their voices are heard to shape services without diminishing service users.
4. Widening participation of Disabled people in service user representation to promote better value for money provision and improved wellbeing for Disabled people.

This research report is part of a collection of materials being produced for this project, in addition there will be separate Good Practice Guidance for Disabled people and for service providers and practitioners.

An overview of the report study and the resulting practice guides will be documented in a Current Issues article for Disability & Society.

Methods and Participant Profiles

This project has been designed and completed by Disabled people who are members of Shaping Our Lives, a user-led organisation and national network of user-led groups in the UK.

The research report and practice guides have been written using evidence collected in twenty-two in-depth face-to-face interviews with Disabled people. The Disabled people who took part lived in the following areas: North East of England, East of England, London and South West. In line with Shaping Our Lives policy each participant was offered an involvement payment and all associated travel and support costs were met.

The research participants were recruited through the Shaping Our Lives network communications to over 470 user-led organisations in the UK, but predominately in England. The recruitment materials asked for participants with more than one experience of being a service user representative and/or experience over a number of years.

Everyone who was interviewed had at least two examples of past representation roles and the majority were still actively involved as service user representatives. Approximately a quarter of the respondents had had five or more roles and the same proportion had had ten or more roles. One person listed over twenty different boards and service user advisory roles. The types of things people had done ranged from Partnership Boards in local authorities, Patient Participant Groups in primary and secondary health care, roles in education and voluntary sector structures, advocacy and carer representative positions. There was also mention of local government structures such as Healthwatch, Clinical Commissioning Groups and transport advisory committees. Half of the people taking part also mentioned a role they had with a local charity or user-group for Disabled people.

Profiles of Participants

Of the twenty-two participants, twelve were women, nine were men and one person identified as non-binary. The age ranges varied with two participants being under 40 years old and two over 70 years old; the remaining participants were equally split between 41 and 55 years old, and 56 and 70 years old. There were no Disabled people under 25 years old in the study. We made strenuous efforts to engage representatives of a hospital based youth service user group however the young people approached were busy with exam commitments and could not fit in an interview. It is also the case that people who take part in representation activities tend to be people who have had many years of using services as an adult. Other profile data is summarised below:

Ethnic origin		Religion/belief		Sexuality	
White British	18	None	5	Heterosexual	15
British Indian	1	Christian	2	Married	1
Black British	2	Roman Catholic	2	Bisexual	2
White European	1	Church of England	1	No answer given	4
		Jainism	1		
		Humanist	1		
		Agnostic	1		
		No answer given	9		

The Disabled people who took part had a broad range of impairments and health conditions. There were four people with varying degrees of sight loss including one person describing themselves as totally blind and one deaf person. Among the other participants the following were used to describe their impairments and health conditions: an acquired brain injury, cognitive impairment, learning disability, mental ill-health with seizures, Multiple Sclerosis, Cerebral Palsy, spinal injury, mobility impairment and two people who identified as a wheelchair user and having poor mobility. One of the research participants was a carer of four Disabled children.

Findings

Section 1 – Involvement Experiences

1.1 How did you get involved?

People reported a number of reasons for becoming a service user representative which included:
- Experience of using services resulted in people wanting to give something back.
- Experience of using services resulted in people wanting to improve things for others.
- Onset of a health condition or an injury resulted in them not being able to work.
- Gave them something positive to do.

"Partly it is me wanting to give something back, to thank the people who helped and supported me and to help make changes, and help with their professional development."

Often the person had been approached by a health professional, social care worker or other local authority lead and asked if they would take part in a consultation process or advisory board. Many felt that it was an opportunity to use skills they had that previously had been relevant at work. Two people had been volunteers and this had developed into representative roles and some people referred to a passion for improving the knowledge and understanding about Disabled people and their wish to share the experience of using services from the perspective of a service user to benefit other people like them. One person had joined a hospital advisory group to try and positively influence the provision of care for someone in their family.

1.2 When did the service representation activities take place?

Of the participants interviewed who were able to give a time frame for their involvements, half had been active in representation roles for more than twenty years and had many different roles over this time. Two people had only taken part in one particular activity that had continued for a number of years and the other people had experience ranging from four to twelve years. All those who have been active for over twenty years are still actively representing the views of service users, although one person said their deteriorating health now limited what they would do.

1.3 How did you feel when you were taking part?

The participants gave many different responses about how their involvement and representation activities had made them feel and included the following positive responses:
- Felt good to be listened to and make a difference.
- Felt good to represent people who cannot represent themselves.
- I could provide information to improve policies.

- Gave me a purpose to help people and not just Disabled people.
- Empowered to talk about issues that affect people like me.
- If it is someone committed (to involving service users) it feels quite good.
- Valued at the time (but after it felt tokenistic as it was not acted on).

Of these positive responses, five out of the seven comments suggest that being able to help improve policies and services for other service users was satisfying and rewarding. One person referred to the sense of empowerment, likening it to being a politician representing their constituency:

"It felt like being an elected representative of a political party."

However, there were more negative responses than positive. These comments have been organised in categories of: a) process, i.e. the organisation and execution of the involvement activity; or b) personal difficulties experienced by service users working as representatives.

a) Process:
- Frustrating as it takes so long to make a difference.
- Annoying as it became clear that it was a tick box exercise.
- Difficult as there was a set pathway and you had to understand this to make a difference.
- Patronised as they were not listening to what I had to say.
- If it is someone not committed it is depressing, frustrating and head-bangingly annoying.
- The service user input is always at the end of the agenda and the professionals start excusing themselves.
- Pointless as they have their regular service users who get listened to more than others.

b) Personal:
- Apprehensive at speaking about an impairment or health condition I know nothing about.
- Difficult if a professional last saw you when you were receiving treatment.
- It can be difficult to listen to other people's experiences.
- Difficult as people do not give me time to speak (person with a speech impairment).

The poor experiences grouped as 'process' problems suggest a number of issues. Firstly, that the representation activities had no meaningful outcome as the process was inflexible, too long and/or tokenistic. Two reasons for a poor experience relate to a feeling that the voices of the service user representatives are not being listened to or heard. The final process issues relate to power imbalances between the professionals organising the activities and the service users taking part.

It cannot be overlooked that there are also 'personal' conflicts and difficulties in taking part as a representative for service users and this may be because of: the

stress it puts on mental health; the general pressures of living with an impairment or health condition; the extensive knowledge needed to take part in some representation activities; sharing lived experiences with other people and sharing experiences with professionals responsible for the care of the representative. However, people who had had good experiences for the reasons above had been able to overcome or manage these personal conflicts through supportive and inclusive processes. One participant described their experiences as:

"Quite complex really, it was difficult but rewarding at the same time."

People also talked about the responsibility and skills needed to speak on behalf of a wide range of service users if this was part of the requirement. One person reflected that it was easy to be a passive recipient of a consultation, but to speak and effect change on behalf of others required you to advocate, critically assess the impact of changes, make clear references in presenting an objection and to be able to think on your feet. Another person talked about needing to grow into a role, listen to what other people had to say and not back people into a corner as this would make discussions difficult.

1.4 In what ways was it a good experience?

When asked about how being a service user representative had been a good experience, people felt:
- Good to be part of a team.
- Gave a sense of purpose.
- Feeling of being wanted and needed.
- That professional knowledge and experience was valuable.
- Motivated and excited when the contribution was acknowledged.
- Good when it made a difference, feeling of being stronger through effecting social change.

One participant commented:

"This was a good time, full of optimism and enthusiasm and it felt like we were pushing on an open door."

There were a number of key factors for good experiences:
- Equality
- Mutual respect
- Ownership
- Structure
- Commitment
- Feedback
- Personal development

Personal development was described in many different ways including training, acquiring new skills, gaining knowledge, opportunity for paid or voluntary work,

increased confidence, opportunity to network/make new friends, increased self-worth and finding out about services and organisations in the area.

"I think the best one for me used to be the Partnership Board because they had a mentoring system and I was getting some training that helped me be a representative."

1.5 In what ways was your representation experience not so good?

There were many responses to this question and they have been grouped into two types of areas: factors that were personally difficult for the service user representative and issues that arose from the third party approach to involving people (processes).

Personal factors included:
- Not being used to being with other Disabled people with different impairments and not knowing how to act and support someone appropriately.
- Drawing on personal experiences can be distressing and exhausting.
- Not having the right knowledge to contribute fully (someone said that when they first started they did not understand the social model of disability).

However, there were many more process problems raised than personal considerations. These have been grouped into sub headings of practical issues of inclusive involvement, the process of inclusive communications and attitudinal issues as below. One person said they would have welcomed the opportunity to sit down and talk about what the 'professionals' were trying to achieve, how they were planning to do it and what would be involved. In this participant's opinion it would give someone a chance to decide if it was appropriate for them and it would feel like they had been part of the whole process.

The responses relating to the process are sub-divided below:

a) Practical process issues:
- Not being sufficiently supported through accessible practices.
- Practicalities such as travel arrangements and parking had not been arranged.

b) Communication process issues:
- Not being listened to.
- Feeling inadequate because information was not equally shared between staff/professionals and the Disabled people participating as service user representatives.
- Professionals not acting on service user suggestions.
- The agenda had been set before the first meeting so there was no opportunity to influence the process and it was not genuinely collaborative.
- Service user agenda items being put at the end of the agenda and not discussed because of time constraints (meetings not chaired appropriately).

- No feedback on what happened as a consequence of a consultation or involvement process.

c) Attitudinal process issues:
- Not having equal power and respect.
- Feeling intimidated.
- Involvement becoming less important because of financial/service pressures.
- A shift back to a medical model approach as a result of negative rhetoric about Disabled people and the impact of austerity policies.

The problem of not being listened to leads to service users feeling that their knowledge is not valued as explained below:

"It is diminishing to realise how the service providers see service users. It is frustrating in the meetings to sense how little credence most of them actually give to service user viewpoints. If our view chimes with theirs they are positive and pleased with how things are going; if the service user perspectives challenge their views then they tend to offer platitudes and try to swiftly move the discussion on."

Someone referred to a service user representative experience as a 'waste of my time as they were not listening'. Another participant stated that the worst was when the professionals hosting the involvement activity did not value their experience.

One person referred to the way health professionals talked about service users as if they were not there and that there was an assumption that the service users would not understand the complexities of the decisions they were making in clinical practice. This person commented that they had learned a lot about what they should challenge their consultant on when receiving care from listening to discussions between clinicians in involvement meetings.

1.6 What things would you change to make these negative experiences different?

The participants provided a comprehensive list of actions they would recommend to mitigate the poor personal and process experiences. These have been grouped as actions for service user representatives and actions for professionals organising service user representation activities.

Actions for service users:
- Induction for people who have recently become a Disabled person and training on the range of impairments and health conditions people may have and how this impacts on their participation.
- Accredited training for Disabled people so they are able to take part confidently.

There is often an assumption that any Disabled person can be an effective service user representative, and generally this is true if they have the training and support

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appropriate for the role. A way to enable all Disabled people to gain this level of knowledge and skills would be to create accredited training for Disabled people in the area of being a service user representative. There have been isolated good practice examples of training to develop the knowledge and confidence to take part as a service user representative, however, this was something only three people mentioned in the research.

Actions for professionals:
- Create a plan, set objectives and provide a framework.
  There needs to be a professional approach to the process with a clear purpose, terms of reference, accessible policy, travel and involvement payment policies and feedback mechanisms.
- Training in hosting accessible events and meetings.
  People organising involvement activities need to understand all aspects of accessible meetings and create an equal playing field. In particular, the place, time and length of meetings need to be carefully planned with service users.
- Training in accessible communications.
  Communications must be accessible in terms of accessible formats, accessible meeting practice so everyone gets an equal opportunity to contribute. There should be no use of jargon that is specific to professionals and not familiar to service users.
- Be committed to working equally.
  A genuine commitment to work in equal partnership and learn from each other rather than a tokenistic process to meet regulatory requirements.

Section 2 – Relationships and Conflicts

2.1 Do you think professionals consider you to be an expert in your service needs when you are using services?

Most people answered no to this question and most did not think that the professionals managing their health and care requirements were aware that they were a service user representative. Two people said that if they asked insightful questions the professional became more engaged with them. It was thought that acting authoritatively and confidently would result in a professional listening more to a service user when they are using services.

Two respondents were very negative and felt strongly that they had not been considered an expert in their own impairment or health condition. One of these participants commented:

"My experience is that the professionals prefer to have victims. I experience an attempt to disempower me. They prefer to make decisions about me without me."

Two people who thought that the professional providing their services were also aware that they were service user representatives said that the professionals were more friendly towards them. A further person felt that they had had a better service.

However, the improved service responses were thought to be more about not 'being reported' for poor service rather than the professional making a connection between the two roles of service user and representative.

"…in the Children's Hospital, once people knew that you were on the parent representative group then they treated you a bit differently. I think they almost become a bit wary of you as if you had to have a Rolls Royce service in case you said anything slightly negative about them when you next got into the meeting…"

2.2 Why do you think professionals see you as an expert when you are using services and what difference does it make?

Those who answered this question positively all said that they had achieved good personal outcomes. It should be noted that these three people were describing social care and not health professionals. One person described their relationship as a 'pseudo colleague'. They went on to say that often a professional would ask their advice and that their considerable knowledge gained through employment in a Disabled people's organisation and representation work helped to achieve their personal goals in assessments. Another person commented that it helped them to negotiate their care needs and to navigate the complex structure of services for Disabled people. The other person who answered yes said that it gave them strength to stand up for their rights and voice their feelings because they are part of a service user group.

"At care level yes, but not in health. Knowing people helps to get a caring service from health professionals but not necessarily a better or quicker service."

2.3 If you are not seen as an expert when you use services, why do you think this is?

The participants felt that there needs to be a cultural change to practice in a way that gives people choice and control over their lives, particularly in the health sector. Financial pressures have reduced the time professionals have and this has also impacted on their consideration of an individual's views.

"Many professionals mean well but can be tokenistic and patronising, especially in the health sector. It is a huge mind set for health to realise that Disabled people want choice and control over their own lives although many Disabled people who have not had the same experience as some Disabled people simply accept this kind of treatment."

In the worst reports people felt that professionals were not listening to their views or dismissing them altogether.

"They are working against me, not with me. They are making decisions in what they think is best for me but not really listening to me."

It was pointed out that being a service user and a professional are not mutually exclusive. There was one comment that said:

"There are mental health service users who have become professionals and some professionals who have become service users but there are not many of those people who have that level of empathy for each other."

2.4 What would you change if you think these experiences should be different?

The research participants gave several suggestions about professional development and learning. It was suggested that there should be more training in communicating with service users and how to appropriately support service users during professional pre-qualification education and in post-qualification practice. A participant said that this training should be delivered by service user-led organisations and that there should be continual professional development.

It was felt there needs to be more awareness about the value of lived experience and one way to achieve this would be for all health and care professionals to be trained in the principles of independent living. However, communication with service users and awareness of the value of lived experience is mentioned in this section again and is dependent on professionals having a relationship grounded in mutual respect with their service users. This should be the same whether the person is a service user representative or a service user receiving services.

"They should take me seriously and help me get what I have asked for. My condition varies, they are not taking account of that and it impacts on my independence – some days I can walk and some days I can't."

One participant described their own endeavours to become knowledgeable about their condition so they could take control:

"I should not have had to become an expert to get the services I needed. The only reason I know so much about my disorder and the services that are available is because the so-called experts didn't know. I had to research it and I was lucky because I was an academic, I knew how to do work and I could educate my family."

Another person referred to the inflexibility of assessment processes and suggested that an organic process that reflected when there were changes to a condition, rather than an assessment on a fixed term basis, would benefit both parties and waste less of the professional's time.

2.5 Do you feel that professionals treat you differently when you are seeking support compared to when they see you in your service user representative role?

Most people thought they were treated differently if the professional was unaware of their service user role, treated only as an expert in their own conditions if they were known to be a service user representative. The experience of receiving services was

reported as a 'top-down' experience, whereas people described their service user representation roles as a more equal relationship where they can challenge decisions and negotiate outcomes. This was attributed to the power imbalance being greater when you are receiving services.

One person described the contrast as follows:

"That has been my experience, they see me differently. For example, I went to the customer service area, just for me, and the receptionist was very abrupt and I didn't know the system. Another customer showed me how to take a ticket and then I just sat there in the waiting room feeling overwhelmed. When I was being a rep I would go straight to the desk and be welcomed."

This person then went on to describe their experience of seeing the professional in this service as follows:

"So that was a negative experience, quite humiliating and demeaning. I was quite cross. Then when I did get to see the worker, she made lots of assumptions, tapping on my computer without looking at me, questioning I knew my postcode. Not listening to me. Is this an experience all customers go through, or just Disabled people, or just me because I am deaf? They should understand there would be communication problems."

In one interview, the participant suggested that poor and disrespectful treatment was specific to the service and not linked at all to the experience of being a service user representative:

"In some services, regardless of whether I am a service user or a rep, I have been disregarded, patronised and infantilised. It hasn't made any difference if I am rep or not."

Someone described how difficult it was when they had been working side-by-side with professionals as a representative and then suffered a relapse. They felt there needed to be more thought about the relationships that develop through being a representative and how these are managed if you become unwell.

"The hardest part is when I had a relapse everyone had seen me being well, speaking confidently and it is all the harder to fall when you are back at their door, needing their help."

Other comments included that professionals can find service user representatives 'scary', particularly if they have complex needs and are able to knowledgably represent themselves and others. This person also said it was difficult to become engaged in influencing policy and services because professionals do not know (or are not confident) about how to work with people with multiple impairments and health conditions.

One participant stated that as a service user you are seeking the views of a professional, and as a representative, professionals are seeking the views of service users. This should be a collaborative process that leads to better and more informed outcomes. If professionals do not listen and act on the views of service users when they are advising on policy and services then the service user representatives feel frustrated and that their view is not valued. It would follow that a similar feeling of frustration would be experienced when service users are not given choice and control over their lives.

2.6 Is it good or bad that people are treated differently when using services if they are a service user representative?

The views of the research participants varied greatly on the issue of whether it was good or bad that people were treated differently because they had experience of being a service user representative. Some respondents just focused on the positive and negative impacts, but some showed concern about how active involvement in policy and service improvements may be detrimental to the treatment and relationships they had with professionals.

Reasons why a service user representative should not be treated differently to other service users when they are in receipt of services:
- So there is no preferential treatment.
- Professionals do not assume that someone who is a service user representative has more knowledge than other people.

Two people said that the collaborative relationship established in a service user representative situation with relevant professionals should be mirrored when people receive services, an expectation of being treated equally in both scenarios:

"Of course it's a good thing, it's influence, it gets change, it gives meaning, it's a contributory relationship, and it's not a recipient relationship. I would advise everyone to be a rep, be involved in a group of similar people."

This was supported by a further participant who was ambivalent, saying there is a need to be more collaborative in everything we do.

There were three opposing reasons given why the treatment should be different:
- Professionals should try and be less familiar when someone is using services to define boundaries.
- Professionals need to respect service user representatives as experts but they treat people just as service users all the time.
- Professionals should treat service user representatives with more respect when they are using services.

"If they know I am an advocate, professionals should give me more recognition, more respect and that would be a good thing."

There were a number of concerns about the impact of being a service user representative when people are using services:

- A service user may be seen as critical of a service or professional and may be less respected as a consequence.
- A professional may fear that critical observations from someone they are providing a service to who is also a service user representative, are more likely to lead to reprisal from senior management.
- Fear of services being withdrawn if someone using a service has experience of advising on a similar service and their comments are interpreted as critical.

Finally, there was one person who suggested that there needs to be more protection and support for service users working as representatives.

"Professionals stay in one place of work for a long time but service users move through different representation roles. There needs to be an independent body that oversees service user involvement to ensure it is a safe process and that their voices are heard."

2.7 Are there any disadvantages to being a service user representative?

There were a number of disadvantages mentioned by participants about being a service user representative. These fell into three categories of disadvantages: disadvantages for the service user as an individual, disadvantages relating to relationships with other service users and the negative impacts on relationships with professionals and services. In this section, participants also mentioned three key positive personal outcomes of being a service user representative and it would be important for anyone considering becoming a service user representative to consider these in relation to the potential disadvantages.

Advantages of being a service user representative:
- Adds to knowledge and skills.
- Builds confidence and self-worth.
- Feelings of making a worthwhile contribution.

Disadvantages of being a service user representative for the individual:
- Demands on your time and this may impact on health.
- Becoming frustrated, demoralised and dispirited. (Reasons may be slow processes, inaccessible processes, nothing happening, not being given time to talk, not listened to).
- Requires comprehensive knowledge and this could lead to more work.
- Stress and distress of negative experiences.

Disadvantages of being a service user representative relating to other service users:
- Perceived favourable treatment from professionals by other service users.
- Isolation and hostility if you have an opposing view.
- Difficult relationships with other service users.

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Disadvantages of being a service user representative with professionals and services:

- Professionals can assume you understand what is happening in service provision.
- Professionals may ask you for advice.
- Potential conflict if also using the service, this can lead to feeling vulnerable. (No process or protection for service user representatives working with professionals who also provide their health and care services).

2.8 Would you like anything about the way you are treated in either role to change?

The suggested improvements by participants, on how their experience as a service user and as a service user representative could be better, have been consolidated into three areas as follows:

Things that would improve both experiences:

- Training for professionals in the different ways to work with service users when they are using services and when they are working as a representative.

Things that would improve experiences of being a service user:

- A single point of contact and defined pathway for people with similar needs in a local authority area so professionals can learn organically.
- System changes so that professionals can work in a person-centred way rather than being process driven.
- A system where poor experiences could be fed back to a group of service user representatives who could then work to change that experience for others.
- Working to the social model of disability and not the medical model.
- Listening to the service user and working with them to get the best outcomes.
- Working in a strengths based way, where the service user perspective is valued and they are treated as an equal.

"If it could be all like it is now with my current social worker, whether that is a specialised service for Disabled people or general public services, where I am treated equally, my experience is valued, like an adult who understands my own needs, that would be amazing and fantastic."

Taking control by challenging poor services can take a toll on service users and two people described these negative impacts as follows:

"Just thinking about the impact that can have on you, not just the experience of being humiliated but the experience of trying to explain why that has an impact on you and that being disregarded as well, then that can undermine your confidence and then it becomes more and more difficult then to access services in the future."

"…those negative experiences become part of your private experience, very negative, very harmful."

Things that professionals could do to improve the experiences of service user representatives:

- Better induction training for professionals to cover the role of a service user representative and all aspects of inclusively involving service users.
- Representatives should be recruited more widely and trained by existing service user representatives.
- The role of service user representatives should be standardised and all professionals should be trained in the standards.
- Better management of service user representative activities.
- Clear and transparent communication.
- Equal priority for service user representative agenda items.
- Assessment of service user skills against the role and provision of necessary support.
- Introductions to everyone involved and peer mentoring.

Section 3 – Advice and Benefits

3.1 Advice to reduce conflict

Participants gave a wide range of advice for professionals on how to reduce the conflict for people when using services and when they are involved as a service user representative. An overarching theme is to recognise the difference between being a service user and a service user representative. In the former people often feel vulnerable and in the latter they can be more assertive. Actions relating to the value of lived experience included:

- Always listen to the service user, even when you do not agree with them.
- Treat service users as an equal.
- Respect and value the contribution service users make.
- Consider service users as experts in their own conditions and impairments.
- Accept that service users may be a representative one day and unwell the next.
- Recognise the value of service user representatives and how they can help to improve services.

"I would like them to understand when you are offering constructive criticism it is not personal. It's about trying to make improvements both for the people offering the service and the people accessing the service."

Other suggestions were for personal development and training of professionals as follows:

- Sign up to the principles of independent living and the social model of disability.
- Re-define the role of a service provider as someone serving a service user.
- Develop insight from talking to service users.
- Do Disability Equality training and Co-production training.
- Involve service users in the monitoring of services.

- Have a clear purpose for involving service users.
- Allow time for people to grow into service user representative roles.
- Professionals and staff at all levels should take responsibility for the inclusive involvement of service user representatives.

3.2 Benefits from being a service user representative

When asked if any benefits had come the way of participants because they are a service user representative, two participants did not answer and it has been assumed that this was because they had not experienced any benefits. Including these two people, there were eleven people that felt they had not directly benefited.

Of those benefits mentioned by the other half of the participants, most of the benefits shared did not relate to their experiences of using services. However, two people did feel that they got a quicker, better and more friendly service when using services because they are a service user representative.

The other benefits described by eleven people have been grouped into personal development benefits and personal advantages.

Personal development benefits:
- Access to training and educational courses.
- Learning about rights and legislation.
- Finding out about other organisations and services in the area.
- Learning work relevant skills such as chairing meetings, preparing reports etc.
- Influencing policy and service development positively.

Individual advantages:
- Social opportunities and meeting other service users.
- Builds confidence, self-esteem and dignity.
- Stimulates mind and gives a purpose.
- Promotes self-care and self-advocacy.
- Provides an opportunity to take part.
- Receipt of financial incentives.
- Altruistic benefits from speaking up for other service users.

"I love to speak for people who don't know what to say and making their lives a bit better… I've learned how to talk up for other people and changing my ways, doing things I never used to do, I have a better life, I help other people, it's a good thing."

There were three negative comments relating to the individual advantages of being a service user representative. One participant was unable to accept financial involvement payments because they were not compliant with tax and benefit rules. Another participant reported that their local clinician said they have made a career out of being a patient (by implication they had skills and confidence and understanding) and therefore they could not have the diagnosis and they did not fit the pattern of someone with dementia. The person concerned wrote to all their

contacts with the good news that they did not have dementia, only to receive results of tests soon after confirming that the diagnosis had been correct in the first place.

Finally, a participant referred to the frustration, despondency and lack of motivation brought on by poor service user representative roles.

"I really want to say services are better, but I am not sure that they are. I am not sure that things are better as a result of having service user representation. It hasn't stopped me trying and the work we did in the early 2000s I think we saw an immediate benefit to what we did. I worry that the gains we did make have gone back."

3.3 New opportunities from being a service user representative

Of the nineteen people who answered this question only one person had a negative response. A third of the participants specifically stated it had led to paid employment. An additional three other people, more than half in total, suggested that becoming a service user representative had led to new roles that may potentially be paid.

Apart from gaining employment as the most common positive outcome, three people described personal development in terms of involvements with other organisations and other representation opportunities that had expanded their knowledge and skills.

Several people described how becoming a service user representative had facilitated new activities through greater confidence, for example, gave the confidence to write articles, challenge decisions, attend regional/national conferences, do radio interviews - "opening up a whole new world".

One person gained the confidence to start a think tank for people with the same health condition and they have been granted an observer contract with the local NHS Trust which is usually only granted to clinical professionals.

As a direct consequence of being a representative two people had done academic qualifications. One of these people was part of the first cohort to study for a post-graduate degree as a Disability Equality Practitioner which the participant really enjoyed. The other person listed management training, partnership working, learning about governance in the charity sector and peer support in addition to their academic educational opportunities.

Other positive outcomes included invitations to aspirational events, other consultations and events. One participant suggested this was because organisations see that you have something important to say. Another person echoed this by saying that being a service user representative validated their experience and gave them confidence to help others.

In general people referred to opportunities to gain skills and personally develop which helps in opening up other opportunities paid and unpaid. Half the people interviewed also mentioned it had led to them joining user-led groups or third sector

organisations, expanding their contacts and experiences. One person stated that although their service user representative role had led to many opportunities and paid work, this was only because of their personal knowledge as a service user.

Two people talked about the benefit to their health and wellbeing; helping them to get well and to manage their impairments and health conditions.

"For me it was a start to getting back out into the world and a step on the journey to being well again."

The one negative comment was that the group the representative takes part in never credits the service user contributions and it is assumed this is why there are no opportunities that arise from the involvement.

3.4 Should there be benefits and what should these be?

The most recorded answer to this question was that financial benefits of some kind should be offered, this could be an involvement payment or some people felt a voucher was acceptable. This was given by more than half of the respondents (11 of 20 answers).

"Payment should be offered. I was doing a job of work and this was undervalued."

Five people also mentioned that expenses should be covered, however, as the question specifically mentions benefits it is possible that other participants would not consider expenses as a 'benefit' but an essential and reasonable expectation.

However, some people referred to the difficulties of accepting payments for service user representation if receiving state benefits and careful management is required in these instances. One person reported that their state benefits had been stopped for 6 months, the organisation that had made the payments was able to provide a paper trail and the benefits were re-instated eventually. This person commented:

"There should be a national co-production standard in England which allows for participation compensation. This already happens in Scotland and Wales."

In contrast, five participants said that there should not be benefits for service user representatives. Three of these people said that being a service user representative is about improving services for other service users in the future and working for the greater good generally. In their opinion this should not be rewarded with benefits. The other two people directly referred to receiving a payment and felt that to be paid as a service user representative created a conflict as below:

"I think if you incentivise it with a financial reward it can take away about what is special about being a service user rep."

"I think that's a really difficult question because there's a fine line between being a service user representative and then swapping over to becoming more viewed as

"professional" and I think that service user representatives should be reimbursed for any expenses that they incur but I don't think that they should get anything more than that because it becomes difficult then to distinguish what their role is."

There is some discrepancy in the responses to this question as participants had different perceptions of what constitutes a benefit. However, in order of priority, the other benefits that were mentioned were as follows:

- Payment of expenses and provision of refreshments.
- Professional development, qualifications and training.
- Voluntary or paid employment.
- Recognition and acknowledgement of the contribution service users make (this is motivating for other people who might be considering becoming a representative).
- Accreditation on published reports and papers.
- Opportunity to talk to other people about the benefits of being a service user.

3.5 Suggestions for professionals about supporting service users when they are taking part as a service user representative

The overwhelming response to this question was to make activities accessible:

"It's about developing inclusive practice. It's about making them aware that service user representatives are integral to the meeting and they shouldn't treat us as an add-on. If they were able to do that they would be able to make much more valuable use of the service users and develop much better services as a result of that."

People stressed that professionals need to make sure that the activity is inclusive of all Disabled people. This includes accessible meeting times, duration, places and materials in the correct accessible format. Part of this is allowing enough time for the activity and giving people plenty of notice. In addition to the practical arrangements, participants referred to exclusion through the use of jargon and 'professional' language that is familiar only to those working in that profession.

"People think that not using jargon, for example, is being patronising. Being patronising is talking to someone as though they are not an equal, but actually talking to them in a language which is accessible, without jargon, is showing them that you are treating them as an equal by allowing them to communicate."

Professionals should also recognise the range of benefits that service users get from representation activities and think carefully about how people can be enabled to develop skills, network etc.

Several participants stated that service providers should not take a benevolent approach. Involvement activities need to be planned and structured appropriately, so that any activity has the right people with the information and structure to achieve the goals.

"As an example, at the moment I am part of creating a service user group for an advocacy project, so I am facilitating setting the group up, a bit on the other side of the table. So I had to identify potential participants, pre-selection process, I had to meet each person and find out their situation and their desire to be part of the group. Once I had done that all those individuals had to be brought together as a group, it's a process which requires thought to get to the point where a group of individuals can then act as a group. You need a leader in the group because some people like to follow but others like to lead, be in charge. You have to gather the right people."

The other multiple response was treat service user representatives as equals and learn from each other. To be able to achieve this, the two areas of accessible processes and planning need to be done well so that there is a level playing field from the beginning.

Other individual comments included:
- Give representatives time to get settled in.
- Strive to give representatives choice and control (as this can change lives for service users considerably).
- Provide all the information needed to make informed decisions.
- Recognise that there are financial and personal costs for people who take part as representatives.
- Involve service users from the beginning and in all decisions.
- Value the opinions of service user representatives.
- Do not leave people out (in this research there was mention of leaving people with learning disabilities out).
- Adopt the social model of disability.
- Be empathetic and unbiased.
- Provide support to enable people to succeed, buddies and mentors may be helpful.

Section 4 – How it Makes People Feel

4.1 Words describing experiences of taking part as a service user representative

In total there were 76 different words and phrases supplied by interviewees. These were broadly categorised positive, negative or neutral.
There were 45 positive words and phrases, 24 negative words and phrases and 7 neutral.

Repeated words and phrases
- Empowering - 5 responses
- Frustration - 4 responses
- Interesting - 4 responses
- Rewarding - 3 responses
- Satisfaction - 3 responses

- Challenging - 2 responses
- Exciting - 2 responses
- Valued - 2 responses

4.2 Words describing experiences of being a service user

There were 69 words and phrases supplied.
There were 19 positive words and phrases, 42 negative and 8 neutral.

Repeated words and phrases
- Frustration - 9 responses
- Not treated as an individual - 2 responses
- (Feeling) connected - 3 responses
- Disappointing - 2 responses
- Disempowering - 2 responses
- Unhelpful - 2 responses

Section 5 –Tips and Advice

5.1 Tips for professionals

These comments were made in response to being asked what advice you would give professionals and have generally not been covered in other areas of the research with exception to the first point about listening, being respectful and inclusive:
- Listen, be respectful and inclusive.
- Treat each service user as an individual, people manage their conditions differently.
- Have an open mind and open agenda.
- There is a need for professionals to understand the difference between service users and service user representatives, especially when they are the same person.
- Professionals should understand that service user representatives are professionals themselves but still need support when they are seeking services as service users.
- Professionals should understand that it is difficult for service users to change their role to service user representatives and should be supported in this change of role.

Several people mentioned a cultural/paradigm shift to be able to work with service users as equals and recognise the power imbalances.

5.2 Tips for service users thinking of becoming a representative

The most popular ideas given as advice for people thinking of becoming service user representatives were:
1. To be prepared to ask questions and don't be afraid to speak up.

2. Listen carefully and think before you speak, be polite and respect others' views.
3. Work out what you want to achieve and plan what you are going to do.
4. *Be interested in the area, passionate and committed.*

"Are you passionate about what you want to do, are you completely committed, do you have knowledge, experience and skills for what is required? If the answer is no to anything, then don't do it."

More than one participant offered the following advice:
- Learn to think strategically for all service users.
- Have some background knowledge of the subject area.
- Be yourself.

Other points made included:
- Never take your own agenda to a meeting.
- Make sure you know what is expected of you.
- Be prepared to be wrong.
- Separate your role as a service user and a service user representative.
- Don't take on too many roles.
- Try to remain professional and not talk about personal experiences - if you act professionally, others will treat you as a professional equal.
- Keep confidential issues to yourself.
- Offer to provide training to ensure meetings/materials are accessible to you.
- Ask for materials in advance so you have time to read them.
- Ask for a brief job description of the role, what it entails, and what you are expected to do e.g. add an agenda item or prepare a short report.
- Don't make assumptions about people's impairments or how an impairment might impact on somebody.
- Understand it's not an easy thing to do.
- Have confidence in your knowledge.
- Be realistic, change doesn't happen overnight.
- Don't be afraid to say you're not well enough to take part, be kind to yourself.
- Be bolder and more assertive than you think is polite in order to get your point across.
- Ensure that your own barriers to equal involvement have been removed by inclusive processes.
- Don't be afraid to say no, do what you can, not necessarily what is expected of you.
- Take it slowly, take your time to get to know the group and its dynamics, don't be afraid to say nothing until you are confident.

"It comes down to motivation. Work out what drives you to want to do this. Usually this is about trying to make a change for oneself, however, you won't get it right until you want to make a change for others too."

Conclusions and Recommendations

The findings from this research offer much practical guidance for Disabled people taking on service user representative roles and for professionals seeking to maximise respectful inclusion of service users in the role. The findings are robust and insightful, being built on extensive data drawn from a diverse sample of service user representatives, some who have many years of representative experience with a wide range of organisations, others newer to the role and in the early stages of working with services in a representative capacity. The depth and breadth of issues raised by the interviewees confirms that it is important to look carefully at the impact on service users of becoming service user representatives. Service user involvement should always be mutually beneficial and strategies need to be in place to make sure this is the case.

We have shown through our findings that when service user involvement is respectful and inclusive this has a positive and mutually beneficial impact for professionals and service users. However, it is also clear that when arrangements for service user involvement do not pay sufficient attention to the dismantling of barriers to participation, service user representatives experience organisational exclusion based on disabling attitudes; they are left experiencing their contribution to service development as neither adequately respected nor properly valued. Further, a problematic tension has also been uncovered whereby service user representatives notice they are sometimes treated more respectfully as a representative compared to when they are using services. This causes people to question this double standard and query if their knowledge gained through lived experience is really valued in either role.

In order to ensure service user involvement is respectful and inclusive, so that the role has positive outcomes for both services and their user-representatives, we have excavated the data to identify Good Practice Recommendations for service providers and also for service user representatives. Finally, Action Steps professionals can use for immediately improving service user involvement are provided which are built from the recommendations service user representatives have contributed to the research.

Good Practice Recommendations for Improving Service User Involvement – Service Providers

Training

- Ensure training in inclusive communication for everyone who will be in the meeting.
- Offer opportunities for service user representatives to take part in relevant training and up-skilling activities.
- Find ways of accrediting participation in training.

- Establish accreditation of all service user involvement e.g. a certificate or record of participation will attach merit to the time and effort Disabled people give to the role.

Access

- Ensure meetings are fully accessible – involve service user representatives in identifying what the access requirements are.
- Identify a person who is the central point of contact for matters leading up to and following meetings.
- Ground rules – at the start of meeting use ground rules to help establish strategies for ensuring everyone can have their say and should be used to clearly signal that all contributions will be treated respectfully.
- Everyone should be required to listen carefully and be polite.

Equal Participation

- Involve service user representatives in setting the agenda for the meeting.
- Avoid having service user input as the final item on the agenda to ensure service user feedback gets the time and attention it requires.
- Make sure service user representatives have advanced receipt of all papers to be discussed in accessible formats well before the meeting.
- Ensure a welcome and inclusive event – have someone to meet and greet service user representatives.
- Follow through on suggestions and input made by service user representatives and have a strategy for feeding back on this.

Good Practice Recommendations for Improving Service User Involvement – Service User Representatives

- Ask for training if you want it and for accreditation of any training.
- Ask for accreditation of your involvement as a service user representative.
- Don't be afraid to say exactly what your access requirements are so that you can participate comfortably in meetings.
- Ask for a named person who can help you prepare and participate.
- Be prepared to ask questions and don't be afraid to speak up (training could help if you feel nervous about this).
- Listen carefully and be polite.
- Work out what you want to achieve and plan your strategy for getting this across in the meeting.
- Know that your involvement is key to making sure services are as good as they can possibly be.

Actions for Change

Here are some easy actions professionals can take to immediately set about improving involvement of service user representatives. These are small, doable consistent action steps and habits that will create more respectful and inclusive service user participation and are key to making sure that people who take on the role of service user representation have positive experiences and outcomes from being involved. Don't be alarmed: these steps are often small (some will take ten minutes or less to complete!) Over time they will improve involvement of service user representatives in ways that will make it more and more possible to drive through better, value for money, cost effective services that Disabled people value.

Four Essential Steps to Improving Involvement of Service User Representatives

Step 1 - Create profiles of the service users you work with and build better connections with them

Have you ever actually sat down and written up a list of exactly who the service user representatives are that are giving their time to the development of the services you deliver? Building a list of the people you already involve can be a hugely clarifying activity. Getting clear on exactly who you involve as service user representatives will help you identify essential access requirements for meetings and also to think about any missing perspectives and who else to involve. To improve involvement of service user representatives, you could get in touch with those already taking part and ask for their ideas on how participation could be improved. Better connection, and building genuine relationships with service user representatives, is a great way to strengthen the impact service users can make to your service and also to ensure the role is positive for them.

Step 2 - Set some 30-day goals for improving involvement of service user representatives

The goal you set is up to you. It might be to let service users know more about how they can get involved, a financial goal to improve access to meetings or travel reimbursement, a plan to make contact with existing representatives and ask them for feedback on how things are going, a new email update on service user recommendations - those are just a few ideas. We suggest 30-day goals because they are short enough to be manageable and will kick-start real change. In 30 days of focused action you can achieve incredible progress for improving service user involvement based on the rich and varied ideas in this report!

Step 3 - Include a call for service user involvement in any communications you send to your service user community

This is something that will take literally three minutes or less to write and can be included in every newsletter or correspondence sent out to service users. Getting

into the habit of always promoting the value of service user representation, and spelling out the benefits for both service providers and service users who take on the role, will have a massive impact on raising the value of the activity. The more clear calls to get people actively involved in service representation the more service users will be able to support service development and to benefit from involvement.

Step 4 - Follow up and ask for feedback

When service user representatives make suggestions follow these through. We know not all suggestions can be fully realised but have in place mechanisms for reporting back on how and whether suggestions have been responded to. Following up with service user representatives, including asking for new suggestions when recommendations get stuck, can be game changing for your service and shows respect for service user representation.

All of these tips can make a huge impact on service user involvement projects.

So, having read this report, we hope you will pick one or two steps to start the process of improving service user representation right away!

Contact us at Shaping Our Lives if you'd like to join our waiting list for our new Service User Involvement Advisory Service.

Appendix I - Glossary of Terms

Disability Equality Training
Training developed within the Disabled People's Movement which outlines the distinctions between the medical and social models of disability and the implications for professional practice and service delivery of these different ways of understanding.

Involvement activity
An activity, series of activities or group set up by an organisation to engage and involve service users in designing, overseeing and/or evaluating one of the organisations services or processes.

Organisation
A body providing a service. Can be a public body (like a local council or GP, a University), a charity (e.g. drug and alcohol services) or a private company (e.g. a residential home).

Professional(s)
This term is used interchangeably with service provider(s) and practitioner(s) in this document. It is taken to mean someone who is paid to work for an organisation in a particular role, like a social worker, nurse, or commissioning officer. It is used as a noun and not as a descriptive term suggesting particular behaviours.

Service user
A person who uses a service provided by an organisation, often in a social care or health care setting. A service user is not always a Disabled person. However, in this document we have used 'service user' to mean a Disabled person who is a service user. Anyone can self-define as a service user.

Service user representative (Representative)
An individual service user who joins in with an activity to share their lived experiences and sometimes speak on behalf of other service users.

The medical model of disability
Disability is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being, for example the ability to climb the stairs or walk to the shops (WHO, 1981)
(In other words, disability is an individual problem, a 'condition' caused by physical, sensory, cognitive emotional impairment).

The social model of disability
Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (Disabled People's International, 1981).
(In other words, disability originates in the built and social environments, and is a matter of how society responds or fails to respond to physical, sensory, cognitive or emotional differences of people with impairments).

Appendix II – Interview Schedule

Shaping Our Lives - Interview Schedule

Improving Understanding of Service User Involvement and Identity

Preamble

We want to find out about your experience of being a service user representative. We would like to talk about how being a service user representative might affect you as a service user . As a small thank you we will give you a £20 voucher.

Reasons why we are doing this study

(i) improve guidelines for other Disabled people taking on service user representative roles and

(ii) give guidance to professionals about how they can ensure respectful inclusion of service users

Confidentiality

All information gathered in this interview will be confidential and will be used anonymously to inform the project report, guidance leaflets and any articles about what we find. Findings may also be used in conference presentations where relevant and to inform other work from Shaping Our lives. We will not use the name of professionals or services mentioned in interviews. If you would like to see a draft report please give us your email address so that we can send it to you for comments.

Monitoring Information (optional)

(It may be best to ask these questions at the end when the interviewee is more relaxed. Answering these questions is optional but if the interviewee does not want to answer please can interviewers give any indications so we can assess the scope of participants for reflection in the report and findings.)

Name of interviewer
Name of interviewee Email address
If interviewee wishes to declare …
Description of disability (inc. mental health and ltc)
Gender
Age
Ethnic origin
Religion and beliefs
Sexual orientation

Question 1

We are interested in the ways you have taken part as a service user representative for health or care services

1a. Please tell us what service user representatitive activities you are involved in or have done before

1b. How did you get involved in these?
(perhaps: Why do you think you were asked to take part? Why did you agree to do it?)

1c. When did they take place (what years)? How much experience of being a service user representative have you had ?

Question 2

We are interested in how you felt when taking part as a service user representative

2a. How did you feel when you were taking part?

2b. In what ways was it a good experience?
(How did this make you feel?)

2c. In what ways was it not so good?
(How did this make you feel?)

2d. What things would you change to make these experiences different?
(Prompts: timing, venue, communication, feedback, outcome)

Question 3

We are interested in how being a service user representative might make a difference to your personal experience of services

3a. Do you think professionals consider you to be an expert in your service needs when you are using services? (For example, when you go to the doctor or a hospital appointment do they see you as an 'expert' if they know you are a service user representative?).

3b. If yes, can you tell us why you feel this way? What difference does it make to the services you get?

3c. If no, please tell us why not?

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3d. What would you change if you think these experiences should be different?

Question 4

We want to learn more about any difficulties or conflict you may have experienced between being a user of services and being a representative advising on how services could be improved

4a. Do you feel that professionals treat you differently when you are seeking support compared to when they see you in your service user representative role?

4b. Is this good or bad and why? Can you say a bit about this?

4c. Are there any disadvantages to being a service user representative? Does the role cause you any difficulties? Can you say a bit about this?

4d. Would you like anything about the way you are treated in either role to change and, if so, how?

4e. Is there any advice you want to share with professionals so there is not a conflict between how they treat you when you are using services and how they treat you when you are taking part as a service user representative?

Question 5

We want to learn more about any benefits or opportunities that may come through your experience of being a service user representative

5a. Do you notice any benefits coming your way in the services you receive because you are a service user representative? Can you tell me about these?

5b. Have any new opportunities come your way because you are a service user representative? Can you say a bit about these?

5c. Do you think there should be benefits offered to people who become service user representatives? What sorts of things?

5d. Are there any suggestions you want to share with professionals about how they can better support service users when they are taking part as a service user representative?

Question 6

6a. What 3 or 4 words would you use to describe your experiences of taking part as a service user representative?

6b. What 3 or 4 words would you use to describe your experiences of being a service user?

Question 7

Is there anything else you would like to share with professionals about the way they interact with you as either a service user in contrast to as a service user representative? Any tips for professionals?

Question 8

We would like to ask you a hypothetical question … if you were going to advise a friend on becoming a service user representative what would you want to tell them ? What tips would you give them? Why?