

“LEARN”ing what is important to children and young people with intellectual disabilities when they are in hospital

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Background: The need to review health service provision for children and young people (CYP) with disabilities and their families in the United Kingdom has been expressed in multiple reports: the most consistent message being that services need to be tailored to meet their individual needs. Our aim was to understand the hospital-related needs and experiences of CYP with intellectual disabilities.

Method: An ethnographic study of a neurosciences ward and outpatient department was conducted within a paediatric tertiary hospital setting.

Results: Five themes, developed using the acronym LEARN, explained what is important to CYP with intellectual disabilities in hospital: (i) little things make the biggest difference, (ii) eliminate unnecessary waiting, (iii) avoid boredom, (iv) routine and home comforts are key and (v) never assume.

Conclusions: It is imperative that the present authors continue to challenge the idea that it is acceptable to exclude CYP with intellectual disabilities from research because of their inability to participate.

KEYWORDS

children and young people, ethnography, healthcare, hospital, intellectual disabilities

1 | INTRODUCTION

Children with disabilities have more hospital admissions than children without disabilities (Mahon & Kibirige, 2004) and often have to attend the same hospital multiple times in a week (Kennedy, 2010). They are also more likely than other children to be absent from school. According to Emerson et al. (2012), as much as 62% of absences by children with profound and multiple intellectual disability were accounted for by illness and 13% from attending medical/dental appointments.

A recent review of the experience of disabled children as inpatients concluded that their experience was “variable and not always optimal” and that “providing information... would improve their experience” (Shilling, Edwards, Rogers, & Morris, 2012 p785). Similarly,

in a small Australian study exploring the perceptions of children with cerebral palsy of the medical consultation, children described wanting to be included even if they did not fully understand what was being said, and to be informed of any tests or procedures in advance, rather than having things “done” to them (Garth & Aroni, 2003). These findings resonate with those reported by Coyne and Kirwan (2012) in their study of children's wishes about hospital life. They found that “being heard and being listened to by doctors and nurses was highly valued” by children with acute and chronic illnesses. Moreover, when these children felt ignored “it made them feel upset.” Studies about experiences of hospitalisation of children with disabilities invariably focus on the views of parents and professionals. Sharkey et al. (2014, pp. 738–739) interviewed both groups about the barriers and facilitators to communicating with children

with disabilities who are inpatients. They revealed that communication was “*less than optimal*” and that “*staff perceived time pressures and lack of priority given to communicating directly with the child as major barriers.*”

The need to review healthcare provision for children and young people with disabilities and their families has been expressed in multiple reports (Care Quality Commission 2012, Department of Health 2013a,b): the most consistent message is that services need to be tailored to meet the individual needs of these patients and it is imperative that their views are incorporated at every level of service delivery. This message applies equally, if not more so to children and young people with intellectual disabilities whose struggle to get their voice heard is widely recognised. The National Children’s Bureau (Martin, 2009) goes so far as to describe these CYP as invisible, arguing that as their needs become more complex the more invisible they become. Despite this, few researchers have focused on how well hospital services are meeting their needs and those of their families. More importantly, the views of CYP with intellectual disabilities about being in hospital are rarely sought. This is despite patient satisfaction being identified as the single criterion by which the quality of services within the NHS should be measured (Kennedy, 2010). The present authors sought to address this major gap in the evidence base by placing this particular group of children and young people at the centre of an ethnographic study, the primary aim of which was to understand their needs and experience of being hospitalised.

2 | DESIGN

This was an ethnographic study of a neurosciences ward and outpatient department conducted over a period of 18 months within a paediatric tertiary hospital setting. Ethnography facilitates intense, ongoing observation of interactions and communications, thereby allowing the researcher to become immersed in the setting (Holloway, Brown, & Shipway, 2010) and obtain a complete picture of actions and events as they occur. This methodology was selected as the most appropriate for ensuring that CYP with intellectual disabilities remained at the centre of the study, providing rich, holistic insights into their hospital experience, including the nature of the environment in which they receive care and treatment and the interactions they and their families have with hospital staff (Reeves, 2008). The combination of repeated observations, interactions and “tailored interviews” provided numerous opportunities for CYP to share views and experiences of their hospital journey, both verbally and non-verbally, in “*their own time and in their own way*” (Lindsay-Waters, 2008, p 3104).

Supplementing these encounters with observations of ward activity and a review of ward documentation helped build a picture of the context in which these CYP experienced hospitalisation. Observational data were particularly key to understanding what hospital life was like for those whose degree of cognitive impairment precluded their active participation in the study, as were informal

discussions and interviews with their parents to capture proxy views. Interviews and informal discussions with staff provided insights into the ward culture surrounding the care for CYP with intellectual disabilities and perceptions on how well the needs of these patients and their families are met.

This is the second in a series of three papers reporting on data from this study, incrementally building a model of individualised care for CYP with intellectual disabilities and their families in hospital. In the first paper (Oulton, Sell, Kerry, & Gibson, 2015), the initial model, developed from staff data (observation, documentation, interviews and informal discussions), was presented. The model comprised five key components: relevant experience and dedicated training, identification of patients with intellectual disabilities, prioritising the little things of importance to them, creating a safe, familiar environment and using appropriate resources. A sixth component, working in partnership with parents, threaded through the model and was viewed by staff as being core to the delivery of individualised care.

In this paper, the present authors draw on CYP data (observations, interactions and interviews) including, where relevant, proxy views of their parents. Our intention is to see how well the model maps onto the needs and experiences of CYP with intellectual disabilities, adding relevant components to the model and identifying any gaps or areas of conflict. The paper is divided into two sections. The first part focuses on the methods used to include this particular group of patients in the research process, together with reflections on what worked well and the challenges. The second part reports on the findings, distinguishing between what CYP with intellectual disabilities were able to say and what the present authors learned from observing their hospital journey and talking to their parents. The third paper in this series will report on data relevant to parent’s own experience; this will be yet a further opportunity to refine the model.

3 | SAMPLE AND RECRUITMENT

All CYP and their parents on the ward during the data collection period were eligible for participation, with the exception of those unable to take part without an interpreter. A small group of senior staff in the clinical area were responsible for identifying eligible families and providing them with study information. A diagnosis of intellectual disability was confirmed using the medical notes. For those parents on the ward, information was given to them if their child was expected to remain in for more than one night and for parents in the outpatient setting whose child was due for admission within the data collection period. Parents were approached first and those who expressed an interest in taking part were then asked to discuss the study with their child. The final study sample comprised nine CYP with intellectual disabilities aged 4–21 years and at least one of their parents. Child participants had a range of diagnoses including rare craniofacial and neurological conditions, autism, hydrocephalus, epilepsy and cerebral palsy. Length of stay ranged from 3 days to 6 weeks. Four participants

were admitted on more than one occasion during the data collection period. Five participants were also observed during at least one outpatient appointment. Two parents declined to participate, one stating that they had too much going on and the other without giving a reason.

4 | CONSENT AND ASSENT

All parents provided written informed consent for their own participation and for their child to take part, except in the case of one young person aged 21 who provided her own consent. Children who understood what was being asked of them and were able to “have a say” in the decision were asked to assent to being involved (Nuffield Council on Bioethics 2015), with the researcher reconfirming their agreement at each visit. Those unable to give assent were included for observation only, with parental permission.

A range of resources was used in the assent process to facilitate participants' understanding of what was being asked of them (Figure 1). These included a patient information sheet comprising text and symbols created using Communicate in Print Software. In addition, a talking photograph album was offered, providing an opportunity for children to replay pre-recorded audio clips each linked to visual prompts, such as photographs of the hospital and of the researcher. An electronic Yes/No switch was used for those with difficulty physically signing the assent form. Assent for one young person was not recorded in advance at the request of her parent, who felt the only way she would be able to show her agreement was if she positively engaged with the data collection activities.

Prior to any data collection, the researcher spent time with CYP playing games, watching television and “chatting” with them. Such engagement was crucial for building rapport (Madison, 2012) as well as developing an understanding of their individual physical, learning and communication needs and abilities, so important with this population of research participants.

5 | METHODS

Participation in data collection varied for the patients in this study, with parents fulfilling either a facilitative or reporting role. Five CYP were involved in the study through being observed only, with parents playing a valuable role as proxies for them, sharing perceptions of their child's needs and experiences. Four CYP were able to actively take part in “tailored interview” sessions as well as being observed. As part of these sessions, two young people carried out four activities, one young person carried out two activities and one child with a short attention span engaged solely in discussion. In these cases, parents played a useful facilitative role, helping the researcher prepare for the interview session, acting as the CYP's aide memoir and/or assisting with communication. Due to the ethnographic nature of the study, the researcher had ongoing informal conversations with parents during their child's admission, which provided supplementary data that added valuable context and depth to some of the children's stories. The type of involvement parents had in their child's data collection sessions was determined by the child/young person's willingness and ability to give their opinion, rather than parent's wish to contribute their own views. Whilst there are risks associated with parent's talking on behalf of their child, there will always be a proportion of patients whose cognitive impairment precludes their active involvement in research but whose needs and experiences, nevertheless, require understanding.

5.1 | Participant observations

Observations were made of general ward activities, including ward rounds, multidisciplinary team meetings, nursing handovers and psychosocial meetings, as well as participant focussed observations of procedures, treatments and outpatient appointments. Observations were often participative, with the researcher interacting with CYP using play, touch and sound. The researcher also spent time at the nurses' station, the front reception desk and in the corridors and purposefully visited on different days and times to capture the full



FIGURE 1 Assent materials

breadth of ward activity and dynamics. Field notes were made contemporaneously and later typed up in further detail.

5.2 | Parent discussions

An ongoing dialogue was maintained with parents about their child's inpatient/outpatient progress throughout the data collection period. There was no interview schedule for these interactions, which tended to be built around what was or had been happening since the previous discussion.

5.3 | Tailored interviews with CYP

Drawing on the Mosaic approach (Clark & Moss, 2011) and other examples of arts-based research methods (Carter & Ford, 2014; Coad, Plumridge, & Metcalfe, 2009; Horstman, Aldiss, O'Leary, Richardson, & Gibson, 2009; Knighting, Rowa-Dewar, Malcom, Kearney, & Gibson, 2011), a toolkit of creative activities was devised to use with CYP during interviews to facilitate them sharing their views and experiences of being in hospital. Specialist training in communicating with people with profound and multiple intellectual disabilities helped shape the contents of the toolkit. The number and choice of methods used with each participant were informed by their abilities and preferences. All activities took place in the cubicle on the ward, except one that was conducted in the young person's home during a follow-up interview. Activities were audio recorded with participant's permission.

5.3.1 | Likes and dislikes activity

An extension to "card sorting" (Malcolm, Gibson, Adams, Anderson, & Forbat, 2013) was developed by the researcher to support participants to share what they liked and disliked about being in hospital. They decorated two small "moneybox" style cardboard boxes (Figure 2), one to represent their "likes" and the other their "dislikes." The researcher helped CYP to think about some of their favourite things or colours when deciding how to decorate them. Symbol cards representing people, places and objects within the hospital were laid out in front of CYP, who were asked to choose one at a time and put it into their "likes" or "dislikes" box. Each time they placed a symbol in a box they were asked "what is it you like/dislike about X?" A few symbols relating to everyday activities such as football/music were included to give CYP an easy starting point and provided a simple check of their understanding of the process. Duplicate cards were available in case CYP wanted to share something they liked *and* disliked about any of the symbols. Blank cards were also provided for them to add their own symbols. Children were given control over which symbols they selected, and in which order, and were informed that they did not have to select every symbol.

5.3.2 | Emotions activity

A simplified version of the likes and dislikes activity was developed with emotion faces cards replacing the likes/dislikes boxes. The



FIGURE 2 Likes and dislikes activity

activity was carried out as described above but instead of placing the symbols in the likes/dislikes box; participants selected the emotion faces card which best-matched how they felt about each symbol. Each time the CYP chose an emotion, the researcher defined it, thereby clarifying its meaning before asking, where appropriate, why they had selected that particular emotion.

5.3.3 | 3rd person craft activity

The aim of this activity was to provide CYP with a way of expressing their views and feelings without having to refer to themselves in the first person. It involved participants decorating a cut-out "figure" using an array of craft materials. This figure once decorated was then used as an avenue for discussion with participants about their hospital experience.

5.3.4 | Sticker activity

A symbol-based questionnaire was modified from Lambert's "stick a star quiz" (Lambert, Glacken, & McCarron, 2008) using Communication in Print software. Each questionnaire comprised four questions to ascertain views on the level of interaction CYP had with nurses and doctors. Children were asked to put a sticker in the Yes or No box to indicate whether nurses or doctors (i) talked to them, (ii) listened to them, (iii) asked them any questions and (iv) answered their questions. The researcher went through each question one at a time, reminding them how to indicate their response using the stickers. After placing each sticker, participants were asked if they wanted to add any further detail.

5.3.5 | Paper person activity

The paper person activity was used to explore how much CYP understood about the care and treatment they received, including

knowledge of medical terminology. They were asked to think about the different things that had happened to them during their hospital stay and where possible to mark these on a large paper body map. Prompts were given when needed, the first being to draw on their identification band. The completed body map was used as a prompt for further discussion.

Each activity presented a number of opportunities and challenges for use with CYP with intellectual disabilities that are summarised in Table 1.

5.4 | Data analysis

Data were analysed using the framework approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013; p. 118) appropriate “for managing large data sets where obtaining a holistic, descriptive overview of the entire data set is desirable.” In this study, the data set comprised CYP, parent and observational data. As Gale et al. (2013, p. 118) point out, “while in-depth analyses of key themes can take place across the whole data set, the views of each research participant remain connected to other aspects of their account ... so that the context of the individual's views is not lost.” This was particularly important in this study in which data obtained directly from CYP were contextualised by participant observation and discussions with parents. This approach is also recognised as being relevant to use for the thematic analysis of other types of data as well as interview transcripts, including documents and field notes from observations (Gale et al., 2013). Unlike other qualitative approaches, framework “is not aligned with a particular epistemological viewpoint or theoretical approach” (Gale et al., 2013 p.

120). It is highly structured and felt to place “greater emphasis [than thematic analysis] on making the process of data analysis transparent and illustrating the linkage between the stages of the analysis” (Smith & Firth, 2011; p. 3).

Contemporaneous handwritten field notes of participant observations were made and typed up in full as soon as possible afterwards (Emerson, Fretz, & Shaw, 1995). Interviews were audio -recorded and transcribed verbatim. Familiarisation of the data involved repeatedly reading written material and when necessary re-listening to audio tapes, including any contextual or reflective notes recorded as part of participant observation or during activity sessions (Gale et al., 2013). Each strand of the data set was then labelled (e.g., communication, environment and space) during a process of open-coding. The next step of building an analytical framework involved multiple stages. The CYP data set was relatively small, and comprised data collected using multiple methods, with variations in the breadth and depth of what was collected for each participant. Hence, in the first instance, a working analytical framework was developed from several transcripts taken from the largest data set that of parents. The research team and members of the study steering committee reviewed the framework over several iterations, looking for redundant and overlapping codes, and identifying new codes. Once the analytical framework was agreed, it was applied initially to subsequent parent transcripts, followed by participant observation field notes and summaries of the data were charted into a framework matrix comprising rows (cases), columns (codes) and “cells” of summarised data (Gale et al., 2013). Data from CYP accounts were then added to the framework before the final stage of data analysis, which involved a process of interpretation

TABLE 1 Opportunities and challenges of methods used with children and young people with learning disabilities

Method	Materials	Opportunities	Challenges
Likes and Dislikes Activity	<ol style="list-style-type: none"> Two sets of hospital-related symbol cards Blank cards Two boxes with opening at the top to insert symbol cards Craft materials for decorating the boxes 	<ol style="list-style-type: none"> Can be personalised Can be fun Generates a creative output Facilitates the sharing of preferences 	<ol style="list-style-type: none"> Time-consuming Visual ability Hand-eye coordination Ability to recognise symbols Ability to draw associations between the physical and emotional Ability to make a choice Concentration level
Emotions Activity	<ol style="list-style-type: none"> Set of hospital-related symbol cards Set of laminated emotions cards 	<ol style="list-style-type: none"> Simple Quick—suitable for those with short attention span Facilitates the sharing of feelings 	<ol style="list-style-type: none"> Visual ability Ability to recognise symbols Ability to draw associations between the physical and emotional
3 rd Person Craft Activity	<ol style="list-style-type: none"> Cut-out cardboard person Craft materials for decorating person 	<ol style="list-style-type: none"> Unstructured activity giving control to participant Can be fun Generates a creative output Sensory based Facilitates the sharing of views and experience through the process of “projection” 	<ol style="list-style-type: none"> Visual ability Hand-eye coordination Fine motor skills Ability to make internal representations Verbal communication
Sticker Activity	<ol style="list-style-type: none"> Stickers Paper-based questionnaire 	<ol style="list-style-type: none"> Structured data collection method allowing direct comparison of participant data Facilitates the sharing of opinions 	<ol style="list-style-type: none"> Reading ability Level of comprehension

involving the generation of themes at the individual case level and across the data set.

6 | RESULTS

Figure 3 illustrates the key themes to emerge from the data. Whilst data from multiple sources contributed to each theme, those highlighted in red arose predominately from the creative activities undertaken with CYP. Themes highlighted in blue emerged predominately from observations of the participant's hospital journey and "discussions" with parents about their child's needs and experiences. To prioritise the narrative of the CYP, the reporting of data that follows is separated into what CYP were able to say and what observational and parent data contributed to their story.

6.1 | What do children and young people say about their hospital experience?

As the quotes in Table 2 illustrate, CYP who took part in "interviews" were able to say what they thought about the hospital environment, their treatments and procedures and interactions with staff. Issues associated with pain, noise, sleep, staff and touch emerged.

The importance of getting a good night sleep and eating tasty food was evident. One participant described how stressful she had found it trying to sleep when she could hear other children crying. She repeatedly said how relieved she felt when she was moved into her own cubicle so she could have some "peace and quiet" and sleep in a comfortable bed. Another participant said that the noise on the ward kept her awake at night and that sleeping in her own bed was what she was most looking forward to about going home. When talking about

their dislikes, some participants described being scared of having their blood taken and having an operation, being in pain, taking medication and worried about missing school/college.

It was apparent from listening to and observing CYP that the way staff interacted with them was hugely important. For example, one participant talked repeatedly about the nurses on the ward and how they made her laugh. She described how important it was that her cubicle door was left open so she could continually interact with them. Having contact with the same nurses, who she knew well, was particularly important. It was through using the third-person craft method that it emerged how much she valued her relationship with the nursing staff. Upon seeing the cut-out figures, she immediately requested to decorate two to look like her favourite nurses and two more to look like herself. She explained that she wanted to give the nurses the figures of herself so they did not forget her. She went on to explain why she liked the nurses so much:

Carly: *This one is of my favourite nurse*
 Researcher: *Why is she your favourite nurse?*
 Carly: *She always looks after me*
 Researcher: *What sort of things does she do?*
 Carly: *When I was in the high thingamabob (high-dependency bay) the boy opposite kept going on and on and on. I was like get him away from me. She was there to calm him down*
 [Carly, 21-year-old patient]

During interviews, two participants shared a sense of uncertainty about the purpose of their admission and what was going to happen to them:

Researcher: *Did you tell your friends why you were coming into hospital?*
 Max: *No, I didn't know why I was coming*
 Researcher: *Anything you were worried about?*
 Max: *Yes, I was worried about why did I come here*
 Researcher: *Did the nurses or doctors speak to you about why?*
 Max: *If they did tell me why I am here I can't remember*
 [Max, 17-year-old patient]

Jamila: *She's sad ... she doesn't like staying in the hospital*
 Researcher: *What is it she doesn't like?*
 Jamila: *When she has to have an operation*
 Researcher: *Are there any questions she would like to ask the nurses or doctors?*
 Jamila: *What they want to do?*
 [Jamila, 14-year-old patient]

The uncertainty Jamila expresses above in relation to her forthcoming operation emerged during the 3rd person craft activity. The likes/dislikes activity revealed more about the level of involvement and information she wanted:

Jamila: *I don't like going to hospital*
 Researcher: *What is it you don't like?*

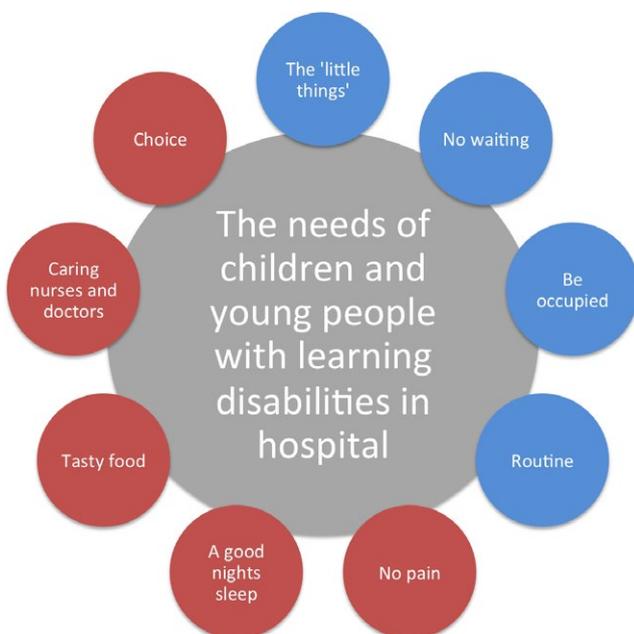


FIGURE 3 Needs of CYP-ID in hospital

TABLE 2 Examples of what children and young people with intellectual disabilities said about their hospital experience

Symbol	Activity	Selection made	Quote
Bed	Likes/dislike box	Like	I like bed, it's got a Lilo under me
Doctors	Likes/dislike box	Like	I had a nice doctor on Monday. He cares about me a lot
Nurses	Likes/dislike box	Like	They make me laugh
Needle	Likes/dislike box	Dislike	I hate it ... it hurts
Tablets	Likes/dislike box	Dislike	I hate them ... the taste
Eye drops	Likes/dislike box	Dislike	They make it all go blurry
Noise	Likes/dislike box	Dislike	It keeps me awake, bleeping and crying
Food	Emotion cards	Happy	I like the rice
Cubicle	Emotion cards	Happy	It is big
Nurses	Emotion cards	Worried	They are going to touch my face
Doctors	Emotion cards	Sad	I don't like it when they turn the screws on my frame

Jamila: When they look at my eyes
 Researcher: What is it about that you don't like?
 Jamila: When they open them
 Researcher: What does that feel like?
 Jamila: Scared
 Researcher: What might they do to make you feel less scared?
 Jamila: Let me open them?
 Researcher: Do you get to do that?
 Jamila: Only sometimes
 Researcher: When they say you can open your eyes for them how does that make you feel?
 Jamila: Smiles

[Jamila, 14-year-old patient]

Researcher: Thinking about your operation, is there something you want to tell me about what you liked or didn't like about it?
 Jamila: Puts the symbol in the dislike box
 Researcher: Why did you put it in that box?
 Jamila: Because people are saying things in front of me
 Researcher: And did that happen sometimes when you were in hospital?
 Jamila: Yes ... it was the doctor
 Researcher: How did that make you feel?
 Jamila: Scared and upset
 Researcher: And what might we do next time you go into hospital to help that?
 Jamila: Ask

[Jamila, 14-year-old patient]

Observation of Jamila's inpatient admission revealed numerous occasions when medical professionals discussed Jamila's surgery with her parents in front of her but not including her in the discussion. On one occasion, this included a discussion of the need for her to go back to theatre unexpectedly. These examples demonstrate the fear and worry that can result when CYP are not involved or given a choice about the level of information they receive from professionals, or the role they might play in their own management and treatment.

6.2 | What do observations of children and young people with intellectual disabilities in hospital and discussions with their parents tell us?

A number of key themes described here emerged from observational and parent data, which together support staff perceptions of the need for an individualised model of care for CYP with intellectual disabilities. As one mother said:

"I do understand that on one hand what they're saying is that normally we do it like this, but I'm thinking, 'Yes, but this is not like your regular scenario.' Georgia, you can't fit a round peg into a square hole. You can't say, 'Right, this is how we normally do it.' We need to look at how do we do it for Georgia, because at the end of the day ... each patient comes in with their own individual needs" [Mother of 13 daughter, parent proxy]

6.2.1 | The little things make the biggest difference

Observational data provided a powerful picture of how important the little things were to this group of CYP. This was demonstrated through seeing the emotional and physical impact on them and their family when these little things were dismissed, ignored or unavailable in the hospital setting. For one participant, being able to continually open and shut doors was something that could distract him for a considerable length of time. For another participant, social contact was the little thing that was important to her, whilst for another it was being able to listen to her headphones and play with a piece of string. The important point is that whilst all CYP may have particular things that are important to them when they come into hospital, those with intellectual disabilities appear to have a significantly reduced ability to cope emotionally without them, sometimes resulting in distress, panic, sadness and challenging behaviour, including repeated spitting, shouting and hitting out. This was observed on numerous occasions, and it was noticeable how quickly the child's emotions could change. Moreover, as two parents explained, this emotional distress could also compromise their child's physical health by triggering an epileptic seizure.

It was apparent from observing practice that there was a lack of documentation and communication by staff about what mattered to CYP with intellectual disabilities in hospital and their lack of knowledge meant they could unwittingly contribute to a patient's distress. In one example, nursing staff repeatedly closed the door upon leaving the cubicle of one participant who reported to the researcher how much she liked being able to wave and talk to nursing staff as they walked up and down the ward corridor.

6.2.2 | Routine

Parents spoke about the importance of not disrupting their child's routine during hospitalisation. It was apparent that there was a link between maintaining the child's routine and knowledge of the little things that were important to them:

"I can't fault the staff they're all lovely. They've done a good job but it's just the little things. Sometimes you don't realise. You're doing your job and you're looking after lots of people and lots going on, something that's kind of maybe minor to them is a big thing to Rebecca. Even the bigger thing on a child with learning disability, things that are kind of minor to other children her age ... it's a lot bigger and she makes a bit more of a bigger fuss about it ... That's why it is important that we get things going right for her so it doesn't disrupt her, we have to try and disrupt her as least as we possibly can." [Mother of 7-year-old daughter]

A number of parents described in detail the emotional and physical impact on them and their child, when this routine was disrupted in hospital. They explained the difficulties their child had understanding why their routine was different, as well as adapting to any changes.

One mother, for example, said that waking her son at 5.30 a.m. so they could get to hospital in time for his surgery triggered an epileptic seizure. Then having got to the hospital on time, he often experienced a lengthy wait or cancellation, something that her son found confusing and extremely stressful. This mother goes on to explain the added challenge of getting her son back to his normal routine when his operation was cancelled because she had prepared him for being in hospital:

"He was a bit confused ... it did upset him in one way, being told, 'Well, you're not going to be doing this, but now you are going to be doing this.' That is why we try to keep everything very minimal when it comes to telling him certain things"
[Mother of 15-year-old son]

As well as maintaining their routine, parents talked about the need for staff to be patient with CYP with intellectual disabilities and to go at their pace:

"You've got to take it at their pace so that is where I think a lot of hospitals, or wherever you go, it's rush, rush, rush, and they're not stopping to think, 'Well that child needs to be given time to process things if you want.' Which is why we'll go through a little, and we tell him little bits, so it's not too scary"
[Mother of 15-year-old son]

"Be patient and understanding, or a bit more patient and understanding than, kind of, your, you know, typical child, let's say. She does need that" [Mother of 7-year-old daughter]

This need for patience and understanding was highlighted most clearly in the case of a 17-year-old with delayed auditory processing, which meant he took a considerable time to respond to questions. Despite this being recorded in his medical notes, observations revealed that staff did not always allow sufficient time for him to answer their questions before answering for him or leaving the room.

6.2.3 | Being occupied

It was apparent from interacting with CYP and their parents and observing their hospital journey just how much they valued having things to do that prevented them from becoming bored. All those who took part in the likes/dislikes and/or emotions activity responded positively when they were shown symbols representing the television, puzzles/board games and a photograph of the ward playroom. One parent noted how much her son was enjoying spending time and talking with the researcher. She went on to say that keeping occupied was her son's greatest need and explained in depth the repercussions of him being "bored" and "lonely" in hospital:

"Everybody is busy and hardly anybody will come and see you ... he'll go, 'Mummy, I'm bored', sometimes when he does that it stresses me out ... I think the more bored he is, the more time he has to think of, 'Why am I here? Why does it have to be me?' ... He'll be very, very moody because he can't do stuff and the only thing he can do is his games and music. An iPad ... you can play games on it, but he hasn't got that so that means, for him, it's just his music. That stresses him ... Normally, he would chat with his friends on Facebook ... but here the reception is bad. No, it's normal games, like Xbox. It never works properly ... It's like outgrown them so they then go to the playroom and it's all children's stuff, nothing for his age, so that makes him really, really bored. If he's lucky enough to have a boy on his ward who likes football then they talk football 24/7" [Mother of 17-year-old son].

This mother highlights a multitude of issues related to the theme of avoiding boredom including a lack of opportunity for patients to mix with other patients of their age/gender, a lack of facilities for patients to maintain contact with friends outside of the hospital, a lack of age-appropriate resources in working order and a lack of time for staff to spend with patients. Another parent raised the issue of staffing, highlighting the need for more comprehensive play specialist provision within the hospital:

"Although they have the play leaders, maybe a few more, because they're so busy with, kind of, all of the children that, kind of, a bit more activity, you, kind of, have the one, and that's good, and she enjoyed it. There needs to be a more constant staff, I think, because it is a long day" [Mother of 7-year-old daughter].

The issue of accessing staff and resources to help keep CYP with intellectual disabilities occupied was highlighted particularly clearly one Saturday when the researcher observed a parent buying craft materials from the hospital shop because the playroom could not be accessed at the weekend. One father describes the added challenges associated with avoiding boredom in a child with "very short-term memory and no real concentration span":

"All Natasha wants to do is either go for a walk around the ward or go to the playroom. She's happy then ... She'll happily go and do something and if you get five minutes out of that, fantastic. Drawing, colouring, games console, anything like that, she'll want to do it, but then within a minute of it all being set up and ready to go, she's not interested anymore. She wants something else" [Father of 8-year-old daughter]

6.2.4 | No waiting

The extensive amount of waiting that these participants and their parents have to do whilst in hospital was observed: waiting for information, results, people, decisions, treatments and so on. Examples of excessive waiting also emerged from conversations with parents:

"It's just like waiting around for things to happen, waiting to go to theatre. I don't understand why that always happens. They say oh you're going to go in at 11 o'clock. 11 o'clock turns into what 12, 1, 2, 3, it's crazy. They say you can't eat anything after, I don't know 5 o'clock or something and you're still waiting at 2 pm in the afternoon. It has always been like that whether you go to clinic or to appointments, it's still the same" [Mother of 14-year-old daughter].

As one mother explained, her son was not only affected directly as a result of excessive waiting but also indirectly, responding negatively to her own reaction, "*we were waiting and waiting, not knowing what's happening. I had anxiety and he obviously picked up on it*" [Mother of 15-year-old son].

Ethnographic observations of CYP and their parents in the outpatient setting brought these concerns to life. One young girl with a very short attention span began shouting, hitting out and self-harming whilst she was waiting to be seen. At one point, she went to hit out at another family walking past but her mother managed to restrain her and stand in the way. At this point, another parent waiting to be seen offered to change her place in the queue. The tension for everyone concerned was palpable. In another example, a patient spent over two hours in the outpatients appointment with her Dad waiting to be seen by different members of staff. She spent the majority of this time walking up and down the corridor talking to other families. Her very short attention span meant that she rarely sat still for more than a few minutes, which was particularly challenging to manage due to her unsteadiness on her feet and tendency to be overly familiar with other children. There was little available to distract her during this time. The "games" console was of interest but it was too difficult for her to control the handset.

7 | DISCUSSION

This study has demonstrated the value of drawing on multiple sources of data to understand the needs and experiences of CYP with intellectual disabilities when they are in hospital. Taking the time to build rapport with them before undertaking any research activities was essential for facilitating personalised data collection. Participants who were able to undertake the creative activities, appeared to engage with them, particularly those that had a tangible output, such as the moneybox and cut-out figure. Despite having limitations, these activities provided an avenue for them to share, to varying degrees, their likes and dislikes, their fears and concerns and their views on the way

staff interacted with them. Some CYP seemed to like receiving information about the study via the talking photo album, highlighting the potential for this to be used as a data collection “tool,” particularly in research involving photography.

Of note is that much of what CYP reported as being important to them was not obviously linked to them having an intellectual impairment but related to them being a patient in hospital, that is, tasty food, a good night’s sleep, having things to do and being pain free. The issues associated with avoiding boredom in CYP with intellectual disabilities came through strongly from multiple data sources, strengthening the claim by Coyne and Kirwan (2012, p. 300) that “Hospitals should be designed to accommodate children of all ages, and should include spaces for socialisation, access to computers, movies and games, and therapies such as pet and music.” It is essential that age is not the only criterion for designing hospital spaces, but that the developmental level, attention-span and physical ability of patients are also taken into account.

Children in this study also highlighted a need for choice, particularly in relation to how much information they receive and their level of involvement in decision-making about their health needs. The importance of hospital staff not making assumptions about what CYP with intellectual disabilities are able to do and understand was key, a finding strengthened by observational and supplementary parent data. These findings build on other studies highlighting the need for better verbal

and written communication with children in hospital (Coyne & Kirwan, 2012; Garth & Aroni, 2003; Sharkey et al., 2014; Shilling et al., 2012).

In the absence of some CYP being able to participate in creative activities, participant observation and parent proxy provided alternative methods for understanding their hospital journey. Participant observation contributed visually rich data of how CYP with intellectual disabilities respond physically and emotionally to being hospitalised. Parent proxy data added an explanation of why they respond to different situations and environments as they do, as well as how their needs can best be met. The findings from these data sources reinforced staff views about the need to individualise hospital care for these patients, vividly illuminating why that should be a requirement rather than a choice for healthcare staff.

The themes from this study have been developed using the acronym LEARN as a useful way of imparting the key messages to healthcare staff (Figure 4). These themes add to five of the six components of the individualised model of care previously conceptualised using interview data from hospital staff. A new component has also been added to reflect a key theme missing from the existing model, one that relates to involving CYP with intellectual disabilities.

The finding that the little things make the biggest difference to CYP with intellectual disabilities reinforces the message from staff that it is these little things that need prioritising in hospital. Both parents and staff provided examples of the emotional and physical impact on

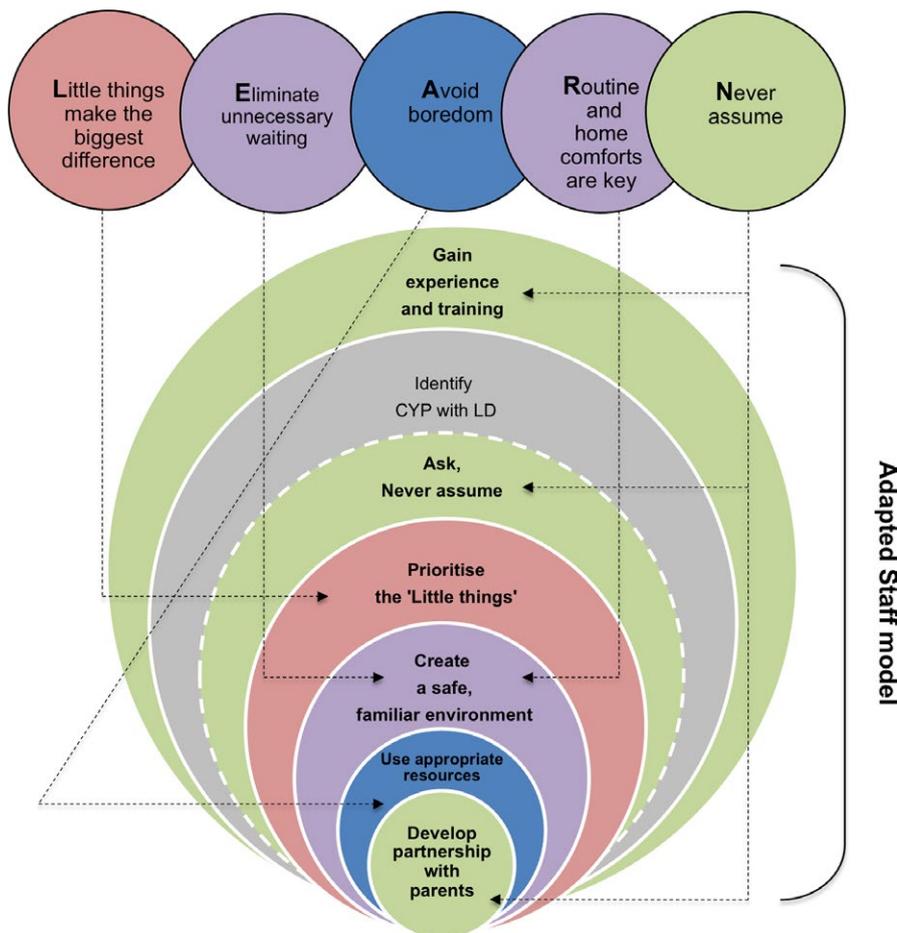


FIGURE 4 Adapted model of individualised care

these CYP when the little things that are important to them are not made available. Observational data reinforced these findings, particularly in relation to CYP with more severe cognitive impairment. The evidence suggests that this, more than any other component of the model, is crucial to the well-being of CYP with intellectual disabilities in hospital. Essential to ensuring staff pay attention to the “little things” is appropriate experience and training that helps them to appreciate why this is so important.

The need to eliminate unnecessary waiting and maintain the routine and home comforts of these patients adds to our understanding of the most appropriate environment for caring for them. As identified by staff, not only does it need to be safe and familiar to CYP with intellectual disabilities, but it also needs to be appropriately equipped with resources to keep them pre-occupied in between appointments, treatments and procedures.

The importance of not assuming what CYP want when they are in hospital or what they can say and do reiterates the need for staff to receive appropriate training and experience in the care of those with intellectual disabilities. This should include skills in developing a partnership with their parents to draw on their expertise and idiographic knowledge of their child. Most importantly, however, staff need to be skilled and confident in communicating with CYP with intellectual disabilities and take the time to ask what is important to them. This component, “Ask, Don’t Assume,” is a crucial addition to the individualised model of care. Only one component of the model, “identifying CYP with intellectual disabilities,” did not emerge from the CYP data.

7.1 | Reflections and limitations

This was a single-site study, involving nine CYP with intellectual disabilities and their families, only four of whom had sufficient cognitive functioning to take part in tailored participatory interviews. Drawing conclusions from such a small data set is challenging, and as such, caution should be applied when generalising the findings. However, the inclusion of data collected through protracted participant observation of CYP with intellectual disabilities in a hospital environment, as well as through parent proxy, augmented the overall picture of what is important to this group of CYP in hospital. In the context of the existing evidence base, this provides a good starting point for considering how to improve the delivery of hospital care and services to this population. The present authors have subsequently been able to draw upon these data, alongside what they learnt about how to engage CYP with intellectual disabilities in research, to secure funding for a national mixed methods study to identify the barriers and facilitators to ensuring equal access to high-quality hospital care and services for CYP with intellectual disabilities and their families (Oulton et al. 2017). In this larger study, the present authors are working closely with local collaborators to ensure that CYP with mild intellectual disability, whose impairment may be less visible, are identified and recruited, in addition to those who are more severely disabled.

Because families were consented to take part in the study whilst they were on the ward and due to the time taken to build rapport, in

some cases the patient was discharged home soon after. This restricted the amount of data that could be collected in the time frame. This situation highlights a potential benefit of recruiting and consenting/assenting families prior to their hospital admission, either during clinic or in the family home. Using ethnography resulted in rich holistic data from parents and CYP from the same family. However, this could result in competing demands for the researcher’s time, which was sometimes difficult to manage. A particular challenge with using ethnography in the hospital setting was not knowing which admission or appointment would be the child’s last within the study time frame. Whilst all CYP received a voucher and thank-you certificate in the post as well as a summary of the findings, it was not always possible to end the research relationship in person.

8 | CONCLUSION

This study has shown how it is possible to involve CYP with intellectual disabilities in qualitative research using a range of research methods tailored to their needs. It is imperative that the present authors continue to challenge the idea that it is acceptable to exclude this population of patients from research on the grounds of their inability to participate.

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