

Being a child with intellectual disabilities in hospital: The need for an individualised approach to care

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Abstract

Background: There is limited qualitative research focussed specifically on what it is like for children and young people with intellectual disabilities coming into hospital, with much of the evidence-base being about those with Autism Spectrum Condition or adults with intellectual disabilities.

Aim: To share rich detail of the emotional and physical impact on children and young people with intellectual disabilities of attending hospital, from their own and their parent's perspective.

Methods: Talking Mats interviews, sticker survey and photography with children and young people with intellectual disabilities, and in-depth interviews, hospital diaries and photography with their parents.

Results and Conclusions: The multiple and compounding layers of complexity surrounding hospital care of children and young people with intellectual disabilities resulted in challenges associated with loss of familiarity and routine, undergoing procedures, managing sensory overload, managing pain and having a lack of safety awareness. An individualised approach to their care is needed.

KEYWORDS

acute care, children and young people, hospital care, Intellectual disabilities, parents

1 | INTRODUCTION

The health needs of children and young people, hereafter referred to as children, with intellectual disabilities are multifaceted and tend to be greater than children without intellectual disabilities. A study by Horridge et al. (2016) for example, found that the former had more health conditions, more health technology dependencies, such as a tracheostomy or gastrostomy, and more family-reported issues, such as school or housing problems, than the latter, as well as an increased likelihood of needing 'round the clock care' (Horridge et al., 2016). They subsequently experience more frequent hospital visits and

longer length of hospital stays than children without intellectual disabilities (Glover et al., 2019; Mahon & Kibirige, 2004; Mimmo, Harrison, et al., 2022), impacting on their school attendance (Emerson et al., 2011). Furthermore, children with intellectual disabilities have been found to have more admissions with at least one incident, compared to children without intellectual disability (Mimmo, Harrison, et al., 2022).

Despite this, there is a limited body of qualitative research focussed specifically on what it is like for children with intellectual disabilities to come into hospital, with much of the evidence-base being about children with Autism Spectrum Condition, adults with

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intellectual disabilities or parent's own experience. Current literature tends to comprise small scale single sites studies or case reports which have highlighted hospital as being a stressful and anxiety provoking experience for this population of patients (Bates et al., 2019; Brown et al., 2012; Brown & Guvenir, 2008; Oulton et al., 2015; Oulton, Sell, & Gibson, 2018; Page et al., 2017; Seliner et al., 2016). One case study, for example, revealed that for one child with intellectual disabilities it took seven appointments over 15 weeks for them to have a blood test taken (Brown et al., 2012). An ethnographic study of hospital in-patient and out-patient experiences of nine families (Oulton et al., 2015) revealed how important the 'little things' are to children with intellectual disabilities in hospital, such as particular objects or activities, and the anxiety they can experience when these are not available. Maintaining their routine, keeping them occupied and avoiding waiting were also found to be central to their well-being in hospital. Similarly, Seliner et al. (2016) described the importance of staff and environment continuity, with parents describing their child as being 'very vulnerable, particularly due to the children's dependence, limited ability to communicate, or fragile medical condition'. Communication as a theme features in a number of papers, particularly in relation to the reliance hospital staff place on parents to communicate with the child with intellectual disabilities and assumptions that a lack of verbal communication reflects a lack of understanding (Aston et al., 2014; Sharkey et al., 2016). A structured review of qualitative studies focused specifically on in-patient experiences of disabled children (Shilling et al., 2012) reported that communication was the key factor determining whether the child and family had a positive or negative experience. It was reported that during outpatient appointments health professionals often talked to parents instead of the child, resulting in feelings of disempowerment (Hubner et al., 2016) and there was concern from parents that children with communication disorders would be misunderstood (Wharton et al., 2005). Notably, only two of the eight studies included in this review focused specifically on the care of children with intellectual disabilities and, in these, only two individual children were directly included.

More recently, a metanarrative of the experience for the parent of a child with intellectual disabilities in hospital identified the importance of the child with intellectual disabilities being recognised 'as an individual with unique needs', and the significance parents placed upon healthcare professionals seeing the 'child with intellectual disabilities as a human being, with a personality' (Mimmo et al., 2019).

Whilst these studies provide valuable insight into the hospital experience for children and with intellectual disabilities, there is an absence of multi-centre research that includes in-depth narratives of the direct impact on the child or young person.

1.1 | Aim

This paper is the first in a series sharing data from phase 2 of a national study, the overall aim of which was to identify of the barriers and facilitators to children with intellectual disabilities and their

families receiving equal access to high quality hospital care in England (Oulton et al., 2016). The focus of this paper is the emotional and physical impact on the child of being in hospital, from their own or their parent's perspective. Future papers will report safety issues, as well as staff and environmental factors that facilitate or prevent equitable hospital care.

1.2 | Research design

We used a four-phase, transformative, mixed-methods case study design. The case study approach, recognised as giving 'a voice to the powerless and voiceless', enabled the views of children with intellectual disabilities and their parents to be prioritised and explored 'in depth and within its real-life context'. Phase one focused solely on data collection at the organisational level (Oulton, Gibson, et al., 2018; Oulton et al., 2019; Kenten et al., 2019). Phase two focused primarily on qualitative data collection with families and staff, with data collected from families reported here. Subsequent phases involved quantitative data collection with a larger sample of families, and workshops with staff to develop content for training materials.

1.3 | Setting and context

Children in England who require hospital care are cared for either in specialist (tertiary) children's hospitals (which may stand alone or be part of a wider NHS Trust) or in general hospital settings (secondary care) that have one or more wards for children. Families in phase 2 of the study were recruited from seven hospitals in England, four specialist children's hospitals and three general hospitals. These hospitals were selected from the 24 hospitals included in phase 1 which comprised all 15 specialist children's hospitals in England and nine general hospitals (Oulton, Gibson, et al., 2018).

1.4 | Recruitment and consent

All parents provided written informed consent to take part in the study and also gave consent for their child's involvement. Children assented to be involved either in writing, verbally, or through alternative communications methods such as eye gaze, depending on their communication skills and preferences. There were three pathways to recruiting children and their families (Figure 1). All children were invited to participate irrespective of their abilities. Word and symbol versions of the patient information leaflet were available. Where possible, the consent/assent process took place in the family home to enable researchers to build rapport with families, ascertain the child's abilities and interests to tailor data collection activities and ensure that the study questions were relevant and sensitive. A visual timetable was used during the assent process to help children's understanding of what would happen during the study and when. Flexibility was

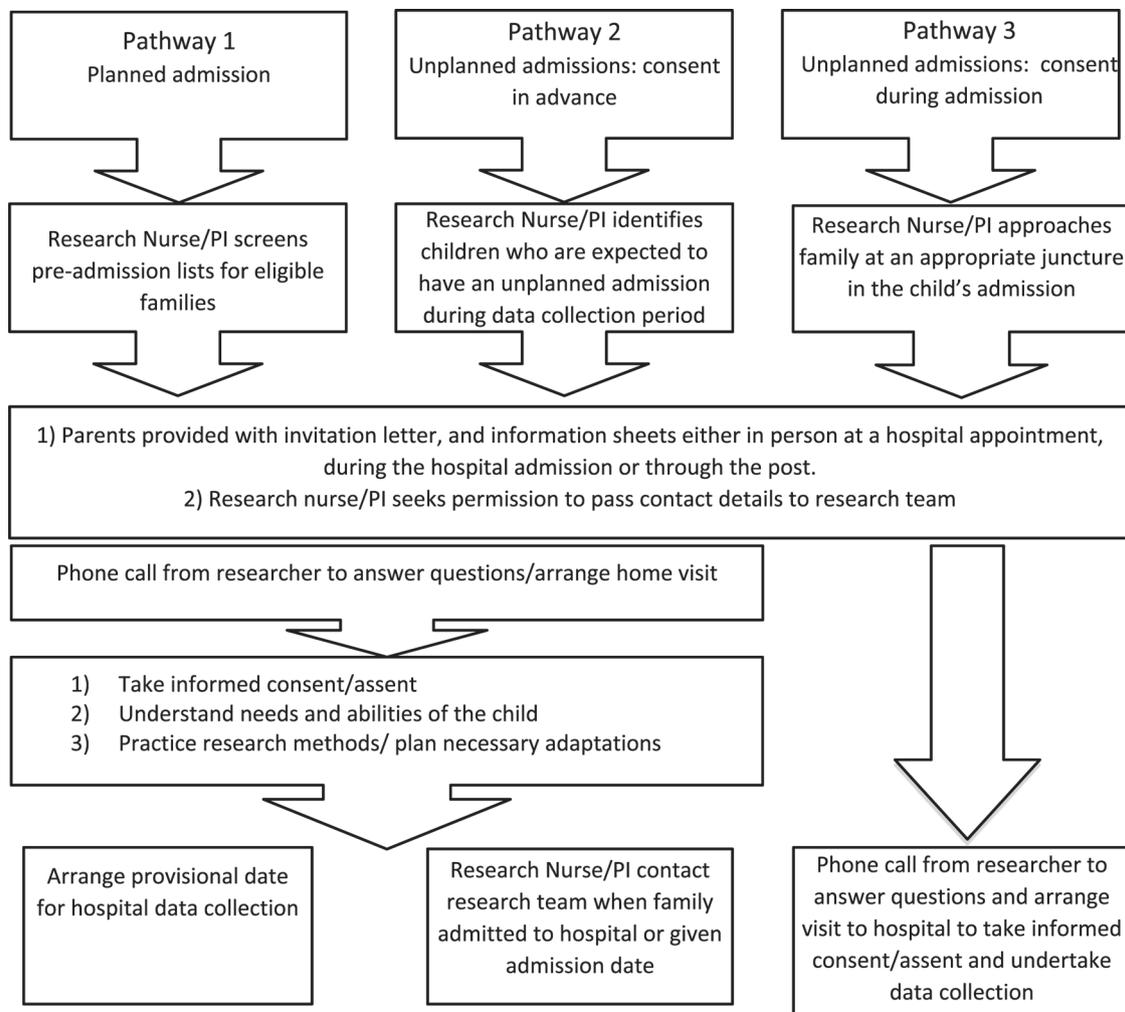


FIGURE 1 Pathway to family recruitment. PI, principle investigator.

key to facilitating involvement of children and this included which activities they undertook, when data collection sessions happened, and how long these lasted for. The child's emotional and physical well-being was prioritised at all times and their agreement to take part was re-confirmed just prior to any data collection.

2 | METHODS AND ANALYSIS

The primary method of data collection with parents was in-depth interviews conducted up to 1 week after the child's discharge from hospital. Parents were given the option of undertaking these in the family home, or over the telephone. The focus of the interviews was the child's recent hospital admission, but parents were invited to draw comparisons with previous admissions, either to the same hospital or other hospitals. Interview data were supplemented with a hospital diary for parents to complete any time of the day/night during the child's admission. This method enabled parents to document their views and experiences as they occurred, at a time that was convenient to them. Parents were also provided with a camera and invited

to capture images of three things that they thought worked well and three things that could be improved about their hospital experience. The photographs were participant-produced, with parents being given full control over the images taken, which were then used as an avenue for further discussion about parents' own or their child's hospital experience (Sigstad & Garrels, 2021). This photo-elicitation provided parents with the opportunity to show their own and their child's world visually, helping provide a richer account of their child's hospital experience (Kyololo et al., 2023).

We utilised a toolkit of data collection methods with children to facilitate involvement by those with a range of communication and support needs. Children could choose to take part in all or some of the activities, either independently or with support from a family member. Firstly, a Talking Mats (2022) based interview utilising a communication symbol tool designed by Speech and Language Therapists, which uses picture symbols to assist people with a range of communication difficulties to express themselves. During the interview, children were shown a selection of symbol cards in turn, relevant to their inpatient experience and asked, depending on their ability, to place the card under one of three choices: thumbs up (like),

thumbs down (dislike) or shrug of shoulders (unsure). Children were encouraged to elaborate, where possible, their feelings about the placement of each card. Children could indicate their preferences verbally, with eye gaze, using communication software or their parents as communication partners. Children were also invited to complete a survey, with the option of a word version, or accessible version comprising widget symbols.

The survey included 13 questions about the interactions they had with healthcare professionals, such as whether they introduced themselves, were friendly, spent time with them, and involved them in making decisions about their care and treatment. Depending on the child's preference and abilities, they either read the survey questions themselves, or the parent or researcher read the questions for them. Children were asked to indicate their response to each question using stickers comprising either a smiley, neutral or sad face. Parent proxy was only used for children whose degree of intellectual disability precluded their involvement.

Lastly, during their admission, children were invited to take the researcher on a tour of their ward, taking photographs of things they liked or disliked. With the agreement of the child, the 'tour' was audio-recorded to capture data relating to what was being photographed. Some children chose to take the photographs themselves, whilst others asked the researcher or their parent to take the photographs for them. Children were free to take photographs of anything they chose, with the exception of other patients, visitors or identifiable information. Photographs of a member of hospital staff required the approval and written consent of that person. Immediately following the tour, the photographs were printed or viewed on the researcher's laptop, depending on the child's preference. As with parents, photographs were then used as an elicitation tool (Bates et al., 2017) to generate further understanding of children's needs, preferences and experiences. All participants were offered copies of the photographs to keep.

All data collection sessions were audio-recorded with participant's permission and transcribed verbatim and then anonymised.

2.1 | Data analysis

Parent and children's interview data were analysed using reflexive thematic analysis (TA) involving the 'six—recursive—phases of: familiarisation; coding; generating initial themes; reviewing and developing themes; refining, defining and naming themes; and writing up' (Braun & Clarke, 2019). We utilised a team approach to analysis, with a small team of experienced qualitative researchers leading on the initial coding process, with every interview transcript being read multiple times, and coded independently by two members of this group. The group comprised the Chief Investigator of the study and both researchers who conducted the interviews. Through a series of team analysis meetings with a wider group of research team members, codes, and then themes, were reviewed, discussed and refined to ensure consensus and agreement, enhancing the trustworthiness of the data analysis process (Brantlinger et al., 2005).

Diagrams were produced and shared with team members during the analysis process to aid understanding of the different themes and the relationship between them. Themes were also shared and discussed with the parent advisory group providing further credibility.

A subset of 20 diaries was read independently by two members of the research team, including an expert parent, who then met to discuss the content and broad themes identified. An initial framework was developed and used when coding the remaining diary content in NVivo 11.

The accessible survey was analysed using descriptive statistics (frequencies).

3 | RESULTS

Forty-two families of children with intellectual disabilities took part in phase 2 of the study (see Table 1), comprising 52 parents and 42 children. The sample of families included a range of family carers including mothers and fathers, grandparents and adopted/foster parents, as well as being diverse in terms of ethnicity, age of parent and child, and parental education. All children had a confirmed diagnosis of intellectual disability and one or more complex co-morbidities. Over 1/4 had visual and or hearing impairment. In the majority of cases (83%) children's hospitalisation was planned. Most children communicated verbally or via other means, but a significant proportion had no formal method of communication. The data collection activities that parents and children undertook are shown in Table 2. No participants expressed any concern or anxiety about the photography task. Parent interviews lasted an average of 90 min.

Four themes were identified from the data as impacting on the emotional or physical well-being of a child with intellectual disabilities when they come into hospital (Figure 2).

The findings, described below, highlight the extent to which an individualised approach to care is needed and the implications for them and their family when this is absent.

3.1 | Loss of familiarity and routine

This theme relates to the impact on children with intellectual disabilities of being in an unfamiliar environment, with unfamiliar people whilst they are in hospital. As one mother said:

For him to be in a strange environment is one thing, but to be in an environment that he doesn't know with people he doesn't know, and no-one to soothe him, it can make anything worse.

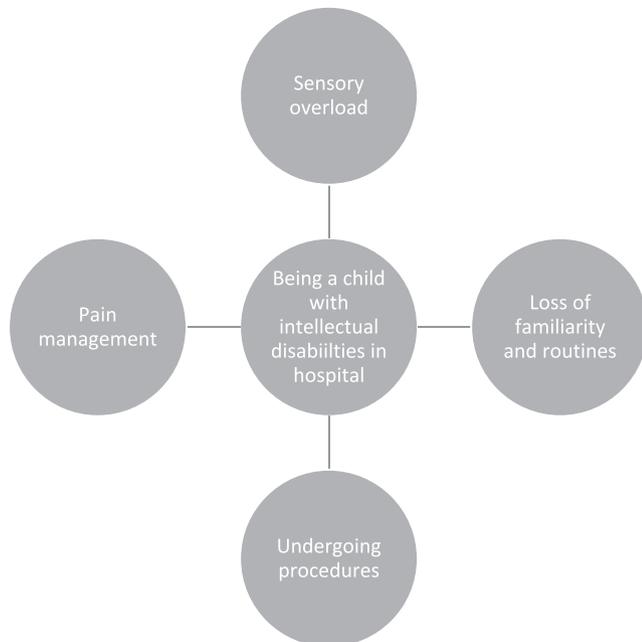
The importance of familiarity was evident during the Talking Mats activity in which nearly all children who were asked about having their own clothes, food, and belongings with them in hospital selected the thumbs up card, indicating their preference for each of these. The same was true in relation to children's views about their parents

TABLE 1 Family participants.

	Domain		Number (percentage)	
Parent/Carer	Parent/carer	Mother	26 (50%)	
		Father	3 (6%)	
		Mother and father	20 (38%)	
		Grandmother	1 (2%)	
		Adopted mother	1 (2%)	
		Foster mother	1 (2%)	
	Age	20–25	2 (4%)	
		26–30	0 (0%)	
		31–35	14 (27%)	
		36–40	10 (19%)	
		41–45	13 (25%)	
		46–50	6 (12%)	
		50+	6 (12%)	
		Missing	1 (2%)	
		Ethnicity	White British	40 (77%)
			White European	4 (8%)
	Asian		6 (12%)	
	African		1 (2%)	
	West Indian		0 (0%)	
	Other		1 (2%)	
	Missing		0 (0%)	
	Education	Secondary	32 (62%)	
		Graduate	15 (29%)	
Post-graduate		4 (8%)		
Employment	Full time carer	29 (56%)		
	Full time employment	13 (25%)		
	Part-time employment	8 (15%)		
	Unemployed	1 (2%)		
	Retired	1 (2%)		
Child or young person	Age	5–7	16 (38%)	
		8–11	13 (31%)	
		12–15	13 (31%)	
	Gender	Male	22 (52%)	
		Female	20 (48%)	
	Diagnosis	Cerebral palsy	14 (33%)	
		Syndrome	9 (21%)	
		Autism Spectrum Condition	9 (21%)	
		Epilepsy	20 (47%)	
		Multiple co-morbidities i.e. cardiac, gastro-intestinal	20 (47%)	
		Visual Impairment	11 (26%)	
		Hearing Impairment	5 (12%)	
		Primary communication method	Verbal	15 (36%)
	Assistive technology		8 (19%)	
	Signing		1 (2%)	
	No formal communication method		18 (43%)	

TABLE 2 Data collection activities.

Method	Parent	Child
Interview	42	N/A
Diary	27	
Talking mats	N/A	42
Survey		42
Photographs/tour	11	19

**FIGURE 2** Key themes from the data.

being present with them, with only one child who was asked, selecting thumbs down in response to this.

The extent of the emotional impact on a child with intellectual disabilities from being in an unfamiliar environment is highlighted particularly well in the following quote.

So, we get to the hospital and then [Child] was wanting to go to the buildings that he knows. Yes, and he's like, 'We're going the wrong way,' and he's screaming mad ... We get to the ward and, obviously, he's looked at the surroundings and he's pacing up and down, and I'm like, 'Oh no.' Then the scenario of the toys. I said, 'Don't get him near the toys too much, he'll start hurling.' What did he do? He started hurling the toys.

Many parents talked about the dependence their child with intellectual disability had on accessing familiar television programmes whilst in hospital and the distress that could arise when they could not access these. Indeed, during the Talking Mats activity when children were shown the image of a television, most (82%) responded with a thumbs up, and during the photo-tour 58% ($n = 11$) of children

took a photograph of a Television and labelled this as positive. In a further two instances, a broken television and lack of access to a particular programme were identified as a negative.

It was apparent that lack of familiarity was exacerbated by a loss of routine, which could negatively impact the child's ability to sleep, cause confusion and irritability, and raise anxiety. As many parents explained, their child relied on certain smells, objects or activities happening at certain times to provide them with a sense of security or guide them about what would be happening next:

Being in hospital for three weeks, to him, must feel like a lifetime because he hasn't had his sensory stories, he hasn't had his hydrotherapy ... that kind of repetition and consistency really makes a difference with him ... He's really irritable and he's harder to pacify because he must be confused at times ... even when he wasn't well, he come home and his face lit up as if, kind of, like, 'I know where I am now and all surroundings'.

You cannot use it [disabled bathroom] at all ... It does, it punctuates his day as well. It's his cue to go to sleep. It relaxes his muscles ... just little things like that and being able to do his massage after his bath. The whole thing is a really important part of his routine ... he hasn't got the familiar smells and things when he's in hospital, and he relies on those.

These quotes highlight the dependence that children with intellectual disabilities have on their routine for maintaining their physical and emotional well-being in a way that appears to set them apart from other children of their age.

Findings from the child's survey (Table 3) illustrate some of the challenges children with intellectual disabilities face when interacting with people who are less familiar with them. Whilst staff were mostly seen as being friendly, respecting their privacy, and telling them what they were going to do before they do it, less than half of children felt staff knew what they liked and did not like or what was important to them.

Loss of familiarity was also apparent in relation to communication, with survey results showing that some children felt staff did not talk to them or explain things in a way they could understand.

Furthermore, during a Talking Mats interview a child with intellectual disabilities explained that hospital staff are not able to communicate with her in the same way she does at school:

Researcher: Which DVDs did you bring?

Child: Sing.

Parent: Sing. Come on, and? Sign. Sing and sign DVDs.

Researcher: Sing and sign. Is that a good one?

Child: Yes.

Researcher: Do you do signing when you're in school?

Child: Yes, I do.

TABLE 3 Responses from the survey about interactions with staff.

Question	Smiley face (%)	In-between (%)	Sad face (%)	Did not answer (%)
Staff are friendly to me	92	5	0	3
Staff say hello to me when they meet me	79	18	0	3
Staff respect my privacy	76	0	11	13
Staff tell me what they are going to do before they do it	68	8	11	13
Staff talk to me in a way I can understand	63	16	11	11
Staff make me feel important	61	11	11	18
Staff tell me who they are	58	21	16	5
Staff know what I like and do not like	45	13	29	13
Staff explain things to me in a way I can understand	42	11	8	39
Staff know what is important to me	42	5	29	24
Staff spend time with me	39	21	24	16
Staff involve me in making decisions about my hospital stay	29	0	13	55
Staff involve me in making decisions about my care and treatment	16	5	17	71

Researcher: You do, and do any of the nurses or doctors around here, do they sign as well, or is that just in school?

Child: That's just in school.

In addition, another child with intellectual disabilities said:

The staff does not give me in a way I can understand ... Staff do not tell me what they are going to do for me, they do not, they never tell me.

3.2 | Sensory overload

The theme of sensory overload relates to children feeling overwhelmed due to over stimulation of one or more of their senses. Examples were provided related to sight, hearing, smell, taste and touch (see undergoing procedures). Most commonly, parents, talked about the difficulties their child faced managing hospital noise, such as bins closing, taps running, doors banging, staff talking and babies crying. One mother said,

They told me that she would be on a ward with three other children, and I explained that is really bad ... She has hyperacusis, so she hears things acutely, and I said, 'The slightest noise, she won't sleep,' and she doesn't tolerate crying children, crying babies, she just has no empathy with them whatsoever, and any noise, really. [Child] gets very distraught when there are too many other noises going on, and then that distresses me and then I don't sleep, and it's a cycle.

This example highlights both the emotional and physical impact of noise overload on the child and the subsequent implications this

has for the parent. The full extent to which noise could be a problem for children with intellectual disabilities was further highlighted by another mother who described her daughter's sense of desperation to escape from it:

Noise-wise, yes ... She said, 'I can't do another night in here.' I did one and I thought, 'Oh, God.' [Child] just said, 'I've got to get out of here, you've got to get me out.'

Further evidence of the impact of noise emerged during the photo-tour with one parent taking a photograph of the ward bay and explaining how her son found being in a room with five other patients too noisy, whilst another took a photograph of the drug treatment room and explained that the noise of the door shutting induced her son's epileptic seizures.

The potential for children with intellectual disabilities to experience sensory overload was also described in relation to the way that staff provided information to them:

She has sensory processing, if you're going to move the bed, tell her first. Don't chatter to her, don't make a big deal out of it, just say, you know, two-word sentences, don't go babbling on ... Invariably, they'll just ignore me and do that, and then it's overload for [Child].

This mother went on to describe the need for adjustments to also support her daughter to follow simple instructions such as laying down on the bed:

That won't happen in ten seconds, that'll take a minute and a half to two minutes for me to coax her to lay down and then she'll grip tightly onto the bed, then

we've got to move it down. Everything goes slowly in the world of Down syndrome and [Child] just needs that extra time ... everything broken down into small compartments, whereas with another child they'd just hop on and done.

Results from the Talking Mats exercise indicated that children with intellectual disabilities tend to view the hospital ward and sleep positively, with two-thirds giving both of these things a thumbs up response. However, this left a third of children who gave these a thumbs down.

3.3 | Undergoing tests and procedures

The third theme relates to the impact on children with intellectual disabilities of waiting for and undergoing hospital related tests and procedures. Most parents provided examples of their child finding this 'overwhelming', especially when they did not fully understand what was happening to them, and around them:

My daughter's face was always, like, her face was always in a daze, as if, 'What next?' In her face, actually saw it, in her face, it was not, 'What next?' In her face, was like, you know, like an animal who we bound with a rope in a corner, and we torture them, we do whatever we want, and then their face become like, 'What I can do? I'm helpless. Do whatever you want.' Her face was like that.

Even being touched by another person could be anxiety provoking for some children, due to sensory overload, which could make carrying out the simplest of tasks a challenge:

He doesn't like people touching him, he doesn't like anyone invading his space so it's going to be difficult with creams, gels and even just putting on a hospital wristband. You know, [Child] doesn't like any of those kinds of things, he doesn't like people interfering with him.

This mother went on to explain the importance of not minimising her child's needs:

It's not that as a special needs parent you're expecting special treatment all the time, but you are expecting some understand and the fact that you can't rush children like ours. You know, I mean, I remember once when one of the nurses went, 'It's just a bit of cream on your hands,' sort of thing. I thought, 'Yes, it is just a bit of cream to you but to my child you've invaded him, you're putting something on him that he doesn't want on there. He can't stand sticky plaster

and it's got to be taped on, so you're freaking him out with everything that you're doing and, "it's only a bit of cream"?'

This sense of being invaded came up in the survey activity, when a child and their parent talked about his dislike of having intravenous lines and cannulas in his hands:

Researcher: Is there anything here that you don't like the feel of?

Child: I don't like the bloods.

Researcher: You don't like the bloods?

Parent: What he's saying is it's all this interfering and all that. When he says bloods, that's because of all of these [cannulas] in his hands. Yes, so that's what he doesn't like.

Researcher: Okay. Before people touch you, so before a nurse comes to look at your knee, do they tell you that they're going to touch you?

Child: No. Can you take it [cannula] away please?

Another mother described the challenges associated with her son having sensors secured to his head for an electroencephalogram (EEG):

Another child might understand what's going on but just not like it ... but obviously chucking in Autism and ADHD and a lack of understanding and communication, that's just asking for trouble. Yes, you're asking for a disaster there.

This parent and others, explained that once their child had reached a certain level of distress then it was almost impossible to reassure and reason with them, which could have extreme consequences physically as well as emotionally:

Obviously, with an autistic child, once they've got distressed, then the calming down time is quite time consuming. You know, he hurt himself. He had bruises all over his legs from chucking himself on the floor ... he took ages to go to sleep and he was crying, which isn't normal at all for him. So, I think the distress was obviously probably playing on his mind still.

It was not just the process of undergoing procedures that children with intellectual disabilities found difficult, but also coping emotionally when a procedure they had prepared for was then cancelled, as one mother described in relation to her daughter's surgery:

That was just horrendous. She screamed all the way home ... It's the psychological, with a child like her, with the special needs, and the Autism and the repetitiveness, you can't just say, 'Oh, it's been cancelled.

TABLE 4 Children's responses to questions about tests and procedures.

Test/procedure	Positive n (%)	Unsure n (%)	Negative n (%)
Blood taken	10 (45%)	2 (10%)	10 (45%)
Blood pressure	11 (48%)	5 (22%)	7 (30%)
X-Ray	10 (67%)	1 (7%)	4 (27%)
Operation	12 (86%)	0 (0%)	2 (14%)
Being weighed	17 (71%)	3 (13%)	4 (17%)
Medication	21 (72%)	2 (7%)	6 (21%)
Intravenous line	8 (47%)	1 (6%)	8 (47%)

Waiting for procedures or appointments was also described as a particular challenge for children with intellectual disabilities, who as well as becoming 'bored' and 'restless', could also become 'distressed' and 'scared'. One parent, for example, described the impact of having to spend hours in the outpatient department with her son during an inpatient admission:

It was crazy... he was still getting over the sleep deprivation; it was just like torture for him to the point that he was hitting and kicking me, and I was trying to keep him up. To do that to him, like a 3-hour appointment and it was sweltering down there, and they had drinks down there but he couldn't drink any of that because he only drinks specific things.

The physical and emotional impact on the mother as well of the child, of trying to manage this situation is clearly articulated here. Another mother, described the multiple challenges associated with her child having to wait hours for his operation without being able to eat:

When you're trying to manage a child with high anxiety and who's on repeat mode for nearly five hours, it's distressing to see him constantly try and reassure himself and not understanding why he's not being allowed to have anything to eat. He's pleading with you, 'I'm starving, please, can I have some food?' I mean, you feel terrible, you just feel like the worst person.

Children with intellectual disabilities were asked about various tests and treatments during the Talking Mats exercise and indicated these as being positive (thumbs up), negative (thumbs down) or unsure (shrugging shoulders) (see Table 4).

The results of the Talking Mats exercise highlight that when asked about particular tests and treatments many children with intellectual disabilities feel positive about these, particularly having an operation, being weighed, taking medication and going for an X-ray. It is worth noting that many of the children in the study had their medications via non-oral routes of administration such as a through a tube directly into the stomach (PEG) which may have accounted for the

finding in relation to medication. Test and procedures that were most likely to be perceived negatively included having blood taken, having an intravenous line, and having blood pressure taken with over half of children indicating these as being less than positive. One child said she did not like needles because 'they sting' and with reference to a plaster on her back, she said, 'I don't like sticky'. Talking about having her blood pressure taken, another child said:

Child: First of all they put a bandage around you, then they do a bear hug, what I don't like.

Parent: She's scared of having her blood pressure taken. They won't do it because she's frightened.

Researcher: How does it feel having your blood pressure taken?

Child: I didn't like the bear hug. It feels angry like that [gestures tensing up her arms].

3.4 | Managing pain

A final theme was related to pain management and the impact on a child with intellectual disabilities of being in pain, of not understanding their pain, or their pain not being appropriately treated.

One mother highlighted just how difficult it was for her daughter to be in pain, whilst waiting to come into hospital for surgery:

She was desperate. I mean, she was crying and begging us. 'Hospital now. Take me' ... The build-up to it was horrendous ... If it was one of my [other children] I could explain quite happily, but when it's on [child's] mind, she's so repetitive ... it is constant 12 hours of, 'My back, my back done. Go now'. It's constant. She doesn't stop ... at 2 o'clock in the morning, she'll be shouting up, 'My back. Doctor'.

It was apparent that even once in hospital, these same challenges could continue, as highlighted by the mother of a 12 year old with Down Syndrome:

In the middle of the night, [child] was screaming and yelling and clawing at her leg, and in an awful lot of distress and pain ... and she couldn't explain that. [Child] doesn't have the vocab to explain that, she just went into a complete meltdown with it. She went into a meltdown and cried herself to-, you know, it was exhaustion and that's when she finally went to sleep.

There was a strong sense from some parents that what works for other children in terms of pain management would not necessarily work for those with intellectual disabilities:

Because [child] can't communicate what he's feeling or what his needs are it's taken for granted. So, pain

management's always been an issue because he can't tell us that he's in pain... let's be on top of that pain, not react to it. So, we had a mutual disagreement with the pain nurse last time. 'Oh, often paracetamol is normally fine'. Well, [child's] not normal and we're not willing to take the gamble because he's just been through so much.

Furthermore, it was reiterated that the way children with intellectual disabilities express their pain can be different from what would normally be expected:

Sometimes she cries, but she also does a hysterical laugh, and she looks like she's having a whale of a time, and giggling her head off ... you could think she's just found something hilariously funny. You have to know there's a manic laugh that means she's in pain.

These quotes demonstrate just how important it is for staff to work in partnership with parents to fully understand the child's individual needs in relation to pain management, especially when the child does not interpret and communicate their pain as would usually be expected for a child of their age.

When shown the 'pain relief' card during the Talking Mats exercise nearly three-quarters of children with intellectual disabilities gave this a thumbs up, indicating that on the whole children felt their pain was well-managed in hospital, but this still meant that one-quarter of children felt negatively about their pain. The following is a conversation that took place during the survey activity:

Researcher: So, having your operation, how was that for you?

Parent: Was it good, bad or okay?

Child: Bad.

Researcher: Bad. Can you tell me why it was bad? What was about it that was bad?

Child: I had the lump out.

Parent: You had the lump out, but why was that bad?

Child: Sore.

The key message across each of the themes was that there are often multiple and compounding layers of complexity surrounding the care of children with intellectual disabilities in hospital and that even those with the same diagnosis as another child have unique needs that require staff to take an individualised approach to their care.

4 | DISCUSSION

By sharing narratives of hospital life, the impact on children with intellectual disabilities of attending hospital has been highlighted. We were able to do this because we utilised a toolkit of research methods and tailored these to suit the needs and abilities of individual children,

and for children who lacked capacity to share their own views, parents were invited to provide views by proxy.

The quotes provide a powerful insight into the intense emotional and physical impact that simply being in a hospital environment has on some children with intellectual disabilities, as well as the challenges associated with the anticipation and build up to coming into hospital. The multiple and compounding layers of complexity surrounding the care of children with intellectual disabilities in hospital resulted in specific challenges associated with the loss of familiarity and routine, undergoing procedures, managing sensory overload, and managing pain.

There was a combined sense of fear, distress and desperation across much of the data that extended to parents' own experience as well as that of their child. These findings build on previous research highlighting the emotional impact that hospital encounters can have on children with intellectual disabilities and their families (Bates et al., 2019; Brown et al., 2012; Oulton et al., 2015; Oulton, Sell, & Gibson, 2018) and the dependence that hospital staff can have on their parents for some of their care (Avis & Reardon, 2008; Mimmo et al., 2019; Oulton & Heyman, 2009) particularly in relation to communicating with the child (Sharkey et al., 2016) and reporting their pain (Malviya et al., 2005). Challenges associated with pain assessment and management in children with intellectual disabilities need addressing. Despite the development of standardised pain assessment tools evidence of their use in practice remains limited (Barney et al., 2020). Crosta et al. (2014, p.116), argues that nurses 'must be more vigilant in assessing pain, must communicate with parents and caregivers about how the child expresses pain, and must use an appropriate pain measure for this vulnerable population'. However, there is evidence that clinicians feel they lack sufficient knowledge and training to do this (Malviya et al., 2005).

The findings reiterate the need for proactive identification and planning of reasonable adjustments, in line with the Equality Act (2010), in partnership with the child and their family (Mimmo et al., 2019), so that any adaptations or resources required are in place prior to an admission, rather than being identified after a child has experienced pain or distress. This requires an individualised approach to care, which includes building rapport, understanding past hospital experiences (Mimmo, Hodgins, et al., 2022), how pain is expressed, and allowing sufficient time to prepare the child for tests and procedures and to undertake these (Bates et al. 2019). As noted by Gerth (2020, p101), 'Each child will come in with a unique personality and needs that can be understood by asking and listening, thereby giving the child agency and allowing them to be a crucial part of their own treatment'. This may go some way to addressing the potential mental health consequences for children with intellectual disabilities of coming into hospital, which warrants particular attention, given their increased prevalence of mental health problems relative to the general population (Melvin et al., 2022).

The inclusion of narratives from experts by experience are viewed favourably in relation to intellectual disability training (National Development Team for Inclusion, NDTI, 2022) and can have a positive impact on changing practice. We believe the examples provided in this

paper, using participants' own words, can support individual staff and healthcare organisations to meaningfully engage with, and deliver awareness training in relation to intellectual disabilities and Autism Spectrum Condition. Such training has recently become mandatory within the UK (Health Education England, 2022) and is anticipated to ensure that health and social staff are 'better able to understand the needs of autistic people and people with a learning disability, provide improved services, reduce health inequality, and eliminate avoidable death' (NDTI, 2021). This has far-reaching importance, given recent evidence of hospital and community-based staff feeling less confident and less capable to meet the needs of children with intellectual disabilities compared to other patients (Oulton et al., 2022). It is essential that any training delivered includes pain assessment and management.

5 | STRENGTHS AND LIMITATIONS

The findings presented were generated from data collected as part of a national mixed methods study, with qualitative data being collected from a large sample of diverse families across seven hospitals in England. A toolkit of methods was used flexibly with families to aid their participation and triangulate results. Children were 'interviewed' whilst in hospital, to aid recall, however this meant some were too tired or unwell to take part in more than one activity. A potential limitation is the self-selecting nature of participants. Furthermore, whilst data collection with parents was conducted following the child's discharge from hospital, it is possible that ongoing contact with hospital staff impacted on the views and experiences shared. A further limitation is the use of parent proxy for children whose severity of disability precluded their own involvement. Whilst parents appeared to welcome the opportunity to explain their son's or daughter's story through a child-focused lens, their powerful and emotive accounts must be considered in this context.

6 | CONCLUSION

Through engaging with many parents and children with intellectual disabilities from across England and giving them the time and means to share their views, we have generated a large body of evidence about what it is like being a child with intellectual disabilities in hospital. Staff and organisations need to understand the reality of the impact that seemingly innocuous, as well as more significant, hospital events and experiences have on the child's emotional and physical well-being. Addressing the training requirements of staff will go some way to ensuring care is individualised to the needs of each child.

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CONFLICT OF INTEREST STATEMENT

Declared competing interests of authors: Angela Hassiotis is a member of the National Institute for Health Research Health Technology Assessment Commissioning committee (2018–2023). Kate Oulton is on the National Institute for Health Research 70@70 Nurse research Leader Programme.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

Full ethics and health research authority approval for this study was obtained prior to the study commencing (London–Stanmore Research Ethics Committee: reference 16/LO/0645). Local research and development approval was also obtained from each of the 24 participating hospital sites. All adults provided written consent and children and young people provided verbal assent, prior to participation.

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