



BMJ Open What do healthcare staff think about the quality and safety of care provided to children and young people with an intellectual disability? A qualitative study using the framework method of analysis

Natalie Ong ^{1,2}, Abbie Lucien,³ Janet C Long ⁴, Janelle Weise,⁵ Merrilyn Walton,⁶ Annette Burgess⁷

To cite: Ong N, Lucien A, Long JC, *et al*. What do healthcare staff think about the quality and safety of care provided to children and young people with an intellectual disability? A qualitative study using the framework method of analysis. *BMJ Open* 2023;**13**:e071494. doi:10.1136/bmjopen-2022-071494

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-071494>).

Received 02 January 2023
Accepted 14 July 2023



© Author(s) (or their employer(s)) 2023. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to

Dr Natalie Ong;
natalie.ong@health.nsw.gov.au

ABSTRACT

Objective To elicit patient safety issues pertaining to children and young people with intellectual disability in hospital from healthcare staff perspectives. This follows a previous paper of parent interviews of patient safety experiences of their child in hospital.

Design Qualitative study.

Setting We conducted semi-structured interviews and focus groups of staff of tertiary children's hospitals based on the domains of the Patient Safety Education Framework and using the framework methodology for data analysis.

Participants There were 29 female and 7 male staff aged between 27 and 70 years from a range of departments and specialties including ancillary staff.

Intervention Questions based on the patient safety framework were developed from consultation with parents, researchers and clinicians exploring staff views and experiences of safety and quality care of these children in hospital. During April 2021 to May 2022, 22 interviews and 3 focus groups were conducted of staff who have had experience caring for children and young people with intellectual disability in the last 12 months in the hospital.

Results Key themes elicited include *Definition of Safety, Need to consider additional vulnerabilities of children and young people with intellectual disability in hospital, Communication is key to safe care, Parent and family perspectives on safe care, Management challenges compromising safety and Service system gaps in preventing, identifying and managing risk.*

Conclusions Staff need to consider additional vulnerabilities, mitigate negative attitudes and biases towards better engagement and relationships with parents, children and young people of this population. Improvement of current systems that prevent the identification, prevention and management of risk and safety issues for this population need to be undertaken. Future developments include combining data from parent interviews, academic and grey literature in developing safety competencies in this population for training and education of staff across the health system.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study included a good number and representation of staff from a range of disciplines including ancillary staff.
- ⇒ The study used the Australian Patient Safety Education Framework as the basis for the interviews and focus groups to identify and address patient safety issues for this population and explored gaps in the framework.
- ⇒ As it was a voluntary study, there is a possibility of missing out on the views of those who did not participate.

INTRODUCTION

Children with an intellectual disability are vulnerable to adverse events within the healthcare system due to staff lack of familiarity with the child's communication abilities and care needs, in addition to poor child and family-centred approaches.^{1–3} These factors lead to poor healthcare experiences during hospital admissions.^{4,5} In addition, healthcare staff feel unprepared and unskilled when it comes to meeting their needs.⁶ Healthcare staff need to know how to develop therapeutic relationships with parents and carers to transform negative stereotypes into positive supportive attitudes that result in improved care quality.⁷ A recent audit by Trollor *et al* demonstrates limited exposure to intellectual disability health in many medical and nursing undergraduate programmes.^{8–10} Enhanced training in the care of children with intellectual disabilities in both undergraduate and postgraduate health professions education has been strongly recommended.^{8 11–13}



In 2006, the Australian National Patient Safety Education Framework (PSEF) was developed, outlining specific competencies of health staff across the layers of the health system.¹⁴ This comprehensive resource for the general patient population did not cover specific competencies for those caring for children with an intellectual disability. Over the last decade, evidence on parent, child and staff experiences has come to light, providing an opportunity to further develop the PSEF by including competencies for staff working with children with intellectual disability.

To identify specific patient safety competencies for this group we reviewed the literature and using a co-design approach we obtained feedback and perspectives from parents and healthcare staff. This study is the second of two papers and focuses on staff experiences of caring for children and young persons with intellectual disability in the hospital setting. We anticipate this study will identify safety and quality issues in the health service in this population and lay the foundations for the development of the adapted patient safety education framework.

Aims

The aim of this study was to identify and describe patient safety issues specifically pertaining to children and young people with intellectual disability in hospital.

METHODS

Participant recruitment

Between April 2021 and May 2022, health staff at two large tertiary children's hospitals and a paediatric palliative care service (Sydney Children's Hospitals Network: Randwick and Westmead campus and Bear Cottage) were invited to participate in interviews or focus groups, held via Zoom. Invitation emails and flyers were circulated to staff from heads of departments. Some heads of departments recommended staff for participation in focus groups. Purposive sampling was used to gain a breadth of staff experience within departments that ranged from those who had higher exposure to children with intellectual disability and those who had less exposure.

Inclusion criteria included staff who had any level of experience caring for children with intellectual disability in the last 12 months through the emergency department, admission to the wards, operating theatres, intensive care units, outpatient departments or in palliative care in the hospitals.

Data collection

The interview guide was developed through consultation with all authors. Questions were derived from the domains of the PSEF to obtain insights pertaining to the domain in the context of a child with an intellectual disability in hospital.

Patient and public involvement

While patients and their parents were not actively involved in this study, the questions were derived from an earlier

study involving parents of children with intellectual disability (under review). Parent advocates in the project advisory group were shown the questions to determine their appropriateness for the interviews.

The interview and focus group guide is presented in [table 1](#).

The interviews and focus groups were conducted by the primary author (NO), a developmental paediatrician with over 20 years in clinical practice and extensive research experience in general and specialist paediatric medicine (neurodevelopmental disorders) which allowed in-depth understanding and interpretation of staff perspectives. Authors' reflexivity through a bracketing exercise was undertaken to mitigate any deleterious effects of preconceptions that may influence the research process. Qualitative data analyses are inherently subjective processes where the researcher is the 'instrument for analysis across all phases of a qualitative research project'.¹⁵ Bracketing is a way of validating qualitative research processes and how results are derived. By temporarily suspending one's own beliefs, biases and subjective interpretations ensures that the research data is not distorted through a lens of our own predispositions or biases.¹⁵ Hence the researcher conducted a bracketing exercise where she reflexively jotted and reflected on how her interactions with patients and families in her clinical role would influence her interpretation of the data. This was discussed with the research group and having an emic perspective from her was seen to be important in providing contextually relevant interpretations with least bias as possible through this exercise. In addition, the second researcher independently coded the data as a way to introduce an etic perspective and an independent viewpoint. The duration of the online interviews and focus groups ranged from 23 to 63 min. The interviews and focus groups were audio recorded and transcribed. All identifying information was removed at transcription.

Data analysis

Data were analysed using the framework method.¹⁶ The framework method sits under the broad umbrella term of thematic analysis or qualitative content analysis. These approaches identify commonalities and differences in the data which is followed by focusing on relationships between different parts of the data and drawing on descriptive and/or explanatory conclusions aggregated into themes. The framework method was chosen because it facilitated multidisciplinary teams to engage in this form of data analysis.¹⁶ The first author (NO) performed coding for all the transcripts and developed the initial coding framework. The second author (AL), a neuropsychologist with research experience, conducted independent coding of 100% of the transcripts using the coding framework. Codes were derived which were condensed into categories then aggregated to subthemes and themes. Similarities and discrepancies were discussed with all authors and resolved through discussions and meetings to reach consensus.

Table 1 Interview guide

Introduction	Staff, age, role and experience working with children with intellectual disability (ID)
Definition of safety.	What does the word safety mean to you? (Prompt: What does it mean to have safe care in a hospital? Can you tell us your experience of what went well? Or one that did not go so well?).
Domains of patient safety.	When thinking about patient safety standards there are seven domains—these care standards of care to ensure that the child or young person with ID receives good and safe care. We want to promote good practice and strive for positive and good experiences, not only to avoid mistakes or near misses.
The first relates to communicating effectively to you and the child or young person with ID.	Can you tell of your experiences communicating with a child or young person with ID? (Prompt: Can you tell me of an experience of good/bad communication in a hospital setting?).
The second relates to identifying, preventing and managing when something goes wrong or a 'near miss' has occurred.	Can you tell me of an experience where something went well/ went wrong or almost went wrong? (Prompt: How was it communicated to the patient and their family? If there was a better way around it? What sort of things would you do? How can things be done differently the next time?).
The third relates to using evidence and information in hospital practice.	Have you looked into any resources of best research evidence on providing care for a child or young person with ID? (Prompt: What would you like to know regarding caring for a child or young person with ID? What do you think would be the best way for health workers, specifically Junior Medical Officers (JMOs) to learn how to care for a child with an ID safely in hospital? Are there any technological advancements that can be used to help?).
The fourth relates to safe work practices.	What are the types of things that would make for safe work practice when caring for a child or young person with ID that you may have noticed? (Prompt: Eg, this could relate to the way members of a team worked together, or certain work practices that were good to prevent mistakes from happening. Can you think of some examples where things were done well? Or times when things were not done well which made you feel uncomfortable and anxious about the child's safety?).
The fifth relates to core attributes of staff caring for a child or young person with ID.	What skills or abilities and attitudes should staff have when caring for a child or young person with ID?
The sixth relates to continuing learning.	What would you like to know in regard to caring for a child or young person with ID? (Prompt: Have you been provided with opportunities in the workplace, on the job learning? How would you like to learn about this topic? Case discussions, ward rounds, grand rounds, Junior Medical Officer teaching, Continuing Professional Development programmes).
The seventh relates to specific topics in patient safety I would like to explore.	The first relates to medication safety. Would you like to comment about relevant experiences?
The next relates to prevention of operating on the wrong site, having the wrong procedure or wrong treatment.	If you have had a patient experience in any of the above, were there any ways that these could have been prevented?
Are there any other areas or topics that need to be included?	

RESULTS

A total of 36 staff participated in the study. We held 22 individual interviews and 3 focus groups (1 with 2 participants, and another 2 with 6 participants). The mean age of staff participants was 45.8 years and ranged from 27 to 70 years. Five staff did not disclose their age. There were 29 female and 7 male staff representing medical, nursing, allied health, management, clinical and ancillary staff across varying levels of seniority. [Figure 1](#) describes the six themes emanating from this synthesis.

Online supplemental data 1. Participant demographics

Theme 1: definition of safety

Safety is more than just absence of harm

Staff provided a wide range of definitions for safety. At a fundamental level it was to 'do no harm physically, psychologically and emotionally' S6. Safety includes being aware of 'the right things attached to that person's MRN...any illnesses, allergies or dietary requirements ... mobility

issues... looking after those things in the right way' S4. Staff recognised key elements of safe care including equity in accessing good care, education and having processes in place to mitigate risk through predicting and preventing issues and harm minimisation.

Staff raised the difference between feeling safe versus being safe. While it was salient to ensure therapeutic safety, psychological and emotional safety was just as important. So, it was not enough to address clinical practice issues to avoid error but 'making sure that each time families come through the service they feel more comfortable, not less, because of the outcomes' S5.

Safety encompasses patient as well as staff safety 'making sure that we don't cause any physical injuries, [with] patients obviously but also that staff aren't physically injured or any other family members or people that may be around' S12. A member of staff commented that managers need to always balance both when making decisions about service delivery.



Figure 1 Themes of staff experiences on hospital care of a child or young person with intellectual disability.

Theme 2: the need to consider additional vulnerabilities for children and young people with intellectual disability in hospital

Diagnostic error and delays from complex care needs, diagnostic overshadowing and behaviours that challenge

A participant reported that many parents of children with intellectual disability ‘don’t present to hospital because they feel it is an unsafe place. We have terrible health outcomes in this population and part of it is because families do not feel they are able to present and be managed well through the acute medical services’ S5. It was also felt that ‘diagnostic overshadowing... is a huge issue...everything is managed as a behavioural issue...acute medical issues are missed or not diagnosed—[or the] diagnosis was delayed’ S5. While it was felt that children with intellectual disability had more complex health needs and were at times over-investigated, more of a concern was the under-investigation and its justification, which increased the risk of missed diagnoses or errors in diagnosis and management due to diagnostic overshadowing (misattribution of behaviour to the disability than an organic pathology).

High vigilance and skills in disability care prevents diagnostic overshadowing

Staff found that the range of intellectual and developmental disabilities were so varied that a high level of knowledge, skill in vigilance, understanding, managing and customising care was required. In addition, communication difficulties, identifying symptoms or deteriorating states was also seen to be a challenge in guiding diagnosis and management, in the context of separating out behaviours from clinical symptoms or from the disability

itself. A staff member recounted a case ‘...of self-injury, ... the ENT said, ‘why have we got to see this boy for?’... The registrar [from another department] said to do an ENT examination. Lo and behold they found a foreign body in the nasal cavity, and they cured the self-injury ... So that’s where you need interdisciplinary interdepartmental coordination, and it illustrates the absolute necessity’ SFG3.

Information exchange challenges

Staff reported that many checks and processes in hospitals generally align well with patient safety regulations. However, safety issues regarding children and young people with intellectual disability in hospitals usually related to difficulties in obtaining, interpreting and providing information, care, or consent especially when the parent was not present. Navigation around the hospital was also a challenge in terms of its safety implications for locating a department for patients or parents with a child with challenging behaviours, reading or second language issues.

Errors still occur despite current safety measures

Staff reported that while there are standard precautionary measures (eg, automatic drug dispensing cabinets, electronic medication records, checking practices, off label prescribing committees, drug information sheets and formularies) errors still occur in this population. This is largely due to unusual dosing, similar sounding medication names and complex medication concentrations, compounded by lack of familiarity in prescribing. Such prescribing experience generally lies in the hands of a select few and more work is needed in the succession planning and training of early career clinicians to take on safe and atypical prescribing practices for this population. For subthemes and illustrative quotes please see online supplemental data 2 table 1.

Theme 3: communication is key to safe care

Communicating with the child or young person with intellectual disability

A staff member reported that ‘we spend our whole time adjusting the communication in terms of what’s going on. For children with more significant disabilities.... I don’t think we often do that well and I guess for those children often that communication is not as good as it could be’ S15 hence noting a need for building rapport and familiarity. Staff reported having difficulties in communication, understanding the child’s behaviour and identifying their care needs. One staff member noted ‘I think we’re pretty terrible when a child with an intellectual disability comes—arrives, that we often don’t do the homework that we should do...but if you have time, it would be really important to do some preparations so that when the child arrived here, the treating team had an idea of the things that might be a trigger for the child—the way of communicating that might be most effective’, S6.

Taking time to customise and provide emotional care

Staff understood the importance of customising their communication with the child. This included using the right level, type and timing of communication and bringing in expertise (eg, child life therapist or speech pathologist) when needed. In addition, staff recognised the need to be respectful, apologise for errors and not make assumptions about a child's communication ability (or lack thereof). Staff recognised that time and energy were required to invest in providing emotional care and while the use of appropriate communication tools and strategies is important, they were not always able to do so.

For subthemes and illustrative quotes please see online supplemental data 2 table 2.

Theme 4: parent and family perspectives on safe care

Parental mistrust from past experiences

Staff recognised that poor communication is the main reason for issues of unsafe care from parents. Staff described that parents are often unwilling to leave their child unattended in hospital due to the risk of an adverse event occurring in their absence. Staff acknowledged that parents could present as 'difficult' due to their anxiety and frustrations of not being heard or dismissed. They were aware that some parents may have experienced multiple hospital presentations and negative encounters with staff leading to increasing mistrust. Staff also reported that parents become frustrated, when due to a lack of familiarity with their child, staff recommend treatment plans which have been tried before which were unsuccessful, unpleasant or led to unsafe care.

Parental information sharpens staff abilities to effectively engage and provide safe care

Staff were aware that not every child is the same and rely on parents to provide them with specific and nuanced information about their child to plan and provide good and safe care and identify subtle changes in symptoms or pain levels. In addition, well informed parents can assist staff to better support their child through a health encounter. Staff also felt the need to explicitly demonstrate their competence in care provision to regain parental trust.

Some staff highlighted the importance of using parent feedback to learn about customising care, understanding the child's needs, information disclosure, opportunities for health promotion and building rapport with their child as one of the best ways to improve staff conduct and practice.

Staff empowering families through supporting parental advocacy through cultural propriety

Staff recognised increased complexity when families come from culturally and linguistically diverse backgrounds through the additional challenges in communicating and responding to their needs. Many of these families often lack knowledge of their rights to advocate for their child, understanding and navigation know-how of services and

the financial capacity to seek private services. Raising awareness through parent education was recommended to empower families to have a voice in advocating for their child's right to equitable healthcare.

Learning from siblings

A member of staff reflected on how staff can learn from young siblings of children with intellectual disability as they recognise their personhood and are not biased against their disability.

For subthemes and illustrative quotes please see online supplemental data 2 table 3.

Theme 5: management challenges compromising safety

Upskilling in identifying neurodiversity and functional capabilities

At times children may not present with a known diagnosis of intellectual disability leading to lack of information in patient management systems. Staff would like to have skills to screen children who may have intellectual or developmental issues which now occurs on an ad hoc basis.

Lack of training and protocols for behaviour support necessitates 'learning on the job'

Staff reported that children and young people with challenging behaviours increase safety risks for procedures requiring intense resources. Staff reported being assaulted as a consequence of not knowing how to respond, due to a lack of protocol and training, 'There are no formalised protocols that's been developed, and this is all things where you sort of learn on the job, because in the past, I've been bitten before, and I've been thumped on the head before' S18.

Communication between teams and external agencies for better preparation and care coordination

Staff reported that communicating non-medical disability specific information during handover (within and across departments) processes is not yet embedded in routine. Getting information about the child's triggers, behaviour, communication style and having a management plan would assist staff in busy environments to understand, plan and implement risk reduction strategies and communicate this to the rest of the team. Not being able to get advance notice impedes staff ability to anticipate the child's needs and prevent behavioural escalations. Some staff reported that using current handover processes (eg, morning huddle or communication book to disseminate information pertaining to clinical states/care or reasonable adjustments) were a good way to improve communication between staff and teams. Continuity of care also extends beyond the hospital into the community and applies to other carers or workers outside of the hospital context who provide care for the child or young person, recognising their shift rosters and ensuring that all involved are also included and informed. These children were also known to be more vulnerable to child protection issues which then further compound their



behavioural and clinical presentation, deserving of the appropriate response.

Need for specialist team to support staff

There was a consensus around the lack of disability health expertise in the hospital and community. Staff felt that a specialist team to assist with the assessment, care coordination, support and management of these children were essential for comprehensive care but also aware of the lack of advocacy for an organisational response in increased support and funding.

For subthemes and illustrative quotes please see online supplemental data 2 table 4.

Theme 6: service-system gaps preventing, identifying and managing risk

Developing inclusive patient information systems

Staff recognised that identifying a child or young person with intellectual disability in hospital was a major issue because with no way of flagging the need for preparation and adjustments, safety and quality of care would be compromised. Identifying a child or young person with intellectual disability acknowledges the unique challenges that these children have when receiving care in the healthcare system. As a staff member stated ‘it’s really getting to know the child before they actually come into that environment and knowing what the triggers for that child are. How can we help them, so that it is the least stressful it can be’ S11.

Improving use of patient safety reporting systems

Many staff and departments acknowledged that making incident reports for this population is not common practice. ‘I don’t think I’ve ever put anything in IIMs (incident management system) about anything of that nature... if a carer submitted a complaint, then that would eventually end up going to [doctor] as the head of department’ SFG2 Without reporting systems that identify the child with intellectual disability, one cannot build the evidence base for patient safety issues and prevent future adverse events. One member of staff reported making incident reports for this population with the hope of system improvements. However, staff reported using their own internal debriefing processes to discuss ways to prevent incidents from recurring and the importance of having a colleague present as witness for documentation and investigative purposes.

Developing reasonably adjusted and inclusive patient/parent led safety reporting systems

It was also emphasised that it is equally important to involve the child in open disclosure and engage parents effectively when managing issues. Often these children and the parents find that they do not have a ‘voice’ when it comes to raising their concerns about near misses or reporting adverse events. This would have serious implications on the health systems abilities to prevent such incidents from recurring in this vulnerable population.

Multiple gaps in staff advocacy, funding and service provision for better and safer care

Staff also acknowledged the presence of other system wide gaps in services. These relate to a lack of staff awareness and advocacy of the needs of patients with intellectual disability, limited mainstream services and funding, inappropriate admissions, poor discharge planning and limited transition to adult services and some groups not qualifying for specific care pathways (due to narrow inclusion criteria). These families often miss appointments and are not chased up therefore get lost in the system or sit on long public waitlists to the detriment of their child’s health. Limited specialty public dental services do not exist in the private sector. Accessing healthcare and transfer of care for children with intellectual disability has also been noted as less than ideal. Most of these relate to poor planning or consideration for the needs of the patient, poor team to team communications and a lack of transfer of critical information especially of reasonable adjustments. For subthemes and illustrative quotes please see online supplemental data 2 table 5.

DISCUSSION

This study was a qualitative analysis of interviews and focus groups of paediatric hospital staff to explore patient safety issues for children with intellectual disability. Overall, staff felt that caring for these children was a challenging task and one fraught with safety issues if they were not supported or encouraged to provide adapted care. Most staff were aware of the complexities in the care of the child and young person with intellectual disability and felt a need to be more supported, resourced or enabled to provide best evidenced care. Staff empowerment comes from developing skills and having a positive mindset when engaged in effective communication, relationships of mutual trust and skills in provision of care and behaviour management.^{7 17 18}

It was generally felt that caring for a child or young person with an intellectual disability and other developmental comorbidities often brings additional challenges and considerations when it comes to planning and delivering care.^{17 19 20} Staff recognised that the whole of the health workforce requires training to be able to provide safe and better care. This is not only at the level of the individual staff but at the departmental and organisational level recognising the influence of departmental and organisational culture.^{2 21} Staff also recognised the lack of policy, protocol or guidance around what is expected, and the skills required for safer and better care.²² Much of what is currently done results from experience, learning from parents and modelled from other colleagues echoing the literature.⁶

Communication

Communication breakdown leads to a multitude of near misses and errors.²³ This not only applies at the patient and family level but also across teams, departments,

between the hospital and community.^{17 19 22 24 25} We have also found inadequate practice of open disclosure and identifying near misses, with an over-reliance on parents to raise concerns.²⁶ These issues not only compromise staff capacity to be able to provide appropriate health-care, identify deterioration and respond accordingly, but erode parent trust in their care abilities.²

In addition, staff are not always cognisant of using normal mechanisms of reporting incidents for service improvements. The advantage of using these mechanisms enables further dissection of the communication error, reduces oversimplification, allows clear pattern recognition and more focused and precise interventions to improve process reliability and learning from these errors.²³ Guttman *et al* further asserts that by deconstructing communication in healthcare into its elemental parts, a more effective organisational learning strategy emerges to enable more focused patient safety improvement efforts to enhance the reliability and validity of information exchange.²³

Parent and family considerations

Parents are the experts of their child and should be considered as part of the treating team. They should be included and provided with information to better plan and prepare their child, anticipate, troubleshoot and support any treatment process. Seeking their views on treatment options and how they think their child would fare is critical to having a smooth and positive outcome. Parents are often willing to assist in monitoring, checking and informing staff when things are not working as expected. Working in partnership with parents contributes to the overall safety and quality of care, benefitting the patient, family and staff.^{27 28} It is also important to remember that parents often shoulder many responsibilities in addition to caring for their child and have a need to be listened to, helped and supported throughout the admission.²⁹

Bias and negative attitudes

There is substantial literature describing bias and negative attitudes influencing the quality of care that staff provide to persons with intellectual disability.^{30–33} Parents often find themselves judged and stereotyped by staff who feel challenged by them.¹ Negative bias towards persons with disabilities is a social construct and to combat this is to deconstruct the categories in which we place persons with intellectual disabilities within.^{34 35} When negative labels and stereotyping affect care quality there is a need to challenge this through reflective practices to deconstruct moments where relations of power occur during conflict or tension.¹ From this study, there is something to be learnt from the pure and non-stigmatising way siblings interact with the child or young person with intellectual disability that should transcend patient-family boundaries. Warm and positive sibling relationships not only promote the socio-behavioural flourishing of the person

with intellectual disability but can be a source of advocacy, support and care in the long-term.^{36 37}

Training programmes that combine a self-aware strategy of reducing bias, having good knowledge about health presentations for these children and a systematic approach to diagnoses helps reduce misdiagnosis or misplaced assumptions leading to errors.^{38 39} These attitudes make it easier to develop partnerships with parents and significant others not only in providing care but being able to make accurate assessments and interpretations of the health presentation.

This study revealed several areas that the current framework (PSEF) does not address. These include using communication adjuncts and strategies to obtain consent and communicate risk, transition to adult health services, parents with vulnerabilities and child protection considerations.

Gaps in staff advocacy, adapted care for clinical processes and pathways and patient information and reporting systems for safety

Many vulnerabilities exist in the healthcare system that render the child or young person with intellectual disability at risk for safety and poor care. In Australian hospitals, people with intellectual disability are not necessarily identified or flagged in the medical or administrative record of hospitals.^{26 40} In our study we found recurring themes of the lack of flagging systems which prevent opportunities for planning admissions, challenges in transfer of patient information across sites, staff lack of skills in engaging, staff assumptions leading to diagnostic overshadowing and lack of working in a child-family centred way.^{6 40 41} In addition, we also found issues with difficulties in interpreting behaviour and identification of early signs of deterioration which contributes to the increased risk of patient safety events. This is in addition to the usual issues around team-to-team communication, admission and discharge planning and adjustments afforded to a paediatric patient.^{22 25 42 43}

Limitations

While there was a relatively small number of staff involved in the study, the staff population had wide representation of disciplines, seniority and included ancillary staff. Participation was voluntary, hence views of non-participating staff highlighting with unique views or different perspectives may also be missed.

Implications

At the level of the individual, staff training needs to include good grounding in the common errors that lead to adverse events when caring for children or young people with intellectual disability. In particular, skills in using communication tools and strategies and including the child or young person and their parents in healthcare decisions, consent and open disclosure. Applying child and family centred strategies involves being cognisant of parental expertise of their child but also recognising that



parents also need support during admission and empowered to provide feedback on service improvement issues and patient safety incidents. Training also needs to raise staff awareness about unconscious bias in diagnostic overshadowing and avoiding any inequities of treatment or care for these children and young people. Finally, organisations and departments need to be held accountable for supporting staff to be able to provide reasonable adjustments and ensure adequate skills training is provided, staffing levels and expertise to prevent burnout, develop inclusive systems of care and reporting and build a culture of using reasonable adjustments as 'business as usual'. Increased exposure to using reasonable adjustments in the undergraduate and postgraduate professional development programmes is also sorely needed.

CONCLUSION

This study elicited feedback from staff working in two tertiary children's hospitals who are accustomed to caring for children with complex healthcare needs. This study reveals staff understanding of many of the issues faced by children and young people with intellectual disability but feel that more can be done to enable more comprehensive and robust initiatives to support their implementation. There is a clear need for training using a specialised curriculum, endorsed by patients, parents/carers, patient safety regulators, clinical governance and continuing professional education. Staff recognise the need for not only the health workforce to develop competencies and skills in communicating, engaging and developing trust relationships with the child and family but also the need for reasonable adjustments in our health systems, information systems and organisational culture. Multipronged approaches are needed for a whole of system change that addresses gaps at the individual clinician, departmental and organisational level. Future developments include combining data from staff/parent interviews, academic and grey literature in developing safety competencies for this population.

Author affiliations

¹Children's Hospital Westmead Clinical School, The University of Sydney Faculty of Medicine and Health, Sydney, New South Wales, Australia

²Child Development Unit, The Sydney Children's Hospitals Network, Westmead, New South Wales, Australia

³Faculty of Medicine, School of Psychiatry, UNSW, Sydney, New South Wales, Australia

⁴Australian Institute of Health Innovation, Macquarie University, North Ryde, New South Wales, Australia

⁵Department of Developmental Disability Neuropsychiatry, University of New South Wales, Sydney, New South Wales, Australia

⁶Office of Teaching and Learning in Medicine, The University of Sydney Faculty of Medicine and Health, Sydney, New South Wales, Australia

⁷Medical Education, Education Office, The University of Sydney Faculty of Medicine and Health, Sydney, New South Wales, Australia

Twitter Natalie Ong @ongbeehwa@ and Janet C Long @JanetCLong

Acknowledgements The authors would like to acknowledge Dr Brendan LooGee and Dr Jacqueline Milne for their contributions in discussion of the data codes and themes and Suzi Drevensek for feedback on the manuscript.

Collaborators Not applicable.

Contributors All authors have contributed significantly to the study design, data collection, data analysis and writing of the manuscript. NO accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish

Funding The authors would like to thank AVANT Grant for the provision of funding for the project.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Sydney Children's Hospital Human Research Ethics Committee 2020_ETH02240. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data summary provided in supplementary material. For more information data can be available upon reasonable request.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iDs

Natalie Ong <http://orcid.org/0000-0002-0962-443X>

Janet C Long <http://orcid.org/0000-0002-0553-682X>

REFERENCES

- 1 Aston M, Breau L, MacLeod E. Diagnoses, labels and stereotypes: supporting children with intellectual disabilities in the hospital. *J Intellect Disabil* 2014;18:291–304.
- 2 Ong N, Long JC, Weise J, et al. Responding to safe care: healthcare staff experiences caring for a child with intellectual disability in hospital. implications for practice and training. *J Appl Res Intellect Disabil* 2022;35:675–90.
- 3 Mimmo L, Harrison R, Hinchcliff R. Patient safety vulnerabilities for children with intellectual disability in hospital: a systematic review and narrative synthesis. *BMJ Paediatr Open* 2018;2:e000201.
- 4 Kuo DZ, Houtrow AJ, Arango P, et al. Family-centered care: current applications and future directions in pediatric health care. *Matern Child Health J* 2012;16:297–305.
- 5 Ahmann E, Johnson BH. Family-centered care: facing the new millennium. *Pediatr Nurs* 2000;26:87.
- 6 Carter B, Simons J, Bray L, et al. Navigating uncertainty: health professionals' knowledge, skill, and confidence in assessing and managing pain in children with profound cognitive impairment. *Pain Res Manag* 2016;2016:8617182.
- 7 Aston M, Breau L, MacLeod E. Understanding the importance of relationships: perspective of children with intellectual disabilities, their parents, and nurses in Canada. *J Intellect Disabil* 2014;18:221–37.
- 8 Trollor JN, Eagleson C, Turner B. Intellectual disability content within pre-registration nursing curriculum: how is it taught? *Nurse Educ Today* 2018;69:48–52.
- 9 Trollor JN, Eagleson C, Turner B, et al. Intellectual disability content within tertiary medical curriculum: how is it taught and by whom? *BMC Med Educ* 2018;18:182.

- 10 Trollor JN, Eagleson C, Turner B, *et al.* Intellectual disability health content within nursing curriculum: an audit of what our future nurses are taught. *Nurse Educ Today* 2016;45:72–9.
- 11 Trollor JN, Ruffell B, Tracy J, *et al.* Erratum to: intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. *BMC Med Educ* 2016;16:260.
- 12 Disability Royal Commission. Public hearing 4: health care and services for people with cognitive disability; 2020.
- 13 Disability Royal Commission. Public hearing 10: education and training of health professionals in relation to people with cognitive disability; 2020.
- 14 Walton MM, Shaw T, Barnett S, *et al.* Developing a national patient safety education framework for Australia. *Qual Saf Health Care* 2006;15:437–42.
- 15 Tufford L, Newman P. Bracketing in qualitative research. *Qual Soc Work* 2012;11:80–96.
- 16 Gale NK, Heath G, Cameron E, *et al.* Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117.
- 17 Hemsley B, Balandin S. A Metasynthesis of patient-provider communication in hospital for patients with severe communication disabilities: informing new translational research. *Augment Altern Commun* 2014;30:329–43.
- 18 Mimmo L, Hodgins M, Samir N, *et al.* “Smiles and laughter and all those really great things”: nurses’ perceptions of good experiences of care for inpatient children and young people with intellectual disability”. *J Adv Nurs* 2022;78:2933–48.
- 19 Doyle C. “The importance of supportive relationships with general practitioners, hospitals and pharmacists for mothers who ‘give medicines’ to children with severe and profound intellectual disabilities”. *J Intellect Disabil* 2022;26:29–49.
- 20 Johnson NL, Lashley J, Stonek AV, *et al.* Children with developmental disabilities at a pediatric hospital: staff education to prevent and manage challenging behaviors. *J Pediatr Nurs* 2012;27:742–9.
- 21 Nagelkerk J, Peterson T, Pawl BL, *et al.* Patient safety culture transformation in a children’s hospital: an interprofessional approach. *J Interprof Care* 2014;28:358–64.
- 22 Gray C, Christensen M, Bakon S. Nurse-initiated and criteria-led discharge from hospital for children and young people. *Nurs Child Young People* 2016;28:26–9.
- 23 Guttman OT, Lazzara EH, Keebler JR, *et al.* Dissecting communication barriers in healthcare: a path to enhancing communication resiliency, reliability, and patient safety. *J Patient Saf* 2021;17:e1465–71.
- 24 L Gleeson L, O’Brien GL, O’Mahony D, *et al.* Interprofessional communication in the hospital setting: a systematic review of the qualitative literature. *J Interprof Care* 2023;37:203–13.
- 25 Patton LJ, Tidwell JD, Falder-Saeed KL, *et al.* Ensuring safe transfer of pediatric patients: a quality improvement project to standardize handoff communication. *J Pediatr Nurs* 2017;34:44–52.
- 26 Ong N, Mimmo L, Barnett D, *et al.* Reported clinical incidents of children with intellectual disability: a qualitative analysis. *Dev Med Child Neurol* 2022;64:1359–65.
- 27 Mimmo L, Woolfenden S, Travaglia J, *et al.* Partnerships for safe care: a meta-narrative of the experience for the parent of a child with intellectual disability in hospital. *Health Expect* 2019;22:1199–212.
- 28 Oulton K, Sell D, Gibson F. Hospitalized children with intellectual disability: parents as partners in their care. *J Appl Res Intellect Disabil* 2020;33:917–26.
- 29 Hagvall M, Ehnfors M, Anderzén-Carlsson A. Experiences of parenting a child with medical complexity in need of acute hospital care. *J Child Health Care* 2016;20:68–76.
- 30 Desroches ML, Howie VA, Wilson NJ, *et al.* Nurses’ attitudes and emotions toward caring for adults with intellectual disability: an international replication study. *J Nurs Scholarsh* 2022;54:117–24.
- 31 Lewis S, Stenfert-Kroese B. An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *J Appl Res Intellect Disabil* 2010;23:355–65.
- 32 Morin D, Valois P, Crocker AG, *et al.* Attitudes of health care professionals toward people with intellectual disability: a comparison with the general population. *J Intellect Disabil Res* 2018;62:746–58.
- 33 Rose N, Kent S, Rose J. Health professionals’ attitudes and emotions towards working with adults with intellectual disability (ID) and mental ill health. *J Intellect Disabil Res* 2012;56:854–64.
- 34 Liachowitz CH. *Disability as a social construct: Legislative roots.* University of Pennsylvania Press, 2010.
- 35 Penrose J, Jackson P. Conclusion: identity and the politics of difference. In: *Constructions of race, place and nation.* UCL Press, 1993: 202–9.
- 36 Hastings R. *Children and adolescents who are the siblings of children with intellectual disabilities or autism: Research evidence.* Cerebra Chair of Family Research University of Warwick, 2014.
- 37 Travers HE, Carlton ME, Carter EW. Social connections among siblings with and without intellectual disability or autism. *Intellect Dev Disabil* 2020;58:19–33.
- 38 DiBrito SR, Lopez CM, Jones C, *et al.* Reducing implicit bias: association of women surgeons’ best practices recommendations. *J Am Coll Surg* 2019;228:303–9.
- 39 Kirby CS, Fedesco HN. Tell me more about alex: helping instructors uncover and mitigate their implicit biases. *To Improve the Academy: A Journal of Educational Development* 2020;39.
- 40 Kenten C, Wray J, Gibson F, *et al.* To flag or not to flag: identification of children and young people with learning disabilities in english hospitals. *J Appl Res Intellect Disabil* 2019;32:1176–83.
- 41 Oulton K, Gibson F, Carr L, *et al.* Mapping staff perspectives towards the delivery of hospital care for children and young people with and without learning disabilities in England: a mixed methods national study. *BMC Health Serv Res* 2018;18:203.
- 42 Rauch DA, Committee on Hospital Care, Section on Hospital Medicine. Physician’s role in coordinating care of hospitalized children. *Pediatrics* 2018;142:e20181503.
- 43 Sonis JD, Aaronson EL, Lee RY, *et al.* Emergency department patient experience: a systematic review of the literature. *J Patient Exp* 2018;5:101–6.