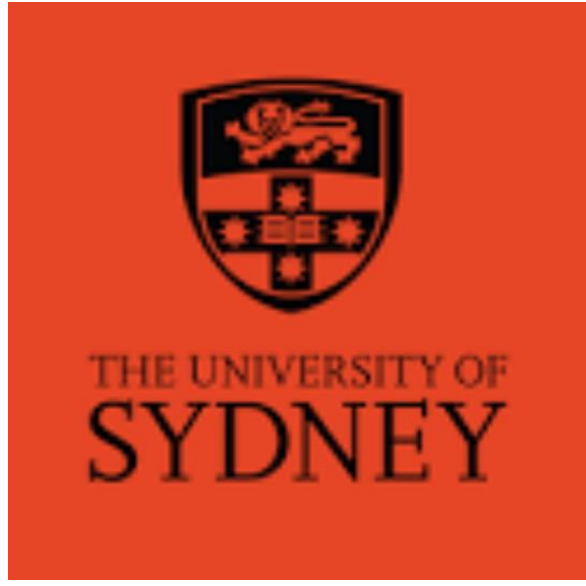




QUALITY AND SAFETY OF CARE PROVIDED BY HOSPITALS TO CHILDREN AND YOUNG PEOPLE WITH AN INTELLECTUAL DISABILITY.

A QUALITATIVE STUDY OF PARENTS AND HEALTHCARE STAFF USING THE FRAMEWORK METHOD.



Introduction

Context and background

Children and young people with intellectual disability are vulnerable to patient safety events within the healthcare system due to staff lack of familiarity with the child's communication abilities and care needs and poor child and family-centred care approaches. (Tuffrey- Wijne 2014, Mimmo et al., 2021).

Healthcare staff feel unprepared and unskilled when it comes to providing care and meeting their needs (Carter et al 2016). Ways for healthcare staff to upskill in providing reasonable adjustments, develop therapeutic relationships with the children and partnerships with their parents is sorely needed that result in improved care quality (Oulton et al 2020, Ong et al 2022).

Project Aims

- 1) Identify patient safety issues in this population from the perspectives of parents and healthcare staff.
- 2) Describe and understand patient safety factors unique to this population in order to modify the Australian Patient Safety Education Framework (APSEF, Walton et al 2016) for children and young people with intellectual disability.

The Framework Method

The Framework method consists of several stages (Gale et al., 2013; Ritchie et al., 2003; see Figure 1) and is based on a common set of principles which comprise qualitative analysis: transcribing interviews, data familiarisation, developing a data coding framework, and grouping codes to generate overarching categories/themes which may lead to theory development (Morse & Richards, 2012).

Take Home Messages

- Children and young people with intellectual disability suffer from poor safety and quality of care
- Staff lack skills in reasonable adjustments e.g. not communicating and engaging the child, work in partnership with parents, adapt processes and systems to identify and meet the needs of this population
- Training is required across the whole of health workforce at the individual, departmental and organisation level.
- Ways to reduce bias and diagnostic overshadowing need to be embedded in CPD-QI initiatives

Figure 2. Parent Interview themes



Method

Project Components

To expand the APSEF, we took a staged approach and drew on multiple sources of data.

- 1) A review of parent perspectives of the hospital experience leading to a systematic review of staff perspectives of safety issues for children with intellectual disability in hospital.
- 2) Analysis of incident management data for SCHN 2017 (children with intellectual disability)
- 3) Semi- structured interviews and focus groups with staff and parents of children with intellectual disability, structured around the existing domains of the Framework.
- 4) Experts in the field participated in a Delphi process to validate competencies required for the development of the Patient Safety Education Framework for Children and Young Persons with Intellectual Disability in the Hospital Setting.

A Parent/ Carer and Expert Advisory and Academic group provided advice for the direction of the project. This project is part of a larger piece of research work as part of Dr Ong's doctoral thesis.

Parent interviews

Parent Demographics	N=13
Gender:	3 male 10 female
Age:	32- 52 years (mean 40.9 years)
Child Age:	5-14 years
Child Diagnosis	Intellectual Disability +/- autism, medical/ physical and genetic syndromes

Staff interviews and Focus Groups

Staff Demographics	N=36
Gender:	7 male 29 female
Age:	20-70 years (45.8 years)
Discipline:	Medical, Nursing, Allied Health, Ancillary (across disciplines and seniority)
Interviews: Focus Groups	22:3

Data analysis

The interviews were transcribed, coded and analysed according to the Framework Method.

Figure 1. The Framework Method

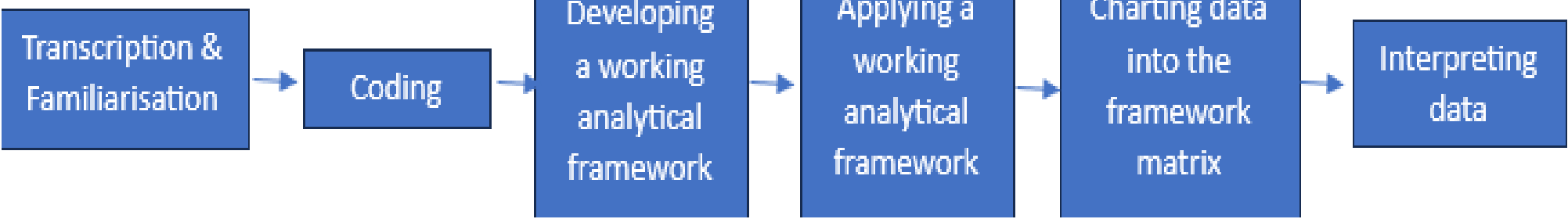
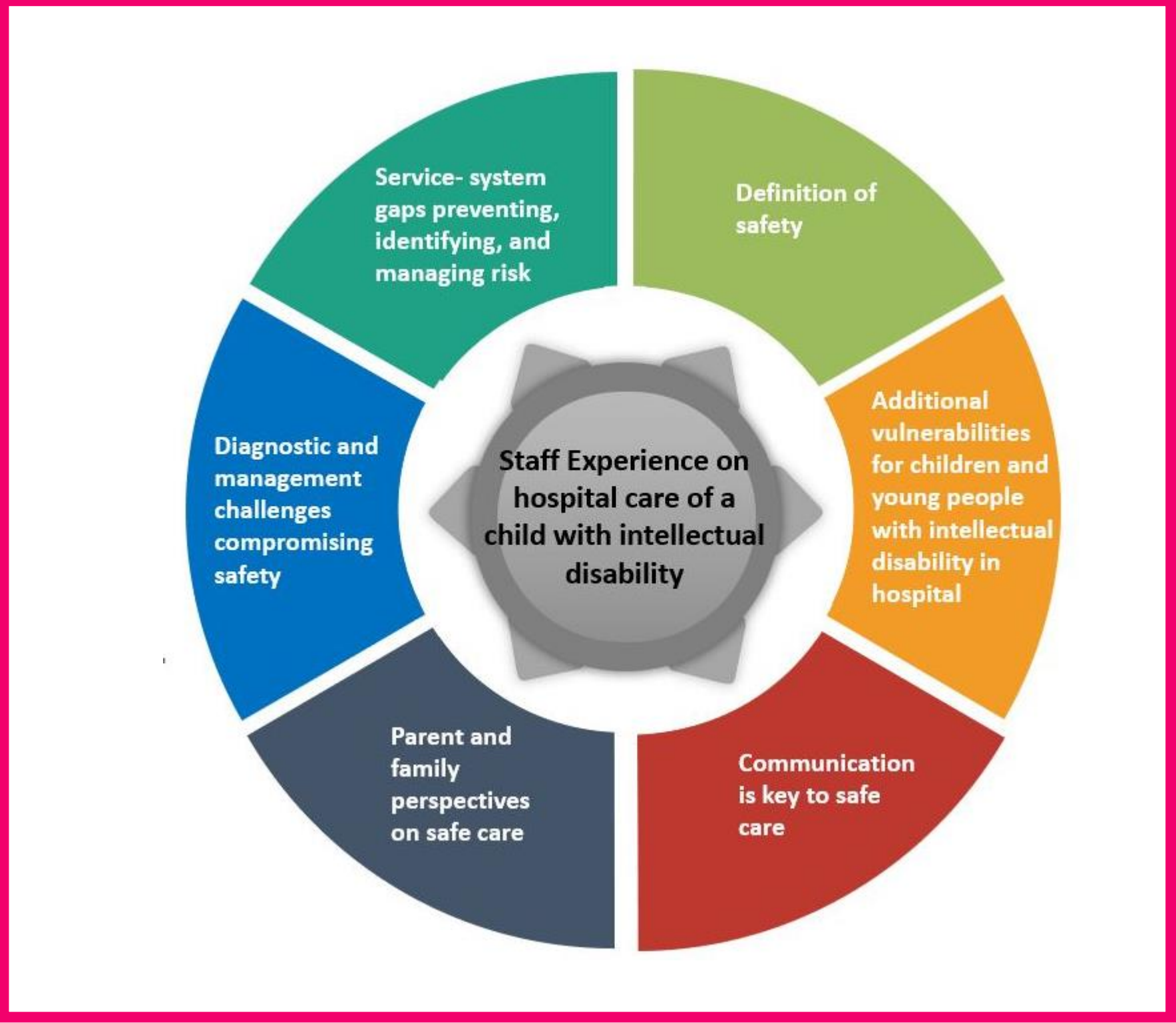


Figure 3. Staff Interview themes



Results

Themes from Parent Interviews

Eight themes emerged from thematic analyses: See Figure 2.

Themes from Staff Interviews / Focus Groups

Six themes elicited from the analysis. See Figure 3

Discussion and Conclusion

Parents highlighted staff issues with **Communication and attitudes**
Lapses in management
Knowledge gaps in developmental and intellectual disability health
Skills in behaviour management and child engagement
Admission planning and process implementation
Environmental modifications
Lack of inclusive practices as contributing to increased risk of patient safety issues.
Including **strategies and safeguards to assist staff to increase their ability to reflect and scrutinise their clinical decision making to minimise diagnostic overshadowing** is also of critical importance

Staff report the need to

Recognise additional vulnerabilities for children with intellectual disabilities
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 training methods that address attitudes and bias, skills in providing reasonable adjustments and improving systems and processes to reduce risk and improve the patient and parent experience. Competencies should be relevant at the individual, departmental and organisational level for authentic diffusion for an inclusive culture.

The development of an adapted Patient Safety Education Framework for Children with Intellectual Disability should consider ways for staff to transform attitudes and reduce bias which leads to adaptations for safer and better care. In addition, issues that apply to quality and safety for these children can be generalised to all children in hospital.

References

1.Carter B, Simons J, Bray L, Arnott J. Navigating uncertainty: health professionals' knowledge, skill, and confidence in assessing and managing pain in children with profound cognitive impairment. Pain Research and Management. 2016;2016
2.Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC medical research methodology, 13(1), 1-8.
3.Mimmo L, Harrison R, Travaglia J, Hu N, Woelfenden S. Inequities in quality and safety outcomes for hospitalized children with intellectual disability. Developmental Medicine & Child Neurology. 2021;
4.Ong N, Long JC, Weise J, Walton M. Responding to safe care: Healthcare staff experiences caring for a child with intellectual disability in hospital. Implications for practice and training. Journal of Applied Research in Intellectual Disabilities. 2022;
5.Oulton, K., Sell, D., & Gibson, F. (2020). Hospitalized children with intellectual disability: Parents as partners in their care. Journal of Applied Research in Intellectual Disabilities, 33(5), 917-926.
6.Richards, L., & Morse, J. M. (2012). Readme first for a user's guide to qualitative methods. Sage.
7.Ritchie, J., Spencer, L., & O'Connor, W. (2003). Carrying out qualitative analysis. Qualitative research practice: A guide for social science students and researchers, 2003, 219-62.
8.Tuffrey-Wijne, Goulding L, Gordon V, et al. The challenges in monitoring and preventing patient safety incidents for people with intellectual disability in NHS acute hospitals: evidence from a mixed-methods study. BMC health services research. 2014;14(1):432.
9.Walton MM, Shaw T, Barnett S, Ross J. Developing a national patient safety education framework for Australia. BMJ Quality & Safety 2009; 19(6):437-442.

