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Enabling Mainstream Systems to Be More Inclusive and Responsive to People with Disabilities: Hospital Encounters of Adults with Cognitive Disabilities

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ENQUIRIES

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Table of contents

Executive summary	3
Introduction	10
Background	11
Methods	14
Participant description	18
Findings - quantitative	21
Comparative trends from the quantitative data	29
Findings - qualitative data	30
The hospital journey	31
Example hospital journey 1. Edward	33
Example hospital journey 2. Darren	34
Example hospital journey 3. Daniel	35
Stage 1. Deciding to go to emergency	36
Stage 2. Arriving and being in emergency	40
Stage 3. Leaving emergency	58
Stage 4. Being on a ward	59
Stage 5. Being discharged from the hospital	72
Conclusions and propositions for action	
Support, information collaboration and knowledge	83
References	90
Tables	
Table 1. Characteristics of participants with cognitive disability	19
Table 2. Interviews and observations across all encounters	20
Table 3. Presentation to Emergency	22
Table 4. Time parts of the hospital encounters beginning in Emergency	24
Table 5. Diagnostic evaluations and outcomes beginning in Emergency	26
Table 6. Post Emergency and Short Stay Unit destinations	28
Table 7. Promising support and information strategies identified in data	86
Table 8. Knowledge gaps and barriers with recommendations	88
Figures	
Figure 1. Study participants and types of data collected	20
Figure 2. AR-DRG for encounters with a diagnosis	25
Figure 3. Stages of the hospital journey	32
Figure 4. Deciding to go Emergency	36
Figure 5. Promising practices observed in deciding to go to Emergency	40
Figure 6. Arriving and being in Emergency	40
Figure 7. Promising staff practices in Emergency	58
Figure 8. Leaving Emergency	59
Figure 9. Being on the ward	60
Figure 10. Promising practices on the ward	71
Figure 11. Being discharged from the hospital	72
Figure 12. Promising practices being discharged	79
Figure 13. Support, Information, Collaboration and Knowledge	84
Appendix 1. Checklists for delivering high quality care for people with cognitive disabilities in hospital.	94

Executive Summary

The study concerns the interfaces across mainstream service systems, people with disabilities and their families, and disability service systems. Maximising the way members of these three groups communicate and work together is a major challenge in the current disability policy environment and one that significantly affects the quality of life of people with disabilities. We take hospital systems as an exemplar mainstream service system and people with cognitive disabilities (intellectual disability and traumatic brain injury) as the exemplar group of service users with disability. Many people with cognitive disabilities have additional impairments (physical, sensory, psychosocial), and their difficulties with cognition, communication and self-direction pose some of the most complex issues requiring accommodations by individuals and service systems.

Aims and method

The study aim was to provide evidence about the processes and practices that enable mainstream services to identify and respond to the particular needs of people with disabilities as a matter of course. Taking a strengths-based approach, identified through this study were promising individual ad hoc and systematic processes and practices – Promising Practices – that helped to accommodate the needs of people with cognitive disabilities and facilitate their receipt of high-quality hospital care.

The study used mixed methods and was conducted in Victoria across two metropolitan health networks and one rural health network. Sixty primary participants (50 with intellectual disabilities and 10 with traumatic brain injury) were recruited as they commenced a hospital encounter and each stage of their journey through the system was documented. Data about patient's experiences and those accompanying them (predominantly family members and disability support staff) were collected using unstructured non-participant observation (107) and semi structured interviews (93). Similar methods were used to collect data about the perspectives of hospital staff involved with primary participants during their encounter (137). An audit of each primary participant's medical file, conducted after their discharge, was used to collect data about medical assessments, treatment and care processes delivered during the hospital encounter. The data was collected between November 2014 and October 2017. The final part of the study involved collaboration with key staff from one of the health networks that participated in the study. The promising strategies and processes identified in the analysis were conceptualised as four inter-related constructs: support, information, collaboration and

knowledge that could be used to guide the development of hospital practices to improve the care experiences and health outcomes of people with cognitive disabilities.

Quantitative findings

During the 35 months of the study, the 60 primary participants had 186 separate hospital encounters, lasting from a few hours to 364 days. Most encounters began in Emergency and 43% resulted in an admission to a hospital ward. When data for the participants with cognitive disabilities in our study are compared to data about hospital use by the general population (AIHW, 2016), a higher proportion arrived by ambulance (61% compared to 24%), they were allocated similar triage codes, and a higher proportion exceeded the benchmark of a stay in Emergency of 4 hours or less (62% compared to 21%). The longer stay in Emergency may reflect the additional time medical staff required to complete a diagnosis and care practices for this group. Contrary to international studies, and anecdote, there was no evidence from our data that the people with cognitive disabilities received poorer quality health care compared to others in the community. Most received a clear diagnosis (75.7%) and 93.3% a plan for what should happen after discharge. Problems with the digestive system, injuries and disorders and diseases of respiratory and nervous systems were the conditions most commonly diagnosed.

Qualitative findings

The qualitative data forms the majority of our findings, and identified (a) aspects of the hospital journey that worked well for people with cognitive disabilities; (b) the difficulties they encountered; (c) the types of accommodations made to take account of their needs; and (d) when and where they occurred and who enacted them. The findings show that:

- Hospital encounters for people with cognitive disabilities frequently involve hospital, ambulance and disability service systems.
- Encounters also involve families of people with cognitive disabilities. The roles that families play in the lives of people with cognitive disabilities are complex and can be poorly understood by hospital staff. Disability support staff and family members of people with cognitive disabilities are not necessarily interchangeable, particularly for those who live in supported accommodation services, whose family members may not be aware of their immediate situation leading up to going to hospital.

- Staff in disability supported accommodation services strenuously try to find alternatives to supporting a person with cognitive disability to go to hospital. The considered nature of their decisions may not be well understood by Ambulance or Emergency staff.
- Staff in disability supported accommodation services rely on the Ambulance Service to take the people they support to hospital because of the difficulties people with complex needs and multiple disabilities have in travelling by car, and the difficulties of more than one staff member leaving the service.
- Many disability support staff and family members have had negative experiences in the past where hospitals have not accommodated the needs of patients with cognitive disabilities. Such past negative experiences influence expectations about the quality of care.
- The roles that disability support staff from supported accommodation services play whilst a person they support is in hospital are not well understood or recognised by disability service policies and this means that staff are often uncertain about how they should act and may act contrary to written policies.
- Most commonly, hospital staff accommodated the needs of people with cognitive disabilities by making adjustments to the way they communicated or interacted with the patient or their accompanying person, provided care, conducted tests, gave treatment or used space.
- Accommodations were often underpinned by collaboration between hospital and disability support staff, and/or families and staff from the hospital and disability service system. Collaboration involved recognising each other's knowledge, valuing the respective roles they played in patients' lives and collectively ensuring the patient received the optimal quality of care. Disability support staff, for example, repeatedly sharing their knowledge about the immediate situation and past history of the patient, briefing hospital staff about support practice and sharing caring tasks, and adopting the role of advocate.
- Accommodations depended on the flexibility, attitude and skills of individual hospital staff. They were often perceived as good practice or the actions of 'stand out' staff rather than being recognised as accommodations that could be shared with other staff.

- The quality of hospital care and accommodations to meet the needs of people with cognitive disabilities are not consistent and there are few system level mechanisms to ensure that all staff are proficient at adjusting their interaction and practice to accommodate the needs of people with cognitive disabilities.
- People with cognitive disabilities were more likely to experience difficulties when they were admitted to hospital wards compared to being in Emergency.
- Emergency was more often perceived as offering good interactive and communication models for working with people with cognitive disabilities. Practices were sufficiently flexible to accommodate the needs and expectations of people with cognitive disabilities and their accompanying people, particularly patient home-based routines. They also appear to have cultures of collaboration and teamwork which support responsiveness to the diversity of people who present for assessment and treatment.
- The hospital administrative systems were not designed to adequately capture accurate information about the living and support contexts of people with cognitive disabilities or the key members of their support networks. Inaccurate and missing information has potentially negative implications at later stages of the journey and decision-making processes.
- Discharge processes were not transparent or inclusive and left patients and those supporting them to return home with considerable uncertainty, which may have led to unnecessary anxiety or confrontations.
- An exceptional hospital encounter of a patient with cognitive disability who remained in hospital 131 days after she had returned to her pre-admission health and functional status demonstrated the economic and human cost of failures to manage complex discharge and decision-making issues for a person with cognitive disability.

Recommendations

Service systems (disability support services, hospitals, ambulance service) and their staff and family members involved in hospital encounters of people with cognitive disabilities need greater reciprocal understanding of each other. In particular, there is a need to understand the role each plays in the day to day life of a person with cognitive disabilities or their

involvement during a hospital encounter. This type of reciprocal understanding will facilitate shared expectations and collaboration during hospital journeys.

At the system level in hospitals, accommodations could be developed and trialed that;

- provide orientation for people with cognitive disabilities, families and disability support workers to the expectations and primary tasks of different hospital staff at each stage of the hospital journey; this strategy would be useful in unsettling previous negative experiences, helping to identify conflicting perspectives and ensuring greater shared expectations.
- recognise and systematically describe in policies, procedures or in-house training resources individual accommodations made by hospital staff, so they can be shared among their colleagues and taught to new staff or in pre-service education.
- address problems with the categorisation about living circumstances of people with cognitive disabilities in records systems that can lead to inaccurate information being recorded.
- reduce the uncertainty of hospital staff and provide guidance to them about the roles for disability support staff and families and ways of working in collaboration with them.
- increase the hospital staff and system level understanding about the disability service system.
- enable hospital staff to have a greater awareness of policy expectations about the rights of people with cognitive disabilities to be supported to make decisions about their own lives and equip them to translate this into their everyday practice.
- create a group of hospital staff with specific expertise around rights based support for decision making when complex decisions about safe discharge and access to accommodation and support options have to be made.
- ensure greater transparency and consultation occurs around discharge planning and a discharge summary of recommended follow up action is available to all patients at the time of discharge.

- understand more about the culture and operations of Emergency as an environment conducive to embedding promising practices and use its features to develop strategies in other operational units to enable them to better accommodate the needs of people with cognitive disabilities.
- adjust Emergency performance benchmarks and funding formula to take account of the longer time required to provide quality treatment and care for people with cognitive disabilities.

The ambiguity and uncertainty in the policies of disability support services, hospital systems and funding bodies, such as the National Disability Insurance Agency, should be addressed to recognise the significance to the quality of hospital encounters of disability support workers who know patients with cognitive disabilities well. These policies should acknowledge and ensure adequate support for the multiple roles they play, particularly in sharing information and expertise with hospital staff about health and care needs of patients and acting as consumer advocates which are integral to ensuring high quality care.

Support, information, collaboration and knowledge - constructs to guide hospital practices

The promising practices identified in the analysis were conceptualised through four inter-related constructs: support, information, collaboration and knowledge. These constructs reflect principles or fundamentals of care to guide the development of hospital practices to improve the care experiences and health outcomes of people with cognitive disabilities.

Both the support needs of people with disabilities and the information needs of hospital staff were best met when health care practices were underpinned by a positive attitude towards collaboration between hospital staff members, the person with cognitive disability and family members, and disability support workers who knew them well and accompanied them during the hospital encounter. Finally, lack of reciprocal knowledge across the hospital and disability systems acted as a barrier or could be seen to have a negative influence throughout the hospital experience having an effect on the ease of collaboration, the flow of information, the provision of support, and ultimately the outcome of the hospital encounter for the person.

For the most part, solutions to these gaps lie in collaborative education and development of resources to support ongoing staff development in the workplace. Such resources are particularly important in times of change as currently in play in the disability sector with the

introduction of the National Disability Insurance Scheme and ongoing law reform in relation to decision making capacity and disability (ALRC, 2014). It is our premise that building on practice through the development of resources and strategies to ensure effective support is provided, accurate information is available, collaboration is facilitated and knowledge is developed is essential to accommodating the health care needs of people with cognitive disabilities in the hospital environment.

Checklist for delivering high quality care for people with cognitive disabilities in hospital

Four checklists for ensuring high quality hospital care for people with cognitive disabilities were developed from the study. They are based on the good practices regarding Support, Information, Collaboration and Reciprocal Knowledge that were observed and heard about. These practices relate to the whole hospital journey – from the event that triggered a trip to hospital to discharge. The checklists are available as a single document and included in the appendix of the full report.

There are two checklists for the key people providing direct support during the hospital journey – Accompanying People and Hospital Staff – and two checklists for Hospital Managers and Administrators concerned with the Processes and Environments that underpin support good support, collaboration, and reciprocal knowledge.

Enabling Mainstream Systems to Be More Inclusive and Responsive to People with Disabilities: Hospital Encounters of Adults with Cognitive Disabilities

Introduction

Strengthening mainstream service systems to better accommodate the needs of people with cognitive disabilities to ensure equity in access and quality of service provision are current policy imperatives stemming from the National Disability Insurance Scheme and the National Disability Strategy (Bonyhady, 2016). In this study, we take hospital systems as an exemplar mainstream service system and people with cognitive disabilities (intellectual disability and traumatic brain injury) as the exemplar group of service users with disability.

People with cognitive disabilities have significantly poorer health compared to the general population. Their substantial health inequalities are both intrinsic to the individual and extrinsic, associated with their high risk of many adverse social determinants of health, including poverty, unemployment and social isolation and poor access to quality health care (Emerson et al., 2011). A large body of international research suggests that the failure of hospital systems to make adjustments to accommodate the needs of people with cognitive disabilities contribute to their health inequalities. This literature demonstrates that people with cognitive disabilities are frequent users of the hospital services (Balogh et al., 2005; Walsh et al., 1997) and are at risk of mismanagement of their health issues and receipt of poor quality care (e.g., Mencap, 2007), and hospital staff have difficulties identifying people with cognitive disabilities, their care needs, providing day-to-day care, adhering to clinical guidelines and finding ways to support patient compliance with treatment regimes (Heslop et al., 2013; Iacono & Davis 2003; Gibbs et al., 2008). There has, however, been limited Australian research about the quality of hospital services received by people with cognitive disabilities or the types of adjustments currently made or necessary to accommodate their needs. Solutions trialed in hospital systems overseas, such as employment of a disability Liaison Nurse, have had some positive outcomes, but have proved difficult to sustain or embed in systems (MacArthur et al., 2015). Their suitability for Australian hospitals and effectiveness remains untested. In this study, we aimed to provide evidence about the processes and practices that enable hospital services to identify and respond to the particular needs of people with cognitive disabilities as a matter of course.

Background

People with cognitive disabilities have substantial health care needs arising from higher rates of health conditions compared to the general population. Contributing to these high rates are health problems that are comorbid or co-occurring with their primary disability (e.g., high rates of congenital heart problems in people with Down syndrome) and poor social determinants that place them at particular risk of poor health and access to quality primary health care (Elliott, Hatton, & Emerson, 2003; Emerson, Baines, Allerton, & Welch, 2012; Havercamp & Scott, 2015). Much research has been devoted to identifying these health inequalities for people with intellectual disability (see Iacono & Bigby, 2016 for a review), but there is a scarcity of research for people whose cognitive disability is from a traumatic brain injury (TBI). Further, there is research into accessing mainstream health services, in particular hospitals, for people with intellectual disability (Iacono & Davis, 2003; Tuffrey-Wijne, Goulding, Giatras, et al., 2014; Tuffrey-Wijne, Goulding, Gordon, et al., 2014; Webber, Bowers, & Bigby, 2010), but not for people with TBI following treatment of the original injury or rehabilitation. Research into the experience of young people with TBI placed in residential aged care settings, post-acute care and rehabilitation, shows that this group shares common hospital care needs with people with intellectual disability (Winkler, Sloan, & Callaway, 2007). These similarities likely reflect an overlap between the two groups in key characteristics, including difficulties with communication and executive functioning, and the potential for problem behaviours to interfere with care processes. Hence, research into the hospital experiences of people with intellectual disability is likely to have relevance for those with TBI, providing a starting point for understanding hospital care for people with these and other cognitive disabilities.

There is anecdotal evidence, international research and some Australian studies that demonstrate mainstream services are not accessible for people with cognitive disabilities. In particular, research has shown that the health system is highly reliant on paid or family carers to assume responsibility for many tasks ordinarily carried out by hospital staff for people without disabilities (Iacono & Davis, 2003; Tuffrey-Wijne, Goulding, Giatras, et al., 2014; Webber et al., 2010). There is also evidence from Australian and overseas research that people with disabilities receive poor quality treatment, thereby indicating the failure of health care services to conform with best practice guidelines and hospital quality processes (Iacono & Bigby, 2016; Mencap, 2012; Tuffrey-Wijne, Goulding, Giatras, et al., 2014).

In Australia, only two small studies have addressed the responsiveness of hospital services to people with cognitive disabilities (Iacono & Davis, 2003; Webber et al., 2010). The findings revealed poor quality care, such as failure to diagnose conditions, and inadequate discharge procedures and information provision to carers. These problems arose from difficulties at the interfaces between hospitals, disability support services and families, whereby poor communication or inadequate understanding of each other's roles and expertise arguably impacted negatively on the quality of care for the person with cognitive disability. A limitation of previous Australian studies was in capturing the perspective of the disability sector only, and not that of mainstream hospitals (Iacono et al., 2014).

In the UK, Tuffrey-Wijne et al. (2014) did explore multiple perspectives by gathering survey and interview data from hospital staff, patients with intellectual disability and their carers. They found that good practice was often reliant on individuals, rather than systematic application of adjustments to meet the needs of this patient group. Major barriers to good care included an inability to flag and track patients with intellectual disability, limited knowledge and understanding by staff about adjustments needed and how to implement them, a blurring of lines of responsibility and accountability for the implementation of adjustments, and a lack of resourcing.

Research that develops multi-sectorial understanding of how hospitals respond, or could respond better, to the needs of people with cognitive disabilities offers the potential to improve the effectiveness and efficiency of hospital care. International research has shown that people with cognitive disabilities are high and costly users of hospital systems, who in comparison with the general population, have more frequent hospital encounters, and tend to stay in hospital longer (see Dunn, Hughes-McCormack, & Cooper, 2017, for a review). In terms of presentations to the Emergency Department (Emergency), frequent use has been defined as 5 or more in a year (Fuda & Immekus, 2006). The lack of data about Emergency presentations by people with cognitive disabilities makes direct comparison to the general population difficult. However, preliminary findings from a disability-health data linkage study in NSW, Australia, shows that between 2005-2010, over 70% of people with intellectual disability who accessed disability services ($n=51,452$) visited Emergency up to 5 times (Reppermund et al., 2017). Emergency presentations by people with intellectual disability, as well as their admissions to wards, have been found often to be for Ambulatory Care Sensitive Conditions (ACSC) (Balogh, Brownell, Ouellette-Kuntz, & Colantonio, 2010;

Dunn et al., 2017; Glover & Evison, 2013; McDermott, Royer, Mann, & Armour, 2018). These are conditions considered best managed through outpatient care and self-management, which should not require hospitalisation; hence hospitalisations for ACSC are argued to be avoidable through good primary health care (Glover & Evison, 2013; McDermott et al., 2018). Examples of ACSC are flu and pneumonia, diabetes, epilepsy and gastroenteritis (Page, Ambrose, Glover, & Hetzel, 2007), which have been found amongst the most frequent reasons for the hospitalisation of people with intellectual disability in Canada (Ailey & Hart, 2010; Balogh, Hunter, & Ouellette-Kuntz, 2005), the UK (Glover & Evison, 2013) and Norway (Skorpen, Nicolaisen, & Langballe, 2016). There is, however, a lack of data to indicate if there are similar patterns in Australia.

Mismanagement in hospitals of people with cognitive disabilities has the potential for severe consequences. In the UK, Heslop et al. (2013) found that avoidable deaths were more common among people with cognitive disabilities than the general population: 37% vs. 13% of avoidable deaths. Two UK reports demonstrated how poor care and active discrimination in hospitals contributed to such avoidable deaths (Mencap, 2007, 2012). Certainly, the Australian studies by Iacono and Davis (2003) and Webber et al. (2010) showed problems with ensuring appropriate diagnostic assessments and interventions are conducted in a timely manner for people with cognitive disabilities in hospital wards. These outcomes may be symptoms of difficulties experienced by hospital staff in identifying people with cognitive disabilities and their care needs, providing day-to-day care, adhering to clinical guidelines and finding ways to support patient compliance with treatment regimes (Iacono & Bigby, 2016).

Ways of accommodating the needs of people with disability has had some focus in the disability literature (Tuffrey-Wijne et al., 2014), particularly through the use of Learning Disability Liaison Nurses in the UK (MacArthur et al., 2015). This strategy, while found effective, is at risk during times of cost-cutting, while also relegating the responsibility for designing and ensuring implementation of reasonable adjustments to a single hospital staff member. Recently, Ailey, Brown, and Ridge (2017) called for organisational and cultural change within hospitals to ensure improvements at the point of care.

Aims

Taking a strengths-based approach, we aim in this study to identify promising process and practices that help to accommodate the needs of people with cognitive disabilities and facilitate their receipt of high quality hospital care. Specific aims were to:

1. Identify promising ad hoc and systematic processes and practices enabling inclusion and responsiveness, and the potential for their integration into systematic strategies for widespread adoption.
2. Understand barriers to responding appropriately to people with disabilities and delivering them quality services.

Methods

Ethical approval and consent

Approval for the conduct of the study was obtained from participating hospital systems and disability organisations, as well as La Trobe University. Written informed consent was obtained directly from or on behalf of participants with cognitive disabilities by a next-of-kin for those without capacity for consent, and directly from other participants.

Participants

Selection. Three groups of participants were selected for the study. The primary participants were adults diagnosed with a specific cognitive disability (intellectual disability or traumatic brain injury, TBI) who experienced a hospital encounter as a patient during the study period from November 2014 to October 2017. The inclusion criteria included that the encounter was not directly associated with the person's cognitive disability, but could be an emergency or planned procedure. Secondary participants were people accompanying a primary participant during the hospital encounter. These people could be family members, paid or unpaid support workers or friends of the primary participant. Tertiary participants were any hospital staff (including nurses, medical practitioners, allied health professionals) who were directly involved in providing care for or information to a primary participant during the hospital encounter.

Recruitment. Recruitment occurred across three hospital systems from which approval to conduct the study had been obtained. Two hospital systems were metropolitan and one was regional. One of the hospital systems comprised three metropolitan hospitals. Two of these

were in the category of 200-500 beds, and data for 2015-16 indicated they had 60,642 and 56,958 Emergency presentations, respectively, and the third hospital was in the 100-199 bed category, with 39,932 Emergency presentations in the same year

(<https://www.myhospitals.gov.au>).

The second hospital system included one metropolitan hospital in the category of 200-500 beds, with 85,007 Emergency presentations in 2015-16. The third hospital system was regional, and fell into the category of 200-500 beds with 50,042 Emergency presentations in 2015-16.

Two strategies were used to recruit primary participants. Advanced recruitment was used to identify adults with cognitive disabilities across hospital catchment areas in order to seek their permission to be included in the study in the event of a hospital encounter during the study period. Their involvement in the study was triggered if they had a hospital encounter during the study period at the hospital. The recruitment process was preceded by briefing sessions (researchers talking to relevant disability services and community health centres) and provision of written materials about the project. Individual potential participant details were provided to the researchers once they had entered a participating hospital encounter.

Just-in-time recruitment occurred at each participating hospital: research staff spent time in Emergency to identify adults with cognitive disabilities who entered seeking hospital assessment and/or treatment. Potential participants were invited into the study and consent was obtained at an appropriate time.

Once consent had been obtained, secondary and tertiary participants were recruited. Secondary participants were identified largely because they accompanied the person to hospital or were present at some point during the encounter. To recruit tertiary participants, information sessions were held with teams within the hospital. Individual staff were invited to participate based on their interaction with primary participants. Health care delivery staff were identified through review of primary participant files and named staff contacted for involvement in the study (e.g., participation in an interview).

Data collection and analysis

Data collection began in one hospital system comprising three hospitals as part of the pilot work for the study towards the end of 2014. Data collection ended in October 2017, 3 months after the last participant had been recruited (35 months in total).

Medical record audit.

As close to completion of a primary participant's hospital encounter as possible, a medical record audit was conducted by a researcher based within each hospital system. Data were obtained from electronic and paper-based records kept in the Emergency and wards. An audit tool was developed for the purpose of this data collection and was used to obtain information on characteristics about the primary participant, his/her history at that hospital (if available), reason for presentation, diagnostic processes and outcomes, movement through the hospital system and discharge processes. Contact points within the hospital were recorded (e.g., departments and services used), as well as other information, such as care/treatments/interventions recommended, received and/or administered.

All quantitative data were entered into SPSS v 24. Descriptive analyses were run at the participant level in order to obtain information about their characteristics, and time in the study. Descriptive analyses were also run at the encounter level (i.e., analyzing each encounter across participants combined) across variables included in the medical audit. Presented here are data for the whole sample; further analyses will be undertaken, in preparation for publication of parts of this report in peer review journals, to explore differences according to type of cognitive disability and across hospital systems within a standardised time period. In addition, relationships across variables will be explored, to determine potential predictors of frequencies of Emergency presentations and re-presentations and length of stay.

Observations.

Where appropriate, research staff conducted observations of interactions occurring for primary participants in various parts of the hospital. These lasted up to 1 hour in duration. These observations and field notes comprised the following types of information:

- interactions between all participants in the encounter (i.e. primary, secondary and tertiary participants).
- the context of interactions between all participants in the encounter (e.g. physical and social context; artifacts; presence of support tools; use of support tools).
- health disciplines of people involved if apparent.

- the patient journey.
- duration of encounter(s).
- language, tone and body language used during the encounter.

Semi-structured interviews.

For each encounter a participant at each level (i.e., primary, secondary and tertiary) was invited to an individual semi-structured interview. Questions addressed their experiences of various aspects of the hospital encounter (including pathway to the encounter), and characteristics of the participant such as their cognitive impairment, living situation, previous experiences of hospital-based care and their expectations of the current encounter. These interviews occurred from 5 to 368 days post-encounter (mean 49 days, median 38 days).

During the interviews an attempt was made to confirm quantitative data collected through the medical record audit, supplement it with quantitative data about secondary and tertiary participants (e.g., name, date of birth, gender, relevant qualifications, role/position in encounter, role/position in health service, relationship to the primary participant), and expand on notes collected through observation. Each interview was digitally recorded and transcribed verbatim for analysis.

All the qualitative data from interviews and observations was entered in to NVIVO. Case summaries were prepared outlining the key aspects of each participant's hospital encounter, and data were coded using a grounded theory approach of initially open and then focused coding. The analysis focused on four key topics – the experiences at each stage of the hospital journey, the needs of the patient with cognitive disability, and others involved in their care or support at each stage of the journey, the types of accommodations made by hospital staff at each stage, and the difficulties experienced during the journey. Regular discussion among the research team was important in refining the coding and the development of categories.

The final stage of the study involved a process of sharing and discussing the findings with key staff from one of the health networks. This consultation informed the development of four constructs to capture the essence of the findings and reflect principles or fundamentals of care to guide the development of hospital practices to improve the care experiences and health outcomes of people with cognitive disabilities.

Participant Description

In total, 60 primary participants were recruited; of these 13 were interviewed. In addition, 67 secondary participants and 82 tertiary participants were interviewed. Primary participant characteristics for the intellectual disability and TBI groups are presented in Table 1.

Inspection of Table 1 shows that most primary participants had intellectual disability ($n = 50$), were male (73%) and aged from 18 – 84 years (mean = 44 years). They tended to live with family (45%) or in shared supported accommodation (40%). Most had at least 1 chronic health condition, most often epilepsy, but many had up to 5. Figure 1 and Table 2 provide a summary of the number of participants, interviews conducted and observations made. The majority of primary participants were recruited from the just-in-time strategy (with only 5 primary participants recruited in advance; these participants had 7 planned admissions).

Table 1. Characteristics of participants with cognitive disability

Variable	People with intellectual disability (<i>n</i> =50)	People with TBI (<i>n</i> =10)	All sample (<i>n</i> = 60)
Gender			
Male	35 (70%)	9 (90%)	44 (73.3%)
Female	15 (30%)	1 (10%)	16 (26.7%)
Age			
Range	18-74	25-84	18-84
Mean (SD)	42.9 (14.5)	50 (18.3)	44.1 (15.2)
Number of chronic health conditions			
	<i>n</i> =44	<i>n</i> =7	<i>n</i> =51
Range	1-5	1-4	1-5
Mean (SD)	2.3 (1.3)	2.4 (1)	2.3 (1.2)
Living situation			
With family	23 (46%)	4 (40%)	27 (45%)
Shared supported accommodation (SSA)	22 (44%)	2 (20%)	24 (40%)
Supported Living [#]	3 (6%)		3 (5%)
Independently	2 (4%)	2 (20%)	4 (6.7%)
Moves between family and SSA		1 (10%)	1 (1.7%)
Missing		1 (10%)	1 (1.7)
Total time in the study (days)			
Range	1-516	2-445	1-516
Mean (SD)	122.4 (152.1)	138.3 (145.2)	125.1 (149.9)
Median	46	108	51

= outside supports are provided to a person who lives alone or with a spouse/ partner with disability.

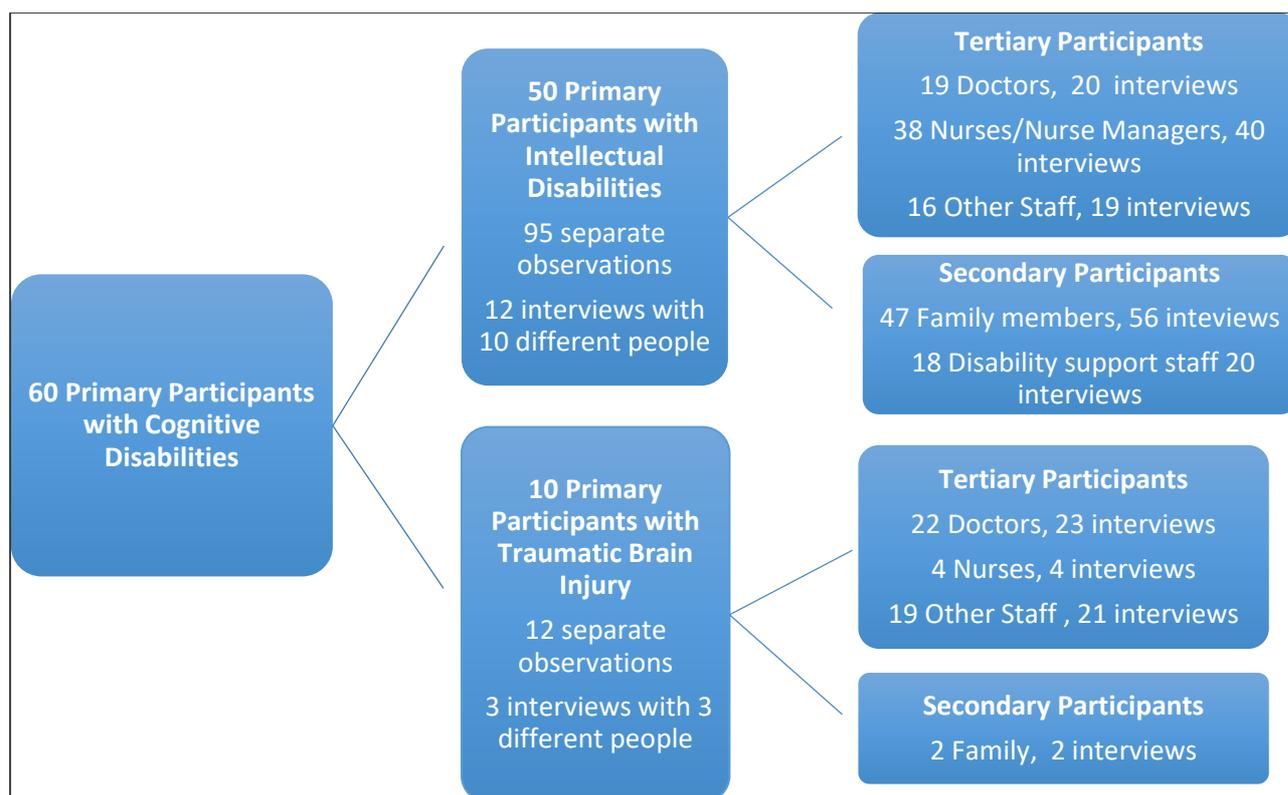


Figure 1. Study participants and types of data collected

Table 2. Interviews and observations across all encounters.

Variable	People with intellectual disability (n=50)	People with TBI (n=10)	Combined (n = 60)
Interviewees (Number of interviews)	148 (167)	14 (14)	162 (181)
Patient with cognitive disability	10 (12, 7%)	3 (3, 21.4%)	13 (15, 8.3%)
<u>Secondary participants</u>			
Parent/ other family	47 (56, 34%)	2 (2, 14.2%)	49 (58, 32%)
Paid support worker/ House supervisor	18 (20, 12%)	-	18 (20, 11%)
<u>Tertiary participants</u>			
Medical practitioner	19 (20, 12%)	3 (3, 21.4%)	22 (23, 12.7%)
Nurse/ Nurse Manager	38 (40, 24%)	4 (4, 28.6%)	42 (44, 24.3%)
Hospital allied health & other hospital staff	16 (19, 11%)	2 (2, 14.2%)	18 (21, 11.6%)
Observations (frequency)	95	12	107
Range across participants	0-4	0-4	0-4

Findings - Quantitative

Hospital Encounters

In total, 186 hospital encounters (i.e., entry to the hospital to discharge or exit) were recorded across the participant group ($n=60$). Primary participants experienced from 1-16 hospital encounters across the total time of the study. Most encounters began with a presentation to the Emergency ($n=179$). Details about these encounters are provided in Tables 3 - 5.

Presentation to the Emergency Department

Summary data about presentations to Emergency are provided in Table 3. There were 150 encounters that began in Emergency for people with intellectual disability and 29 for people with TBI. For most encounters (61%), participants arrived by ambulance; for 33% of encounters, it was by private car. People with TBI (76%) were most likely to arrive by ambulance.

Data about who accompanied the person in the first instance to hospital was often missing (40%), for 31% of all encounters, it was recorded that it was a family member and for 24%, a paid carer, while for 4% it was recorded that no-one accompanied the person.

On entry to Emergency, patients are assigned one of five triage codes: 1. Resuscitation, requires immediate attention (within seconds); 2. Emergency, requires attention within 10 minutes; 3. Urgent, requires attention within 30 minutes; 4. Semi-urgent, requires attention within 60 minutes; and 5. Non-urgent, requires attention within 120 minutes. Across the 179 encounters that begun in Emergency, 84% were coded as urgent or semi-urgent (Table 3).

Most of the encounters ($n=119$, 66%) were second or subsequent presentations to Emergency that occurred during the period of the study. Very few occurred within 72 hours of discharge from the previous encounter ($n=12$), the international indicator of an Emergency discharge failure (Agency for Healthcare Research and Quality, 2014). Time between re-presentations to hospital ranged from less than a day to 364 days (mean=50 days; median=18 days, see Table 3).

Table 3. Presentation to Emergency.

Variable	People with intellectual disability (n =150)	People with TBI (n =29)	All Sample (n =179)
Transport			
Ambulance	88 (58.7%)	22 (75.9%)	110 (61.4%)
Private car	54 (36%)	5 (17.2%)	59 (33%)
Unknown/missing data	8 (5.3%)	2 (6.9%)	10 (5.6%)
Escorting person			
Family	44 (29.3%)	11 (37.9%)	55 (30.7%)
Paid carer	43 (28.7%)	-	43 (24%)
Other	2 (1.3%)	1 (3.4%)	3 (1.7%)
None	5 (3.3%)	2 (6.9%)	7 (3.9%)
Unknown/missing data	56 (37.3%)	15 (51.7%)	71 (39.7%)
Triage Code			
1 Immediate attention	3 (2%)	1 (3.4%)	4 (2.2%)
2 Within 10 min	17 (11.3%)	4 (13.8%)	21 (12.3%)
3 Within 30 min	73 (48.7%)	19 (65.5%)	92 (51.4%)
4 Within 60 min	54 (36%)	4 (13.8%)	58 (32.4%)
5 Within 120 min	1 (0.7%)	1 (3.4%)	2 (1.1%)
Not recorded	2 (1.3%)	-	2 (1.1%)
Second or subsequent presentations to Emergency			
Frequency	100 (66.7%)	19 (65.5%)	119 (66.5%)
Time between discharge and re-presentations (days)			
Range	0-364	1-339	0-364
Mean (SD)	46.94 (64.32)	63.63 (84.98)	49.61 (67.9)
Median	18 <i>n=24</i>	17 <i>n=2</i>	18 <i>n=26</i>

Variable	People with intellectual disability (n =150)	People with TBI (n =29)	All Sample (n =179)
<i>Within 3 days (72hrs) of discharge from previous presentation*</i>			
Range	0-2	1-2	0-2
Mean (SD)	1.08 (0.78)	1.5 (0.71)	1.12 (0.77)
Median	1	1.5	1

* measured in days according to dates

Time in parts of the hospital

Table 4 provides summary data for the time spent in various parts of the hospital for encounters that began in Emergency. Time in days for the whole encounter (entry to Emergency to discharge from the hospital system) ranged from 1 to 137 (mean = 5.6; median =2). Time in Emergency (hours) ranged from less than an hour to 30 hours, with the mean of 6.5 (median = 5), exceeding the benchmark of 4 hours (AIHW, 2016). Time in Emergency was less than 4 hours for 68 or 38% of encounters.

Table 4 also provides data on time (hours) spent in a Short Stay Unit (SSU). These units are used to provide intensive observation and treatment, reduce inappropriate hospital admissions, and improve patient flow through provision of timely assessments and treatments; guidelines indicate that time in a SSU should not exceed 24 hours (Department of Health & Human Services, 2017). Inspection of Table 4 shows that for 35 encounters in which patients moved from Emergency to a SSU (see also Table 5 for destinations from Emergency), time spent in the SSU ranged from a half hour to 60 hours, with a mean of 12 (median = 8). It should be noted that the time in a SSU exceeded 24 hours for only three encounters. For 84 encounters, patients were admitted to a ward (Table 5), spending from less than a day to 136 days (4.5 months) in one or more wards. The most time in a ward was spent by one patient with intellectual disability, who moved across hospitals and ward types in the one hospital system. This participant recovered quickly from the original health problem (stroke symptoms) that brought her to hospital. The reasons for her extended stay were

complex, illustrating some of the issues that arise at the interface between hospital, family and disability, which are discussed in a later section of the report.

Table 4. Time in various parts of the hospital for encounters beginning in Emergency.

Variable	People with intellectual disability (n =150)	People with traumatic brain injury (n = 29)	All Sample (n = 179)
Across whole encounter (days)			
Range	1-137	1-100	1-137
Mean (SD)	5.51 (12.81)	6.66 (18.45)	5.69 (13.82)
Median	2	2	2
Emergency (hours)			
Range	1.02-29.97	0.42-20.58	0.42 – 29.97
Mean (SD)	6.50 (4.75)	6.68 (4.95)	6.53 (4.77)
Median	5.02	6.1	5.05
Short Stay Unit (hours)			
	n=31	n=4	n=35
Range	0.5-60.1	6.87-51.75	0.5-60.1
Mean (SD)	11.16 (12.91)	20.31 (21.11)	12.21 (13.97)
Median	7.42	11.32	8.0
Individual Wards (hours)			
	n=74	n=10	n=84
Range	3.72-3255.58	4.62-2356.53	3.72-3255.58
Mean (SD)	202.08 (414.72)	344.79 (722.84)	219.06 (458.35)
Median	82.92	54.72	82.52
Ward (days)			
Range	0.15-135.65	0.19-98.12	0.15-135.65
Mean (SD)	8.42 (17.28)	14.37 (30.12)	9.13 (19.1)
Median	3.54	2.28	3.44

Diagnostic categories

The types of diagnostic test or processes (e.g., blood tests, imaging) varied from 0 to 7 across the total group, with mean of 2.6 (median = 2), as shown in Table 5. For most encounters (76%), a clear diagnosis was evident from the medical audit, for 4.5% a queried diagnosis was provided, and for 20%, a diagnosis was not evident (Table 5). For those diagnoses that

were evident ($n=134$ encounters), a code was provided according to the AIHW Australian refined diagnosis-related groups (AR-DRG, see <https://www.aihw.gov.au/reports/hospitals/ar-drg-data-cubes/contents/data-cubes#>). The results are presented in Table 5 and Figure 2.

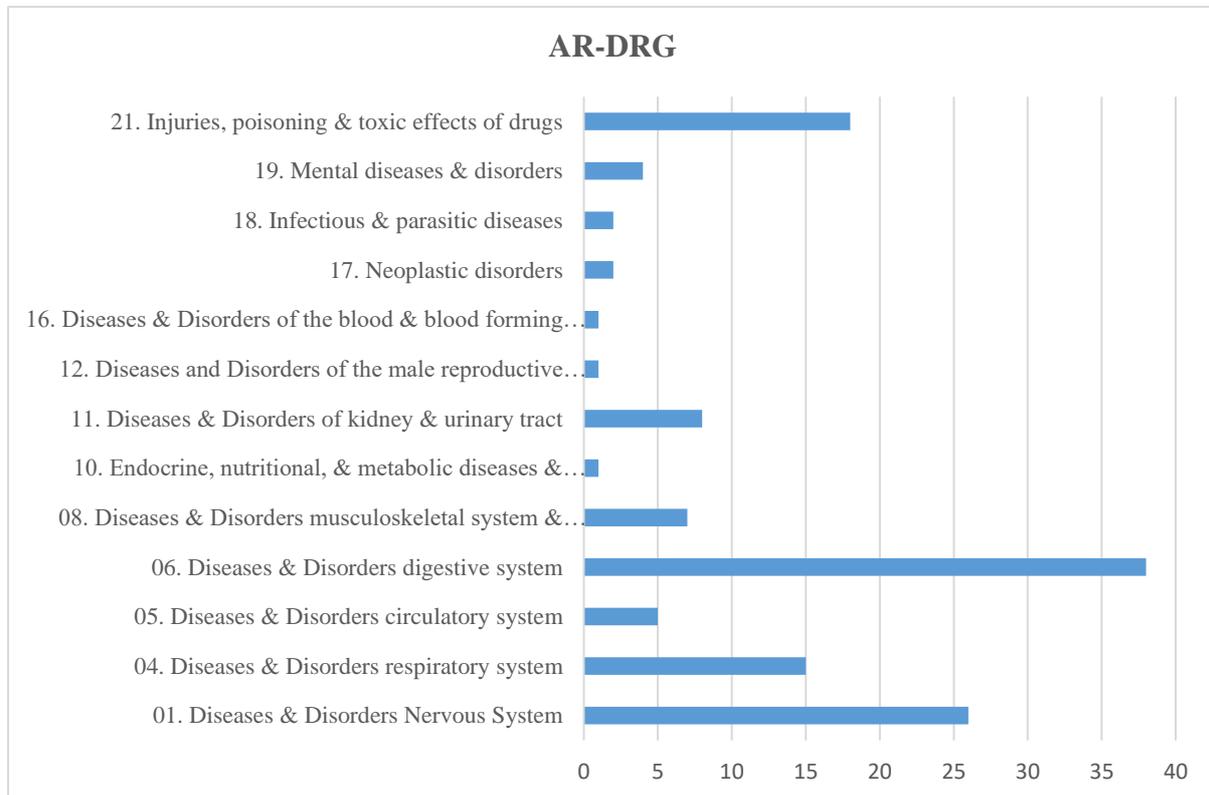


Figure 2. AR-DRG for encounters with a diagnosis ($n = 134$)

As is evident from Figure 2, the most frequent diagnoses were for diseases and disorders of the digestive system (often constipation), injuries (note, poisoning and toxic effects of drugs were not represented in the data), diseases and disorders of the nervous system (most often seizures in patients with a history of epilepsy), and diseases and disorders of the respiratory system (most often pneumonia, often with aspiration).

Table 5. Diagnostic evaluations and outcomes for encounters beginning in Emergency.

Variable	People with intellectual disability (n=150)	People with TBI (n = 29)	All Sample (n = 179)
Total types of diagnostic test types			
Range	0-7	0-6	0-7
Mean (SD)	2.51 (1.51)	2.9 (2.08)	2.62 (1.62)
Median	2	3	2
Diagnosis			
Provided	113 (75.3%)	21 (81.3%)	134 (75.7%)
Queried	7 (4.7%)	1	8 (4.5%)
Not evident/ missing	30 (20%)	7 (18.8%)	37 (19.8%)
DRG Group Level Codes[^]			
	<i>n</i> =113	<i>n</i> =21	<i>n</i> =134
01. Diseases & Disorders Nervous System	18 (15.9%)	8 (38.1%)	26 (19.4%)
04. Diseases & Disorders respiratory system	13 (11.5%)	2 (9.5%)	15 (11.2%)
05. Diseases & Disorders circulatory system	5 (4.4%)		5 (3.7%)
06. Diseases & Disorders digestive system	34 (30.1%)	4 (19%)	38 (28.4%)
08. Diseases & Disorders musculoskeletal system & connective tissue	7 (6.2%)	-	7 (5.2%)
10. Endocrine, nutritional, & metabolic diseases & disorders	1 (0.9%)	-	1 (0.7%)
11. Diseases & Disorders of kidney & urinary tract	8 (7.1%)	-	8 (6%)
12. Diseases and Disorders of the male reproductive system	1 (0.9%)	-	1 (0.7%)
16. Diseases & Disorders of the blood & blood forming organs and immunological disorders	-	1 (4.8%)	1 (0.7%)
17. Neoplastic disorders	2 (1.8%)	-	2 (1.5%)
18. Infectious & parasitic diseases	2 (1.8%)	-	2 (1.5%)
19. Mental diseases & disorders	1 (0.9%)	3 (14.3)	4 (2.2%)
21. Injuries, poisoning & toxic effects of drugs	16 (14.2%)	2 (9.5%)	18 (13.4%)
Missing	5 (4.4%)	1 (4.8%)	6 (4.5%)

[^] denominator is the n for encounters for which a diagnosis was evident.

Post-Emergency Department and Short Stay Unit

Thirty-one percent of presentations to Emergency resulted in direct discharge home, with 20% going directly to a SSU, and 43% to a ward, most frequently a general medical ward (see Table 6). Destinations from the SSU ($n=32$ encounters) were mostly home (81%), with 19% resulting in a ward admission.

A plan for what should occur post-discharge was evident in the medical audit for most encounters, but it was often difficult to determine how many of these were provided as a formal discharge plan. For 55%, the recommended follow-up was to see a General Practitioner and/or specialist, or visit an outpatient clinic (Table 6).

Table 6. Post Emergency Department and Short Stay Unit destinations and follow-up for encounters beginning in Emergency.

Variable	People with intellectual disability (n =150)	People with TBI (n = 29)	All Sample (n = 179)
Discharge			
Plan for what should occur in medical audit	143 (95.3%)	24 (82.8%)	167 (93.3%)
Destination			
Self Discharge ^a	1 (0.7%)	8 (27.6%)	9 (5%)
Home	50 (31.6%)	5 (17.2%)	55 (30.7%)
Short Stay Unit (SSU)	31 (18.9%)	4 (13.8%)	35 (19.6%)
Ward	66 (46.3%)	11 (37.9%)	77 (43%)
Transfer to another hospital system	2 (2.1%)	1 (3.4%)	3 (1.7%)
Destination post-SSU	<i>n</i> =31	<i>n</i> =1	<i>n</i> =32
Home	25 (80.6%)	1 (100%)	26 (81.2%)
Ward	6 (19.4%)		6 (18.8%)
Ward Types*	<i>n</i> =72	<i>n</i> =11	<i>n</i> = 83
General Med	33 (45.8%)	3 (27.3%)	36 (43.4%)
Neurology	7 (9.7%)	2 (18.2%)	9 (10.8%)
Orthopaedic	3 (4.2%)	1 (9.1%)	4 (4.8%)
Surgical	14 (19.4%)	1 (9.1%)	15 (18.1%)
ICU	5 (6.9%)		5 (6%)
Plastics	1 (1.4%)	1 (9.1%)	2 (2.4%)
Acute Medical	6 (8.3%)	2 (18.2%)	8 (9.6%)
Cardiology		1 (9.1%)	1 (1.2)
Other	3 (4.2%)		3 (3.6%)
Recommended Continued Care across all encounters[^]			
Hospital in the Home	5 (3.3%)		5 (2.8%)
Rural District Nursing Service	4 (2.7%)		4 (2.2%)
Other	15 (10%)	4 (13.8%)	19 (10.6%)
None indicated	119 (79.3%)	20 (69%)	139 (77.6%)

Variable	People with intellectual disability (n =150)	People with TBI (n = 29)	All Sample (n = 179)
Missing	7 (4.7%)	5 (17.2%)	12 (6.7%)
Recommended Hospital Follow-up across all encounters^a			
GP	32 (21.3%)	5 (17.2%)	37 (20.7%)
Outpatient Clinic	31 (20.7%)	4 (13.8%)	35 (19.6%)
GP & OP	16 (10.7%)	1 (3.4%)	17 (9.5%)
GP & Specialist	2 (1.3%)	1 (3.4%)	3 (1.7%)
Specialist	5 (3.3%)	1 (3.4%)	6 (3.4%)
Other	25 (16.7%)	7 (24.1%)	32 (17.9%)
None indicated	32 (21.3%)	4 (13.8%)	36 (20.1%)
Missing	7 (4.7%)	6 (20.7%)	13 (7.3%)

a = destination unknown, * Ward type n may be higher for those being transferred to the Ward from SSU; denominator is the n of those who were admitted to the ward either from Emergency or SSU ^ recommended continue care and/or hospital follow-up may have been suggested either at the time of discharge from Emergency, SSU or the ward dependent on the hospital pathway that the participant encountered

Comparative Trends from the Quantitative Data

Comparisons to national data, reported mostly by the Australian Institute of Health and Welfare (2016), provide some insights into areas of difference, or those warranting further exploration. The high rate of male presentations (73% of participants) contrasts with the national average of 51% (AIHW, 2016). Further, the arrival by ambulance rates found in this study (61%, overall), particularly for participants with TBI (76%), are much higher than the average of 24% for 2015-16 national data (AIHW, 2016). On the other hand, triage codes of urgent and semi-urgent (84%) found for participants with cognitive disability reflect the national combined proportion of 79% (AIHW, 2016). In terms of quality performance indicators (AIHW, 2016), relatively few encounters of participants with cognitive disability (38%) met the benchmark of a stay in Emergency of less than 4 hours in comparison with the national data of 73% (AIHW, 2016). Further, the median stay of 6 hours for people with TBI was a little longer than the median of 5 hours for people with intellectual disability, but the difference in sample size warrants caution in interpreting this difference. For those

encounters that included time in a SSU, almost all were within the 24 hour benchmark (Department of Human Services, 2017), and most resulted in a discharge home. It would seem from these results that the SSU provided an effective strategy for reducing admissions and providing an environment outside of Emergency to complete diagnostic and care processes.

Despite the trends in the data that suggest some differences, we found no evidence in the quantitative data of poor quality hospital care for people with cognitive disability. In fact, the longer times spent in Emergency, for example, may reflect the willingness of hospital staff to take extra time that could be needed to ensure adequate diagnostic and care processes – certainly, the data for the different types of diagnostic tests conducted suggests this to be the case.

In terms of the diagnoses received by patients with cognitive disability, a Norwegian study provides an indication of the most frequent diagnoses of patients with intellectual disability presenting to hospitals on a yearly basis from 2008-2011 (Skorpen et al., 2016). In this study, data were linked across hospital records and a national disability register. The pattern of AR-DRG found in the current results (Figure 1) reflects the Norwegian data in that they were mostly captured in the 10 most frequent diagnostic groups reported by Skorpen et al., (2016). In particular, in both studies, the highest rates were reported for problems with the digestive system, injuries, and disorders and diseases of the respiratory and nervous systems. A report from the UK indicates that people with intellectual disability frequently present to hospitals for Ambulatory Care Sensitive Conditions (ACSC): that is, those that could be prevented or treated through good primary health care (Glover & Evison, 2013). Diagnoses, such as seizures/epilepsy, constipation, and pneumonia, would be considered ACSC, and their high frequency may reflect poor utilisation of primary health care services (Iacono & Sutherland, 2006). Unfortunately, little is known about health care utilisation or health conditions for people with TBI. The fact that there were recommendations for what should occur post-discharge for most encounters, with a General Practitioner referral often made, suggests an attempt to connect with the primary care system. However, the extent to which these recommendations were effected or resulted in appropriate care, could not be determined from these data.

Findings - Qualitative Data

Our aim was to track the hospital journeys of people with cognitive disabilities to better understand their experiences and expectations, as well as those of the people who

accompanied them on the journey and hospital staff with whom they interacted. In particular, to identify aspects of the journey that worked well for people with cognitive disabilities, the difficulties they encountered, and the types of specific accommodations made, when and where they occurred and who enacted them. The data provide rich descriptions of patient and accompanying peoples' experiences and staff actions, and some explanatory insights into why accommodations were made or difficulties encountered.

In summary, hospital encounters were complex multifaceted journeys that involved multiple people at each stage: the patient; people accompanying them, who were family or paid staff from disability support services; and hospital staff who were in administrative, medical, nursing or ancillary roles. Throughout the journeys documented in our data, many opportunities for tensions or difficulties arose, some of which stemmed from differing perspectives, expectations and misunderstandings between those involved. Staff from the two key formal systems (hospital and disability support services) and an informal system (families) were often involved in collaboration and negotiation, as they navigated the interface between systems. The nature of cognitive disabilities is such that there is a continuing need for adjustments to accommodate a person's need for support with decision making, understanding and communication. The patient themselves and each person involved with them during the journey brought their own perspective based on past experiences, current personal situation and context, professional training and organisational expectations. Thus, many factors shaped hospital experiences and have to be considered in thinking about how to bring about change.

The Hospital Journey

The 60 participants with cognitive disabilities in this study were diverse. They came to hospital from a range of social contexts for a variety of health reasons, had a wide range of requirements for support with daily living, and were diversely supported throughout their hospital journey by disability support workers and family members. In most cases, they proceeded through at least three of the five stages that made up a hospital journey – deciding to go to Emergency – arriving and being in Emergency – leaving Emergency – being on a ward – being discharged from hospital. Figure 3 portrays each stage of the journey and the main experiences or actions of a patient.

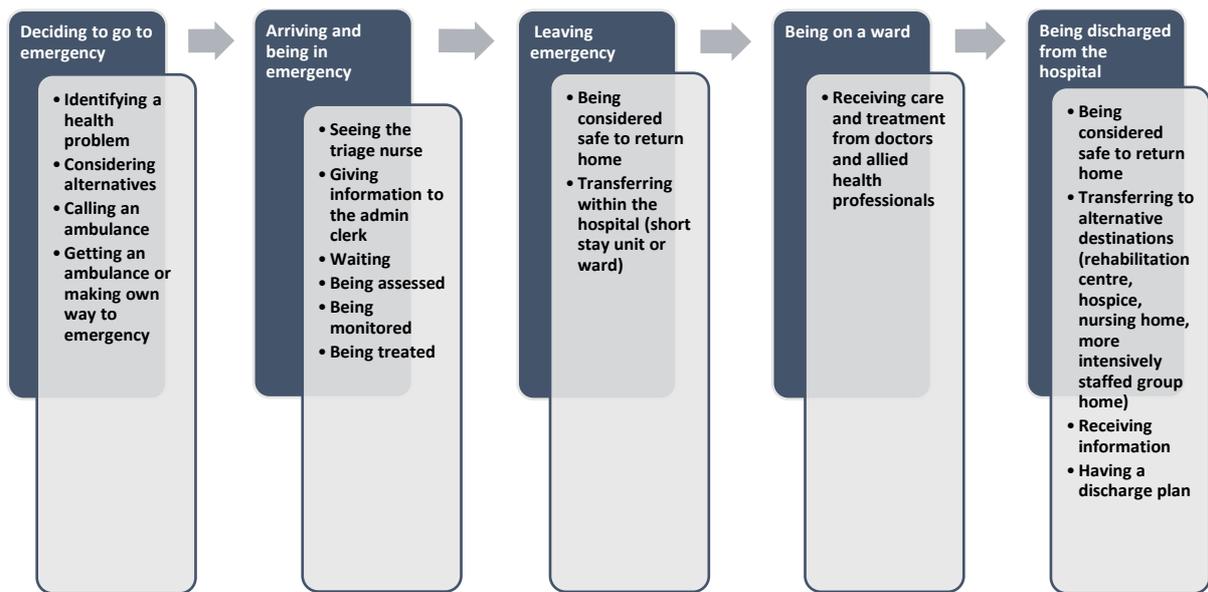


Figure 3. Stages of the hospital journey

Each stage of the journey had its own logic, characterised by the central concerns and actions of hospital staff and those accompanying the person with cognitive disability. The entire hospital journey for each patient was unique, consisting of different combinations of stages, sites, people, and actions, which taken together created their hospital experience. Patients came into contact with multiple nurses and doctors; it was unlikely that any one of these would be present for the entire journey or familiar with the entirety of the patient's experiences.

Example hospital journeys

These brief descriptions of the hospital journeys of three participants, Edward (PG53), Darren (PG57) and Daniel (PG33) help to illustrate the diversity and some of the promising practices and other issues we identified. Note all data has been de-identified and all names used are pseudonyms.

Example Hospital Journey 1. Edward

Edward, a man aged 50 years, lived in a disability supported accommodation service managed by the Department of Health and Human Services. He was described as “a happy go lucky man” by Amelia, one of the support workers from his home. He has Down syndrome, intellectual disability and limited verbal communication skills. He has three sisters, two of whom live in Melbourne, and a brother.

Edward had three hospital encounters over a two-month period, each of which lasted less than 24 hours. During two of the encounters he spent time in a Short Stay Unit, but was not admitted to a ward. Each time, he was accompanied by a disability support worker from the accommodation service, arriving twice in an ambulance and once by car. The service has a protocol requiring support workers bring a pre-completed hospital administration form with the person’s details, a summary of their medical history and any other relevant medical forms.

Edward arrived for his first encounter in Emergency at 21:33. Abdominal pain was noted as the presenting problem. He was given Triage Code 4 (semi-urgent, to be seen within 60 min), but was seen immediately by a nurse who took blood for tests and inserted an intravenous drip. At 23:04, he saw a doctor, who ordered X-rays and later made a diagnosis of urinary retention. Initially, without physically moving from one cubicle to another, he was transferred to Short Stay. At some point during the night, an indwelling catheter was inserted and he did move to another cubicle. In the morning, he was seen by the care coordinator who had checked with the accommodation service supervisor to ensure the staff there could manage to support Edward with the catheter. He was then seen by a doctor at 11:10 and discharged at 11:30. The discharge plan was to provide some immediate education to the support worker, when they arrived to pick him up, about catheter care, organise some follow up education for staff through the hospital community outreach service, and arrange a follow-up visit to the hospital in 2-3 weeks for removal of the catheter, and, depending, on the outcome a follow up referral to Urology.

Less than 24 hours later, at 09:42 the following day, Edward arrived again at Emergency, this time coming by car with a different support worker. He had pulled the catheter out during the night and was in pain. The presenting problem was noted as urinary retention. He was given Triage Code 3 (urgent, to be seen within 30 min), but was seen within 10 min by a doctor and care coordinator. His primary nurse recognised him from the previous day. The doctor rang the accommodation service to talk directly to the support worker who had been on duty when Edward had pulled out the catheter, conducted various tests and prescribed antibiotics and some pain relief. Edward was discharged at 12:47, with a plan to await an appointment with Urology, and instructions that if he returned with abdominal pain, a catheter should be inserted, followed by admission.

Just over a month and a half later, at 09:23, Edward arrived at Emergency for the third encounter, with the presenting problem noted as “other”. He was given Triage Code 4 (semi-urgent), but seen by a doctor within a minute of arrival. Sometime later he went to the Short Stay Unit, where diagnoses of urinary retention, constipation and gout in the right wrist were made. He was treated with an enema and laxatives, his right arm put in a splint and anti-inflammatory medication prescribed. He was discharged at 21:49 with a plan for an appointment with Urology and to attend his GP about his wrist.

Amelia the disability support worker who accompanied Edward during his second encounter felt she had been well prepared, and reported that she had known Edward for about 12 months, had been briefed by her supervisor and been able to refer to the hospital admission form she had brought from the house to help answer all the questions asked of Edward. She felt the “whole process was really good”, the nurses had been “lovely” and the doctor

very helpful even to the extent of helping her support Edward to give a urine sample. She had held Edward's hand during much of the time. She reflected that perhaps he should have been kept longer in the hospital on the earlier visit to see how he coped with the catheter.

The nurse who had seen Edward during the second encounter said she had not had much experience with patients with intellectual disabilities, but she had known to speak lower, calmer with shorter sentences and use simpler English. She talked about the value of a 'carer' being there with Edward, who had been able not only to answer questions about what had happened in the lead up to coming to hospital, but also about medication and his medical history. She said it had saved hours and avoided the need to call lots of people. The encounter with Edward had been very straightforward from her perspective.

Apollo, the doctor who had treated Edward on the second encounter, had found having the 'carer' there very helpful for communication and that the folder of information about Edward's medical history was very useful. He noted that the carer had a good relationship with Edward, stating that "she had helped a lot because the patient was out of his usual comfort zone".

Edward's sister, Agata, was not directly involved during any of the hospital encounters, but had been advised about them by staff at his accommodation service when Edward was discharged after the second encounter. She was knowledgeable about nursing work and procedures in Emergency, and talked about an episode about two years ago when Edward had been admitted with a mass in his bladder. At that time, she had persuaded the hospital to keep him as an inpatient rather than discharge him home with a catheter as she had felt he would not cope and simply pull it out. In her view, Edward was unable to communicate his medical history to the hospital staff, and staff at the house where he lived might not have known about this history as he had not been living there for long. She felt she should have been contacted by staff from the house or hospital as she was the person who knew Edward's long term history. She was puzzled about who gave consent for the catheter and its suitability for Edward, who would not understand why it was there.

Example Hospital Journey 2. Darren

Darren, a man aged 46 years lived with his wife and two daughters. He experienced a traumatic brain injury at least 5 years ago and had attended a rehabilitation program for approximately 9 months. His hospital encounter in this study lasted for approximately 4 hours. He was driven to Emergency by a work colleague, following a fall from a ladder onto metal scaffold and had pain on the left side of his body and difficulty moving. He was given Triage Code 2 (emergency, requires attention within 10 min) and taken directly into a cubicle when he arrived. The nurse who first treated him noted that as a result of the trauma he had experienced, he should have been taken to a resuscitation cubicle, but none had been available. He was seen by an Emergency doctor on arrival and shortly after a nurse who set up IV fluids, commenced blood collection for tests and used a collar to immobilise him until the nature of his injuries were clear. He had a CT scan of his chest, brain, abdomen and spine and was seen again by a doctor 2 hours later. The collar was removed around that time, and his walking was assessed by a physiotherapist. His work colleague left when his wife arrived about an hour before he was discharged. The doctor suggested that he stay in the hospital overnight so that any damage to his hip could be assessed, but Darren did not want to stay and agreed to sign the form required by the hospital to discharge himself. After about 30 minutes delay from when this was decided, as a result of poor communication between the doctor and nurse, Darren was discharged.

Example Hospital Journey 3. Daniel

Daniel, a man aged 55 years, lived with his wife and worked in a supported employment nursery. Both he and his wife have intellectual disabilities and were supported by their respective siblings. Daniel was being treated for pancreatitis and had epilepsy and high levels of cholesterol. He came to Emergency by ambulance, having fainted in the waiting room of his GP's surgery. He arrived at Emergency at 10:38, was admitted to a general surgical ward at 14:18, and was discharged home 2 days later at 13:30. His presenting problem was noted as collapse/unconscious and he was given Triage Code 3 (urgent). He was initially accompanied to Emergency by his sister-in-law, who had taken him to the GP surgery. His brother met him in Emergency and his sister also came for several hours on that day. A range of diagnostic tests were conducted including blood tests, X-rays and a brain scan, and he was given antibiotics in Emergency. On the ward, he was given intravenous fluids for rehydration and telemetry monitoring was undertaken. He was diagnosed as having had a septic episode and discharged in the afternoon of the second day on the ward, with a recommendation that follow-up action about medication be taken by his GP. He was also advised to return to his GP or Emergency if he experienced shortness of breath again.

Daniel's brother and sister both felt that their role was to provide support to Daniel, ensuring that he understood what was happening, and that the staff were aware of his difficulties with understanding what might be said to him. His brother also suggested it was important for Daniel to have a familiar face to provide reassurance. He was pleased with the way the staff talked to Daniel and praised the approach of one of the young doctors who explained well to Daniel what he was going to do.

Daniel's sister, a nurse, saw him three times during his hospital stay, but had taken a less active role than her brother and had tried to stay out of the clinical decisions. She had taken Daniel home when he was discharged and was disappointed that all the medication he brought into the hospital was not given back to him, which caused him some anxiety upon realising he did not have it when the next dose was due.

The doctor who saw Daniel twice in Emergency, but had not seen him after that, said that he had realised that Daniel had an intellectual disability. He had continued to ask Daniel questions but adjusted his language so that it was simpler, used fewer open questions, and relied on additional information provided by his brother. He said that it had been useful having the brother there as a cross check of information. From his perspective, he thought things had gone well and he had done little differently to that for other patients.

Daniel had been stressed in Emergency, and was pleased to be taken onto the ward where it was less busy. He said he had found some of the words used by medical staff difficult to understand, and struggled to read the menu and meal order form, and had to ask the staff member to read it to him. He said the doctor had talked to him about being discharged and told him to take things easy for about two weeks.

Stage 1. Deciding to go to Emergency

This stage involved the person, usually with their family or support staff identifying a health problem, considering alternatives to going to Emergency, calling an ambulance and getting to Emergency either by ambulance or by making their own way there.

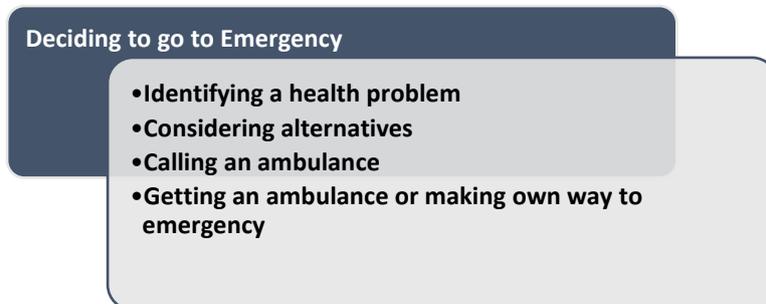


Figure 4. Deciding to go Emergency

Identifying a health problem and considering alternatives

Some people with cognitive disabilities recognised that they were ill, injured, or in pain, and told support staff or family members, or asked their opinion before attending a hospital Emergency Department. Others with high and complex support needs relied wholly on disability support staff to recognise changes in their behaviour or symptoms. The often long-term relationships and regular contact disability support staff had with the people they supported meant many were well placed to recognise changes in individuals unable to effectively communicate. For example, disability support workers June and Beryl had known the person they supported to go to hospital for many years,

We're quite close because I've known Mark for 24 years... he was one of the first clients I met and I worked for a significant amount of time permanently at the house where he resides. And now I work in another house, but I do see him casually, I work around there casually. But the house where he lives is close to the house where I work mostly, so he drops in here to say hello to me a lot, and I see him every week a lot.

(PG10)

Cassandra is a lady, quite serious. She's not a party popper. She's quite a serious person and she wants to be taken serious and of course treated with respect, like we do for everybody, and she has quite a lot of health issues and you can tell it's – she's

mid 40s – you can tell it's getting worse... She has not much family involved. Her mum died long ago. (PG40)

The decision to go to Emergency was not taken lightly and often seen as a last resort. People with cognitive disabilities, family members and support staff took various actions to avoid going to hospital, including consulting with family members, GPs or the telephone Nurse-On-Call service and acting on their advice. For example, Diana, the foster mother of Kathleen (PG9), a young woman with high and complex support needs, said “I try my hardest to keep her out of hospital”. She had tried an anti-vomiting treatment at home over several days to stop Kathleen’s vomiting. It was only when Diana thought that Kathleen had aspirated while vomiting that she decided it was necessary to go to hospital. This decision was based on knowing Kathleen well, the circumstances whereby she was at risk of aspiration and observing a worrying pattern in her condition even though she did not know for certain that this was the underlying problem,

So, I took her into hospital. Concerned because the medication didn't work. She was still vomiting...she'd vomited the week previous too and I managed it at home. So, I didn't know what was going on, but I definitely was aware that she seemed to have aspirated, and I thought well you know, the only way I'll know if there's a problem is to take her to hospital and have an X-ray, because she can't have an X-ray in a normal X-ray clinic because they don't have hoists...I figured she needed to stop vomiting or she was going to aspirate again, or become dehydrated very quickly. So that's what led us to go into hospital. I try my hardest to keep her out of hospital. (PG9)

Similarly, Beryl, the house manager of the supported accommodation service where Cassandra (PG40) lived, had tried using GP-prescribed anti-nausea medication in the first instance, to avoid going to hospital because of vomiting and dehydration. She said,

...we had some medication left from the first time – anti-nausea medication, we gave her that...but then over Easter we just couldn't stabilise her. She couldn't keep anything down and she was dehydrated and she sort of went downhill. She really didn't look well and she had other things as well, like she had a rash on her body and she had very white limbs, what looked alarming to us, and she was shivering...We thought, ‘there's something really, really wrong.’...Like the body was shutting down. That's what it looked like. So, we were really very worried and we were actually

happy for [hospital] to say, 'We have to admit her and need to find out and investigate a bit more'.

The disability support staff involved in deciding a person should go to hospital worked across various settings. Some were part of 24-hour supported accommodation services and others provided intermittent outreach or drop in support to people living more independently in the community. Drop in outreach workers may not always be available to support a person to decide to go to hospital and may only become aware of a person's health issue when they make a scheduled visit to the person. For example, when disability outreach worker Rhonda visited Jeff (PG64), a man with an intellectual disability, she discovered he was unwell and had already gone to Emergency by himself but been advised to return home. She sought advice from Nurse on Call and then checked with a senior staff member before making a final decision to go to the hospital. She said, "I rang the Nurse-On-Call, and they said call an ambulance. So, I thought nah, I'll just take him up. I rang my boss to confirm, grabbed a car, and just drove up"

Calling an ambulance or making their own way to hospital

Most people with cognitive disabilities came to Emergency by ambulance, having rung 000. A few had difficulties getting an ambulance to attend. Their experiences illustrate the importance of having someone available to help represent their situation to staff in the ambulance service and the types of knowledge and skills disability support workers or others acting as advocates might require when communicating the problem to the ambulance service. As his mother explained, Jeff, a man who shares a house with another person with intellectual disability, was refused an ambulance and had to make his own way to the hospital. She said,

On Sunday, he rang me in the morning, and told me that he was in terrible pain...we said to call the ambulance... He rang the ambulance, but he told me that the ambulance wouldn't come. So, he walked up to the hospital. (PG64)

The request to the 000 operator by Beryl, a supported accommodation house manager for an ambulance to take Cassandra (PG40), a woman with high and complex support needs was rejected by the operator and Beryl was passed onto the Nurse-On-Call Secondary Triage

Service of ambulance requests¹. She was asked to justify her request and to consider taking Cassandra to the hospital herself. This response suggested that the triage service staff did not understand the constraints that disability support staff in supported accommodation might face in taking one of the people they supported to hospital or the risks involved in car travel for someone with complex support needs. As Beryl explained,

...they wanted me to take her myself and I said, 'No, I'm not doing that because she's vomiting. If I have her in the bus in the back, I cannot do anything when she vomits.' He said, 'Well sit her upright.' I said, 'I can't, her chair doesn't do that.' He said, 'Well take another staff member'. I said, 'I don't have another staff member because I have five people here and I'm going and leaving my co-worker with five people here to go with Cassandra and where do I get another staff member?' 'Well family?' I said, 'No, I don't have anybody here.' ... you can take somebody yourself to Emergency, and we've done that in the past, but with Cassandra vomiting and getting nauseous every time I moved her, I said, 'I'm not prepared to do that. This is too dangerous. She will aspirate and get pneumonia'.

This had been Beryl's first experience of being screened when she dialed 000 for an ambulance and she was worried that her staff might confront this barrier in the future, pointing out the need for them to be aware of how the process now worked and how to deal with it. She said, "I would like to have more information about this as well to tell my staff, 'this is what might happen if you call 000', and I don't want my staff to take a risk-taking people to hospital".

These examples illustrate the importance of disability support workers taking an advocacy stance and being clear about the needs of the person with cognitive disability. They also suggest the importance of staff responding to 000 calls and the new ambulance triage services understanding the risks involved in transporting people with complex support needs in ordinary cars or organisational buses, and the situations in which staff in disability support services may find themselves.

Although going to hospital was perceived as a last resort by disability support staff, it was a relatively common occurrence in their work. Some house managers had made practical

¹ This outlined on Ambulance Victoria's website as involving paramedics in "000 calls classified as low medical priority, where the patient's condition indicates that an ambulance may not be necessary and an alternative service can be provided. This helps free up ambulances for life-threatening cases." <http://ambulance.vic.gov.au/paramedics/types-of-paramedics/>.

preparations to make the process a little smoother for the people they supported. Beryl, the house supervisor for PG40 said,

So, we made a list for every person here, what to take when they go to hospital. So, we don't forget the toothbrush and we don't forget maybe a deodorant and a nice perfume or we did nails, nail polish and things like that. Something you can do with Cassandra to give a bit of familiar feeling...her blanket and her little speaker with music so she could listen to her audio books and her music. I think that's important.

Figure 5 summarises the promising practices of disability support staff that were observed during this stage of deciding to go to Emergency. These reduced the chances of having to go to Emergency, helped to ensure access to the ambulance service when it was necessary and ensured the person took some personal possessions with them.

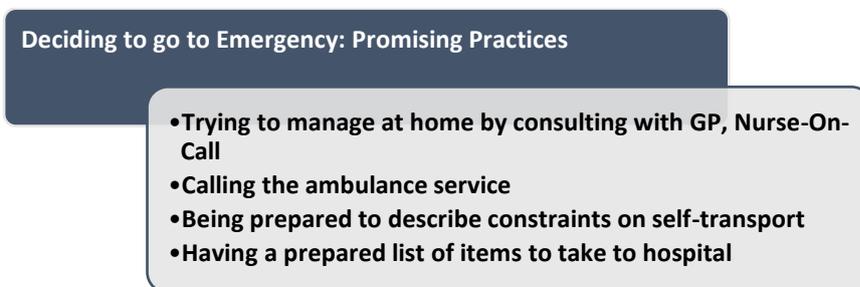


Figure 5. Promising practices observed in deciding to go to Emergency.

Stage 2. Arriving and being in Emergency

The second stage of the hospital journey was arriving and being in Emergency. As figure 6 shows, this stage had various sub-stages, although progress through them was not necessarily linear. For example, waiting and being monitored recurred throughout people's time in Emergency. In detailing these sub-stages, we have drawn out the expectations of those involved, the positive accommodations made by staff for the perceived needs of the patient with cognitive disability and some of the difficulties and frustrations experienced.

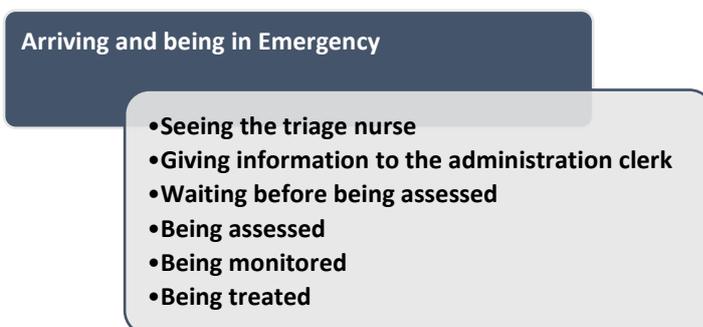


Figure 6. Arriving and being in Emergency.

The shift-based, segmented way Emergency departments are organised mean that patients are unlikely to have the same primary nurse or doctor throughout the time they are there. One of the main features of Emergency that flows from this organisation is the need for patients or those accompanying them to provide detailed information multiple times to different staff about who they are, and about the patient and reasons for being at the hospital.

Seeing the triage nurse

Once a patient arrived at Emergency the process of information gathering commences with a triage nurse who has to make judgments about the seriousness of a person's condition and how quickly the person should be seen. This was done by asking the person to explain what was wrong, and why they had come to the hospital. The accuracy depends on the triage nurse asking questions that are understandable to the person or those accompanying them, and, in turn, the person being able to provide the medically relevant information required.

Most participants did not mention the triage process, possibly because it occurred quickly at the beginning of their entry to the hospital and before any form of treatment had begun. For a few, however, triage was memorable and patients' negative experiences left them feeling they had not been taken seriously. For example, Oscar, the father of Adolfo, a young man with intellectual disability who had recently been discharged from intensive care, had taken him to hospital in the middle of the night concerned about the bandage on his legs. After waiting about 2 hours, Oscar left the hospital with his son because he felt Adolfo could not tolerate waiting any longer, and that his concerns had been dismissed by the triage nurse. He said:

There was only one person before us...and they went in and then we were there for 2 hours with nothing. I was getting quite optimistic about seeing a doctor. It was his legs, I was worried about his legs, and that they needed dressing and stuff. And there were two women at the desk and one of them said she was a something nurse, because when I couldn't see a doctor and I'm going, "Well, do you want to look at his legs, could you look at his legs, please?" And she's behind the desk saying, "Oh, no, no, no, I can't go around there and do that." ...So, we waited around and I said, "What's going to happen, is there a doctor?" She said, doctors have to prioritise, there's been some Emergency things. So, she said just go to your doctor, your GP, tomorrow.

(PG60)

Some disability support workers took a strong advocacy stance at this stage, and had provided important contextual information about the person's immediate symptoms. In their

view, this meant triage staff were more easily convinced of the necessity of the person with cognitive disability being seen quickly by a doctor. The difference between what happened when Jeff (PG64), a man with intellectual disability went to Emergency on his own and was sent home, and when he was accompanied by his outreach worker Rhonda, illustrates the significance of having an accompanying person who also knew the person with intellectual disability well. Rhonda, who described herself as being “demanding” said

I was a little bit more demanding than he would have been and gave a bit more explanation for them. And eventually got seen and they did an X-ray, discovered that he had kidney stones on the left as well and was in a lot of pain. [So, when you say you were more demanding, what does that mean?] Well, [Jeff] will get put off very quickly if someone isn't listening to him... He's got full speech, but he can't really explain a lot of things. And I guess I know being a mum what kind of things to get their attention, in a way, medically. [I explained] that he's got a very high pain tolerance and if he's in pain, then that's genuine. And that he had had kidney stones in the right, we can't be sure they're not on the left...He'd been vomiting and diarrhoea all night. He's epileptic. He can't be low on anything because he'll have seizures. And I'd explained that he'd been sent home, that I wasn't happy with it, just sort of a little bit pushy. I'm never rude, but I will be blunt if I need to be for them. And they were very good after that. We got put through - they were very busy, and they put us in the very critical or the high - where you go if you're having a heart attack, pretty much, that cubicle.

In contrast, another example of a positive experience during triage suggested that some staff are skilled in responding to people in difficult situations such that advocacy by accompanying people may not always be necessary to ensure appropriate attention. The sister of Winnie, a woman aged 40 years who had intellectual disability and was at an early stage of Alzheimer's Disease, described the sensitivity with which the triage staff responded to both her own and her sister's distress when they came to Emergency. She said,

...we took Winnie to the doctor because we could tell that she was in a little bit of discomfort because she was constipated but she was deteriorating so we thought that yeah, she was just getting too hard to handle...the doctor [GP] just basically gave us a print out of all of her medical history and said take her to ... Hospital, so that's what we did. So, I took her in and basically yeah, but she was there for about 5 weeks... [In triage] they were so good because we were... very emotional because basically we

love Winnie and we've looked after her for 4 years... We just couldn't do it anymore so we walked in and we were upset and Winnie was upset. I had to drag her from the car which was hard but there was a volunteer there and she was amazing. She was so good. And then the nurse was even better, the triage nurse, didn't even ask, just took the paperwork from me, told us we were doing a great job and took her straight through. They were so good. So that was a really good experience because they basically said we've looked after her so well, you're doing a good job, and she was a care coordinator, the triage lady nurse, so that was good.... Once Winnie got through to the room in the Emergency Department she was a lot more settled because they gave her a drink... it was just hard because we had sort of dragged her in and she got almost a bit violent, which she's never been violent in her whole life. (PG27)

The GP's advice in this situation and whether coming to Emergency was the most appropriate pathway into longer term residential care for Winnie raises questions about primary care that are outside the scope of this study.

Giving information to the administration clerk

A second part of the stage of arriving at and being in Emergency was entering the patient's personal details into the hospital administration system, which was done by an administration clerk rather than the triage nurse. Getting onto the system meant that the triage notes were linked to other basic patient information and any previous medical records through a patient number. This provision of patient details provided the opportunity to ensure that the hospital system had accurate information about the person with cognitive disability and the person's social context, which could be used by the health or other professionals involved with the person at some stage of the hospital journey. It was, however, an opportunity often missed: we found many discrepancies between what was recorded in the system and the reality of people's living situations. These discrepancies appeared to arise, primarily, because of the way in which systems were set up and information was categorised.

Recording accurate information

Living situations recorded by both triage nurses and administration clerks were often inaccurate. For example, categories in electronic records system in at least one of the three hospital networks did not distinguish between the quite different types of living situations that are not private homes. In the absence of categories for disability supported accommodation, such as group homes or supported living, category names, such as

Supported Residential Services (SRS), which are private services with limited personal support, *rooming houses* or *nursing homes* were used. Use of these terms to describe the living situation of a person who resided in disability supported accommodation failed to convey the level and type of support provided. For example, group homes provide 24-hour support and staff often have long term relationships with the people they support and are likely to know them well. These staff are unlikely to have medical or specific health knowledge or be able to provide nursing care. In supported living services, outreach or drop in staff provide regular support with domestic and other tasks, but may not have a mandate to be involved in other aspects of people's lives.

Mislabeling and consequent misunderstanding about the term used for a patient's living situation, as entered into the hospital records at the triage and administration stages, may have unintended consequences later in the hospital journey. Hospital staff with inaccurate information or a poor understanding about where a person lives, the nature of the support they receive in their daily lives, or their key support people are at risk of making assumptions about the type of medical support a person might have after discharge. Current categorisation in record systems is inaccurate but it is also clear that terminology about disability support and accommodation services is changing with the introduction of the NDIS. Hence, it will be important to revise categories or terms for use in hospital information systems so they capture clear and accurate information about the types of support and living situations of people with disabilities.

Identifying accompanying others

At some hospitals, at this stage stickers were available to identify accompanying people as family of patients. In a hospital system, in which every member of staff has a lanyard and label, this practice does allow for easy formal recognition of non-hospital staff and their role vis-a-vis a patient. There was no sticker, however, to recognise disability support workers, the result of which was to prioritise family members over other accompanying people, and potentially convey a message that all family members are similar and will be equally informed about the circumstances of a patient. While stickers may not be ideal, there appears to be no formal way that hospitals acknowledge the potential roles of disability support workers during the hospital journey of people with cognitive disabilities, which may complement or replicate those played by family members for other patients. The practice at this stage of the hospital journey was symbolic of the uncertainties about the roles of

disability support workers and their relationships to patients with cognitive disabilities evident throughout the journey.

Waiting before being assessed

Waiting rooms at each hospital varied in size, furniture and other content. Some were large and busy at most times of the day and night, had televisions and magazines, or charging banks for mobile phones. Some had block seating not suitable for people with physical disabilities and quiet spaces that appeared designated for children. While all Emergency Departments were wheelchair accessible, some were more difficult to approach on foot because of hills, stairs or unclear pathways.

These and other potential difficulties in the waiting room were mentioned by only a minority of participants, mostly people with traumatic brain injuries and their family members. They described finding the waiting room environment and/or the act of waiting itself stressful, particularly when it was for long periods, or they believed that they were being ignored by hospital staff. Several participants both prior to and during the study had given up at this stage and decided to go home rather than wait any longer.

Staff in Emergency were well attuned to the difficulties associated with waiting and the frustrations experienced by patients or accompanying people, and tried to make accommodations. For example, in the case of Curtis, by pushing him through more processes in Emergency quickly,

Joe is the grandfather of Curtis, a young man with intellectual disability, high and complex support needs, and a terminal illness. Joe felt that Curtis was being ignored in the waiting room. He became agitated and directed his frustration at triage staff after waiting for some hours in a busy Emergency Department. Emergency doctor Lindy recognised that Joe was 'pretty upset' when a triage nurse pointed him out. He was standing and pacing around, kept asking - so you know how nurses look after a few cubicles. So, he kept talking to the nurse saying, "Why isn't anyone picking him up? Why isn't anyone picking up my grandson? He's dying, he needs help." And, he was just very, very angry. A nurse (possibly a triage nurse) requested that Lindy use her discretion to see Curtis more quickly: "Look this patient, he's been waiting a while, could you just quickly pick them up?" (PG51)

Being assessed, monitored, and treated in Emergency

The next stage of the journey in Emergency was being allocated a room or cubicle, and a bed or a chair in an environment that was typically busy, brightly lit, and noisy, irrespective of the time of day or night. Assignment to a space in Emergency marked the transition from waiting to being regarded as a patient although still not formally admitted to the hospital. Neither was it the end of waiting. The steps to diagnosis and decisions about treatment or further follow up were often long and slow. They could be characterised as seeing the Emergency nurse, seeing the Emergency doctor, having the tests, waiting for the results, and being treated or referred for further investigation, observation or treatment. The nurses and doctors had clear expectations about their agendas or the things to be done at this stage, and were juggling these activities for multiple patients. For people with cognitive disabilities and those who accompanied them, these structured steps and practices often seemed opaque and haphazard and they were unclear about what was happening, often asking questions such as, why do I have to wait to see the doctor? How long will it take? When will I know what is happening next?

Patients were left alone intermittently, but each assigned an Emergency nurse, as their primary source of contact and who they saw at least hourly. Their nurse often changed during the period they were in Emergency as shifts ended and new nurses took over. Emergency nurses had three main tasks to do: make the patient feel comfortable by introducing themselves, build rapport and prepare them to be seen by the doctor; monitor the patient's condition by taking routine hourly observations of vital measures, such as pulse and blood pressure and other tests directed by the doctor and assessing subjective feelings of pain; and provide basic nursing care to keep the patient safe. Much of what happened to patients in Emergency was beyond the nurses' control, and they were often unable to determine or to tell patients what was wrong with them or how long they would have to wait to see a doctor. These things were unpredictable, depending on the urgency of their condition, the doctor's availability, and the busyness of the Emergency Department at the time.

Nurses accommodating specific needs

We found examples of nurses accommodating specific needs of patients with cognitive disabilities. Many did this as a matter of course by focusing on the patient and taking time to build rapport. Emergency nurses repeatedly described working with people with cognitive disabilities as basically the same as working with any patients, requiring a flexible approach. There were, however, many examples that could be interpreted as nurses adjusting their

approach to accommodate particular needs of patients with cognitive disabilities. For example, some nurses said they checked on people with cognitive disabilities more frequently, modified the way they spoke by using simpler terms, speaking more slowly, checking for understanding and making use of communication aids such as the FACES pain scale (a picture-based indicator of how the patient is feeling).

As the following examples illustrate, accommodations included not only giving additional attention to patients or changing communication, but also actions to reduce anxiety by finding quieter spaces or making medical procedures less burdensome,

Melody, an Emergency nurse described using de-escalation strategies to support Henry, a man with a traumatic brain injury and a recent (and unrelated) face wound who wished to self-discharge before being seen by a doctor. This nurse spent more time talking to and checking on Henry, who was unaccompanied, and gave him nicotine alternatives to cigarettes. Eventually, she also sought support from her Acting Nurse Unit Manager and security staff to support Henry to go outside and have a cigarette. This option involved bending the rules as hospital sites are smoke-free areas. Taking patients outside to smoke is problematic as hospital staff and security have no control once the patient is off-site, but the hospital staff collaborated with Henry as a last-ditch effort to keep him at the hospital and provide him with the medical care he urgently needed. (PG77)

Malcolm, a man with intellectual disability, was moved to another room in Emergency, away from a noisy patient, as soon as this was possible. The disability support worker said, “There was a guy there who was creating a few problems and so they [nurse] said well we’ll move him now that we’ve finished everything we’ll move him...and he’ll be in a quiet area then.” (PG50)

April, a young woman with an intellectual disability, limited spoken communication and obesity was very distressed when brought in to the Emergency Department by her parents. She was quickly transferred to the resuscitation area for immediate investigation of a leg wound. The treating team was informed of April's cognitive disability in advance. The nurse described modifying the administration of painkillers to lessen April's distress, drawing on her previous experience with vulnerable patients. She said, we also gave her some pain killers before we had a look at the wound. So, we gave Intranasal Fentanyl. It’s administered through her nasal passage and that

settled her quite well so we were able to manage that in case she did have pain, even though she didn't voice pain as such...It's a spray. It has an applicator and you spray it up the nasal passage and it's absorbed that way. It's quite useful in people with disabilities and pediatrics because it's not invasive, doesn't require needles and things like that. (PG17)

Nurses used various strategies to develop rapport with patients with cognitive disabilities, including acknowledging their personhood by making them their primary focus, while also drawing on accompanying people to help round out information or using familiar cultural references, such as the football, to help put the patient at ease. In one instance the nurse and doctor had continued explaining to the patient what they were doing despite the man being in a state of seizure. (PG28)

Acknowledging anxiety and providing appropriate types of diversion and reassurance were important adjustments. For example, the grandfather of Curtis described how the nurse taking a blood sample verbally and physically reassured him by holding his hand,

And you know, she held his hand and chatted to him, and she was doing the same as the other one - she was looking for veins. (PG51)

Nurses had access to the equipment necessary to lift patients with physical disabilities. For example, when June, a disability support worker, was asked about how prepared the Emergency staff were to treat Mark (PG10) a man with a cognitive disability who required mobility assistance, she said,

Very prepared, like they brought along a hoisting machine to lift him up. They didn't balk at any of the care that he needed, they were very well-prepared. But having said that, it's a brand-new hospital, so it would want to be.

Nurses collaborating with accompanying people

Although their primary focus was on patients, Emergency nurses described engaging and supporting accompanying family members. They provided emotional support by listening to their concerns and acknowledged their significance to the patient and their knowledge of them. This was illustrated by the comments of Viola an Emergency nurse and her interactions with the mother of Gary, a man with intellectual disability and high complex support needs and severe epilepsy. Viola, felt she had gained most of the information she needed to care for Gary from his mother, saying,

All the information I got about his condition and what he's normally like and what needs to be done for him was from Mum plus also a bit of a handover and reading what had been done on the previous shift. (PG63)

While Viola hadn't been certain of the nature of Gary's disability, she had recognised that his mother understood his vocalisations and actions. In addition to this, she said that Gary's mother had explained how best to deliver his medications (crushed through the PEG tube), and what was usual for him in terms of movement and periods with his eyes open and closed. Importantly, Viola's comments suggest the value of nurses talking directly with someone who knows a patient with cognitive disability well to find out about their condition, rather than simply reading handover notes. As Viola was one of several nurses who took responsibility for Gary while in Emergency, his mother would have been asked to explain his situation several times.

Nurses also accommodated the need for patients' home-based routines to be maintained and talked about Emergency as supporting the continuation of what is usually done at home. In practice, this meant that family members, or other accompanying people were not only supported to be present, but also to continue caring. Nurses enabled home based routines and care, such as giving medications, feeding through a PEG tube and taking care of personal hygiene, to be continued in Emergency by family members. For example,

Gary's mother who was his full time carer, stayed with him. Viola, the Emergency nurse saw her own role as providing basic nursing care, but also in supporting his mother to care for him. Viola was careful to 'assist', in her words, his mother, rather than replace her. She said, "I was looking after three patients in total and for this particular patient his mother was in the cubicle the whole time...So the main thing we were doing for him, obviously, observations, we were turning him, helped mum give him a wash, assisted her in giving him his PEG tube feeding...[I]t was basic nursing care and then assisting mum. She was pretty hands-on with him. I was trying to give her a bit of a break because she's the full time carer." (PG63)

There were many examples too, where nurses were able to establish an easy rapport with disability support workers, listen to their advice about supporting the patient with cognitive disability they knew and collaborate with them in providing care. As one support worker described,

I gave him his dinner, or helped support him to eat his dinner and then I could sense he was becoming a lot more relaxed, and they put him into a, what do you call that sort of semi-admission? Short stay unit, they put him into there, and once he became comfortable in there and he was having a joke with the nurses, and I could see he was relaxed, that was when I left. (PG10)

Nurses had little trouble understanding and accepting the role of family members. However, they often talked about being unclear about the role of disability support workers in Emergency, which was also the case for some disability support workers. Some support workers believed that they had a clear direction from their organisation to stay in hospital for the duration of the patient's Emergency stay, while others believed they were not allowed to assist the patient in Emergency or could only stay until the patient is settled.

Seeing the Emergency doctor

The primary role of Emergency doctors, who patients saw intermittently, was to investigate the problem and keep the patient medically safe. They did not necessarily know for some time what was wrong with or how to treat the patient. As one Emergency doctor, explained their priorities are different to that of GPs or other medical practitioners whose patients might attend for particular conditions,

We don't know the person...our focus is, well what might kill the person and what we might be able to fix. And then when there's nothing that's going to kill them or do them harm and there's nothing we can fix, then we sort of start looking at everything else and that could be hours down the track... Whereas if you see someone who knows you and whose focus is just then on dealing with the things that you are genuinely worried about... our agenda's not the same as the patient's often because our agenda is all about dealing with emergencies and often the patient actually has something else. (PG65)

Like nurses, doctors had their own agenda, which, in comparison with nurses, tended to fall more easily into a chronological series of things to be done. These included acquainting themselves with the patient's history through triage notes; introducing themselves to the patient and accompanying people; talking to the patient about what had brought them to Emergency and taking a history focused on the time-sensitive lead-up to their presentation at the hospital; performing a physical examination; ordering tests, where necessary; formulating a working hypothesis about what may be wrong; making a diagnosis of the most likely cause

and developing a treatment plan; and treating the patient or referring elsewhere for treatment. Doctors treated multiple patients and much of their work in formulating a diagnosis and treatment plan was done with colleagues, rather than through direct contact with the patient.

Emergency doctors accommodating needs

Doctors needed timely information about the patient and changes that had led up to their coming to Emergency. Although a longer term fuller medical history might be relevant, Emergency doctors had been more concerned with the shorter term and the days leading up to being in Emergency. They explicitly recognised the value of accompanying people in providing information the patient could not. They understood that a family member or disability support worker often knew the patient and his/her normal behavior and could explain what had changed or why they were concerned. However, doctors sometimes had found such information difficult to obtain if an accompanying person was stressed and worried. To get the information they needed doctors adjusted their interpersonal approach when talking with patients, and made judgements about who could provide the most consistent, credible information.

Many doctors said they were familiar with patients with cognitive disabilities, with some saying that they saw patients from this group on a weekly basis. Most had been comfortable interacting and adjusting their style to take account of their needs and those accompanying them. They described similar adjustments to those of the nurses: speaking directly to patients who they recognised as the central person, even though they may not understand everything being said; continuing to direct their attention to patients who they were aware could not understand or did not use words to communicate, while also encouraging those accompanying them to fill in gaps or round out answers; and talking to patients about any physical procedures, often using simple terms.

However, this practice of speaking directly to patients irrespective of their understanding was not always understood or appreciated by accompanying people. One mother, for example, said she did not like the way the Emergency doctor spoke directly to her daughter with cognitive disability rather than to her.

The time sensitive nature of the information doctors required meant that family members who did not live with a patient were not always in the best position to provide it, and disability support workers often made better informants. In the absence of a well-informed accompanying person, doctors described making phone calls to nursing homes and disability

supported accommodation services to find out more information about how the patient's condition had changed recently. One doctor explained the difficulties she experienced in assessing a woman with intellectual disability and cerebral palsy who had come to Emergency by ambulance with no accompanying person,

The referral wasn't very clear about why she was here but I was told to go and assess the patient. She wasn't verbally communicative or [did not have] any form of communication as far as I could tell. There wasn't a carer or anyone with her or anyone around to help me out, so it was pretty difficult at first.... I went back and I had to go through the notes, go through the paramedic notes and find out who to contact and what was going on. I called the nursing home so I could find out their referral because there wasn't a piece of paper to really explicitly say (PG75, E 2).

Transmission of information

Transmission of information from one hospital staff member to another involved in the care of the patient was an important aspect of the work in Emergency: doctors needed information from people who knew a patient well about the immediate past, while nurses needed information about particular care needs. Information often had to be repeated more than once as nurses and doctors changed or brought in colleagues to help with a diagnosis. It was evident that both doctors and nurses often preferred verbal information and briefings about their patients rather than relying on written material. One doctor, for instance, talked about the risk of "putting too much stock" on a patient's past records or written information, which could result in not looking hard enough for the acute problem. This same doctor however did suggest that it would be beneficial if medical records provided an earlier alert to likely communication difficulties, saying,

...if we had better medical records where we saw early some kind of narrative description of where this person's at in terms of their communication and coping skills and so forth...I don't need a scoring system or how many IQ points a person has... I just need to know what a professional's interpersonal interactions with this person is like so that I can try and interact with the person in a way that is going to be useful to them. (PG65)

Our data and the absence of information on medical records, such as this doctor described, suggests the importance of an accompanying person for people with cognitive disabilities and the qualities that person required. Family members, who were often most readily recognised

as the legitimate informants, did not always live with the person or necessarily know about the immediate changes that had triggered the decision to go to Emergency. Some people came unaccompanied, and not all family members chose to, or were able to stay throughout the patient's time in Emergency. When a person had a disability support worker, that person was often the best informant for nurses and doctors and many, such as June and Beryl (referred to earlier) knew the patient they accompanied very well. Despite this, Emergency Departments had no apparent means of formally acknowledging the role or status of disability support workers, or mechanisms to be alerted to or compensate for the absence of an accompanying person who knew the person well.

A similar neglect is found in policies of disability support services. For example, the formal policies guiding government disability supported accommodation services in Victoria about hospital attendance regard disability support workers and family members as interchangeable (DHHS, 2012,2015). Essentially, so long as someone is present until the person is admitted, the policy suggests that it does not matter who that person is, and that as soon as a family member arrives there is an expectation that the support worker return to their house shift. Our findings demonstrate that the practice of staff did not always reflect these policies, even when patients progressed to the next stage of the hospital journey and were admitted, as this example from one supported accommodation house illustrates,

We called the ambulance, we called the dad and told him, and then I followed the ambulance to the hospital and then we sat – I sat in the hospital and we organised staff to take over for me, to relieve me because I already had done an eight-hour shift. So, we got a staff member coming in and also somebody staying overnight in Emergency and then the next day it was clear she has to be admitted, so we organised staff. We had always a staff member there 7 to 3 and then 3 to 11, and then overnight the nurses were looking after her. (PG40)

Doing the tests

What doctors did next after taking a history and examining the patient was often described as 'doing all the tests'. There was a sense from both doctors and accompanying people that they took the time needed to fully explore patient's conditions and patients were not given less attention because they had a cognitive disability. We found only one example where a doctor said he had held back on doing a standard test when he saw that the person was a repeat attender at hospital and had had this test done multiple times. However, this doctor had a

strong rationale for his decision, expressing concern about the health risks of this test being done repeatedly, and deciding to use an alternative series of tests that held a lower risk for the patient,

Corey had presented at Emergency 15 times during the study - often complaining of hip pain. He was well-known to triage staff, but his concerns were not dismissed by Emergency Department doctors who had conducted all the medically relevant tests, including CT scans, each time. At encounter 10 Dr Mason said, “the scan itself isn’t without its own complications. Lots of radiation over the course of your lifetime increases your risk of developing a cancer from the radiation...So the fact that he’d had 32 since 2008 was a lot of radiation...was a bit disappointing that it got to 32 to be honest, but that’s the way the system works sometimes. You’ve just got to treat everything at face value. And so, I decided from the start that we wouldn’t be looking at doing a CT, regardless of his story...I ordered some less invasive tests. So, we did a plain X-ray which is much less radiation. We did a urine test trying to find out if there was blood which would normally point towards a stone...he’d never had a stone found in all of the 32 CT scans he’d had done...And that was the reason why I was very firmly not going to do another scan. (PG43)

Doctors described investigating the patient’s current condition, taking into account their baseline presentation. One described, for instance, looking for meaningful causes of the sudden moaning and screaming of a patient who did not use words to communicate. Rather than dismissing this as challenging behavior because she had an intellectual disability, he examined her to see if there was a cause for her pain and found that her arm had become wedged in the bed. After releasing her arm, she stopped yelling out. In another instance, a doctor said that he had only concluded that the pain reported by a patient with TBI was possibly psychological in origin after other causes were investigated and excluded, and the patient reported no improvement in response to administration of pain medication.

During their investigations, doctors had often sought opinions on clinical symptoms from other doctors. Support worker June described one such situation,

Well they brought in several doctors to look at it, because I think to be honest, I got the feeling a couple of the doctors were amazed and they were calling other doctors to get opinions. So, there were quite a few doctors that came and looked at his feet, but

in the time I was there, no they weren't dressed, they were still making decisions about what they were going to do, and how they would deal with the problem. (PG10)

Medical tests or procedures were often adjusted to take account of the patient's needs. For example, use of an ultrasound to guide the process of taking blood, or administering a sedative to ensure a patient remained still for a scan.

Contrasting positively to the past

Interactions with Emergency doctors were generally described by accompanying people as positive and often contrasted to their negative experiences in the past. Older family members, for example, said that now doctors wanted to hear what they knew and thought about the health of the person with cognitive disability, in contrast to their past experiences when doctors had not wanted to hear anything from them. As the grandfather of one young man said, "early days, the friction was [bad], 90% of the staff were not helpful. I would say now that only 10% of staff give me a pain in the neck. I think that improved that much." (PG41)

Disability support workers generally spoke of Emergency nurses in positive terms, noting their warm and reassuring manner towards patients with cognitive disabilities. Similarly, patients with cognitive disabilities or the people accompanying them most commonly mentioned the positive difference that the interaction style of nurses made to their experiences. These were variously described as compassionate, empathetic, friendly and respectful. Nurses were perceived to acknowledge the personhood of people with cognitive disabilities, take time to talk to patients, use language they understood, and engage in comforting small talk or make jokes. For example,

Terrance, a young man with intellectual disabilities said that most nurses had asked him how he was, but both he and his mother Fiona spoke more positively about a nurse who chatted and joked with him. (PG7)

Daniel, a man with an intellectual disability, said that on the whole the hospital staff did "a good job, they do a really good job". He said they asked for consent to examine him and also asked him direct questions, but he had had some trouble with some of the words they used. (PG33)

Alice, a young woman with TBI commented very favourably on the way she had been treated by staff in Emergency, contrasting it to previous experiences of staying on a hospital ward. She said, "They were great. They do everything and anything, they really do... They were good to me, you and they sort of, we'll have jokes and if we

could joke we'd joke. But other than that, you know, they were there and they were sort of showed a lot of courtesy and stuff to my mum and they understood that it was frustrating for me...And they said that they understood and that I was quite young for this to happen. So, they understood like my frustrations and they even said they will try and give their best and do their best, and they did, they really did. The whole time I was with them in Emergency, they really did. It's like being in another hospital compared to going up into the ward. (PG11)

Beryl, an experienced house manager said about her experience of the Emergency Department when she had brought a young woman with intellectual disability and high support needs, "I have to say that Emergency is always good. I have, yeah, mostly really good experiences there in Emergency. They don't know much about the people...They look only at the medical stuff of it. They look really only at the survival of the patient. They're trained to do this, so they do one thing after the other... I think they're really good and to make the decision admission or not... they make that decision and they also talk to us as well – what we think. They're usually good..." (PG40)

However, participants' previous negative experiences of Emergency meant that accompanying people often regarded positive experiences as the exception rather than the rule, associated with particular individuals rather than staff practice in general. For example, June a long-time support worker for Mark, a man with high and complex support needs, described the nurses she encountered as making a major difference compared to previous, less positive hospital encounters with other clients. She said,

To be honest, I think just the nurses on duty on the day, they were all lovely. Whereas in the past down there, I've had nurses that have been really not that friendly and they give you that huffy puffy treatment like 'Oh God, this is all just too hard' but certainly it didn't feel like that with this experience, they were all lovely. (PG10)

Pre-conceptions that going to Emergency would be a negative experience based on what has occurred in the past are important to recognise and unsettle. The current, apparently more positive experiences of the way doctors in Emergency respond to people with cognitive disabilities may in some part be due to the impact of the training about intellectual disability that has been embedded into medical education in Victoria for the last 20 years and overseen by the Centre for Developmental Disability Health.

Few but memorable negative experiences

Negative experiences in Emergency were uncommon, but intense or memorable when they occurred. For example, a disability support worker said that a doctor had given the impression that he was ‘cluttering up’ Emergency by being present with the patient’s wheelchair. Diana, the mother of Kathleen, a young woman with intellectual disability and high and complex support needs had felt the Emergency doctor was insensitive and influenced by a negative attitude towards intellectual disability when he asked her if a resuscitation plan was in place for Kathleen. She said,

He said to me, “And what about resuscitation?” I’m thinking we’re not even in bloody ICU. She’s not critically ill. Is he making a judgment call because of her intellectual disability, and that’s exactly what it was. I said to him, “Mate, her quality of life is as equally good as yours. Would we want you to be resuscitated if you were in the same position?” and he just laughed. Ha ha ha, that was funny. I didn’t find it funny. I actually looked shocked when he said it, and he said, “Hasn’t anyone broached that with you before?” And I said, “She’s been in ICU before post an operation. Nobody’s ever felt it needed to be asked.” No one’s ever considered that that’s an issue.” “Oh,” he said. So, I thought that was really inappropriate. I did feel him asking what about resuscitation was wholly and solely based on her IQ. I don’t for a minute believe he would have said that if it had have been me...I was a little bit cranky about that. So that wasn’t a good start in Emergency. Anyway, we got out of there. (PG9)

There was no information in our data to explain why the doctor had asked about resuscitation or whether this was a standard admission question, but Diana had not been asked it before. Importantly, however, this question in the context of a medical situation that was not considered serious was perceived as insensitive by Diana’s mother, and perhaps reflects the type of diagnostic overshadowing that has occurred in health care for people with cognitive disabilities in the past.

There was only one instance of demonstrable diagnostic overshadowing whereby treatment had been requested and was refused because a patient had a cognitive disability. An Emergency doctor requested the Enhanced Crisis Assessment Team (ECAT) be involved in assessing a patient with intellectual disability who did not use words to communicate and was terminally ill. The ECAT team refused to even physically attend to the patient’s bedside as

they argued they would not be able to treat him because of the severity of his cognitive disability. (PG51 E4)

Summary

Our data suggests the importance of a person with cognitive disability being accompanied by someone, either a family member or disability support worker who knows the person and their immediate health problems well, who can contextualize their pre-existing care and support needs and act as an advocate in Emergency. As information was likely to have to be shared numerous times as staff changed, having an accompanying person throughout rather than just at the beginning of the journey was important. Figure 7 summaries some of the promising practices observed or suggested by Emergency staff that would help to accommodate the person's needs, many of which equate to good person centred practice.

Being in Emergency: Promising Practices Staff

- **Adjusting communication, interaction and delivery of treatment to each individual.**
- **Focusing on person's needs and building rapport: checking frequently, using simple language, speaking slowly, checking understanding, using communication aids, showing compassion & empathy, being friendly & respectful, reassuring & engaging in comforting small talk**
- **Collaborating with accompanying people to maintain care routines and understand the person**
- **Acknowledging support workers role**
- **Having electronic record systems that include categories and information relevant to people with cognitive disability (e.g., supported accommodation living situations, communication & coping skills)**
- **Providing information about what to expect and how Emergency works**
- **Being responsive to escalating stress: moving to a quiet space, modifying procedures & investigations**
- **Supporting home-based routines to continue in Emergency**

Figure 7. Promising staff practices in Emergency

Stage 3. Leaving Emergency

There were two main destinations after Emergency, home, or admission to a hospital ward. A third midway option was to spend some time in a short stay unit (SSU), an area alongside Emergency in most hospitals. These units enable a longer period of observation to ensure a patient is safe to discharge, or to give more time for a decision to be made in circumstances where further action remains uncertain. Admission to a SSU area allows for continued medical supervision of patients who fall into a grey zone between being ready to discharge

and requiring admission and may also be used at times for Emergency Departments to meet their time targets.

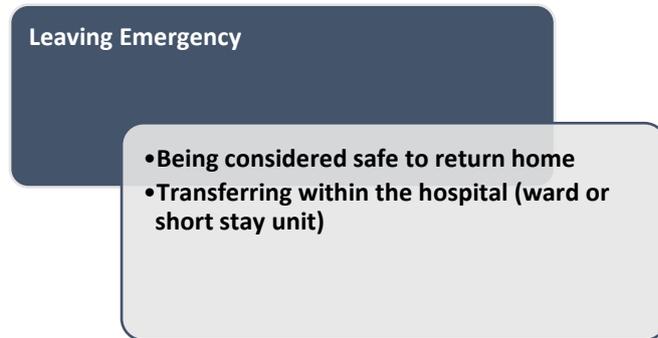


Figure 8. Leaving Emergency.

Decisions about destinations were made on the recommendations of a variety of doctors and nursing administrators. They were often segmented and specialised, seeming to occur ‘behind the scenes’ and only communicated to the patient and their accompanying person at the end of the process, which meant having to wait and experiencing uncertainty. If a patient could be effectively treated within Emergency or was assessed as safe to discharge, this was done directly from Emergency. An Emergency doctor recommended ward admission if they thought it was needed for effective treatment. One doctor described seeking admission for a patient whom he felt needed more conservative treatment in hospital because of the risks posed by discharge. If an Emergency doctor decided a patient should be admitted, a request was made to the doctor from an admitting team to assess the patient and process the admission. Movement to a ward was considered to be officially ‘an admission’.

Stage 4. Being on a Ward

Admission to a ward marked the start of formal hospital admission, which was potentially significant in terms of hospital practices and policies that guide the work of nurses and disability policies that guide the work of disability support workers. Nurses are expected to enforce hospital policies and practice, for example, following routines, lifting safely and giving medications. Disability policies expect, that at this stage, the hospital replaces the disability service as having responsibility for patients with cognitive disabilities who usually live in disability supported accommodation. As Figure 9. shows, being on the ward involved receiving care and treatment from medical, nursing, and allied health staff.

Being on a ward

- Receiving care and treatment from medical, nursing and allied health staff

Figure 9. Being on the ward

Unlike Emergency, where nurses did hourly observations of the patient, on the ward, nurses typically had far less time allocated for one-to-one patient care and an apparently more rigid pattern of work. On medical wards, for instance, observations were done at 4 hourly intervals, nurses worked in pairs in completing their responsibilities for 4-8 patients; in the mornings, they were expected to complete a set routine, including giving medications, assisting with toileting, showering and eating.

As in Emergency, the experiences of people with cognitive disabilities on the wards were varied, some patients or their accompanying people felt they were not cared for as well as they should have been, while others talked positively about their experiences, remarking on the quality of care they received. On the wards, individual nursing, medical and allied health staff had accommodated the needs of people with cognitive disabilities in various ways, and, at the organisational level in one hospital, a pilot program of allied health assistants had been initiated to provide extra support. However, adjusting standard routines or practices to the needs of people with cognitive disabilities or the expectations of their accompanying people had been less straightforward than it had appeared to be in Emergency and met with various obstacles, primarily related to limited availability of staff time and clarity about roles of accompanying people.

Patients with cognitive disabilities required particular accommodations by staff on the wards that had arisen for several reasons including,

- the presence and willingness of family members or disability support workers to be involved in or advise on caring,
- their need for additional assistance to support eating, drinking and personal care,
- their anxiety or need for reassurance created by an unfamiliar environment and constantly changing staff,

- their communication difficulties and the need for adjustment to ensure understandability,
- questions of consent and decision making where the person requires significant support to make a decision or their capacity to make a decision is questioned.

Accommodating needs

Collaborating with families and support workers

Many family members had expressed a desire to be present and supplement the care provided by nursing staff or ensure it was similar to familiar home-based routines. Nursing staff had accommodated this preference by working collaboratively and flexibly with patients' families, acknowledging the importance of existing routines or the often highly-developed and technical expertise of families about caring practices. For example, one of the nurses caring for Curtis a young man with intellectual disability, had said about his family situation,

They have their routine. That was kind of voiced at the start, his routine, so he wasn't out of place and he wasn't in a weird environment where nothing was going the same way than what he does at home. So, he doesn't feel out of place as well. (PG51)

On the other hand, some nurses found it difficult to develop a collaborative approach to caring with family members who wanted to play a significant role. For example, one family member talked about how she was left alone by nurses to undertake much of the personal care for her daughter. It should be noted, however, that her comments were made in the context of nurses being aware of how critical she was of the quality of care her daughter received which may have colored the attitude of the nursing staff. She said,

I was changing her bed when they came back. I went and found the linen. I changed her bed. The whole six days she was in there I changed her bed myself every day, and I washed her myself every day, and I asked them for a bowl to wash her. Not one nurse said, "If you wait half an hour I'll give you a hand." Not once was I offered assistance in her care...I just plodded along and did what I was doing. So, nobody offered anything which was really bizarre. And the nursing staff, because I was there they just stayed away. They just stayed away...Well they saw her being cared for. So, they just kept away. They came in and did the bare essentials like medications and observations and that was it. (PG9)

Despite ambiguity about the role of disability support workers in hospitals and disability policies suggesting they should not provide support to their clients who were hospital patients, they had played a number of important roles in supporting patients. In many instances, they had successfully formed collaborative relationships with nurses. Disability support workers had often been present on a ward, sometimes visiting clients in their own time. They had perceived their presence in itself as important for the emotional wellbeing of patients. Disability support workers said for example,

I've spent quite a lot of time with Cassandra and, as I said to you before, when she was in the hospital I was on annual leave so I went in and I was visiting her just purely as a friend, not as a staff member or a support person. (PG40)

I feel I played an important role, because I was there to offer comfort and reassurance to Mark, and to reduce Mark's anxiety is no mean feat, because if he gets really upset, he can become quite aggressive. But I knew that that wouldn't happen because he's quite comfortable with me and I knew that the reassurance I was offering was well received. The level of anxiety really diminished. (PG10)

Nurses accepted the presence and willingness of disability support workers to assist in caring, share their knowledge of the person with cognitive disability and show them "how to do things". As disability support worker Francesca explained,

Just visited, to see how she is, get updates while we're there, give some assistance in relation to how to care for her. We actually have a policy. In our policy and procedures Residential Service Practice Manual - tells us that once the patient has been admitted to hospital then we're not really supposed to help in relation to physically assisting feeding, that sort of thing, or care... But often we can't help ourselves and we may [help]- just to make it easier for the residents, and the staff there of course. (PG39)

Another disability support worker had talked about the type of hands-on care she and others from her organisation provided to a client in hospital, which had been prompted by their concern about the lack of skills in supporting someone with disability among nursing staff. Notably, according to this staff member, the policies of the non-government organisation she worked for were different from those of the government organisation in the earlier example. She said,

She can't talk for herself. The [hospital] staff are not trained to look after people with such severe disabilities. They're not trained for it. They had no idea how to use that food in the PEG, they had no idea. Most of the nurses were standing there, no idea how to get anything into her stomach and with the pump... they had no idea how the pump works either and they used it wrong. So, policy is we go to hospital with people and if they need it, we stay overnight as well to just assist the nurse, to help them, to give information, to be there for the nurses and for the doctors to be able to give them good care. (PG40)

As well as caring tasks, both family members and disability support workers suggested that they had played a significant advocacy role through their presence on the ward. This advocacy occurred by monitoring what was happening for patients, being willing to ask questions and draw attention to poor quality care if they saw it. As one mother said, her role was to,

Be her voice, to be her advocate and also just to keep her alive. To say this needs to be done, that needs to be done or just to do it... and it's to make sure her needs are being met, and they were. I met them <laughter>. Her needs were met. I suppose its answering questions and things. I would hate her to have thought she was in there on her own. I really don't believe she'd be alive...I really don't believe she'd be alive if I wasn't in there." (PG9)

A supervisor of a supported accommodation service said about the advocacy role played by the disability support staff in her house as well as the importance of collaborating with hospital staff,

We advocate for Cassandra. Cassandra can't talk, so they [hospital staff] often get it wrong because they don't know Cassandra so well." ...It's always stressful and some of my staff really don't like much to go because they have to make decisions and they have to say to the doctor or nurse, 'No, you can't do this.' They have to advocate for Cassandra which is not easy... You need to be able to really, yeah, stand up for yourself and for Cassandra, for Cassandra's wellbeing.... they don't know Cassandra as a person. They don't know her history.... So, as I said, if we would work together that would make perfect sense and would give really good care for Cassandra and for everybody who goes to hospital. (PG40)

Doctors as well as nurses had formed collaborations with families or disability support workers to accommodate the needs of patients with cognitive disabilities and provide them with better care. One surgeon was described as being “absolutely incredible” because he allowed a disability support worker to be there with the patient in pre-op and post-op to reduce his fear (PG30). However, this type of accommodation was not common and there were examples where other staff did not allow a familiar support worker to be present in this way, or agreed only reluctantly after encountering difficulties with the person with a cognitive disability refusing to comply with expected procedures.

We observed and heard about many instances of hospital staff adjusting their practice to accommodate the expectations of families or disability supporters about their roles in relation to patients with cognitive disabilities. Still, some staff had expressed frustration about these family or support workers continuing to administer medicines, provide PEG feeds, and lifting the patient, which were contrary to hospital policies. As the earlier quote indicates, one mother felt uncomfortable that staff kept their distance and some disability support workers felt they were less welcome than families and not welcomed by some staff. One support worker said,

They [hospital staff] sometimes don't accept us really well and listen to us because we're not medical people, I feel, we're just carers. They listen a lot more to families. It's a lot different in their attitude if the family's there. (PG40)

Forging collaboration between hospital staff, families and disability support workers was an important accommodation made by staff that took account of the needs of patients with cognitive disabilities, compensating for their difficulties in self advocacy, and often complex communication and care needs. The success or failure of this type of accommodation may require clearer recognition of respective roles of family and disability support workers, clearer guidelines on the part of both hospital and disability systems, and communication of clearer expectations to family members.

Other forms of accommodation

Eight allied health assistants had been introduced as a trial in one health network to provide resources in the form of additional staff who could spend extra time with patients who required it. This initiative had not been specifically targeted to patients with cognitive disabilities, who formed only one group of their potential client cohort. However, the way one of the Assistants had described her role aligned with some of the additional support needs

that had to be taken into account for patients with cognitive disabilities. These functions were having time to work more intensively with patients by taking over or assisting nursing staff with non-clinical and time-consuming tasks, such as bathing and assisting patients with meals, and having time to put patients at ease by sitting with them or finding games to play or other types of entertainment to pass the time. She talked about her experience with one participant in the study,

[I] had needed information about the patient in order to know how to reduce his boredom and over several days she learned his 'likes' and noticed how his behaviour differed with different, unfamiliar people. Continuing care was important, said she, as she learnt a lot more about him on this second admission from talking to his family and learning how to interpret his non-verbal communication: "This mean this..." She also admitted she was less intimidated by the patient's appearance on this admission, whereas she had been initially scared and confronted by his appearance.

This type of more structural accommodation was regarded only as partially compensating for the low staff patient ratios. As one assistant said, "What happens when I'm not there?" and talked about her experience of beginning a shift and realising that a verbal handover had failed and the patient had not been supported to eat.

Some nurses appreciated the role of health assistants but also expressed mixed feelings about lesser qualified staff performing aspects of nursing duties. On the one hand, they recognised the need for better staff ratios and more time for patients; on the other hand, several were worried that the lower paid assistants would erode the nurse's role as carer. At least one nurse felt frustrated that trained nurses no longer had time to perform what she saw as the broader care that was once fundamental to nursing, and thought that nurses risked becoming solely dispensers of medication. In her view, this diminished the caring aspect that had attracted her to nursing.

People with cognitive disabilities had often been perceived as being more anxious than other patients about medical procedures, and finding it harder to manage the boredom of being in hospital or the stress of being in an unfamiliar place surrounded by frequent changes in people on the ward. Similar to staff in Emergency, those involved in care for patients on the wards had adopted various strategies to adjust their interactions with patients to take these needs into account. Individual nurses were described as "taking a bit more time" with interactions and care tasks (PG30) and others simplified words and sentences. One mother

talked about the way one nurse in particular provided high quality care for her daughter. She said about this nurse,

One of them was really excellent... Well she just knew to come over and cuddle Piper and to say to Piper 'Everything will be alright', but the other staff that were around, you could see they were frightened. They didn't know how to react because they hadn't been trained in it. They were in a ward for just ordinary people, three ordinary blokes who could say to them 'Hey I want a drink' or 'Can you come and fix that?' but Piper didn't have that. She hasn't got that ability. (PG31)

From this mother's perspective, this nurse, unlike the others, had been confident in her interactions with someone with cognitive disability, and "just knew physical contact, and offering verbal reassurance [were needed]?"

Lorraine, a social worker, described taking more time and speaking more softly with Madonna, a middle-aged woman with an intellectual disability and her elderly parents,

Look, I tried to make it as private as I possibly could, so I drew the curtains over and tried speaking softly and tried engaging rather than bombarding them with questions, just really got them to kind of engage. So, at the start - that's probably why it took a little bit longer. It's like - not that you don't come from a caring environment with everyone, but in this case, you take a little bit more time, so more from a caring approach - "How's it going? Gee, it must've been very difficult for you as a family," that sort of thing. And then they kind of started the ball rolling as to their situation. (PG56)

Later in Madonna's hospital journey when she was on a rehabilitation ward, Tori a physiotherapist described how the staff changed their style of communication to try to understand her perspective when she became upset,

Yeah, everyone modified their communication really well and tried to really understand what she was upset about when she became upset and took the time to communicate with her. No one seemed to brush her off. As I said, I saw her mainly with physio and then just around the corridors, so I'm not 100% sure, but occupational therapy staff were very comfortable with her. Nursing staff I spoke to - none of them had any issues and all related really well with her. The mum didn't report any problems; we always touch base when we see a patient. "How's it going? How's the nurses?" She always said, you know, she was pretty happy. (PG56)

Tori described how staff had modified their rehabilitation program in order to engage Madonna, and take account of her being easily distracted,

We didn't really do any conventional physiotherapy kind of exercises, which is like knee raises and hip adduction and all that kind of thing and step-ups. We were doing things like I had a little toy monkey getting her to kick the monkey, getting her to stomp on the monkey, jump on the monkey, getting her to stand up on a step and give me a high five, making obstacle courses so she had to get lots of hip movement and lots of balancing. She made friends with some of the other patients and so she'd watch what they were doing and she'd want to replicate them, which was great, it was very useful. Also, we kept it flowing pretty quickly so every five minutes or so, when she started to get distracted we'd just change the exercise up and do something else and then we'd reintroduce it again when it became a bit more fun... you had to think on the fly a little bit ... (PG56.)

Very few staff said they had received specific training for working with people with cognitive disabilities, but said they had used their professional expertise to adapt their ways of communicating or working to take account of their individual patients' needs. Tori for example, said he enjoyed the challenge of "thinking on my feet and adapting my treatment to something a bit more fun and interesting", while Mandy an occupational therapist saw the adjustments she made to her way of working in order to better engage Madonna as an essential part of her job,

I would say because for each patient's it's a different activity so we would just modify the activities to suit what they did. I think, as an occupational therapist that's one of the skills that we are taught to do. We modify a lot of the tasks to suit the patients and demands. I've worked with patients who really like baking and we used a baking session to increase that – instead of doing it sitting, we do it standing to increase their standing endurance. Yeah, so we do activities like that to get them to participate, because it's really hard when they don't want to cooperate and we can't get what we need out of them, they are not moving forward in their rehabilitation. (PG56.)

In a similar way to those in Emergency, staff on the wards said they had sometimes adjusted the way they used hospital space to accommodate the particular needs of a patient with cognitive disability. For example, they located them near to nursing stations where they could see and be seen by nursing staff more easily, allocated individual rooms on wards, and there

was one example in which staff co-accommodated a mother and daughter with cognitive disability on the same ward. However, accommodations of this type depended on hospital staff making a professional judgement that the patient required hospital space to be used in a flexible way as well as there being free or flexible space available at a given time.

Similar to Emergency, on the wards, face-to-face in-the-moment exchanges were preferred when communicating information about patients that was not tightly regulated by medical protocols for medication. For example, one assistant said that extra files containing information about a patient's social context and preferences that had been brought to the hospital by staff from his disability accommodation service had been placed in a bottom drawer – out of sight, out of mind – rather than on display and consulted.

Difficult experiences

There were a number of instances where family members described poor quality care for a patient with cognitive disability. They had drawn this to staff's attention. As a result, staff had actively intervened – hence, we do not know how serious the consequences might have been had the poor care not been reported. For example, Diane, Kathleen's mother, talked about the culture of her daughter's ward as "slack" and described numerous problems and errors during her encounters with ward nurses. She contrasted this negative experience with her previous positive experiences in the same hospital. Problems she had identified included not placing Kathleen in a room that was highly visible to the nurses' station, despite her risk of vomiting and choking; not attending to her when she had vomited; making medication errors; and staff not introducing themselves to Kathleen or Diane when they entered the room. She said,

She was placed in a two-bed room with another nonverbal person who was unable to ring a buzzer and a long way from the nurse's station and I said, "This could actually kill her putting her here. She's vomiting. She could aspirate. You're not going to hear it"... I said, "I need to leave. It's not safe for her to be here." [staff said] "Oh no, we'll hear her." They walked out of the room. She immediately vomited. Nobody came back. ...I didn't have any nurses introduce themselves....when I turned up in the morning she was lying in a pool of vomit again...Anyway they decided because she had a loose bowel motion overnight that she may have gastro. So that was good, because they put her in a single room up near the nurse's station...her safety was fine while I was there. ...One morning I turned up, it was actually the last morning I

turned up and she was lying completely flat in bed. Now with somebody who's got compromised breathing, you would never lie them flat in bed and she had actually vomited, and they were doing the nursing round...and they say, "Oh Kathleen's doing really well." I said, "Actually she's lying in a pool of vomit," ... We had a horrific experience one day where a nurse brought in the wrong medication. She'd double dosed her in one drug and had left off another, and I pointed it out to her. She came back three times before she got it right. I kept telling her she was doing it wrong. She was getting it wrong. The fourth time she came in laughing going, "Oh, fourth time lucky I think." (PG9)

Diane had expressed concern about complaining, feeling it might "put the nurses offside", but had gone to the unit manager when she observed a potential medication error. Her complaint had been acted upon and she saw an immediate improvement, which in her view had only been short lived. Family members of various patients reported mixed experiences of complaints systems. Several had made formal complaints about care, but had been dissatisfied with the response they received or were frustrated about inaccessibility as phones were answered only during office hours.

Although, not as confronting as Diane's experience, in our data there were a number of situations in which hospital staff failed to recognise or make accommodation to take account of the needs of patients with cognitive disabilities. These included situations that involved:

- Poor communication. Examples were not talking directly to the patient with cognitive disability. Alice was frustrated with staff talking directly to her mother and said 'they occasionally glanced at me. That's what they do, they do the glance...They do not directly talk one to one to me.' (PG11)
- Making assumptions about care needs without checking with family or support workers who knew the person. For example, on one ward, nurses had assumed that a patient with high complex needs required a bed bath rather than offering either a shower or bath and providing the necessary assistance.
- Failing to give sufficient attention to advice given by disability support workers or family members about additional care or monitoring needs of a patient. For example, a parent talked about the inadequate way in which liquid food had been prepared, saying,

There was a novice nurse. She wasn't bad but she just doesn't have the experience. She was meant to mix Tony's medications with sustagen...It was

disgusting. There was a lot of powder and there were lots of foam on top. Tony can't drink it because he can't swallow it. I felt that because she lacked the experience, she doesn't know how to make it probably so she just did whatever she can and I told her that the way she did it would make it difficult for Tony to drink it- he can't drink it. It should have a milky texture. (PG16)

In another example, a disability support worker complained that her advice was ignored about where the young man she supported should be located on the ward, and the need to monitor him when a nasal tube was inserted. She said.

So, he was given a bed at midnight...I said look, Aiden is not good on his own isolated, he wants to be where there's activity and where he's got good access to people, just to see people, to see what's going on. They did put him in a room by himself which was not opposite the nursing station and I don't know why because they were aware of that, whether there wasn't room, but he pulled out his nasal gastric tube, for example – which I said that he would do that if he's not, [monitored] you know, and some of that is just because he needs more additional support and when I asked them about the additional support, they called it special, they said well he wouldn't really qualify because he wasn't doing anything that was, you know, would warrant it. (PG20)

- Failing to provide careful, personalised individual care. One disability support worker said, “it kind of feels like if you deviate from how we want you to be in hospital it just gets a little bit too hard and they don't think about it.” (PG30)
- Misunderstandings between nurses and disability support workers about the discretionary rather than formal role support workers played in supporting their hospitalised residents. For example, one support worker talked about the unrealistic expectations that some nursing staff had about their role in supporting a patient at meal times. She said,

He was certainly being attended to in a positive way and yeah, it's good to see nursing staff if they have got questions that they asked. I found it was positive with the exception of one nurse reporting that they were very unhappy we hadn't visited on a couple of days and yeah, I think our coordinator did complain about that to the nursing manager because the nurse had effectively told off the staff member who'd gone to visit and who explained our circumstances that if we're short staffed or there's another factor occurring at the house, then we can't get

there but we'll always communicate that. Like we call and say, "Look, sorry today, this afternoon, we're not going to make it. We're short staffed" or "We have another resident ill and we're short staffed" you know, whatever the reason was. (PG 30)

- Concerns were also expressed by disability support staff about the difficulty they experienced in trying to obtain information about what was happening for a patient they supported, as there was no single contact point throughout the hospital journey. Asked about what would have improved the hospital experience, one support worker said,

Maybe having one contact person would be great but I don't know how logistical that is. Each time we would deal with a different nurse or a different nurse in charge. That was sometimes tricky. Having some of that one main contact person would've been great. I obviously know that's - logistically can be hard. (PG39)

Summary

For patients, being on the ward was in many ways similar to being in Emergency. Patients with cognitive disabilities needed to be supported by someone who knew them well and could collaborate with hospital staff in understanding and meeting both their pre-existing and their new care needs. Similarly, many of the adjustments to staff practice on the wards were similar to those in Emergency representing good person-centred practice and collaboration with families or disability support staff. In contrast, more so than in Emergency these practices were likely to be hindered by misunderstandings or conflict about respective roles of hospital and disability support staff. Figure 10 summaries promising staff practices on the ward.

Being on a ward: Promising Practices Hospital Staff

- **Working collaboratively & flexibly with family and disability support workers when present and recognising their expertise**
- **Acknowledging the importance of existing routines**
- **Taking time and being attentive with the person, being reassuring**
- **Adjusting communication: using simple language, speaking slowly, checking understanding, using communication aids**
- **Facilitating privacy when needed**
- **Locating in a high visibility room/bed**

Figure 10. Promising practices on the ward

Stage 5. Being discharged from the hospital

Discharge is the final stage of the hospital journey. Often assumed to be a process, this had been experienced by people with cognitive disabilities and those who accompanied them as a decision, often suddenly announced without warning. Discharge had followed these steps: a decision made by a doctor based on clinical indicators; assessment that the patient was safe for discharge, which involved a social worker if there were any doubts; communication of the decision by nursing staff to the patient and their support people; and actioning discharge.

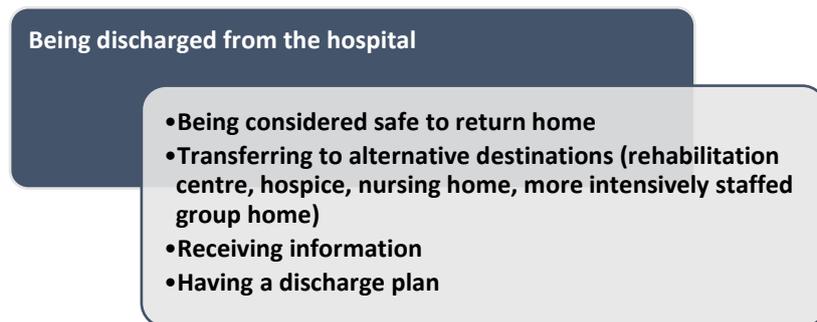


Figure 11. Being discharged from the hospital.

Being considered safe to return home

There had been no obvious point at which people with cognitive disabilities or those who supported them felt they could raise concerns or ask questions about being discharged; although in some instances they did speak to the doctor who made the decision. One disability support worker for example, talked about her frustration when staff had not been consulted and an agreed discharge plan was changed at short notice. She said,

...on the Sunday I got a call just as I was on the way to work from the staff member at the house to say that the hospital had called and they would be discharging Keith and she had said, “No, we’ve been told it wouldn’t be till maybe next Tuesday or so”, it would be a few more days, and they said, “No, he’s well enough to be discharged home and he’ll have antibiotics.” So, we got our on call involved [because the manager was not on call] and they were unable to stop the discharge and it went ahead. (PG 30)

On this occasion, the patient who was discharged became unwell again and within 3 hours was taken back to hospital and was readmitted. The support worker felt that one of the reasons for the earlier than planned discharge and subsequent readmission were the

misunderstandings by hospital staff about the support this person could receive at home. She said,

One of the challenges we often face is that it's certainly often written on the discharge paperwork that we're a nursing home and we're not. We have no nursing staff, we have no registered nurse on a shift. We have only disability support workers and we can't provide any monitoring, other than our general observations. So, no temperature taking, no you know, urine testing. We can't do any of those kind of things. And yeah, we often feel that there is an expectation that our skills are higher than they are and that Keith would be okay in our care because we could provide a level of care that we actually can't provide. So that was a very negative experience. (PG30)

When a discharge decision was formally challenged, a formal process was triggered, and a meeting called, with a hospital social worker acting as the key person overseeing discharge as occurred in Hanna's case (see below). A minority of family members and disability support workers described examples of resisting a decision to discharge a patient before they felt the patient was ready or could be safely cared for in supported accommodation. As one disability support worker put it in describing a house manager's intervention, "He only came home when she felt he could be managed safely in the home".

Transferring to alternative destinations

A small number of participants had died during their hospital encounter. In some instances, this had been the result of sudden, acute conditions, in the presence of co-morbidities. Another small number had not returned to their previous home as their hospital admission acted as a tipping point to revisit previous decisions about the suitability of their accommodation and support. For others, their "safe discharge" had been questioned by managers of supported accommodation services who suggested that the service either did not have the resources to safely support the patient once discharged or could not support them because of the impact on other people living in the same service. The reasons for this related to the patient's deteriorating health, complex needs, or comorbidities revealed during their hospital encounter. The necessity for safe discharge meant the hospital had become the default residence for these people until issues were addressed through formal discharge planning processes.

Hanna (PG3), a middle-aged woman with intellectual disabilities stayed in hospital for 136 days, despite her being medically well enough to be discharged after 5 days. Her case was undoubtedly an exception, but illustrates how the ordinarily complex and time consuming nature of discharge decisions could be magnified when a person with cognitive disability is involved and questions arise about their capacity and who has the right to provide support for their decision making. This case demonstrates too the high economic and personal cost of poor decision making at the last stage of the hospital journey, the critical importance of reciprocal understanding by the hospital and disability systems, the significance of access by hospitals to staff skilled in understanding the disability system and the ways in which disability support services can manipulate a person's residential outcome.

Hanna is a 46-year-old woman, who in the past had lived independently, but at the time she was hospitalised was sharing accommodation with 3 other people and receiving drop in support with a range of domestic tasks. The accommodation support was provided by the same disability support organisation that managed the day centre she had attended for many years.

Hanna had recognised that she wasn't feeling well, experiencing numbness on the left side of her mouth and her left hand. The day program called an ambulance and her parents. She was taken to hospital by ambulance with a suspected stroke, arriving at 09:04, given Triage Code 2 (urgent) and seen by a doctor at 09:20. By early that afternoon, various tests had been conducted and she was admitted to a neurological ward. Over the next few days she was seen by medical staff and allied health staff, including a social worker, occupational therapist, speech pathologist and physiotherapist. She was diagnosed with a transient ischemic attack (TIA) and determined to be medically stable and returned to her pre-morbid level of functioning within 5 days. During the first few days of her stay, however, it was decided she was not safe to be discharged to her home. She was transferred to a rehabilitation ward in another hospital in the same health network on day 5. Neither Hanna nor her parents were given information about the transfer and Hanna was left for several hours in a transfer lounge waiting, not knowing what was happening and growing increasingly anxious. The poor communication about the move and having to share a room with older people with dementia created stress for Hanna. Nursing staff felt the rehabilitation environment was not suitable for Hanna as she was much younger than other patients. Following a meeting with hospital staff and her family, the decision was made to move Hanna back to the original hospital into a newly opened ward for patients requiring complex discharge planning. This move occurred after she had been in the rehabilitation ward for 7 days, and she remained on this ward for 124 days before being discharged to a disability supported accommodation service that was staffed 24 hours a day.

While Hanna was on the ward she experienced a fall that did not result in any injury. She was well supported by nurses who endeavored to find her tasks to stop her getting bored and was treated by various allied health staff for mobility and occupation. Nevertheless, she was bored, anxious and felt socially disconnected from her network around the day service she had attended. At one point, she wrote a note for one of her case meetings that she 'felt like she was in prison'. As the doctor on the ward said, "I think she came to us because she had a transient ischemic attack... but she fully recovered from that." The records suggest her mobility improved during the time she was in hospital, but she experienced anxiety about her future and lost a degree of confidence in her own abilities. It was evident that the cost to the hospital would have been significant, particularly in terms of nursing, auxiliary care and allied health services.

The main contributing factor in Hanna's extended stay was that, within the first few days of her admission, it was decided that she could not return to her home. At some point, before she was admitted to the neurological ward, she was determined to be 'homeless in hospital' because there was no safe place for discharge.

Many of the details of the decision-making process remain unclear, but our data from the review of hospital records, 4 observations and 13 interviews with family, disability support services, allied health, nursing and medical staff, do raise a number of issues - how was a decision reached so quickly into the hospital journey that it was unsafe for Hanna to return to her existing home? What evidence was this decision based on? Why was such a narrow range of alternatives considered? What collusion or taking advantage of the situation occurred? What support for decision making was available to Hanna to help her understand options, explore her preferences and protect her rights?

The original decision that Hanna could not go home was reached quickly: that is, within 3 days of her admission. A social work note stated, “SW informed RN and neuro team that the pt currently has nil suitable accommodation for d/c, and awaiting further input from DHS to approve appropriate accommodation. Neuro team agree not to d/c pt today or over weekend.”. This original decision that Hanna did not have suitable accommodation to return to was never revisited. It appears to have been based on Hanna saying to the occupational therapist on day 2 that she didn’t feel confident to be at home on her own. It was taken at face value and there are no records of considering provision of additional support to Hanna at home in the short term to help her regain confidence and feel safe again, or that she was taken home so that her confidence and competence could be assessed and adjustments to equipment or other resources considered.

The social worker convened various family and discharge meetings at which Hanna was not present, but which included staff from the disability support service she used, and the Services Connect staff from the Department of Health and Human services (DHHS). During these meetings, possibilities considered included Hanna going to stay with her elderly parents or going to an aged care facility or a Special Residential Service (SRS). All were dismissed and the only option actively pursued was finding a place in disability supported accommodation that had 24-hour support. DHHS is responsible for allocation of places in this type of accommodation and their representative at the meetings and then in liaison with the social worker could not say how long it might take for a vacancy that was considered suitable for Hanna to become available.

The face validity of the decision that Hanna could not go home, and the judgement that she required a home with 24-hour support was strongly reinforced by staff from the disability support service that managed Hanna’s day and accommodation service. Indeed, this service had been advocating that Hanna needed alternative accommodation for some time, and had continued to do so despite an assessment the year previously that her support needs had not changed. The decision was also supported by her parents who wanted their daughter to have secure accommodation; they were advised by the disability support service to resist suggestions that Hanna might stay with them for a while. The decision was questioned initially by the team leader from DHSS and it is not clear why she did not pursue her uncertainty.

...my [initial] query was to say that we’d been told by [disability support service] that she can’t go back and return where she was? And I was saying ‘Why not? Have her needs increased? Has there been an assessment? Do we know what her needs are? Why is it different?’ And at one stage I was told it really hasn’t changed that much but she can’t go back there.

It may have been she was a lone voice of dissent. It may have been that the disability support service took Hanna’s hospitalisation as an opportunity to exert leverage on DHHS to gain new accommodation with 24-hour support for her. Staff may have used the long-term relationship between the service, Hanna and her parents to help ensure a common view, and to suggest that Hanna relinquish her tenancy on her existing home. It seemed that this action was taken in the first week or so of Hanna being hospitalised, which removed any possibility of her returning home with extra support, resulting in her being homeless.

Other factors helped to reduce the chance of the decision being more deeply considered and reinforced the view that Hanna would be unable to return home. Consistently, the word “stroke” was used, implying a more serious condition than the minor TIA Hanna experienced.

The result was the belief that Hanna's day-to-day support needs had changed as result of a health condition, when they had not. Hospital staff knew little about community living and people with intellectual disabilities, they did not have a good understanding of Hanna's potential level of independence, of the different types of supported accommodation available, such as the difference between an SRS and disability supported accommodation, or the potential flexibility achieved by having additional drop in support. The social worker on the ward reported being much more experienced with older people than younger people with disabilities; hence she was unlikely to have been aware of the potential options for Hanna and judged success in finding suitable accommodation in terms of Hanna avoiding an aged care option. Finally, no one, either from the hospital, DHHS or disability support services appeared to understand Hanna's right to be supported to understand her options and to make decisions, or to have taken any action to support these rights or question the use of the term "shared power of attorney" by her family, which was unlikely to be applicable to a person with intellectual disability such as Hanna. Her experience is indicative of an expensive episode of care for the hospital. Further, the extended period of uncertainty and stay on a ward took a toll on Hanna's well-being and confidence. More than 23 individuals, many of whom appeared to have a pre-existing agenda, were involved in the decision-making processes. A question worth asking is whether hospital staff had sufficient knowledge about working with people with disability and expertise about disability services and policy to effectively lead the process and to ensure the best possible outcome for the patient and protect the interests of the hospital.

The decisions, usually made by others with an informal or formal mandate, that a person with cognitive disability cannot return to their home were far reaching, as most out of home destinations were larger, and more congregated and restrictive than people's previous homes. Destinations had included rehabilitation centres and alternative forms of accommodation, such as a hospice, a nursing home or more intensively staffed group home. This finding suggests that hospital systems and DHHS might need to give more attention to new knowledge around provision of support for decision making and increased expectations of transparent and defensible processes that demonstrate the participation of the person with cognitive disabilities in decision making and the representation of their will and preferences and minimum restriction of their rights (see for example, Bigby et al., 2017; Douglas, Bigby, Knox & Browning, 2015)

Having a discharge plan

Discharge summaries or letters are the primary means of documenting what has occurred during a hospital episode and the follow up actions that should be instigated. The format and accessibility of these documents varied across hospitals.

In one hospital, discharge summaries were written by a doctor who was a member of the admitting team, although not necessarily the admitting doctor or one who had treated the patient. They were pro-forma documents with predefined headings for text boxes, including

principal diagnosis, clinical synopsis, results of tests, procedures, problems, past medical history, and prescribed medications. The treatment plan was described using dot points and hospital shorthand such as SHx for social history, PMx for past medical history was used throughout the document. The summaries told an abbreviated story of the hospital episode, but one which was largely inaccessible to anyone who was not a health professional. Discharge summaries were recorded electronically and accessible to hospital staff on its system. They were not necessarily given to patients and might not even have been written before a patient was discharged. A summary may have been sent to the patient's GP sometime after discharge, but we do not have data on this as we did not follow participants past the point of discharge. In one hospital network, discharge summaries were written only for patients who had been admitted to a ward. As a result, there may not have been a documented account of what had occurred in Emergency for patients who ended their journey there. However, on discharge, from either Emergency or a ward, some patients received a doctor's letter but this was not a consistent practice. A patient may also receive a nurse discharge sheet, documenting that they have had their possessions returned and with written advice to see their doctor. The inconsistent provision of written advice given to patients at one hospital network at the time of discharge and the timely preparation of electronically available summaries potentially posed a problem for some patients with cognitive disabilities and chronic conditions. For example, two participants, Patrick (PG52) and Corey (PG43), returned to hospital quickly after discharge, before the discharge summaries from their previous admissions were written and on the electronic system.

In another hospital network, discharge summaries were written in a more accessible and narrative format. The first page, under the heading 'summary' described the patient and reasons for attending the hospital. The information was written in plain English and readily understandable by the lay reader. For example, the Short Stay Unit summary for one patient (PG50) clearly stated why the patient was there, what happened, the tests ruling out more serious conditions, the medication given on discharge and directions to consult the GP. The documents included only a few acronyms and abbreviations, such as LMO (Local Medical Officer usually understood as a GP), and were relatively accessible.

Our review of discharge documents and the differences across hospital networks raises issues that warrant consideration by hospitals and further investigation including; barriers (such as organisational culture, time and technology) to providing patients and the people who support them with accessible discharge documentation; the potential dangers of not documenting a

hospital episode in an accessible way; how people with cognitive disabilities and the people who support them understand and follow through on treatment plans if they do not receive written information; and how the transfer of discharge information to patients and their support people can be improved or enhanced.

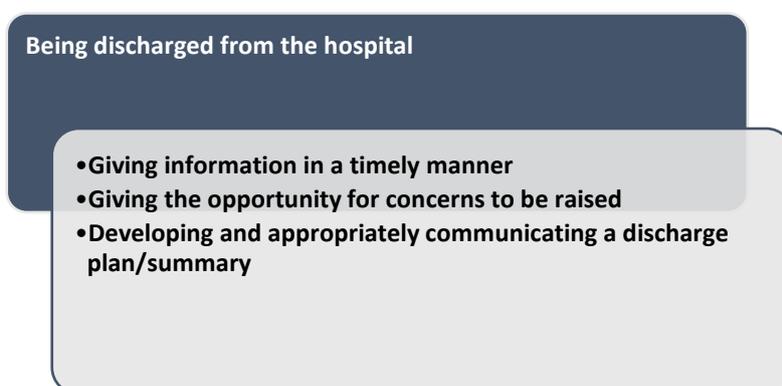


Figure 12. Promising practices being discharged.

Conclusions and propositions for action

This is the first large scale study in Australia that has investigated the hospital experiences of people with cognitive disabilities and those who accompany them, and which also included the perspectives of staff in both the hospital system and disability service systems. The findings demonstrate that people with cognitive disabilities are relatively high users of hospital services, particularly Emergency Departments. Our data suggest the quality of hospital care for people with cognitive disabilities has improved in recent years, and is no longer reflective of the predominantly negative experiences that families and disability support workers recalled from the past. Hospital experiences were however, inconsistent, and overall, we identified many more positive examples of staff accommodating the needs of people with cognitive disabilities than examples of poor or discriminatory practices. Notably, however, there was little evidence of system level accommodations or policies to embed, support or recognise adjustments made by individual staff. Accommodations fell into two broad categories, adjustment to practice and collaboration. First, individual hospital staff adjusting their interactions with the patient with cognitive disability and their strategies for things such as gathering information, conducting tests and performing treatment. Second, collaborations between hospital staff, family members and disability support workers whereby they shared expertise about care practices and utilised knowledge about patients with cognitive disabilities to reduce their stress and anxiety and maximise the quality of medical and nursing care.

The promising practices identified provide a solid basis for understanding the types of accommodations that need to be made for people with cognitive disabilities. Our data provides the basis for further investigation to identify how these individual accommodations can be incorporated at a system level, for example into hospital and/or disability service system policies, and systematically incorporated into standard practice and procedures. Families and staff from disability support services can also benefit from the knowledge we have developed about the expectations of those in the hospital or disability system at different stages of the journey which can enable them to better support the interests of a patient with cognitive disability about whom they care.

The findings of this study point towards a series of propositions about ways to ensure more consistent and positive care and experiences in hospital for people with cognitive disabilities.

Propositions

1. Service systems (disability support services, hospitals, ambulance service) and their staff and family members involved in hospital encounters of people with cognitive disabilities need greater reciprocal understanding of each other. In the particular, the role each plays in the day to day life of a person with cognitive disability or their involvement during a hospital encounter. This type of reciprocal understanding will facilitate shared expectations and collaboration during hospital journeys and address the following findings from this study:

- Hospital encounters for people with cognitive disabilities frequently involve hospital, ambulance and disability service systems.
- Many positive experiences and accommodations are underpinned by staff from each system collaborating with each other and valuing respective roles.
- The roles that families play in the lives of people with cognitive disabilities can be poorly understood by hospital staff, as they may not reflect their assumptions, particularly in the case of patients with cognitive disabilities who live in a supported accommodation service.
- Ambulance service staff could have more understanding of the consideration given to alternatives to going to hospital by disability supported accommodation staff and the immediate situation of caring for multiple clients they may be facing.

2. Orientation for people with cognitive disabilities, families and disability support workers to the expectations and primary tasks of different hospital staff at each stage of the hospital journey would be useful in unsettling previous negative experiences, helping to identify conflicting perspectives and ensuring greater shared expectations. This will address the findings from this study that:
 - Many disability support staff and family members have had negative experiences in the past where hospitals have not accommodated the needs of patients with cognitive disabilities. Such past negative experiences influence expectations about the quality of care.
3. The individual accommodations made by hospital staff should be recognised and systematically described in hospital initiatives about access for people with disabilities, so they can be shared with their colleagues and taught to new staff or in pre-service education. This would address the following problems identified in this study:
 - Many of the positive accommodations were made by individual staff members. These were rarely explicit or acknowledged as accommodations, and were more likely to be seen as related to the professional expertise of staff – as a result, experiences of people with cognitive disabilities were more inconsistent than they might have been as some staff were more proficient at making individual adjustments than others.
 - Most commonly, hospital staff accommodated the needs of people with cognitive disabilities by making adjustments to the way they communicated, interacted with the patient or their accompanying person, provided care, conducted tests or gave treatment, and used space. Many of these adjustments involved collaboration with family members or disability support staff, and recognition of the knowledge and roles they played in patients' lives. Making these types of accommodations depended on the flexibility, attitude and skills of individual hospital staff. They were often perceived as good practice or the actions of 'stand out' staff rather than being recognised as accommodations that can be shared with other staff.
4. At the system level in hospitals accommodations could be developed that would;
 - Address problems with the categorisation about living circumstances of people with cognitive disabilities in records systems that can lead to inaccurate information being recorded:

- reduce the uncertainty of hospital staff and provide guidance to them about the potential roles for disability support staff and families and ways of working in collaboration with them.
- increase the staff and system level understanding about the disability service system.
- enable staff to have a greater awareness of policy expectations about the rights of people with cognitive disabilities to be supported to make decisions about their own lives and equip them to translate this into their everyday practice.
- create a group of staff with specific expertise around rights based support for decision making when complex decisions about safe discharge and access to accommodation and support options have to be made.
- ensure greater transparency and consultation occurs around discharge planning and a discharge summary of recommended follow up action is available to all patients at the time of discharge.

These recommendations would address the following findings from this study:

- The exceptional case in this study that demonstrated the economic and human cost of failures to manage complex discharge and decision-making issues for a person with cognitive disability.
 - The very few system level accommodations that were identified other than the pilot Health Assistant program in one hospital network.
 - Hospital administrative systems that were not designed to adequately capture accurate information about the living and support contexts of people with cognitive disabilities or the key members of their support networks. Inaccurate and missing information has potentially negative implications at later stages of the journey and decision-making processes.
 - Discharge processes that were not transparent or inclusive and left patients and those supporting them to return home with considerable uncertainty, which can lead to unnecessary anxiety or confrontations.
5. Understanding more about the culture and operations of Emergency may provide a model for embedding promising practices in other operational units in the hospital that would enable them to better accommodate the needs of people with cognitive disabilities. This recommendation would address the following findings from this study:

- People with cognitive disabilities were more likely to experience difficulties when they were admitted to hospital wards compared to being in Emergency departments.
 - Emergency departments were more often perceived as offering good interactive and communication models for working with people with cognitive disabilities. Practices were sufficiently flexible to accommodate the needs and expectations of people with cognitive disabilities and their accompanying people, particularly patient home-based routines. They also appear to have cultures of collaboration and teamwork which support responsiveness to the diversity of people who present for assessment and treatment.
6. The significance of disability support workers who know patients with cognitive disabilities well to the quality of hospital encounters and the multiple and varying roles they may play should be unambiguously recognised in the policies of disability support services, by hospital systems and funding bodies such as the NDIA. This recommendation would address the following findings from this study:
- The potential roles that disability support staff from supported accommodation services are not well understood or recognised by disability service policies and this means that staff often act contrary to written policies.
 - Disability support staff collaborate with hospital staff by, for example, repeatedly sharing their knowledge about the immediate situation and past history of the patient, briefing them about support practice and sharing caring tasks, and adopting the role of advocate.
 - Disability support staff and family members of people with cognitive disabilities are not necessarily interchangeable, particularly for those who live in supported accommodation services, whose family members may not be aware of their immediate situation leading up to going to hospital.

Support, information, collaboration and knowledge - constructs to guide hospital practices

Promising strategies and processes evident through analysis of the large body of interview, observational and medical audit data collected over the three year duration of the study can be conceptualized through the four inter-related constructs shown in Figure 13: support, information, collaboration and knowledge. These four constructs reflect principles or

fundamentals of care to guide the development of hospital practices to improve the care experiences and health outcomes of people with cognitive disabilities.

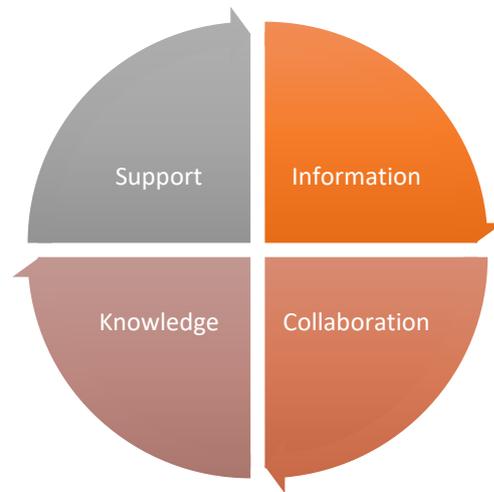


Figure 13. Maximising provision and receipt of high quality healthcare Support, Information, Collaboration and Knowledge

The primary need of people with cognitive disabilities during a hospital encounter, from its triggering event through investigation and successful resolution or management of the health problem to discharge is **support** across the journey. Support is required to accommodate the needs experienced by people with cognitive disabilities in a range of activities associated with the hospital encounter. During the data collection for this study promising practices to accommodate these needs were seen to be used and reported by people with cognitive disabilities, hospital staff, and the family members and disability support workers who accompanied people with cognitive disabilities at different times and in various environments during the hospital encounter. Promising support strategies were identified as those which were perceived as facilitating receipt of high quality health care and maximizing the wellbeing of people with cognitive disabilities.

The primary need of hospital staff as people with cognitive disabilities move through a hospital encounter is the ready availability of reliable, current and person-specific health and care **information**. Such information enables staff to provide high quality care and reassurance during assessment, diagnosis, treatment and discharge processes and facilitates a hospital event that is as comfortable and stress free as possible for the person. Resources and strategies that maximized information flow were evident from interview and observational data. In most cases the promising strategies used through the hospital encounter could be seen

to play a dual role. That is, strategies that effectively provided support to people with cognitive disabilities simultaneously had a positive impact on information flow.

Both the support needs of people with disabilities and the information needs of hospital staff were best met when health care practices were underpinned by a positive attitude towards **collaboration** between hospital staff members, the person with cognitive disability and family members and disability support workers who knew them well and accompanied them during the hospital encounter. The full range of support and information strategies including instances of collaborative practice extracted from the data are summarized in Table 7 according to the focus or context of the strategy: people/players in the hospital experience, hospital processes, the environment and resources.

Finally, lack of reciprocal **knowledge** across the hospital and disability systems acted as a barrier or could be seen to have a negative influence throughout the hospital experience having an effect on the ease of collaboration, the flow of information, the provision of support, and ultimately the outcome of the hospital encounter for the person. Knowledge gaps apparent in the hospital and disability systems with recommended changes are summarised in Table 8. For the most part, solutions to these gaps lie in collaborative education and development of resources to support ongoing staff development in the workplace. Such resources are particularly important in times of change as currently in play in the disability sector with the introduction of the NDIS and ongoing law reform in relation to decision making capacity and disability (Australian Law Reform Commission, 2014). It is our premise that building on practice through the development of resources and strategies to ensure effective support is provided, accurate information is available, collaboration is facilitated and knowledge is developed is essential to accommodating the health care needs of people with cognitive disabilities in the hospital environment.

Table 7. Promising support and information strategies identified in the research data

Context	Strategy
People	<p>Accompanying person (family member, disability support worker) who:</p> <ul style="list-style-type: none"> • knows the person well (personal details, likes, dislikes, ability, living situation) • tells hospital staff their role and relationship with the person • knows health background generally or has a prepared summary of this information (e.g., comorbidities, chronic conditions, ongoing medications, allergies, treating health practitioners) • knows current problem and precipitating circumstances • knows how to interact/communicate effectively with the person and can support others to do so • knows the person’s typical behavioural responses (positive and negative) • knows how to reduce the person’s anxiety and allay fears • knows strategies to reduce boredom during extended waiting periods • can contact others who know the person well and can provide support • can advocate for timely, individualized care • is prepared to provide information and explanations on multiple occasions and to multiple people <p>Hospital staff who:</p> <ul style="list-style-type: none"> • treat person with respect and dignity • are able to modify communication/interaction style to promote the person’s understanding • give their name and identify their role and function in the care process • know the role and the relationship of accompanying person/s • have basic knowledge about disability service systems, disability support services and the role of disability support staff • accept/support continuation of home-based personal care, medication, diet and meal time practices and preferences • respect and support the person’s right to participate in decision making • knows that cognitive disability can have an impact on a range of functions (e.g., comprehension, expression, memory- immediate, recent and longer term, judgement, inhibition, fatigue, mood) • provide clear messages and reassurance about what is happening in the moment and what to expect next • work collaboratively across the health team and with accompanying persons, family members and disability support workers • recognize and enlist the input of allied health professionals to address specialized areas of function and outcome • are prepared to repeat information about condition and progress on multiple occasions and to multiple people • recognise that provision of quality care to people with cognitive disabilities is likely to require additional time • regularly check the situation and do not leave the person unattended for long periods of time • notify the person if a change of staff or change of routine is taking place.

Table 7 cont. Promising support and information strategies identified in the research data (cont)

Context	Strategy
Processes	<ul style="list-style-type: none"> • include history and personal detail options that are sensitive to characteristics of people with cognitive disabilities (e.g., categories for living circumstances include the types of accommodation that people with disability are likely to have) • focus on continuity of care across hospital environments and discharge destinations • consider use of a clinical flag in the medical file to alert staff to the presence of cognitive disability that may act as a barrier to the success of the person’s encounter with the health system • include mechanisms and procedures to activate additional support when judged necessary by hospital staff • acknowledge the need for additional time required to provide quality care to people with cognitive disabilities • provide clear guidelines about responsibility of patient care including guidance about the role of family and disability support staff in delivery of patient care • enable nomination of a staff member to act as the primary contact person for the duration of the hospital encounter • facilitate feedback and timely responsiveness to concerns and complaints • focus on timely discharge to a safe destination of the person’s choice • require a written plan for ongoing management following discharge: what to do and when, what medication to take and when, who to see and when, action to take if problem returns/worsens
Environment	<ul style="list-style-type: none"> • flexible, space to move • quiet space away from crowded areas available • signage that can be seen and easily understood (e.g., large print, colour coded, pictorial, transparent symbols) • person can be located in line of sight of hospital staff • able to accommodate personal possessions that increase the person’s comfort level • avoid unnecessary change when the person is settled in a particular environment (cubicle, room, ward)
Resources	<ul style="list-style-type: none"> • access to low tech communication aids (e.g., pictorial pain scales and basic needs boards) • access to information/expertise about delivery of disability specific care (e.g., PEG management) or use of assistive devices (e.g., speech generating devices).

Table 8. Knowledge gaps and barriers with recommendations

Knowledge Gaps/Barriers	Recommendations
<p>Hospital System</p> <ul style="list-style-type: none"> • Disability service system information • Medical record system • Policy • Review and Development 	<ul style="list-style-type: none"> • Ensure staff access to information about the disability service system, disability services and the role of disability support staff • Ensure hospital record systems accommodate accurate documentation of disability specific background information • Trial introduction of a clinical flag that alerts hospital staff when a patient has cognitive disability so that staff are aware that they may need to adjust the way they interact/communicate with the person and increase the time they allocate to care procedures • Provide (policy) guidance about responsibility for care and the role of collaborative care with family and disability support staff including adjustment of care routines to accommodate home based routines • Provide (policy) guidance about adjustments to time, space/environment, procedures and staff ratios that may be needed during care for people with cognitive disabilities • Develop a targeted review process to evaluate practice including a feasible means of collecting feedback (positive and negative) from patients with cognitive disabilities and accompanying people. • Complete a targeted review of discharge policies, procedures and outcomes for people with cognitive disabilities • Embed mechanisms to recognise and share good practice strategies and effective adjustments across staff • Consider specific staff role/s (e.g., nominated contact person for patients admitted with cognitive disabilities, who works office hours and can access and interpret nursing and medical notes) • Build connections and have regular consultations with large disability support providers in the hospital network catchment area.

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Appendix 1: Checklists for delivering high quality care for people with cognitive disabilities in hospital

CHECKLISTS FOR DELIVERING HIGH QUALITY CARE FOR PEOPLE WITH COGNITIVE DISABILITIES IN HOSPITAL



ENQUIRIES

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Why use these checklists?

Background

A study of the journeys through **hospital care of people with intellectual disabilities and traumatic brain injury** identified that Support, Information, Collaboration and Reciprocal Knowledge are fundamental to delivering high quality hospital care, and thereby ensure positive experiences and good health outcomes for people with cognitive disabilities. The full report of the study is available from <http://hdl.handle.net/1959.9/563533>

Support

The primary need of **people with cognitive disabilities** across the hospital journey is **Support** to accommodate their needs. Support is required from the triggering event through investigation and successful resolution or management of the health problem to discharge. Support is provided by hospital staff, family members and disability support workers who accompany people with cognitive disabilities at different times and in various environments during the hospital encounter.

Information

The primary need of **hospital staff** in providing care to people with cognitive disabilities across the hospital journey is **Information**. Staff need readily available health and care information that is reliable, current and person-specific. Such information enables staff to provide high quality care and reassurance during assessment, diagnosis, treatment and discharge processes, and facilitates a hospital experience to be as comfortable and stress free as possible for the person.

Collaboration

The support needs of people with cognitive disabilities and the information needs of hospital staff are best met when health care practices are underpinned by a positive attitude towards **Collaboration between hospital staff members, the person with cognitive disability, family members and disability support workers** who accompany them.

Reciprocal knowledge

Reciprocal knowledge across the hospital and disability systems supports collaboration, the flow of information, the provision of support, and ultimately, the outcome of the hospital encounter for the person.

The checklists

Four checklists for ensuring high quality hospital care for people with cognitive disabilities were developed from the study. They are based on the good practices regarding Support, Information, Collaboration and Reciprocal Knowledge that were observed and heard about. These practices relate to the whole hospital journey – from the event that triggered a trip to hospital to discharge.

There are two checklists for the key people providing direct support during the hospital journey – **Accompanying People and Hospital Staff** – and two checklists for **Hospital Managers and Administrators** concerned with the Processes and Environments that underpin support good support, collaboration, and reciprocal knowledge.



Good Practice Checklist for Accompanying People, Family Members and Disability Support Workers

- ✓ **Has the patient been accompanied by a person who knows them well in terms their**
 - personal details
 - likes and dislikes
 - ability and needs
 - living situation
- ✓ **Has the accompanying person informed hospital staff of their role and relationship with the patient**
- ✓ **Does the accompanying person know or have a prepared summary of the patient's health background**
 - disability or disorder in addition the person's primary disability (e.g., autism, hearing impairment)
 - chronic health conditions
 - ongoing medications
 - allergies
 - treating health practitioners
- ✓ **Does the accompanying person know about the patient's current health problem**
 - what may have caused or contributed to it
 - what happened in the hours prior to coming to hospital
- ✓ **Can the accompanying person advise staff on how best to interact/communicate with the patient**
- ✓ **Can the accompanying person support others to interact/communicate effectively with the patient**
- ✓ **Does the accompanying person know the patient's typical behavioural responses (positive and negative)**
- ✓ **Can the accompanying person advise staff on how to reduce the patient's anxiety and allay fears**
- ✓ **Can the accompanying person advise staff on strategies to reduce boredom for the patient during extended hospital stays or waiting periods**
- ✓ **Can the accompanying person contact others who know the person well and can provide support**
- ✓ **Is the accompanying person confident to advocate if necessary for timely, individualised care for the patient**
- ✓ **Is the accompanying person available and able to provide information and explanations on multiple occasions and to multiple people**



Good Practice Checklist for Hospital Staff Members

- ✓ **Do staff treat the patient with respect and dignity**
- ✓ **Do staff modify their communication/interaction style to promote the patient's understanding**
- ✓ **Do staff give their name and identify their role and function in the care process**
- ✓ **Do staff know the role and the relationship of accompanying person/s to the patient**
- ✓ **Do staff have basic and accurate knowledge about**
 - disability service systems
 - disability support services
 - the role of disability support staff
- ✓ **Do staff accept/support continuation of**
 - home-based personal care
 - medication
 - diet and meal time practices and preferences
- ✓ **Do staff respect and support the patient's right to participate in decision making**
- ✓ **Do staff know that cognitive disability can have an impact on a range of functions**
 - comprehension and expression
 - memory- immediate, recent and longer term
 - judgment and inhibition
 - fatigue and mood
- ✓ **Do staff provide clear messages and reassurance about:**
 - what is happening in the moment
 - what to expect next
- ✓ **Do staff work collaboratively across the health team and with accompanying persons, family members and disability support workers**
- ✓ **Do staff recognise and enlist the input of allied health professionals to address specialised areas of function and outcome**
- ✓ **Are staff prepared to repeat information about the patient's condition and progress on multiple occasions and to multiple people**
- ✓ **Do staff recognise that providing quality care to people with cognitive disabilities often requires additional time**
- ✓ **Do staff check the patient's situation regularly and not leave the patient unattended for long periods of time**
- ✓ **Do staff notify the patient if a change of staff or change of routine is taking place**



Good Practice Checklist for Managers and Administrators about Hospital Processes

- ✓ **Do hospital records include history and personal detail options that are sensitive to characteristics of people with cognitive disabilities**

such as categories for living circumstances that include the types of accommodation likely for people with disability
- ✓ **Is there potential to use a clinical flag in the medical file to alert staff to the presence of cognitive disability**
- ✓ **Do hospital processes allow for mechanisms and procedures to activate additional support when judged necessary by hospital staff**
- ✓ **Do hospital processes acknowledge the need for additional time required to provide quality care to patients with cognitive disabilities**
- ✓ **Can a staff member be nominated to act as the primary contact person for the duration of the hospital journey**
- ✓ **Are there processes in place that facilitate feedback and timely responsiveness to concerns and complaints**
- ✓ **Do hospital processes allow for a focus on continuity of care**

across hospital environments (e.g. Emergency to Short Stay to Ward)

discharge destinations (e.g. the family home, disability group home, aged care)
- ✓ **Is there a focus on timely discharge to a safe destination of the patient's choice**
- ✓ **Is there a requirement for a written plan for ongoing management following discharge that covers**

what to do and when
what medication to take and when
who to see and when

action to take if problem returns/worsens
- ✓ **Do staff have access to information about**

the disability service system
disability services

the role of disability support staff



Good Practice Checklist for Managers and Administrators about Environment and Resources

- ✓ **Does the part of the hospital where the patient is located provide a space that can be flexibly organised**
- ✓ **Is there quiet space available away from crowded areas**
- ✓ **Can signage be seen and easily understood through the use of**
 - large print
 - colour coded, pictorial or other easy to understand symbols
- ✓ **Is the patient in line of sight of hospital staff**
- ✓ **Can a patient's personal possessions be stored in a secure place so that the patient can**
 - access their possessions
 - be reassured of the location of their possessions
- ✓ **Is it possible to avoid unnecessary change when the patient is settled in a particular environment (cubicle, room, ward)**
- ✓ **Does the patient have access to communication aids**
 - hospital pictorial pain scales
 - hospital basic needs boards
 - the patient's own communication aid
- ✓ **Is information/expertise about delivery of disability specific care (e.g. PEG management) or use of assistive devices (e.g. speech generating devices) readily available and accessible**