Executive Summary

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

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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 interrelated 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.