



**LA TROBE**  
UNIVERSITY

LIVING WITH DISABILITY  
RESEARCH CENTRE

# Increasing Hospital Access and Quality of Care for People with Cognitive Disabilities

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# Project Team

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Video of Frank and Cassandra on the Ward

# Hospital experiences of adults with cognitive disabilities

- Bigby et al. (2018)
  - Prospective study of 60 adults (50 with intellectual disabilities; 10 with acquired brain injury)
    - 35 months, 186 hospital encounters, mostly ED to Discharge
  - Quantitative data
    - Medical audits
  - Qualitative data
    - Interviews of patients ( $n=13$ , 15 interviews), family ( $n=49$ , 58 interviews) or disability support workers ( $n=18$ , 20 interviews), hospital staff ( $n=82$ , 88 interviews)
    - Direct observations ( $n=107$ )

# Select Quantitative Results

- Iacono et al. (2020)
  - 186 hospital encounters lasting from a few hours to 364 days
  - Most came in via the Emergency Department, with 62% staying beyond 4 h benchmark
  - Little evidence of poor care
    - 76% received a clear diagnosis (most often digestive problems – 75%)
    - 93% had a plan for post-discharge
  - Still
    - High rates of re-presentations (66%) with 26% within 72 hours for people with ID

# Qualitative Findings

- Problematic practices arose when
  - there was a failure to share knowledge and information
  - little coordination of care across family or disability staff and hospital staff
- Resulted in
  - failed discharge processes
  - extended hospital stays
- Positive but ad-hoc practices documented

# Translate research findings

## Aim

- Systematically embed the documented positive, but ad hoc **processes**
- Website Resources structured around a **framework** that captured these positive processes
  - Demonstrated through video clips based on what was seen or reported to have occurred in hospitals
  - Explanations according to relevant Framework elements
- Pathways
  - Hospital staff
  - Family/ close others
  - Disability Support Staff

# Pathways

Hospital staff



Disability staff



Family/ close others



Quality hospital care for people with cognitive disabilities



# Hospital Staff Pathway



**Knowing** about people with cognitive disabilities and the disability sector.

**Informing** - what they need to find out about and share in relation to this patient and accompanying others

**Collaborating** with other hospital staff, family, and disability support staff, always with the patient with cognitive disability at the centre.

**Supporting** the patient and their relative or disability support worker in ways that accommodate the patient's needs.

# Disability Staff Pathway



**Knowing** what you need to know about hospital processes.

**Informing** hospital staff about the patient and their needs.

**Collaborating** with hospital staff and family, always with the person with cognitive disability at the centre.

**Supporting** the patient and their relative in ways that accommodate the patient's needs.

# Family/ Close Other Pathway



**Knowing** what you need to know about hospital processes.

**Informing** hospital staff about your family member and their needs.

**Collaborating** with hospital staff and disability support staff, always with the person with cognitive disability at the centre.

**Supporting** your relative in ways that accommodate their needs.

# Before we watch Frank again!

- Cassie, Frank's daughter, is nonverbal, but uses some signs and pictures to communicate
- Cassie has had many previous hospital experiences
- She has trouble physically moving or adjusting her position or posture when in bed, and so needs help to reposition herself for comfort, but also to reduce the potential for choking.
- Frank's previous experiences of having to remain present and vigilant, and to take on the caring tasks himself, has caused him not to trust that hospital staff can or are willing to assist.



Video of Frank and Cassandra repeated

# Demonstrating the framework: Hospital and Family Pathways



Parents or other family members who have been the main carer for a person can become frustrated when they feel that person isn't receiving the best care. They have often had poor prior experiences, and may feel that they are the only ones who know how to best support someone with cognitive disability, especially when they have relied on the family member for both care and to advocate for their needs. Here, however, Frank has been open to Glenn's offer to help, and to be guided by Frank. This interaction shows mutual respect, providing a strong basis for collaboration.

# Waiting in ED: Hospital Pathway



Curtis and his dad, Ray.  
Waiting in ED





# Informing & Supporting: Hospital and Family Pathways



- Quinn let Ray know that there was still a long wait.
- She also acknowledged Ray's concern, and acted on both the information he provided her and responded calmly to his concern.
- Ray let Quinn know about how Curtis' behaviours showed that he was getting more distressed because of increasing pain and discomfort.
- Reassured somewhat himself, he could, in turn, reassure Curtis, whose distress could relate to a combination of pain or discomfort, and anxiety in being in an unfamiliar environment.



## Same scene ... different accompanying person



Curtis and Johnno, his disability support worker, waiting in ED



## Knowing and Informing: Disability Staff Pathway

### Knowing

Although most people have some experience of an emergency waiting area, how they work and factors that influence the wait may not be well understood by the public.

- The number of people in the waiting area doesn't reflect what is happening within the Emergency Department.
- Ambulance arrivals are not seen by people in the waiting area.
- Nurses need to judge the urgency of each patient's condition as part of the triage process.
- After the initial triage, patients are seen according to the urgency of their medical/ health problem rather than in the order of their arrival in the waiting area.

Hospital staff may not know how people with disabilities, especially those with communication difficulties, express pain and distress.

### Informing

You have an important role in explaining to hospital staff how the person indicates or communicates pain, discomfort or distress. In this scene

- Johnno repeated information he may have given earlier, but this time for a new nurse at the counter, whom he had not spoken to earlier.
- He explained to Quinn, the nurse, how he knew that Curtis was more distressed, and the possible reasons - suggesting the noise and uncomfortable chairs were problems.
- This information let Quinn know that Curtis would need a quiet place to wait.
- Johnno also informed Quinn that he was worried about being forgotten, letting Quinn know to reassure Johnno that he would not be
- Johnno, in turn, was able to reassure Curtis by letting him know that the Nurse was going to try to find him a quieter and more comfortable place to wait.



## Knowing: Hospital and Disability Staff Pathways



- Hospital staff may have incorrect or inaccurate information about the patient's living situation.
- They may think the patient has ready access to nursing or other medical care, such as is provided in Aged Care.
- This misinformation may be in the patient's hospital records.



## Informing: Hospital and Disability Staff Pathways



Jeff, Amelia, Jeff's disability support worker, and Jenny, getting ready for discharge

- Amelia wants to make sure that Jeff receives the health monitoring he needs when he returns home.
- When Jenny finds out that there will not be a nurse or other staff trained to monitor his temperature and organise for a blood test, she postpones discharge so that she can look at appropriate ways to provide for these in his home.
- Amelia reassures Jeff who wants to go home.

# Evaluation Process

- Stakeholder groups
  - People with intellectual disabilities
  - Disability support workers
  - Parents
  - Hospital staff

## Script Feedback

- Interviews and focus groups

## Video Feedback

- Interviews and focus groups

## Website

- Surveys
- Interviews

# Video Feedback

- Character portrayal
  - Support worker unrealistic
  - Support worker good advocate for client's needs
  - Parent too full on, unrealistic expectations
  - Parents need to be ready to advocate
  - Hospital staff, in the main, listen well

## Communication

- Good involvement of the person with disability
- Poor involvement of the person with disability (Jeff sleeping, talking over Cassie)
- Information should have been passed on earlier (contextual issues)
- Technical inaccuracies
  - Dr has long sleeves and ring
  - DSW would not change the bandage
  - Cassie's is too supine if she is at risk of choking



A pair of deep red, textured curtains are pulled back to reveal a bright blue spotlight shining on a dark stage floor. The text 'to be continued' is written in a white, elegant cursive font across the center of the scene.

*to be continued*





## Credits

- Thanks to
  - Maitree – special thanks to Damian - Director, Leigh – Director of Production, Lynne - sound, Caitlin- Production Coordinator, Bailey – Runner)
  - Callee, Gerard and Robert (~ Cassie, Jeff and Curtis)
  - Extras (especially Kate)
  - Jo (Building police)

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# References

Bigby, C., Douglas, J., Iacono, T. (2018). *Enabling mainstream systems to be more inclusive and responsive to people with disabilities: Hospital encounters of adults with cognitive disabilities report for the national disability research and development agenda* <http://arrow.latrobe.edu.au:8080/vital/access/manager/Repository/latrobe:42635?>

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