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UNIVERSITY

LIVING WITH DISABILITY  
RESEARCH CENTRE



# Enabling Hospitals to be more Inclusive and Responsive to People with Intellectual Disabilities

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# Background

- People with intellectual disabilities are frequent and costly users of hospital services (Balogh et al., 2010; Glover et al. 2019).
- International literature suggests they are at risk of mismanagement of health issues and poor quality care in hospitals (Kelly et al., 2015; Mencap, 2007; Heslop et al., 2013; Sheehan et al., 2016)
- Problems often associated with failure of hospital staff and procedures to make adjustments to accommodate their needs (Heslop et al., 2013; Iacono & Davis 2003; Gibbs et al., 2008; Iacono et al., 2014; Sheehan, 2016).

## Knowledge about Hospital Care in Australia

- Very little evidence hospital use or costs
- Two small Victorian studies - perspectives of the disability sector (Iacono & Davis, 2003; Webber, Bowers & Bigby, 2010)
  - delays or failure to diagnose or treat
  - disregard of carer information
  - poor management of medication for pre-existing conditions
  - inadequate support for eating, drinking and other aspects of personal care.
- Preliminary findings NSW disability-health data linkage study - 2005-2010, over 70% of people with intellectual disability who had accessed disability services visited ED up to 5 times ( $n=51,452$ ) (Reppermund et al., 2017)

# Aims

- Strengths-based approach
  - To identify individual ad hoc and systematic processes and practices – ‘Promising Practices’ – that accommodate the needs of people with intellectual disabilities and facilitate receipt of high-quality hospital care or obstruct it
- Participants – people with intellectual disabilities, paid support staff, family members and hospital staff
- Mixed methods – observation, interviews, medial record audit
- Three hospital networks in Victoria - two metro and one regional.
  - Metro 1 - Three hospitals, two 200-500 beds and third 100-199 bed category,
  - Metro 2 - One hospital 200-500 beds
  - Regional - 200-500 beds

# Methods

Primarily just in time recruitment

## 50 Primary Participants with Intellectual Disabilities

18- 74 years  
middle-aged male  
1-5 chronic health conditions  
46% living with family  
44% shared supported accommodation

95 separate observations  
12 interviews with 10 different people

## Tertiary Participants

19 Doctors, 20 interviews  
38 Nurses/Nurse Managers, 40 interviews  
16 Other Staff, 19 interviews

## Secondary Participants

47 Family members, 56 interviews  
18 Disability support staff 20 interviews

### Inductive analysis

- stages of hospital journey
- adjustments, facilitators or barriers of quality care

# Quantitative Snap Shot

## Episodes in 3 month period

- Mean 1.9 – range 1-9
- Most begun in emergency (ED)
- \*59% arrived by ambulance

## Quality of care indicators

- 62% triage coded urgent or semi urgent
- \*Average time spent 6.5 hours range 1- 30 hours
- 91% of episodes included diagnostic tests range – 0-7
- Very few re-presentations within 72 hours of discharge
- 75% clear diagnosis

## Destinations

- 46% ward- 31% home 19% short stay unit
- Plan for follow up 95%

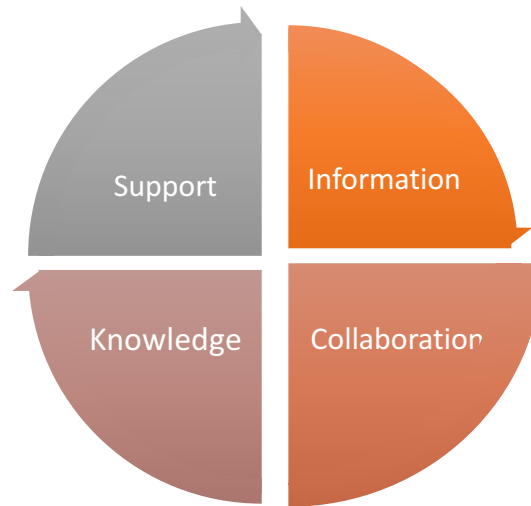
- \*More by ambulance than general population
- \*Few met ED national benchmark stay
- ED willingness to take extra time?

# Features of the Hospital Journey

- **Multiple stages** –interactions with staff – not necessarily connected to each other–requires repeated information exchange
- **Interfaces between people from different service systems** – different cultures, expectations, historic baggage, perspectives
- **Uncertainty about roles** – people do not necessarily understand each other and respect roles and are uncertain about own roles
- **Families often play a non normative role** – paid staff and family not interchangeable
- **Costs when things go wrong** re poor decision making and limited access to expertise - 136 days
- **Disability staff and family spend time trying to avoid hospital– and preparing**
- **Disability staff are often reliant on ambulance services**

# Fundamentals of good practice

- Primary need of the person with intellectual disability is **support** throughout the journey
- Primary need of hospital staff is **information** – reliable, current, person specific health and care information
- Support and information needs best met through **collaboration** between families, hospital and disability staff
- Lack of reciprocal **knowledge** by stakeholders about each other acts or adjusting practice acts as a barrier



# Support through the journey – Person Centred Practice

**Adjusting communication and interactions** with person –providing care, conducting tests, giving treatment

- Simplifying communication

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. (SW.PG56)

- Spending more time

Yep, for most patients with an intellectual disability you have to allow more time and whether that's just for communication purposes, for safety purposes or just care, providing care can take longer. (DR.PG51)

- Trying to understand feelings and sensitivity to the patient's vulnerability and need for reassurance

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. (FamilyPG51)

## **Flexible use of space**

- locating patients where they could be seen - allocating quieter spaces in ED.

There was a guy there who was creating a few problems and so they said we'll move him now that we've finished everything we'll move him...and he'll be in quiet area then



## Adjusting treatment

we gave her some pain killer before we had a look at the wound. 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's not invasive, doesn't require needles and things like that. (PG17)

We didn't really do any conventional physiotherapy kind of exercise...we kept it flowing pretty quickly so every five minutes or so, when she started to get distracted we'd just change the exercise 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. (Physio)

## Preparation

So, we made a list for every person, 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...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.

# Information –accurate & timely

- **Working out the best informant**

The referral wasn't very clear about why she was here. She wasn't verbally communicative. 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 (DR.PG75, E 2).

- **Basic information not always available for hospital or disability staff**

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)

The [discharge] 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

# Collaboration

- Recognise each others knowledge, roles and collective endeavour.
- Disability staff shared knowledge immediate and past history, briefed hospital staff about support practices, shared caring and adopted role of advocate - though mandate to do this variable

Just visited, to see how she is, get updates while we are there, give some assistance in relation to how to care for her. We actually have a policy - 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)

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)

- Hospital staff respect the knowledge of others, support carers and adjust their practice

Viola, the Emergency nurse saw her role as providing basic nursing care, but also in supporting his mother to care for him. Viola was careful to 'assist' his mother, rather than replace her. ...It was basic nursing care and then assisting mum. (PG63)

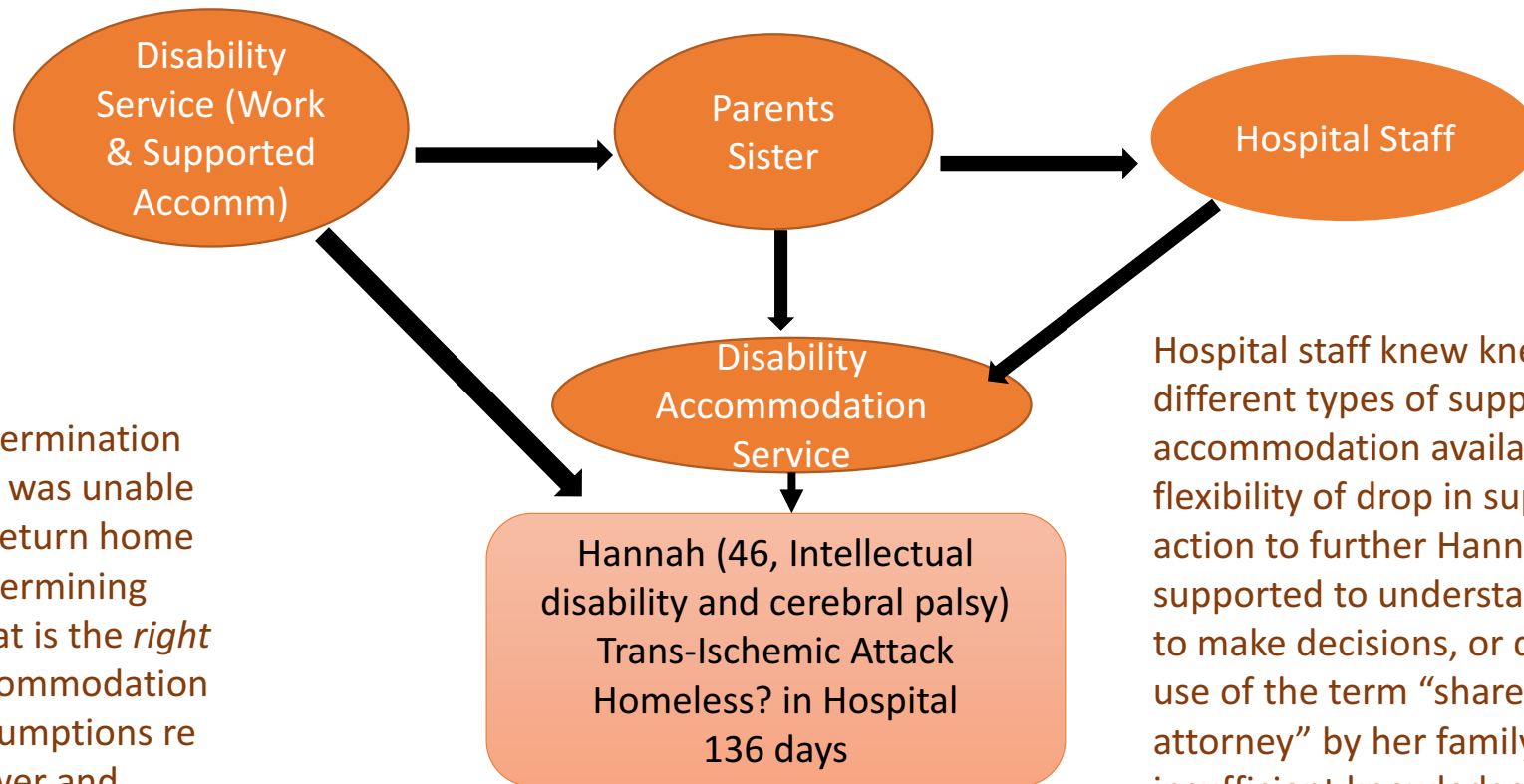
# Knowledge Gaps

- About responding to people with disabilities
  - 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)
- Absence of reciprocal **knowledge** across hospital and disability systems acts as a barrier to collaboration, flow of information, the provision of support
- For example, hospital system and staff vis a vis the disability system – role of workers, support available in different types of accommodation, policy perspectives about rights and decision making

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)

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. (PG30)

# Interface of separate worlds with little mutual knowledge



- Determination she was unable to return home
- Determining what is the *right* accommodation
- Assumptions re power and decision making

Hospital staff knew little of the different types of supported accommodation available or the potential flexibility of drop in support. No one, took action to further Hanna's right to be supported to understand her options and to make decisions, or question the mis use of the term "shared power of attorney" by her family. Hospital staff had insufficient knowledge about working with people with disability and expertise about disability services and policy to effectively lead the process.

# Need for mutual knowledge and understanding of different imperatives and perspectives

- **Accompanying people understanding that medical staff need**
  - very specific time sensitive information on changes in recent days and months
  - here and now rather than full historic background from reliable proxy
  - to identify reliable proxies familiar, responsive and attentive to patient, able to communicate and comfort the patient
  - to work on verbal rather than detailed written information
- **Medical staff understanding about**
  - nature of disability support system – types of supported accommodation
  - decision making rights – who and how
  - relationships between patient and support staff - not like that of nurse and patient - often long term and committed
  - families lack of trust from past experiences

# Serendipitous and Uneven Adjustments

- **Lots of good practice** – person centred, flexible, positive attitudes and high level professional skill
- **ED more flexible than wards**
  - culture of collaboration and team work which supports responsiveness to very diverse group
- **Good practice is Serendipitous** - not recognised – or shared - or taught
- **Few system level mechanisms** to ensure staff proficient in interactions or collaboration
  - **Admin system** not designed adequately to capture accurate information re living situation
  - **Cognitive disability not always flagged** – means no forewarning or statistics
  - **Discharge process not transparent** - leaves uncertainty – unnecessary anxiety

# Its nowhere near as grim as we expected - Need to codify and build on good practices

- Surprisingly high levels of satisfaction and praise for staff compared to past experiences
- Little evidence of poor quality care – representations, diagnosis, follow up plans
- Make more explicit adjustments by describing in policies, procedures, and training
- Reduce uncertainty and improve collaboration by increasing hospital staff and system level knowledge about the disability service system.
- Create a group of hospital staff with specific expertise as resource for others
- Better orientate family and disability staff to tasks of different hospital staff at each stage of the journey.
- Understand more about the culture of ED as an environment conducive to embedding promising practices
- Adjust ED benchmarking formula to reflect longer time to provide quality treatment for people with intellectual disabilities.
- Address problems with the categorization of living circumstances in records systems.
- NDIS funding and organizational policies acknowledge and ensure adequate support for the multiple roles staff 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.



# Thank You

Full report available

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. Melbourne: Living with Disability Research Centre, La Trobe University.

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# References