



**LA TROBE**  
UNIVERSITY

**Living with  
Disability**

RESEARCH CENTRE

Supporting inclusion of people  
with cognitive disability



**"Our agenda is not the same as the patient's"  
Emergency doctor and nurse accounts of treating  
people with cognitive disabilities**

**Christine Bigby, Quibell, Jacinta Douglas, Teresa  
Iacono**

# People with Intellectual Disabilities - Experience of Hospital Care

Systematic review of research most from overseas suggests (Iacono, Bigby et al., 2014)

- Health systems stand out as unresponsive to particular requirements of people with intellectual disabilities
- Frequent and costly users of hospital services (Balogh et al., 2005; Walsh et al., 1997).
- At risk of mismanagement of their health issues and receive poor quality care in hospitals (Mencap, 2007; Heslop et al., 2013)
- Problems with the quality associated with failure of hospital staff and procedures to adjust to accommodate needs (Heslop et al., 2013; Iacono & Davis 2003; Gibbs et al., 2008).
- Hospital staff have difficulties 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.
  - High reliance of family or paid disability staff to ensure basic needs are met
  - Continued evidence of negative attitudes by nurses and other hospital staff
  - Staff continue to lack knowledge of intellectual disability
  - Cultural differences can contribute to the experience of discrimination

# But what about Hospital Care in Australia

Little evidence hospital quality, use or costs

Two small Victorian studies - responsiveness of hospital perspectives of 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.

One off case studies

- risk of mismanagement and poor quality care in hospitals (Vic Public Advocate, Community Visitors Program, NSW Ombudsman)

NSW patterns of admission and readmission different for people with disabilities in general:

- not routinely identified in the system
- admissions are more frequent
- stays are shorter
- readmission rates are higher. (PWC, 2012)
- No research captures perspectives of hospital staff

# Why Adjustments Might Be Necessary

## Individual characteristics associated with impairment & Assumptions of the health system

- Difficulties with communication, comprehension, self care and management, decision making
- Poor self directed customers - reliance on others to navigate and mediate interactions
- Non normative living situation – congregate or group care
- Non normative family situations - adults living with parents
- Issues of informed consent and who makes decisions
- Syndrome specific health issues –and need for specialist knowledge
- Complex health needs or diagnostic overshadowing

## Yet

- Health professions have limited training about specific needs of this group
- Not routinely identified by hospital systems
- Not included in consumer participation initiatives

## Reasonable adjustments

- Poorly understood - Often not made - Systematic strategies often short lived (Tuffrey-Winne et al., 2013, 2015)

# Study Aims

- Explore some of the barriers to delivering quality hospital services.
- Identify ‘promising practices’ – that facilitate inclusion and responsiveness
  - Practical resources for staff in hospitals & disability services
  - Knowledge and tools to empower people with disabilities and their families

## Three hospital networks

- Two metro Melbourne Metro
- One regional
- Challenges – recruitment - consent - locating, interpreting complex institution as outsiders
- Work in progress – presentation today focus
  - Overview of data about contact with Emergency Depts
  - Qualitative data about agendas of different players – insights into understanding each others perspectives and achieving a better alignment

# Method and Participants

Just in time  
recruitment

## Primary Participants

50 people with intellectual  
disability  
Medical audits 129  
Observations 95  
Interviews 12

## Tertiary participants 79

Doctors 20  
Nurses 40  
Administrators  
and Ancillary Volunteers 19

## Secondary participants 76

Family 56  
Significant others incl.  
Paid staff outsider the hospital  
20

Variables	N 50
Gender	
Male	35 (70%)
Female	15 (30%)
Age	
Range	18-74
Mean (SD)	42.9 (14.5)
Number of Chronic Health Conditions	
Range	1-5
Mean (SD)	2.3 (1.3)
Living Situation	
With family	23 (46%)
Shared Supported Accommodation	22 (44%)
Supported Living	3 (6%)
Independently	2 (4%)
Hospital encounters within first 3 months of participation total	95
Range	1-9
Median	2
Mean (SD)	2.23 (1.83)

Variable	Total Encounters for ID Group Across all Sites (n =95)
Transport	
Ambulance	54 (57%)
Private car	41 (43%)
Escorting person	
Family	32
Paid carer	28
None	3
Unknown/ missing data	32
Triage Code	
1 Immediate attention	3
2 Within 10 min	12
3 Within 30 min	41
4 Within 60 min	36
5 Within 120 min	1
Not recorded	2
Re-presentations	
Frequency	45
Range	2-9
Mean	3.42
Median	3
Time between (days)	
Range	0-84
Mean (SD)	20.87 (22.67)



## "Our agenda is not the same as the patient's" – senior Emergency Doctor

- 'Having an agenda' is a term often used pejoratively as code for self-interest.
- But 'agenda' began in the 17<sup>th</sup> century as a sense of 'things to be done' (Oxford dictionary).
- Emergency Departments are sites of 'things to be done', but what things and by whom?
  - What are the agendas of ED hospital staff?
  - What are the agendas of people with intellectual disability while they are patients?

# Agendas - ED Doctors and Nurses

What do they want to know and need from patients with intellectual disability and their support people?

ED nurses has three main objectives:

1. To talk to the patient, make them comfortable, and prepare them for being seen by the doctor.
  2. To take routine, hourly observations of the patient, and other tests as directed by the doctor.
  3. To keep the patient safe.
- ED nurses described working flexibly with patients and their support people, with some saying they try to maintain care and dietary practices the same as usually done at home.
  - But much is beyond their control. They are often unable tell patients what is wrong with them, or how long they will wait to see a doctor.

## Emergency Doctors 'things to be done' consist of a series of chronological tasks:

1. To acquaint themselves with the patient's history.
2. To talk to the patient.
3. To take a history, which is often focused on the time-sensitive lead-up to presentation at the hospital.
4. To perform an examination and tests, where necessary.
5. To identify what they believe is going on – to formulate their observations as medically useful information – and with colleagues make a diagnosis of the most likely cause and treatment plan.
6. To treat the patient or refer them elsewhere for treatment.
7. To keep the patient safe.

ED doctors will not necessarily know what is wrong or how to treat the problem. Their role is to investigate and keep the patient medically safe.

# What the Doctor Agenda Requires from People with Intellectual Disability and the People who Support them:

- Timely information about the person and any changes in the lead up to their hospitalisation.
- Information about who the person is, what they are like, their longer medical history (which may or may not be relevant to the current hospitalisation).
- Understanding and patience from the person and their support people about how ED works and the time it is likely to take.
  - That ED staff have to go through practices to ensure they get diagnosis and treatment correct, which might mean the person has to repeat their story multiple times and/or have tests and/or wait for results and/or wait for specialists and/or wait for a bed.
  - That they are caring for multiple people at once and that this means it might take a long time, but that they are keeping people safe.
- That ED staff might not be able to fix the problem.
- Support from their ED peers to better support people who do not want to stay in hospital or who need treatment or space modified to accommodate them in ED.

# What ED Staff Think People with Intellectual Disability Need While they are Patients

- To be spoken to with courtesy and respect, and to be listened to and/or closely observed for nonverbal communication.
- To have their presenting condition fully investigated, understood, treated or referred, as anyone else would be.
- To have staff separate medical and social issues, and respond to them appropriately.
  - They are alert to the fact that people present to ED for multiple reason not all of which are clinical concerns.
- To be kept safe within the hospital.
- To have someone speak up and advocate for them.
- To have someone thinking about their whole hospital encounter and if the treatment will work/continue when they go home.

## What People with Intellectual Disability say Mattered to them while Patients

- Friendly, affable, nice and comforting hospital staff - nurses who would engage in a joke with them. Despite the busy and stressful environment nurses were identified as good at comforting small-talk.
- While Terrance said most nurses asked him how he was, both he and his mother Fiona spoke more positively about a nurse who chatted and joked with him

*T They just said, “How are you? How are you and your foot?”*

*F You had the male nurse.*

*T Yeah. And I said—*

*F I was just going to say he was getting married, and you said to come in with a veil on*

*T Yeah, he did. He had a veil on the next morning he came in wearing this on his last day. (Terrance and his mother Fiona).*

- Hospital staff who took their time to talk to the person and use language they can understand, were remembered.

# What people with intellectual disability say mattered to them - continued

- Hospital staff who ask permission for tests, tell them what is happening next, and contact their support people when needed.
- 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 did have some trouble with some of the words they used:

*“Some of the words you come up with [in hospital], it’s a bit hard to comprehend. And see even that word what I just said [comprehend], it’s a word I don’t use.”*

- Food and drinks that are pleasant and easy to eat or drink.
- Being familiar with the hospital and knowing what to expect, such as having gone there before.

*I: So what was the hospital encounter like for you for that five days?*

*T Good.*

*I: Good? Why’s it good?*

*T Well, because. Because I’d gone there before...A fair while ago too.*

*F ...He’s been up there about three or four times. (Terrance and his mother Fiona.)*

# Incompatible Agendas: Complex Patients

- ED doctors recognised some patient agendas that were incompatible with their role.
- Corey presented at ED 15 times during the study - often complaining of hip pain.
- He was well-known to triage staff, but concerns not dismissed by ED doctors. Had conducted all the medically relevant tests, including CT scans, each time.

*“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.” – Dr Mason, treating ED doctor*

- Dr Mason at encounter 10, incompatible agenda with Corey’s
- Corey expected medical investigation.
- Dr Mason, however, explained that his treating agenda would not include more high risk tests that Corey did not need but would include admission as an inpatient:

*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.*



# Discussion

- Very different picture from the literature – mostly competent skilled staff
- Different agendas – mostly compatible agendas - what staff think people with intellectual need and what they expect of staff
- Many examples of adjusting communication, approach to information seeking, environment and treatment
- Clinical attention on presenting condition and ED staff make efforts to distinguish it from intellectual disability and other pre-existing morbidities, contrary to fears of diagnostic overshadowing
- Ideas about change that flow from understanding ED doctor and nurse's agendas.
- ED doctors and nurses need accurate and timely observations of the patient in recent days.
- Family and support workers treated as interchangeable by ED staff and policies in group homes.
- So long as a person is present until the person is admitted, it does not matter who that person is
- As soon as a family member is present, the support worker is allowed to return back to their house shift.
- Support worker often spent time with the patient in the days or hours leading up to their hospitalisation and it is they who can offer the most medically useful information to the ED staff to understand and assess what is wrong.

# Conclusions

- Agendas of ED staff might only be partially understood by people with intellectual disability and supporters
- ED staff might only partially understand agendas of supporters and people with intellectual disability
  - particularly who is who and what their role is
- Transparency might aid difficult discussions, rather than leaving people feeling unheard or misunderstood.
- Some agendas might be incompatible with their professional role or capacity to respond to them, as was the case with Corey and Dr Mason.
- Insights into understanding perspectives from quite different systems and world views – help in adjusting expectations and complementarity rather than conflict.

Thank you

## Contacts:

[C.Bigby@latrobe.edu.au](mailto:C.Bigby@latrobe.edu.au)

[J.Douglas@latrobe.edu.au](mailto:J.Douglas@latrobe.edu.au)

[www.latrobe.edu.au/lids/](http://www.latrobe.edu.au/lids/)

