



LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE

Resources for strengthening hospital inclusion of people with intellectual disabilities

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**Research Translation:
Enabling Hospitals to be more Inclusive and Responsive
to People with Intellectual Disabilities**

Aims

People with intellectual disabilities are frequent and costly users of hospital services.

Aimed to understand more about hospital experiences of people with intellectual disability from their perspectives and others involved in the hospital journey

Strengths-based approach

- 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.

Methods

Primarily just in time recruitment

50 Primary Participants with Intellectual Disabilities

18 - 74 yrs, av. 42.9
 most middle-aged males
 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

Features of the Hospital Journey

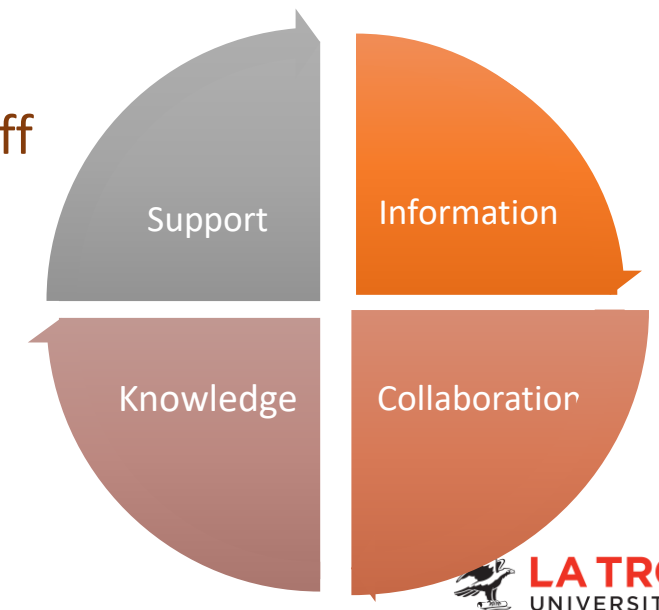
- **Multiple stages** – interactions with many staff – not necessarily connected to each other–requires repeated information exchanges with different staff
- **Interfaces between people from different service systems and involved differently in the person's life** – family members, disability support staff, ambulance and hospital staff – have different cultures, expectations, and perspectives
- **Uncertainty about roles** – people do not necessarily understand or respect each other's roles or the understand systems they are part of - and are uncertain about own roles –
- **Historic baggage** - disability support staff and family members have had negative experiences in the past which influence expectations about the quality of care.
- **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 day stay
- **Disability staff and family spend time trying to avoid hospital and preparing** – not well understood by others

Good practice is serendipitous and uneven

- **Identified lots of good practice that adjusted care and treatment to the needs of people with intellectual disabilities** – person centred, flexible, positive attitudes and high-levels of professional skill
- **Adjustments were Serendipitous** - not recognised, shared or taught simply seen as good practice
- **Adjustments depended on skill, attitudes and flexibility of individual staff**
- **Staff in emergency more flexible than wards**
 - culture of collaboration and team-work which supports responsiveness to very diverse groups
- **Few system level mechanisms** ensure staff are proficient in making adjustments, 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** – means uncertainty – unnecessary anxiety

Fundamentals of Good Practice

- A primary need of the person with intellectual disability is **support** throughout the journey - support occurs in the interactions between the person and others involved in caring or treating or accompanying them
- A primary need of hospital staff is **person specific information** – that is reliable, current, about health and care
- A primary need of all stakeholders (person, family, hospital and disability staff) is **knowledge** about each other and their systems
- Support, information and knowledge needs are best met through processes of **collaboration** between families, hospital and disability staff
- There is a dynamic interplay between these four elements



Translation of Research into Training Resources



Project Team

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Reference Group

- **Bendigo Health**
- **Golden City Support Services**
- **Eastern Health**
- **Yooralla**
- **Parent**
- **Person with Intellectual Disability**

Stakeholders

Hospital staff
Disability support staff
Family
People with Intellectual disability

Funder

**National Disability Insurance Agency/
Department of Social Services**

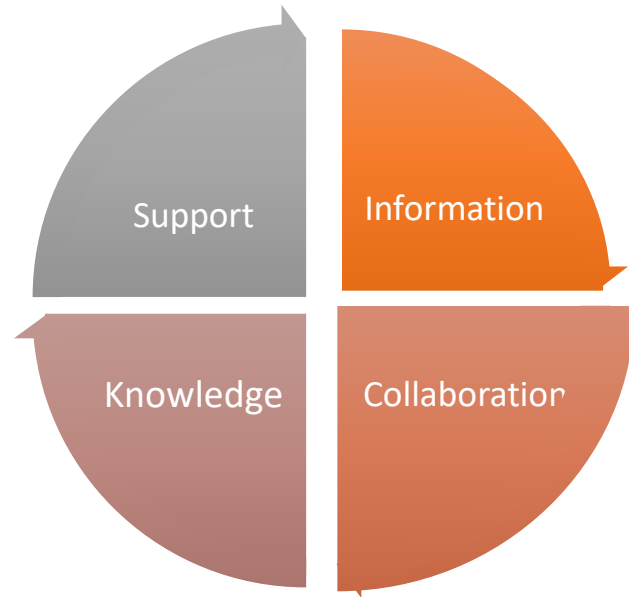
Mainstream Capacity Building

Training resource: Quality Hospital Care for People with Intellectual Disabilities

Aim

- Systematically embed the documented positive, but ad hoc **processes**
- Website Resources structured around the **framework**

Fundamentals of Good Practice



Framework for Quality Hospital Care



Key Features: Pathways



**HOSPITAL
STAFF**



**DISABILITY
SUPPORT STAFF**



FAMILY



**INTELLECTUAL
DISABILITIES**

Key Features: Introduction



Key Features:



The Framework



The content of this resource is from research following the journeys of people with intellectual disabilities through metropolitan and regional hospitals.

This research showed that quality hospital care results from the interplay of four elements:

- Knowing about hospitals and their processes
- Informing and sharing information relevant to this patient
- Collaborating with hospital staff and any involved disability support staff
- Supporting the person through the hospital journey

Key Feature: Authenticity



Key Features: Video clips – Authentic scenes



Key Feature:

Applying the Framework



Knowing that

- Some adults with intellectual disabilities live in group homes or other types of supported accommodation; most live with their families.
- The accompanying person is often a disability support worker or family member.
- Their past hospital experiences may have been negative.
- Pain, discomfort and anxiety can interfere with how a person communicates.

Key Feature:



Informing

You will need to ask the accompanying person about

- their relationship to the patient
- their availability to stay with the patient
- how the patient communicates pain or distress
- what the person is likely to understand and how they usually communicate

You will need to talk to the patient and accompanying person about

- possible long wait times
- strategies you have available to reduce their anxiety

Key Feature:



Collaborating is when you

- are willing to answer questions from the accompanying person
- ask questions that will help you understand the role of the accompanying person
- respond to their concerns and offer possible solutions

Key Feature:



Supporting

Patients with intellectual disabilities will feel supported when you

- talk to them directly and ask permission to direct questions to the accompanying person
- make adjustments to reduce their anxiety or discomfort

The accompanying person will feel supported when you

- respond to their anxiety with calmness
- tell them what you can about wait times
- attempt to resolve current or anticipated problems
- show that you value their role

Key Feature:

Summary

Knowing something about the disability service system and people with intellectual disabilities will be useful background when a person with intellectual disability comes to the Emergency Department.

A person with intellectual disability who presents to an Emergency Department is likely to be accompanied by a family member or disability support worker. It is important to establish that person's role and to collaborate by sharing information that will assist with efficient appraisal of their condition. At the same time, you need to demonstrate respect for and inclusion of them and the accompanying person. Quality hospital care for patients with intellectual disabilities requires implementing the framework from the first point of contact with the patient and the person with them.

You can find more information under [Resources](#) about intellectual disability, where people with intellectual disabilities live, and an infograph on who accompanies people with intellectual disabilities to when they go to hospital.

Key Feature:



Activities

These are provided to support your learning, individually or in a group. You can write responses in the workbook sections available for download.

Individual

Group

Download Workbook Section

In your workbook, write your responses to the following:

1. Identify who might accompany patients with intellectual disabilities to a hospital Emergency Department.
2. List the types of information that an accompanying person could tell you about a patient with intellectual disability.
3. Explain the reason for directing your communication to a person who you think has intellectual disability.
4. Describe how you could obtain the information you need as efficiently as possible, while still demonstrating respect.

Key Feature: Resources

The framework and information in Resources come from research conducted by members of the Living with Disability Research Centre in Victorian metropolitan and a regional hospital.

Choose

- **Downloads** for Infographic summaries of information from this research and fact sheets, and videos and a full workbook for each of the Hospital Staff, Disability Staff and Family pathways;
- **Other Resources** for access to the full report and associated checklists, a published article and links to other learning resources from the Living with Disability Research Centre; and
- **Credits** for details of individuals and organisations involved in creating this resource, and funding.

Evaluation

Survey

- Stakeholder group/ demographics
 - Experience in supporting a person with intellectual disability in hospital
- Applying the framework to a video scenario
- Engagement with and usefulness of resource components
- Ease of use

Interviews

- Explore application of framework and other aspects of the resource from stakeholder groups
- Potential for training
- Reactions and comments from people with intellectual disability

Reference Group were key in
Recruitment

Survey findings

58 respondents

- 14 Hospital staff (23.73%)
 - 50% have had no training about people with intellectual disability
- 32 Disability support staff (52.54%)
 - 53% have supported someone with intellectual disability to go to hospital - 70% in the last 2 years
 - 71% have had no training about supporting clients who go to hospital
- 13 Family/friend (22.03%)
 - 85% have had experience accompanying/being with that person during a hospital experience – 73% in the last 2 years

Expectations of learning from resource were mostly regarding

- Supporting and advocating for people with intellectual disability
- Hospital processes and collaboration with hospital staff

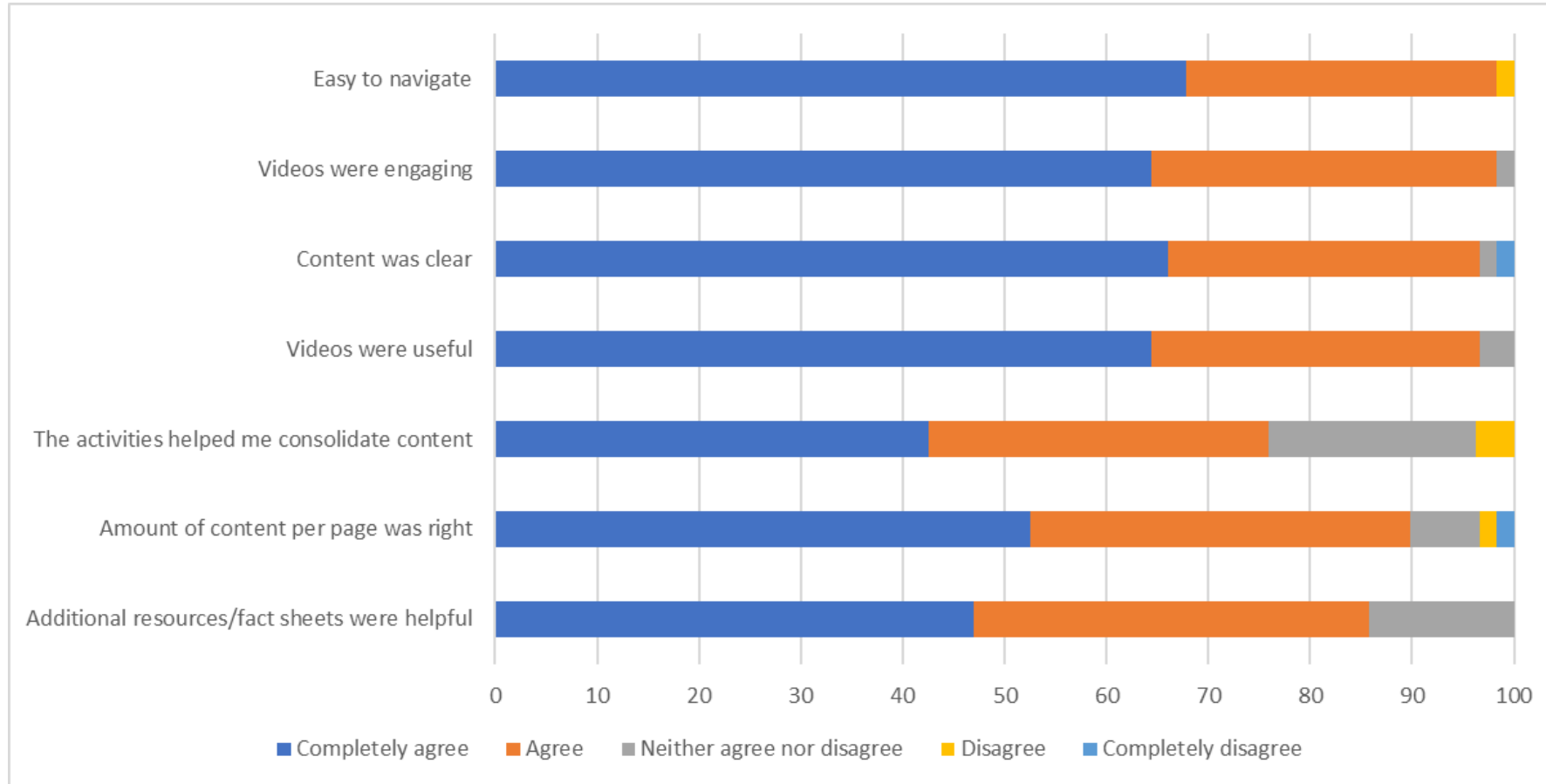
"Supporting people with intellectual disability to get the most of their supports, to get the right treatment and fair treatment. To have their voices heard. To assist hospital staff in best supporting and treating a person with intellectual disability" (Disability Support Staff)

"I expected to learn more about the experiences of people with disability accessing hospital services, the challenges that they face, as well as the challenges that hospital staff face" (Family/ Friend)

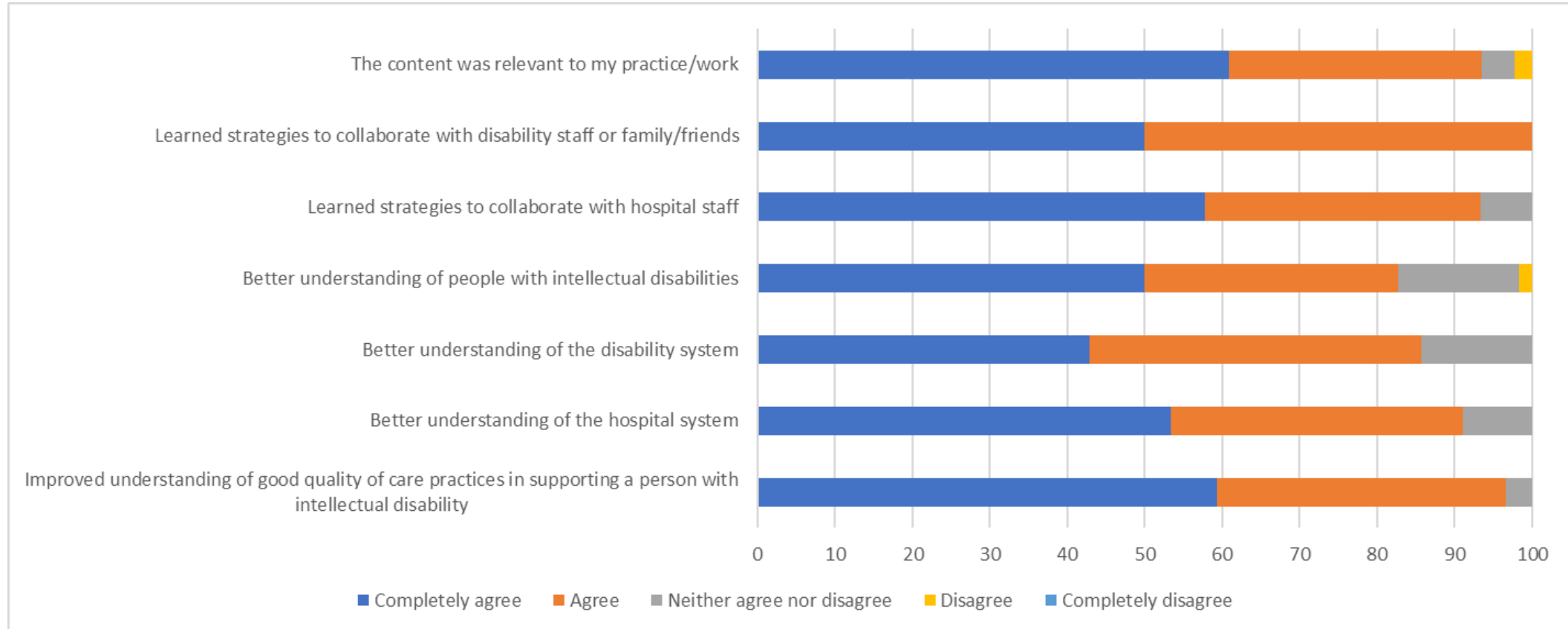
76% reported that their expectations were met

22% reported that their expectations were somewhat met

Rating aspects of the resource



Rating content from the resource



Improved preparedness after completing the resource was mostly regarding

- Knowing to/how to communicate and collaborate to support the person with intellectual disability
- Advocating for the person with intellectual disability
- Knowledge of hospital systems and procedures

"I feel more prepared in engaging in collaborative communication with hospital staff when I support a client to present at hospital for treatment" (Disability Support Worker)

"More understanding of how to communicate with disability workers, strategies to use to communicate with people with intellectual disabilities, and ways to show I am listening and taking on board family/support worker concerns" (Hospital Staff)

45% reported feeling a lot more prepared

50% reported feeling a bit more prepared

93% would recommend this resource to others

Interviews: Hospital Staff

I ... really liked the journey, from waiting in Emergency through to ward stays and discharge. That definitely seemed to cover the majority of the issues we come across.

I think definitely providing ED staff with this information would really help because I know a lot of the issues such as healthcare workers getting confused between an SDA or a disability combination at boarding house and nursing homes, we come across that really frequently. So, I felt that that was really clearly identified in this resource.

I loved the use of AAC in the videos because that really shows how they can meet the person at their level.

I think the ease of use I think was really important for me ... quite time-poor, as are most clinicians on the ground, so I think that the time it took to go through it, it was quite succinct, very easy to use, easy to read.

And I think that's probably more the way that I've seen learning be delivered previously, where it's like, "Well, we're going to show you a really worst-case scenario, and you've got to tell us what's wrong," whereas this is the opposite, where it's like, "Actually, this is best practice."

Interviews: Family

It's good you have that circle diagram, it's quite easy to remember and what we would use. Yes, I think what I took away from it is that it's important that you verbalise and clearly articulate what your needs are during that situation."

I think from a carer's perspective or a support person's perspective, certainly it does make you pause and reflect on what actions you could take. And the videos, I watched all of them very carefully and I think that they were good examples of how you might articulate your needs and come to an agreement.

Final Words



Thank You



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Robert



Callee



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