



# QUALITY HOSPITAL CARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES

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About this Learning Resource



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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 as a translation of our research

## Aim

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

# 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 infographic 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

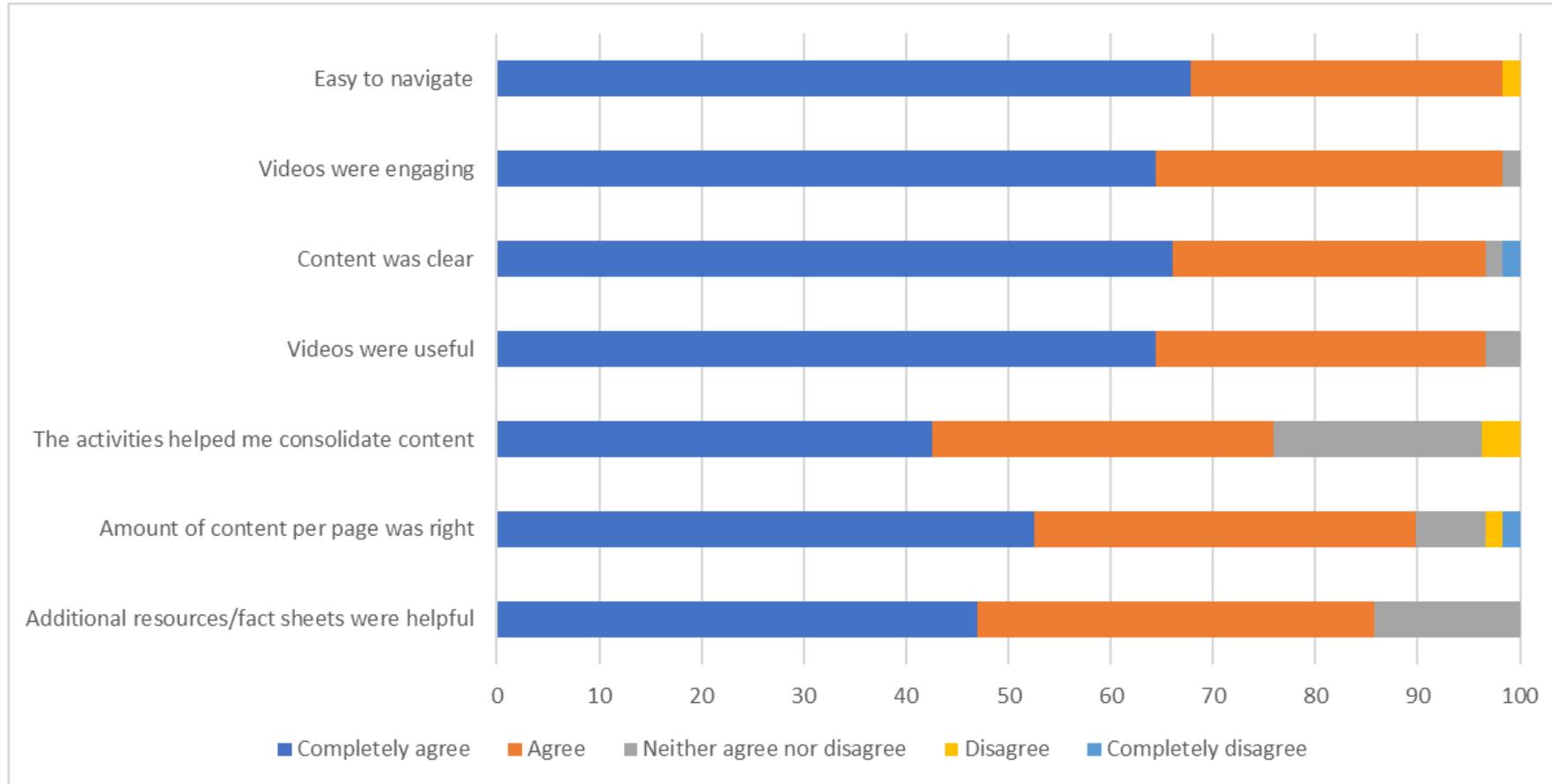
*"Supporting people with intellectual disability to get the most of their supports, to get the right treatment and fair treatment. To have their voices heard. To assist hospital staff in best supporting and treating a person with intellectual disability"* (Disability Support Staff)

*"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)

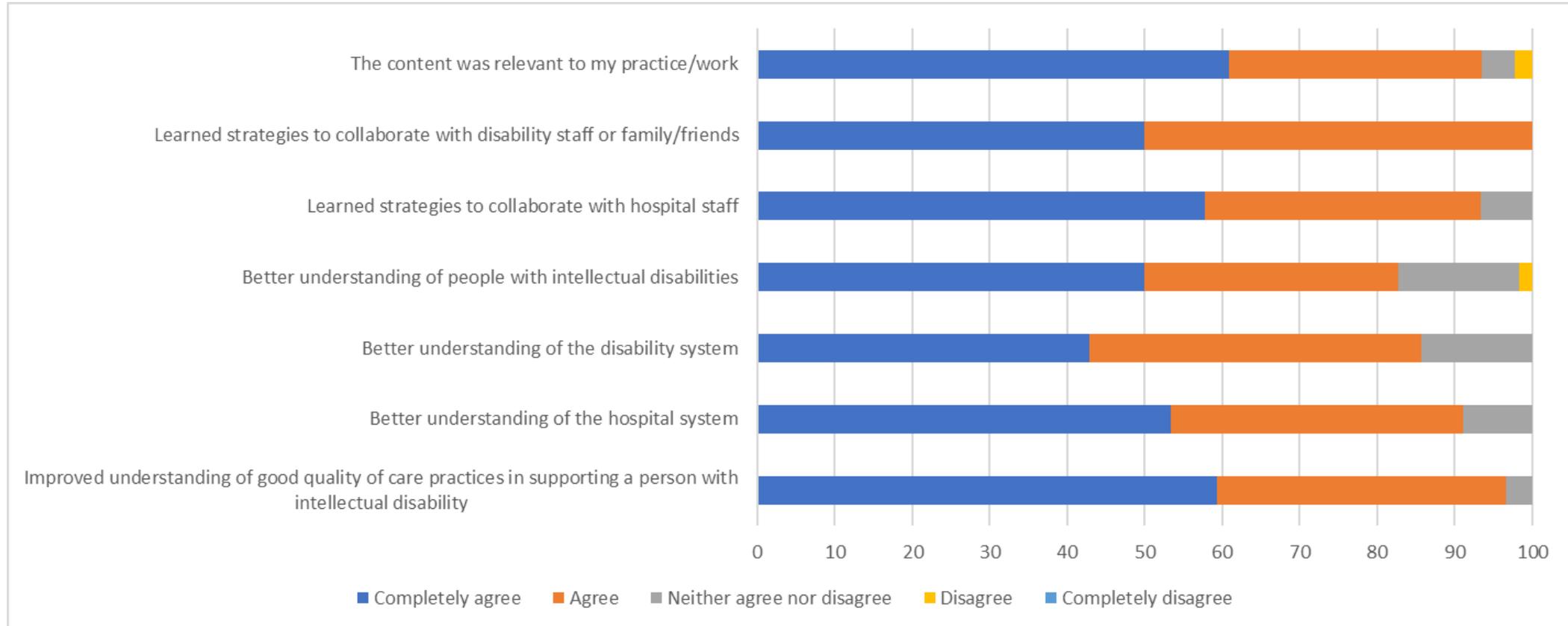
**76% reported that their expectations were met**

**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

*[T]here have been hospital visits in the past, I think when [name] was much younger – so they were much easier in a way...but thinking about what that process would be like now, I think there'd be a lot of significant challenges with him being in that environment and long wait times and things like that. I can definitely see the value of using something like that to prepare us for that experience because it would be quite a challenging one.*

*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



Callee interview

# Thank You



**Gerard**



**Robert**



**Callee**



<https://www.hospitalinclusion.au/>

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