



LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE

Quality Hospital Care for People with Intellectual Disabilities



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

What was this project about?

We developed online and freely available teaching resources

- Our aims was that people would use theme to systematically embed positive, but ad hoc **processes**, that we found when conducting a study into the experiences of people with intellectual disabilities in hospital
- The findings from our studyhelped us develop a **framework** for quality hospital care
- The website resources are based on this framework.
- If you want to read more about this research, you can download the report available from <https://www.hospitalinclusion.au/other-resources>

Four fundamentals of good practice in providing quality hospital care formed the basis of our Framework – shown in our logo



Key features of our website

- The following slides describe the key features of the website, which is where all the training resources can be found.

Key Features: Pathways – you select the pathway most relevant to you or your role



**HOSPITAL
STAFF**



**DISABILITY
SUPPORT STAFF**



FAMILY



**INTELLECTUAL
DISABILITIES**

Key Features: An introduction for each pathway provides an overview of what you will learn about



Key Features: Here we explain each element in the Framework

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

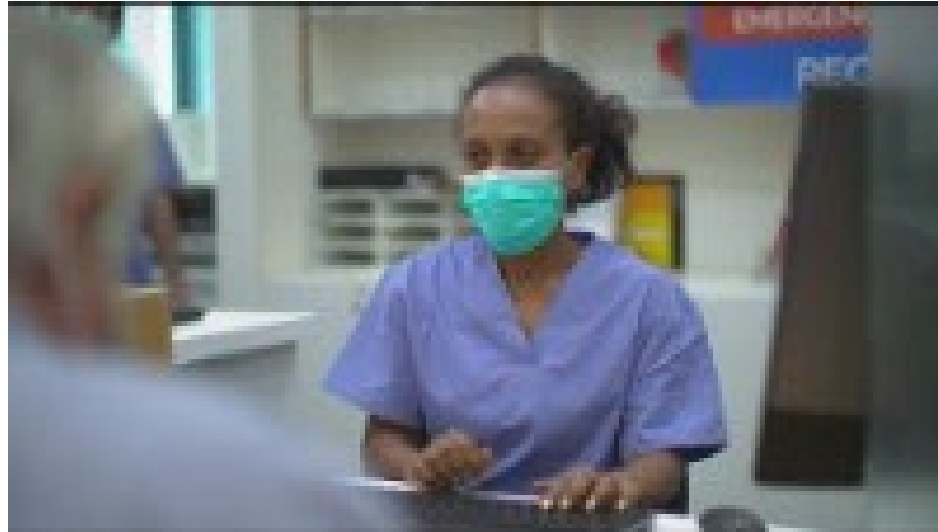
Key features: Authenticity of the Video Clips

- We wrote scripts from our research that showed real-life experiences, but with good practices. Then we asked people with disability, hospital staff, disability staff and family members of people with intellectual disability what they thought of our scripts. We made some changes to the scripts.
- Maitree, a professional media company, filmed actors in places that showed life-like hospital spaces
- Our actors included people with intellectual disability
- Then we asked people with disability, hospital staff, disability staff and family members of people with intellectual disabilities what they thought of our video clips. Maitree did some final editing of the videos.

Key Feature: Hospital Spaces



Key Features: Video clips – Real life situations involving people with intellectual disabilities



Teaching and Learning

- We organised the video clips in each pathway to show situations in each part of the hospital . We explained parts of the Framework in relation to each video clip.
- We wrote a summary for each situation
- We wrote some activities that you can do as part of a group or on your own
- You can see how these teaching and learning elements are presented in the following slides

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

This section has additional information or 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

- We wanted to know what people who might use our website think about it by
 - Asking people to go through their pathway then answer a questionnaire
 - Asking people to tell us more during an interview
- The following slides are about our evaluation

Evaluation

Survey – it had questions about

- Stakeholder group/ demographics
 - Experience in supporting a person with intellectual disability in hospital
- Applying the framework to a video clip
- How useful they thought the website resources would be
- How easy it was to use the website
- The following slides provide some key findings

Interviews – we talked to people to

- Find out more about relevant and useful the website resources are
- If the website resources would be useful for training in hospitals or disability services

Survey findings

59 respondents

- 14 Hospital staff (23.73%)
 - 50% have had no training about people with intellectual disability
- 32 Disability support staff (54.24%)
 - 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

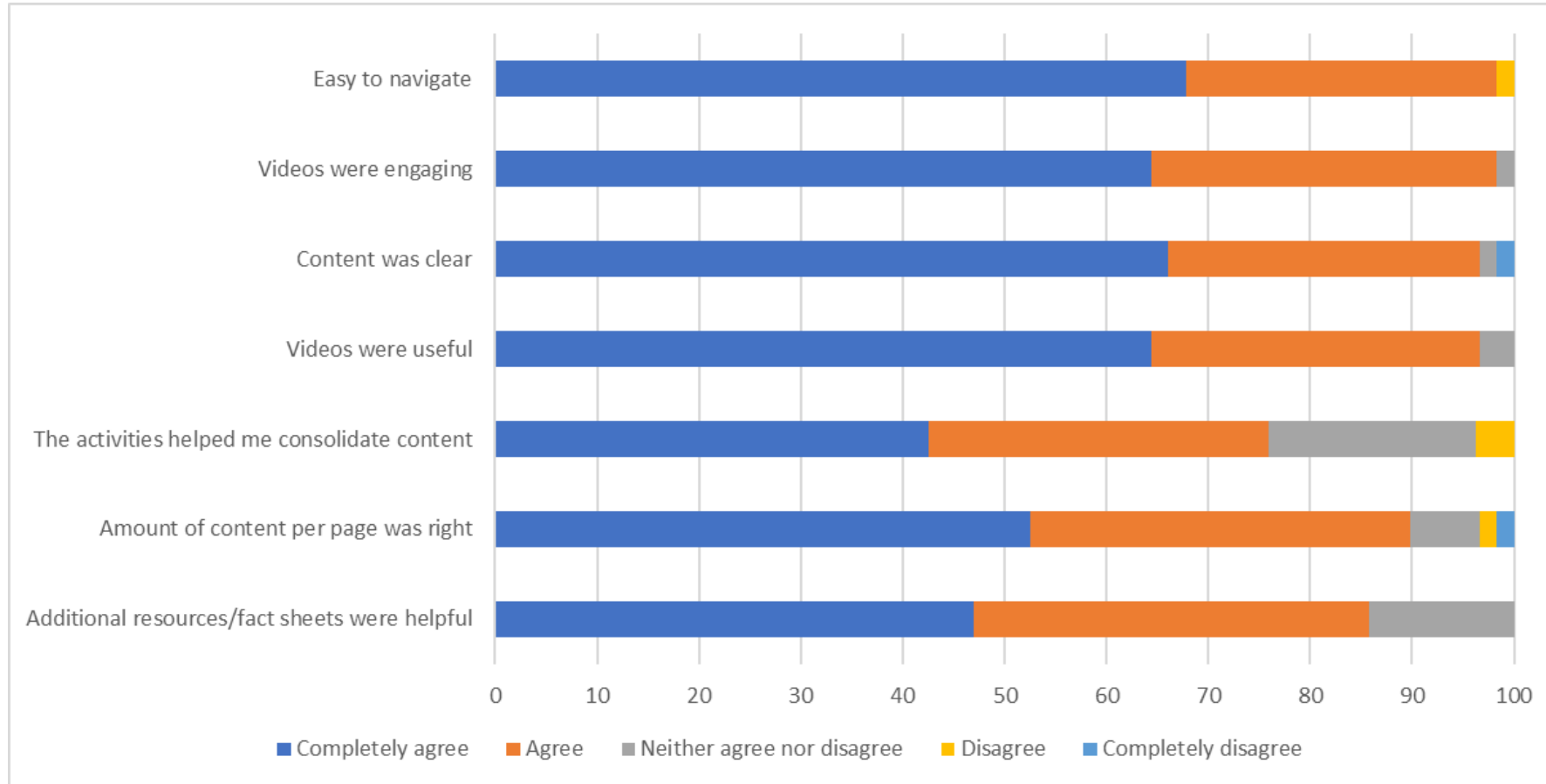
"Supporting people with intellectual disability to get the most of their supports, to get the right treatment and fair treatment. To have their voices heard. To assist hospital staff in best supporting and treating a person with intellectual disability" (Disability Support Staff)

"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)

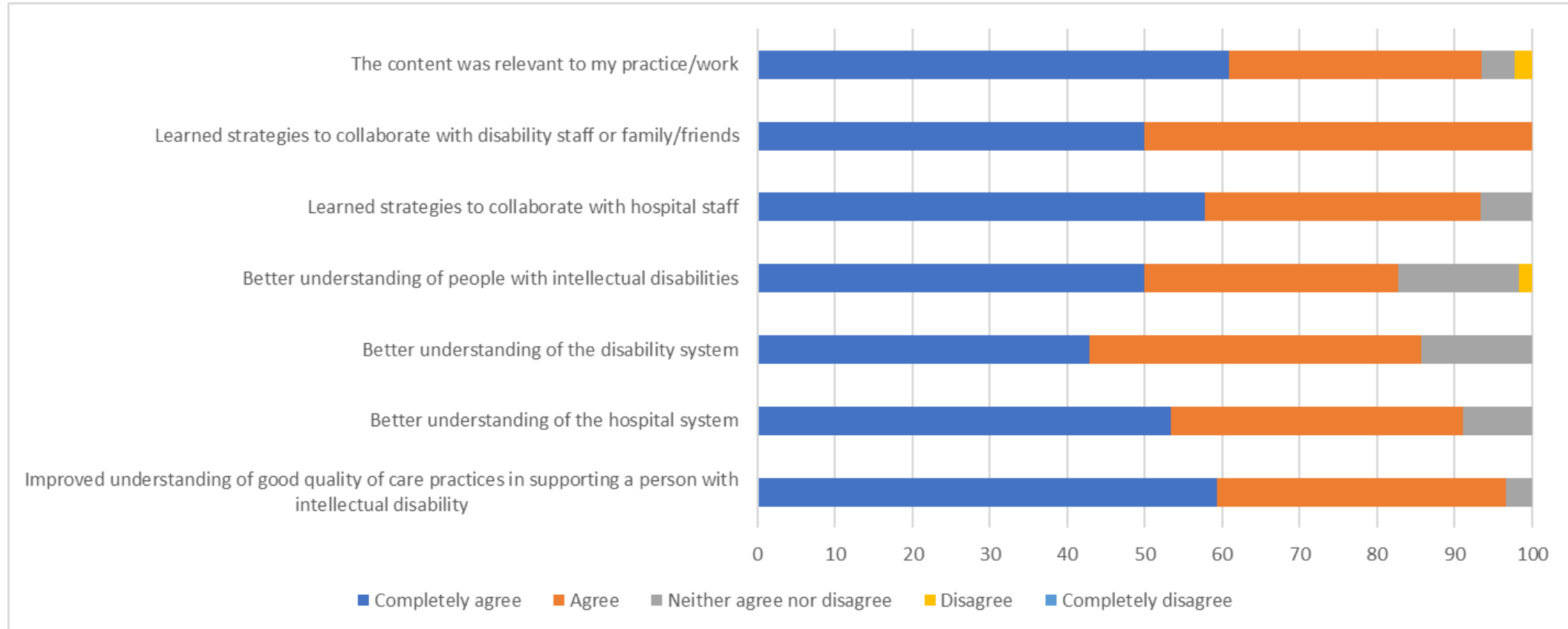
76% reported that their expectations were met

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.

Interviews: People with Disability

- An adult with disability felt that this resource was most useful for adults with mild intellectual disability (i.e., to make direct use of the People with Intellectual Disability Pathway). They also thought that it would be good for a person's Support Worker to have been through the Disability Support Staff Pathway.
- Another adult with disability, who said that often others have difficulty understanding them, was glad to see hospital staff talking directly to a patient, and giving them the chance to communicate for themselves. This person thought it was important that staff know that a patient might need help communicating, as shown in a video.

**Finally,
we'd like
to thank
our main
actors ...**



Gerard



Robert



Callee



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

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