

# **Looking Back, Looking Forward: Inspiring the Next Generation of Nurses in Intellectual Disability Health Care**

**Janelle Weise, Senior Research Fellow, Project Manager**  
**Katrina Sneath, Lived Experience Researcher**  
**Tahli Hind, Lived Experience Researcher**  
**Claire Eagleson, Project Officer**  
**Seeta Durvasula, Senior Research Fellow**  
**Michaela Kobor, Workplace Support Officer**

<sup>1</sup> National Centre of Excellence in Intellectual Disability Health, 3DN, UNSW Medicine & Health, UNSW Sydney

**PANDDA Conference, 14<sup>th</sup> October 2024**

# Acknowledgements

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Katrina Sneath

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Prof Gary Velan

Dr Janelle Weise

Dr Jenna Zhao

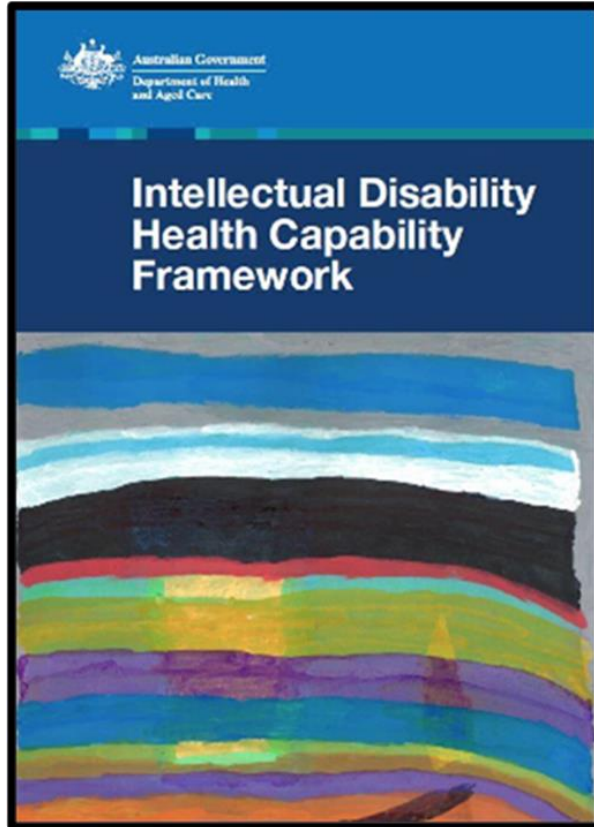


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# Intellectual Disability Health Capability Framework



1. Background
2. Development of Framework
3. Implementation and Resources



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# Intellectual Disability Health Capability Framework

## Background

**Tahli Hind**— Lived experience researcher

**Katrina Sneath** — Lived experience researcher

**Michaela Kobor** — Workplace support officer

**Janelle Weise** – Senior Research Fellow

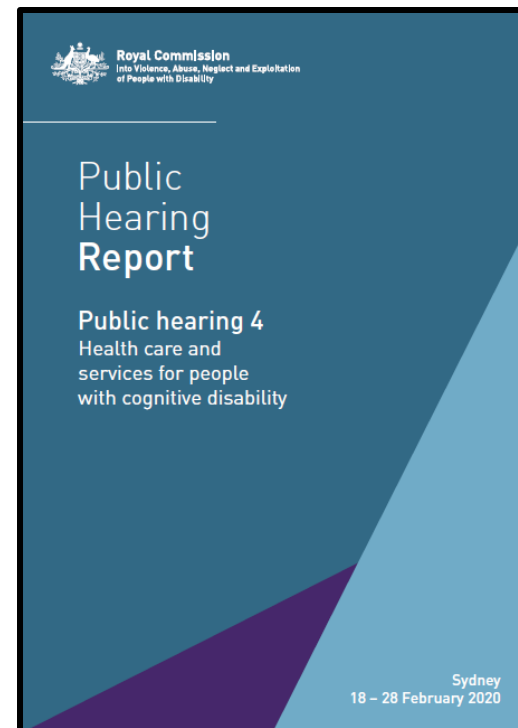
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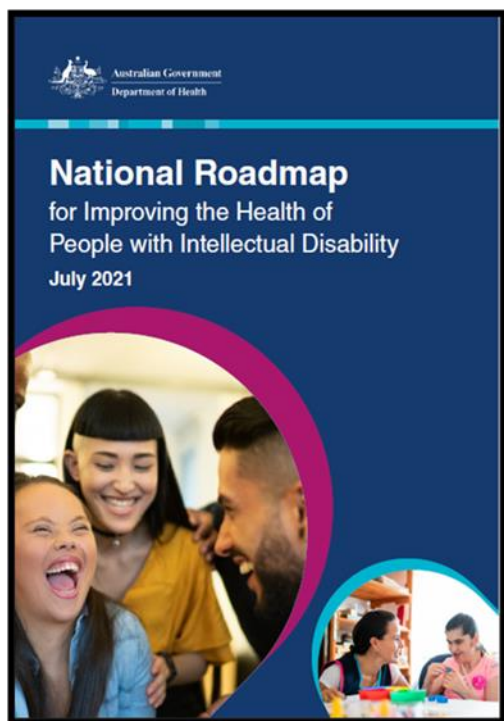
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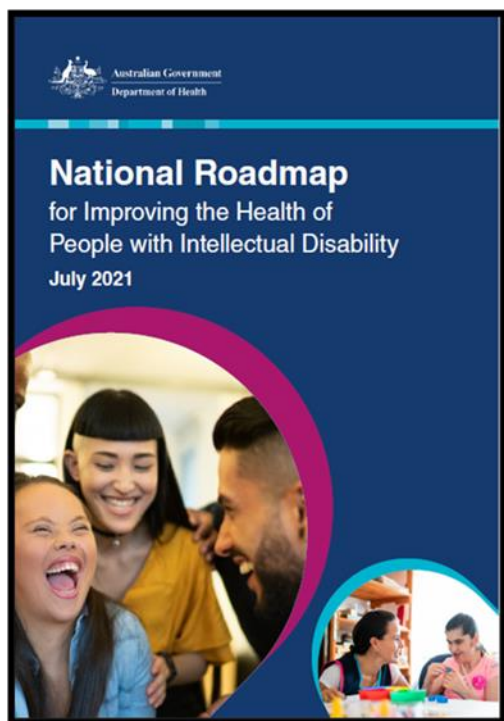
Short term (1-3 years)	Medium term (4-6 years)	Long term (7-10)	Desired outcomes
<b>C. Better support for health care professionals to provide better care for people with intellectual disability</b>			
<p><b>Continue</b> to support roll-out of the Primary Care Enhancement Program (PCEP) which will provide greater support for primary health care professionals to provide more effective care to people with intellectual disability.</p> <p><b>Design</b> and develop intellectual disability competencies, curricula content, and tools and resources to develop health professionals' knowledge of intellectual disability and instil positive attitudes.</p> <p><b>Consult</b> on establishing a National Centre of Excellence in Intellectual Disability Health.</p>	<p><b>Embed</b> training and continuing professional development in medical, nursing and midwifery, allied health, oral health, and pharmacy training programs.</p> <p><b>Work</b> with states and territories to build on the proposed establishment of a National Centre of Excellence, by further developing a national network of specialised intellectual disability health services.</p>	<p><b>Work</b> with states and territories to expand the national network of specialised intellectual disability health services to ensure it supports people with intellectual disability living in every state and territory.</p>	<p><b>Health</b> care professionals have appropriate knowledge, skills and attitudes to provide quality, appropriate and disability-informed health care for people with intellectual disability.</p>



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Why is it important for nurses to learn about meeting the health needs of people with intellectual disability?



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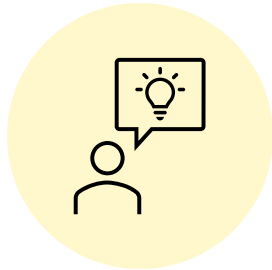


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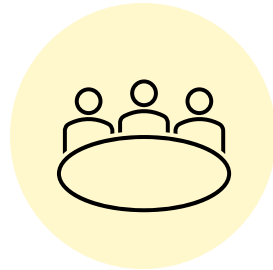




# Working in partnership



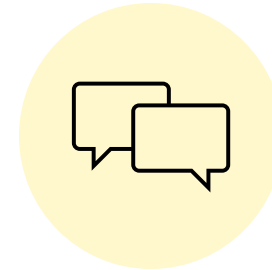
LIVED EXPERIENCE  
RESEARCHERS  
AND  
WORKPLACE  
SUPPORT OFFICER



LIVED EXPERIENCE  
REFERENCE GROUP



ARTISTS  
WITH  
LIVED EXPERIENCE



COMMUNICATING  
WITH PEOPLE



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Why is it important to have people with intellectual disability involved in projects like making the Framework?

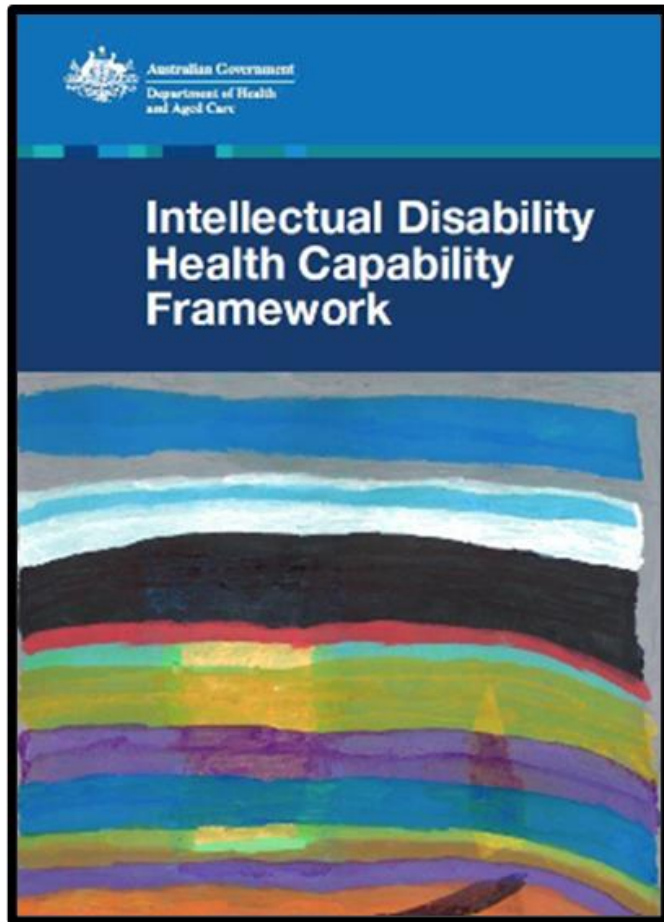


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- For students completing any pre-registration health, allied health and dental health programs.
- Describes core capabilities and learning outcomes.
- Provides guidance and tools to accreditation bodies and educators.
- Voluntary integration.



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# Intellectual Disability Health Capability Framework

## Development of the Framework

**Katrina Sneath** — Lived experience researcher  
**Michaela Kobor** — Workplace support officer  
**Claire Eagleson** — Project manager

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Intellectual Disability Health, UNSW Sydney



Access the Framework



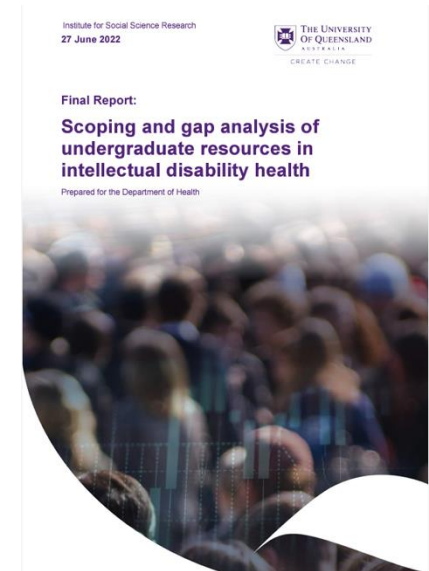
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# First steps to develop the Framework

- ❖ Establishment of the drafting group
- ❖ Guided by the Intellectual Disability Health Education and Training Expert Advisory Group
  - ❖ Representing 18 groups including PANDDA; Council of Deans of Nursing and Midwifery Australia & New Zealand; and Australian Nursing and Midwifery Accreditation Council
- ❖ University of Queensland scoping review and gap analysis

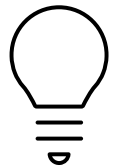


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# Consultations on core capabilities



**Core capabilities** - key knowledge, skills and attitudes around intellectual disability health

## Stakeholder group

- ❖ People with intellectual disability
- ❖ Carers, family and support workers
- ❖ Health professionals and academics

## Example feedback

- ❖ Recognising power differentials
- ❖ Seeing behaviour as communication
- ❖ Value of co-education



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# Finalisation of the core capabilities

- ❖ Draft core capabilities
- ❖ Open consultation – 93 submissions
- ❖ Delphi survey – 23 participants with expertise in intellectual disability health or curriculum development



Feedback updated 9 Aug 2023

Closed 27 Jan 2023  
Opened 22 Nov 2022

## We asked

The department asked for feedback about the core capabilities to support the Intellectual Disability Health Capability Framework (framework) in an open consultation from 22 November 2022 – 27 January 2023. The proposed framework for consultation included the following capabilities:

Contact  
[IntellectualDisability@Health.gov.au](mailto:IntellectualDisability@Health.gov.au)

- Intellectual Disability Awareness
- Communication
- Quality Evidence- Based Clinical Care
- Coordination and Collaboration
- Decision-Making and Consent
- Responsible, Safe and Ethical Practice.



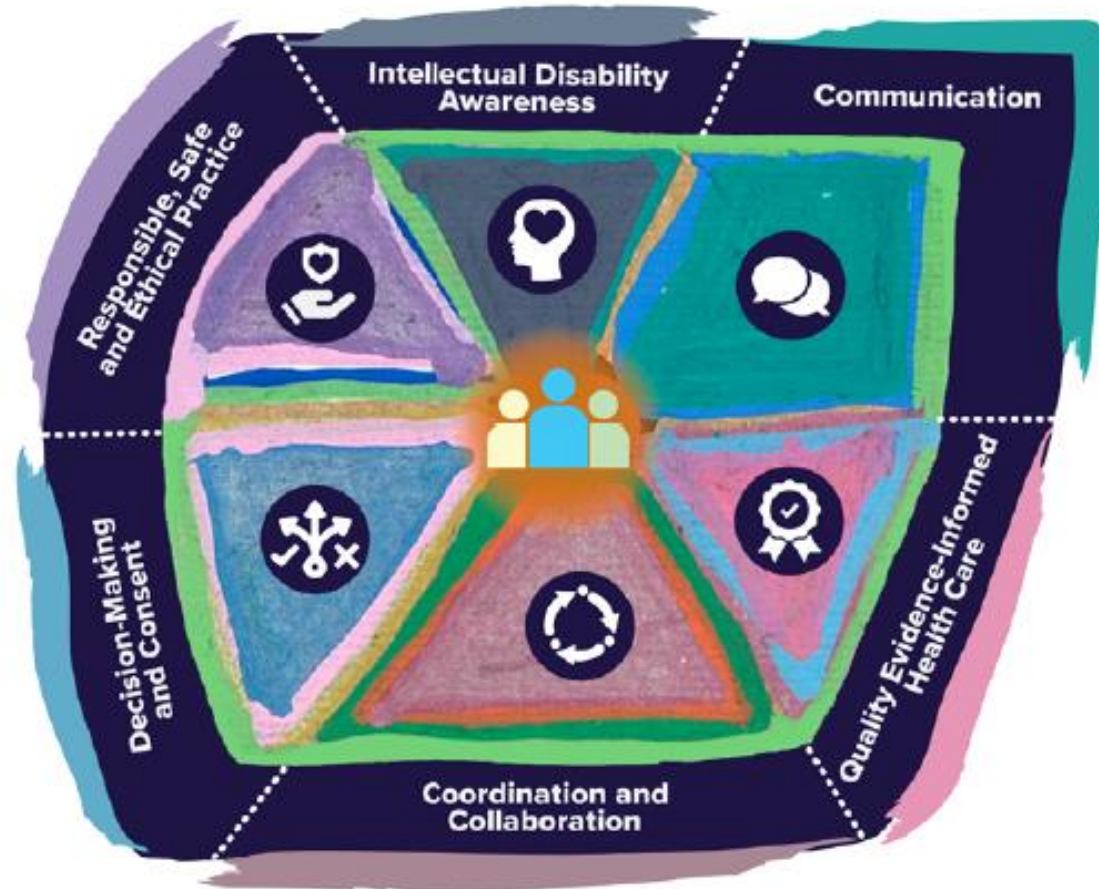
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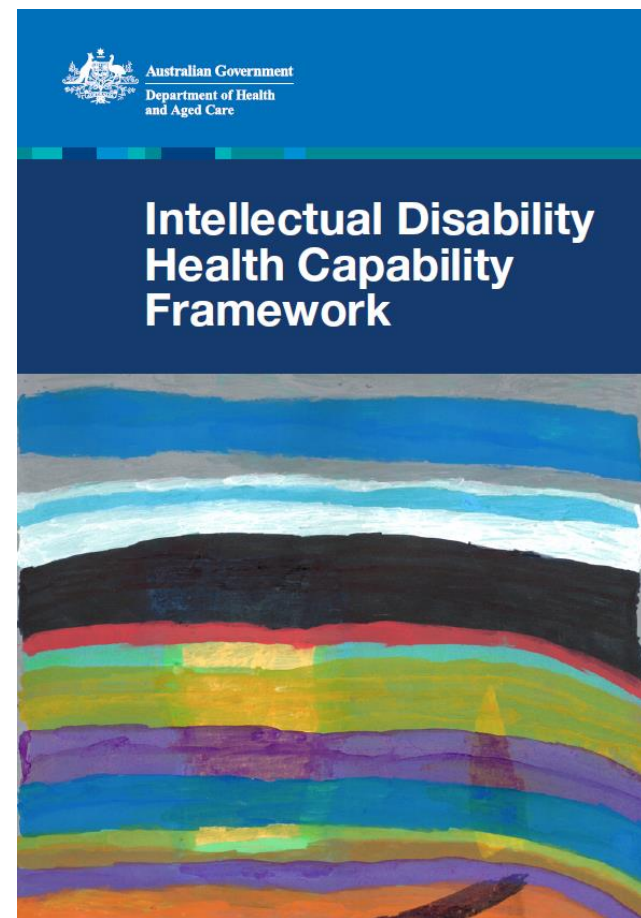
# The Capabilities

46 Capabilities  
across 6 areas

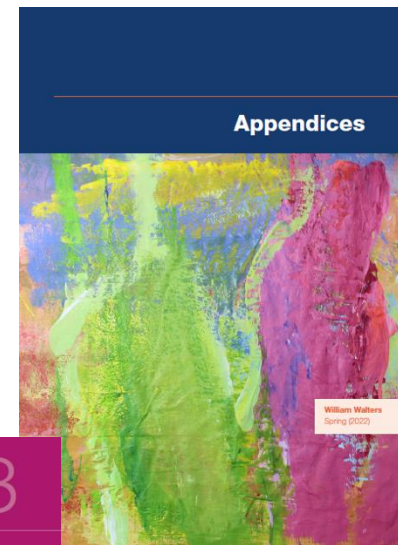
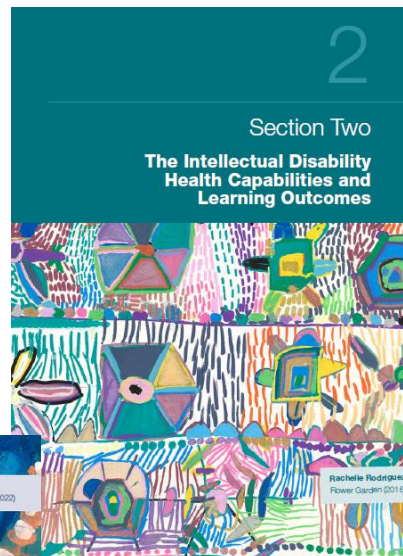
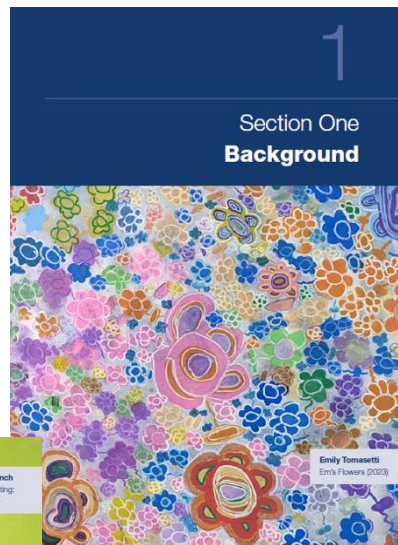
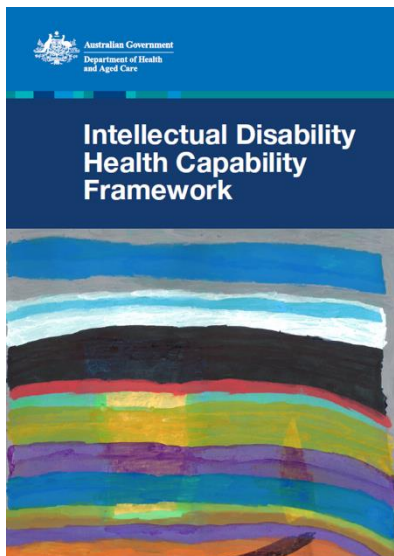


# Creating the Framework

- ❖ Drafted learning outcomes and integration advice
  - ❖ Consultations with
    - ❖ Intellectual Disability Focus Group
    - ❖ First Nations representatives
  - ❖ 2<sup>nd</sup> Open Consultation – 33 submissions
  - 56 people provided feedback



# Artwork – Studio Artes

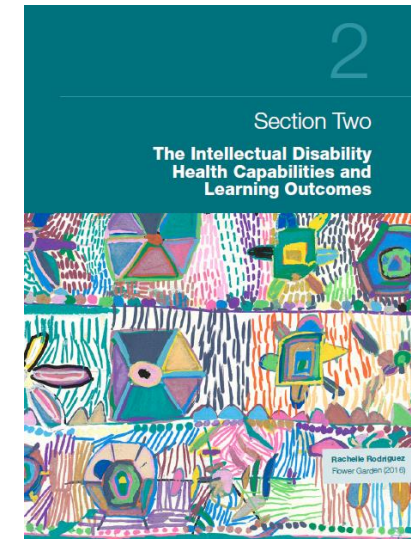


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# Learning outcomes



## 3 Levels

(Miller, 1990; Anderson et al, 2001)

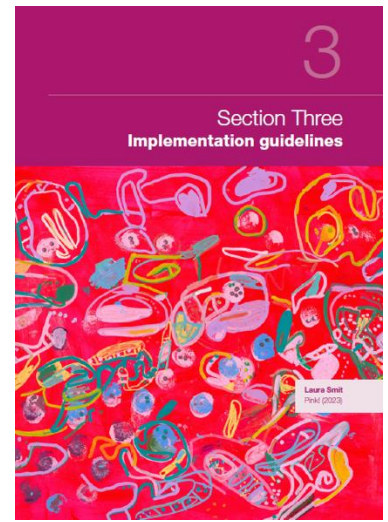
1. Know about
2. Know how
3. Shows how/does

<b>2.3</b> Behaviour as a form of communication	Recognise that behaviour is a form of communication and use it to inform assessment, diagnosis and care for people with intellectual disability.	Discuss why it is important to recognise behaviour as a form of communication.	1
		Describe the causes, manifestations, and potential interpretations of behaviour as a form of communication to inform assessment, diagnosis, and care provision for people with intellectual disability.	2
		Investigate how a person's behaviour has changed, the potential causes, and what it may be communicating, utilising support networks' knowledge, as appropriate.	3
<b>3.14</b> Preventative health care and promotion	Employ proactive health care practices and health promotion activities that are adapted and responsive to the needs of people with intellectual disability and correspond to known health risks at a population and individual level.	List the main health enablers and health risks for people with intellectual disability.	1
		Identify the screening and health promotion activities relevant for people with intellectual disability.	2
		Discuss how to adapt preventative health and health promotion activities to the needs of people with intellectual disability.	3



# Implementation guidance and tools

- ❖ Using the Framework with other frameworks
- ❖ Partnerships
- ❖ How accreditation authorities and self-regulating health professions can use the Framework



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# Implementation guidance and tools

## ❖ How education providers can use the Framework

- Deans, and education and curriculum leaders and managers
- Curriculum coordinators, placement coordinators and educators

Table 3: Steps for implementing the Framework: Curriculum coordinators, placement coordinators and educators

Step description	Considerations and strategies
Review current curriculum to help inform where and how the Capabilities can be integrated.	<p>Map current curriculum content against the Capabilities and identify i) gaps and ii) potential areas to incorporate specific intellectual disability content.</p> <p>See the <i>Program content mapping tool</i> we have developed to assist in this review.</p> <p>Consider when placements should occur in relation to required learning outcomes.</p>
Examine potential integration approaches, depending on gaps identified. This may include integrating content into existing areas or introducing new items in the curriculum.	<p>Potential approaches to implementing the Framework in courses include:</p> <ul style="list-style-type: none"> <li>• Integration of intellectual disability health content within existing curriculum areas where there is conceptual overlap with Framework content (e.g., focus on adapting communication for people with intellectual disability within existing ‘communicating with people’ content).                             <ul style="list-style-type: none"> <li>– It is recommended that teaching overtly focuses on intellectual disability, rather than merely covering content with reference to groups with diverse needs, to ensure the specific needs of this population are met.</li> <li>– Content such as reasonable adjustments, person-centred care, and capacity to consent is also applicable for other groups with diverse needs.</li> <li>– Educators will likely find considerable conceptual overlap between Framework and curriculum content; new sections of curriculum content will not be required in many cases.</li> </ul> </li> <li>• Creation of a module within an existing course.</li> </ul>



What were the best parts about working on this project?

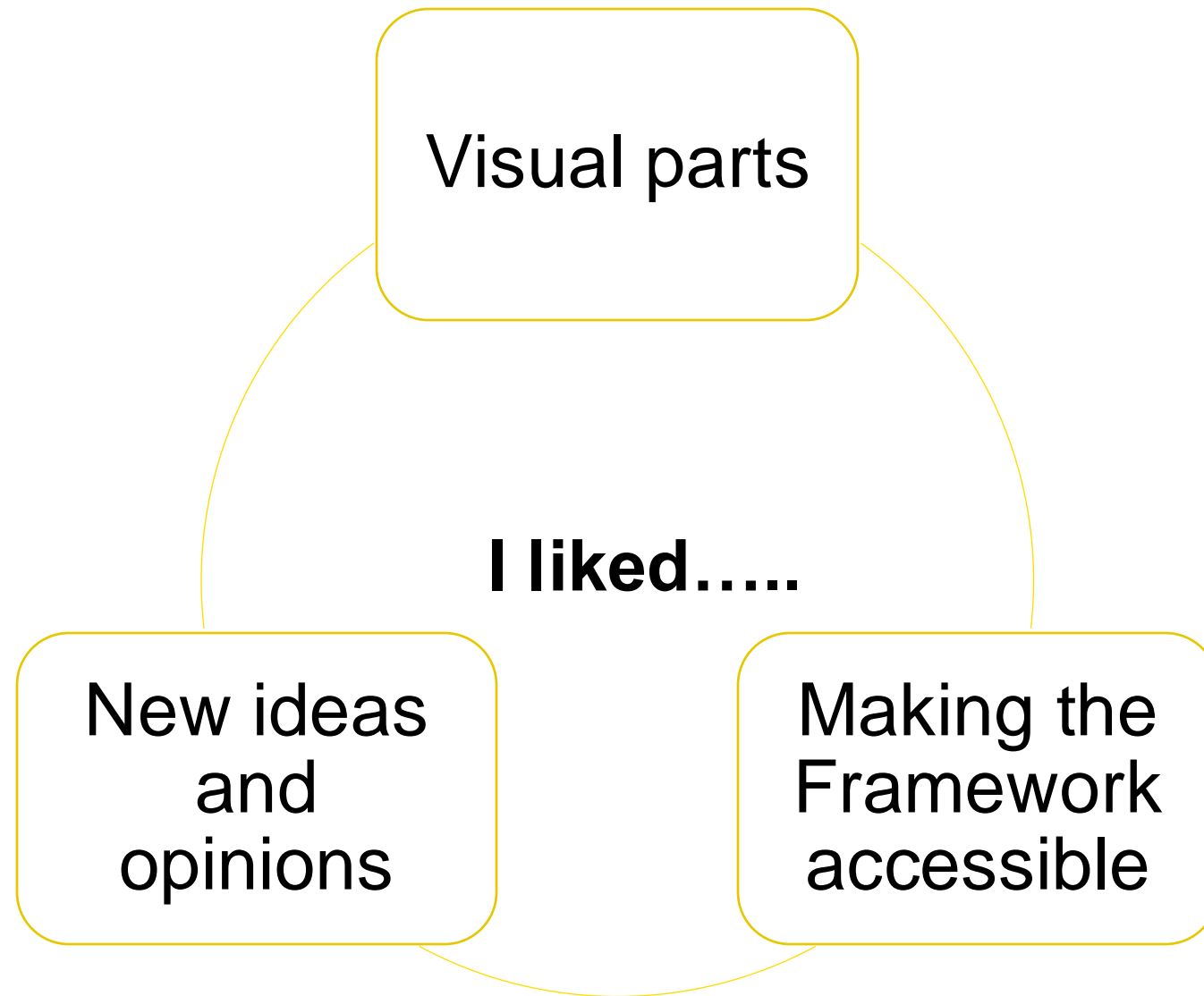


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# Intellectual Disability Health Capability Framework: Implementation and Resources

**Tahli Hind** – Lived Experience Researcher

**Katrina Sneath** – Lived Experience Researcher

**Michaela Kobor** – Workplace Support Officer

**Seeta Durvasula** – Senior Research Fellow

National Centre of Excellence in Intellectual Disability Health  
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# Framework

**Published April 2024**

## **Next stages**

- ❖ Consult with accreditation bodies that mandate principles and content in pre-registration curricula
- ❖ Identify existing teaching resources
- ❖ Develop new teaching resources to support implementation of Framework in curricula
  - ❖ Consultation with people with lived experience, carers, students, educators
- ❖ Lived experienced researchers involved in consultations and resource development



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# Accreditation Sector

- ❖ Mapped accreditation standards to Capabilities for 19 health disciplines, including nursing.
- ❖ Consultation with accreditation authorities
  - ❖ Information pack, including discipline –specific health outcomes for people with intellectual disability sent
  - ❖ Consulted about feasibility, potential methods, barriers and facilitators to integrating the Framework into curricula



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# Accreditation sector consultation

- ❖ Survey/focus groups - 28 accreditation experts in 13 disciplines
  - ❖ Preference for using existing standards about diverse populations, rather than new standards about intellectual disability
  - ❖ Use Framework and information about intellectual disability as guidance
  - ❖ Integrating Framework into professional (post-registration) / continuing education may have larger impact
  - ❖ Call for resources for accreditation bodies and education institutions
  - ❖ Importance of the voice of people with lived experience to advocate for integration of Framework into curricula highlighted



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# Curated list of existing resources



- ❖ Mostly free; need to register for some
- ❖ Mapped to Capabilities
- ❖ Podcasts, webinars, E-learning, web pages

## ❖ **Some examples:**



- ❖ ACI Intellectual Disability Network
  - ❖ Discharge case studies, *Say Less, Show More*, Intellectual disability training videos
- ❖ Primary Health Networks - webinars
- ❖ La Trobe University - *Quality Hospital Care for People with Intellectual Disabilities* - eLearning
- ❖ 3DN - eLearning, podcasts, guides etc.
  - ❖ *Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals; Intellectual Disability Mental Health Connect; Dementia in People with Intellectual Disability: Guidelines for Australian GPs*
- ❖ Canadian Hygienists Association - *Lifelong Smiles for Individuals with Intellectual Disabilities* - eLearning



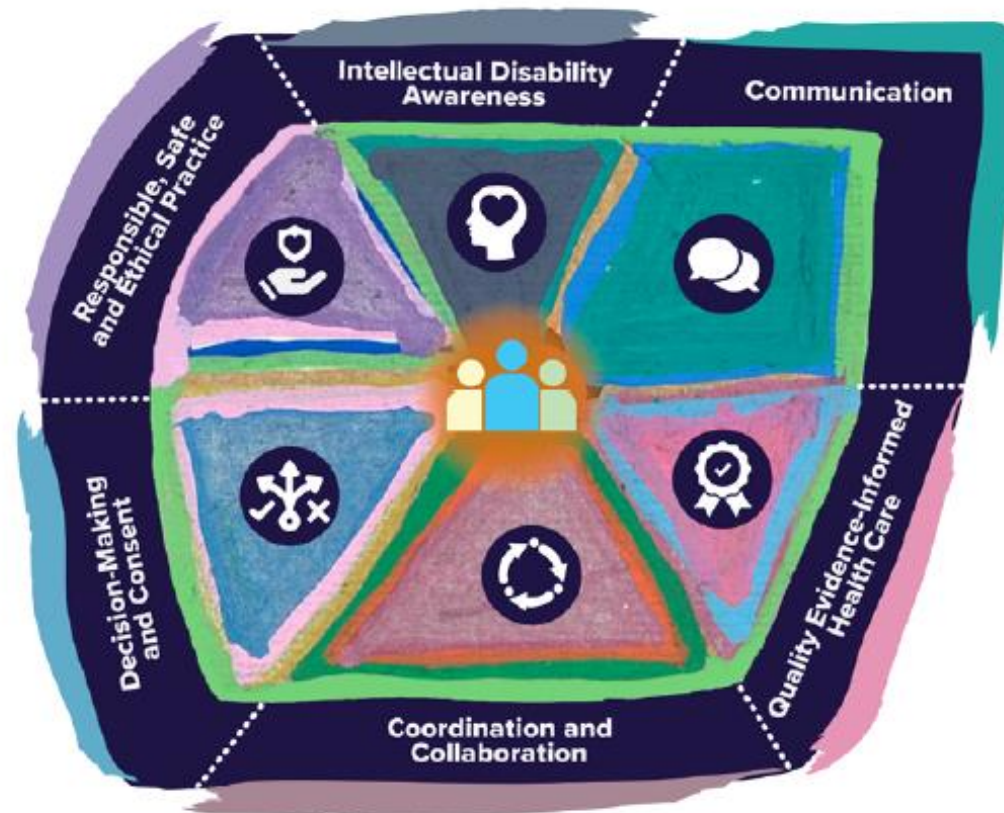
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# Development of Additional Resources

6 clinical case studies that focus on each of the 6 capabilities with suggested discussion questions for each case study



# Other resources



Introductory lecture and tutorial plans



2 short films based on 2 case studies



Simulation scenario examples



Example assessment questions



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# Further resource development and process

Toolkit to guide educators on co-education – how to involve people with lived experience in education

- Toolkit development guided by consultations with people with intellectual disability, their support networks, educators and disability organisations

Additional consultations with educators on how Framework can be integrated into curricula; with students about how they would like to learn about intellectual disability.

- These consultations are informing further resource development

Guidance for educators on how to develop their own discipline-specific resources



# Next steps

Dissemination and promotion of Framework

Framework and Resources to be uploaded to the National Centre of Excellence in Intellectual Disability Health(NCoEIDH) Knowledge Exchange Hub website

Leading to the next project for the NCoEIDH, Workforce Capacity with focus on continuing education for post-registration clinicians



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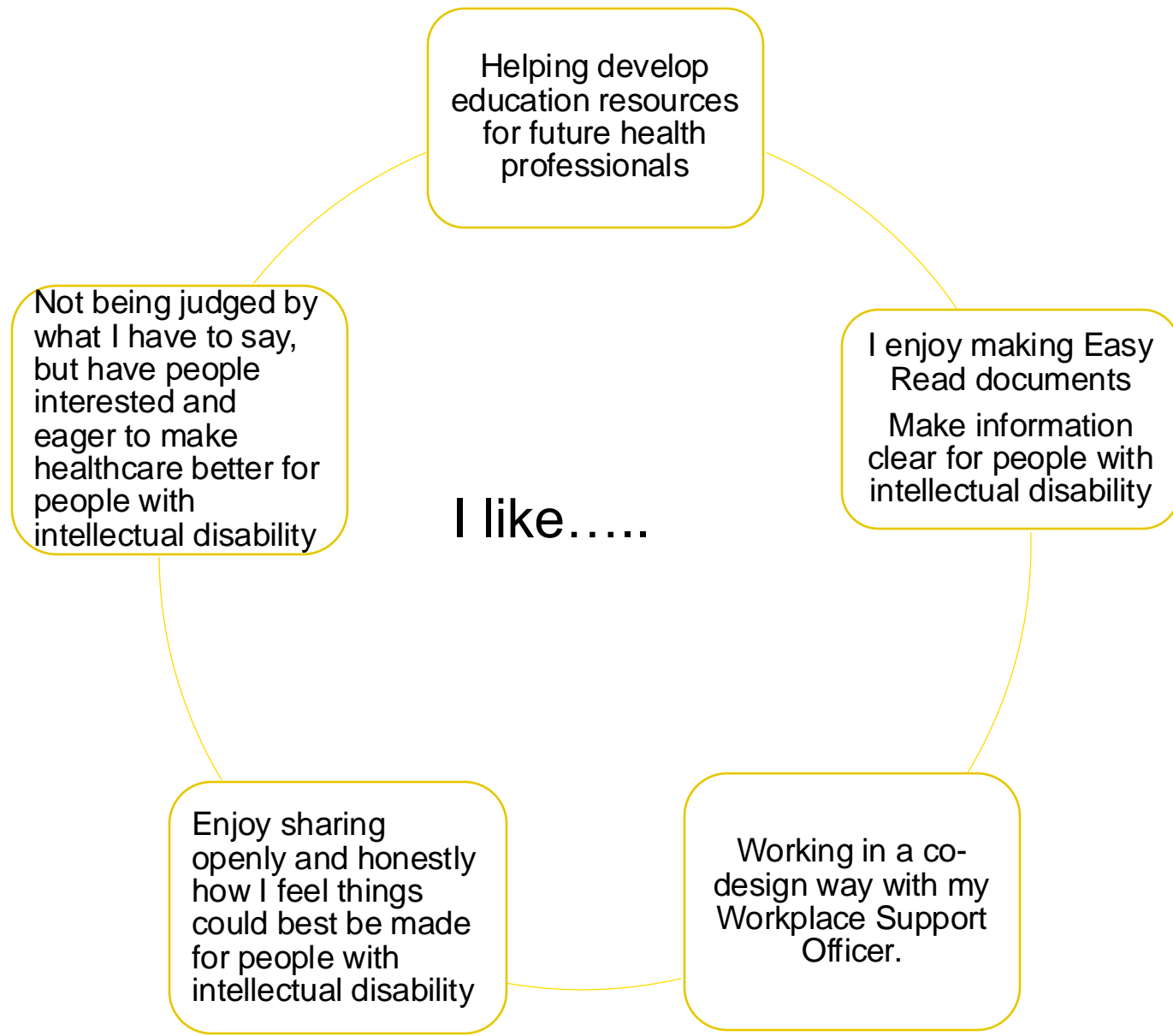
What were the best parts of working on this part of the project?



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Knowing is **not** enough;  
We must **apply**.  
Willing is **not** enough;  
We **must** do.

-Bruce Lee

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# Call to Action – what can you do?



- ❖ Download the Framework



- ❖ Read more about guidance and modifiable Capacity Assessment Tools that can be used to audit and review curricula (Appendix 2 of the Framework)
- ❖ If involved in education, consider opportunities to integrate Framework content into nursing and midwifery curricula.
- ❖ Request the accreditation mapping report for nursing and midwifery from [IntellectualDisability@Health.gov.au](mailto:IntellectualDisability@Health.gov.au)



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# Call to Action – what can you do?

- ❖ Encourage Australian Nursing and Midwifery Accreditation council (ANMAC) to integrate Framework content into accreditation standards and guidance that promote acquisition of the Capabilities
- ❖ Let people with lived experience know about the Framework (Easy Read resources are available on the Framework download page)
- ❖ Sign up for alerts when education resources become available



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What would you like people to do  
with the  
Intellectual Disability Health  
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I would like people to use the Framework

Katrina

The Framework will help them provide good health care for people with intellectual disability  
They can also better support people with intellectual disability to be more involved in their own health care

I hope future nurses and other health professionals will learn from the Framework



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I would like people to share the Framework.  
I want people with intellectual disability to get good health care

Tahli

I would like people to give us feedback so we can keep improving the Framework and Resources

I would like us to keep telling people with intellectual disability and their support people about the Framework



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# More information

Framework <https://www.health.gov.au/resources/publications/intellectual-disability-health-capability-framework>

Sign up for alert when teaching resources are available

<https://www.3dn.unsw.edu.au/intellectual-disability-health-capability-framework-resources>

## Contact:

Claire Eagleson [c.eagleson@unsw.edu.au](mailto:c.eagleson@unsw.edu.au)



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