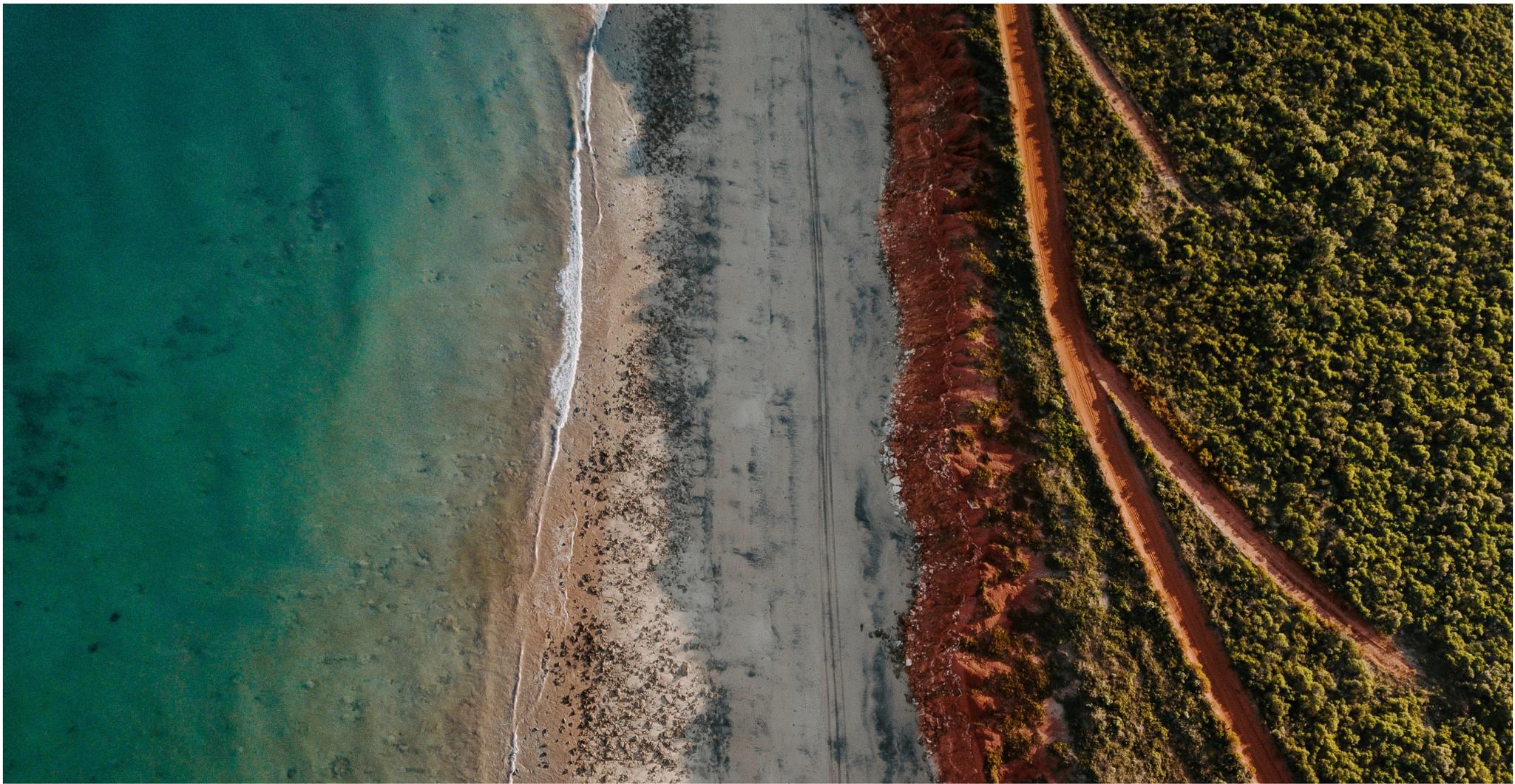


**Supporting the health of people with  
intellectual and developmental disability  
by improving health literacy of caregivers**

**Rachel Skoss**



## **ACKNOWLEDGEMENT OF COUNTRY**

The University of Notre Dame Australia is proud to acknowledge the traditional owners and custodians of this land upon which our University sits. The University acknowledges that the Fremantle Campus is located on Wadjuk Country, the Broome Campus on Yawuru Country and the Sydney Campus on Cadigal Country.

# About me...

Parent of a teen with intellectual disability

- Caregiver
- Service user
- Advocate

Health service researcher/evaluator

- Interface between disability and:
  - health
  - mental health
  - education
- Health literacy
- Service utilisation
- Care integration
- Quality of life
- Transition(s)



Educator

- Resource development for caregivers, people with disability, front-line staff, organisations, clinicians



# What I am going to discuss today...

1. An overview of health literacy
2. Research
  - Health service utilisation in the disability sector
  - Health literacy of caregivers
3. Development and use of the health care guide

*Why is health literacy important? The health system and health information can look like a bucket of mosaic pieces, which separately and of themselves may have little connection.*



*Health literacy helps to recreate the path for people from those pieces so they can find and engage with health services effectively.*



# What is health literacy?

Health literacy =  
The characteristics of the person + the things and supports they  
need

Skills	Knowledge	Motivation	Beliefs	Confidence	Resources	Supports
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to

Access	Understand	Appraise	Retrieve	Use
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information and services to make decisions about their health and  
the health of their family and community

Communities vary:

- Different people
- Different experiences
- Different beliefs, values, practices
- Different needs
- Different demands
- Different approaches needed



- Often, one service model... but one size does not fit all. Services are often “if we build it, they will come” rather than being purposely designed for each community.

# Health literacy and service use

Adapted from Figure 2.6, Health literacy development for the prevention and control of NCDs: Volume 2, Geneva: World Health Organisation, 2022

A person from the community...	Problems perceived by health services...	Problems perceived through a health literacy filter
is unaware of services or approaches a service	Many people in communities do not access services	People need: <ul style="list-style-type: none"> <li>• Knowledge of services, including entry steps</li> <li>• Confidence to approach services</li> <li>• Trust in services</li> <li>• Knowledge about healthcare entitlements</li> </ul>
is accepted into the service / receives service	Dropouts or failure to attend Demographic or health status groups do not participate	People need to: <ul style="list-style-type: none"> <li>• Understand health service processes</li> <li>• Negotiate with health providers</li> <li>• Have their needs understood</li> </ul>
participates in relevant programs or service	Difficult to recruit people to programs or services (e.g. prevention) Dropouts or failure to attend	People need to: <ul style="list-style-type: none"> <li>• Be able to select what might be useful from a range of options</li> <li>• Feel more comfortable making decisions about health</li> <li>• Address other concerns that are a higher priority before they focus on their health</li> </ul>
finds service responsive	Dropouts or failure to attend Care provided does not achieve desired health outcomes	People need to: <ul style="list-style-type: none"> <li>• Engage with providers to explain needs, ask questions and negotiate</li> <li>• Know what services can do and provide (and what they can't)</li> <li>• Receive information in ways that suit different learning needs and styles</li> </ul>
fully understands and engages with service	People find it hard to establish rapport with services or participate in own care Disappointing experience (low user satisfaction) and outcomes	People need to: <ul style="list-style-type: none"> <li>• Make sense of health information in the context of their daily life</li> <li>• Be supported to put what they have learned about health into practice</li> <li>• Know what to do and how and when to do it (i.e. practical information)</li> </ul>

# Health literacy assessment (Richard Osborne & colleagues, Swinburne Uni)

## Health Literacy Questionnaire (HLQ) dimensions:

1. Feeling understood and supported by healthcare providers
2. Having sufficient information to manage health
3. Actively managing health
4. Social support for health
5. Appraisal of health information
6. Ability to actively engage with healthcare providers
7. Navigating the healthcare system
8. Ability to find good health information
9. Understand health information well enough to know what to do

## Electronic-HLQ dimensions:

1. Ability to process information
2. Engagement in own health
3. Ability to actively engage with digital services
4. Feel safe and in control
5. Motivated to engage with digital services
6. Access to digital services that work
7. Digital services that suit individual needs

## Health Education Impact

### Questionnaire (heiQ) dimensions:

1. Health-directed activities
2. Positive and active engagement in life
3. Emotional distress
4. Self-monitoring and insight
5. Constructive attitudes and approaches
6. Skill technique and acquisition
7. Social integration and support
8. Health service navigation

# Background to the research...

## What we know...

People with disability living in supported accommodation settings may:

- Have complex health needs
- Need support to access health services

## What we don't know...

- How are people with disability supported to access health services?
- How are people using services?

The work was funded by a WA Department of Health Research Translation Project grant.



# Research overview

Aim 1 questions (observational case study):

- What health services do people use?
- What level of support is provided?
- What types of follow-up are required?
- What is the quality of health information exchange?

Aim 2 questions (health literacy/self-efficacy survey for care workers):

- What is the health literacy of support workers?
- How confident are support workers in providing support for health?

Aim 3 questions (qualitative study):

- What are the perspectives of different stakeholder groups when it comes to health for people with IDD regarding:
  - Proactive and preventative care
  - Management of chronic conditions
  - Management of acute care episodes
  - Best practice care examples
  - Gaps in care
  - Experiences and expectations

# The health literacy guide

## Part A – promoting good health

- Healthy lifestyle
- Proactive and preventative care

## Part B – managing health conditions

- Managing chronic health conditions
- Managing mental health conditions
- Understanding change in someone's health status
- End of life care

## Part C – using health services

- Primary care in the community
- Hospital based care

## Part D – building health-related skills and knowledge

- Communicating about health
- Decision-making in health
- Building coping skills to manage health (and health appointments)
- Finding good information



## Part E – understanding the health system

- The Australian health system
- The healthcare team
- Making complaints in the health and disability systems

# Health promotion

## Ensuring access to health promotion messages:

- Curriculum for people with IDD (e.g., Health Matters diet/exercise)
- Easy-read resources
- Direct care workers able to know where to find credible information and provide practical support for healthy living goals

## Including health promotion in care plans

- Explicit policies regarding health promotion/care plans
- Provide opportunity for healthy living goal-setting exercises
- Prioritise implementation of healthy living goals (e.g., staffing, funding)
- Upskill direct care workers (e.g., Health Matters, DDWA's FlexAble (<https://ddwa.org.au/online-learning/flexible-course-outline/>))

# Proactive and preventative care

- Participate in population-level health screening opportunities
- Promotion of health planning
  - Oral hygiene
  - Mental health
  - Healthy lifestyle behaviours/reduction of risky behaviours
- Skill development
  - Health literacy skills
  - Decision-making skills
  - Communication skills
- Planning (e.g., for transition)
  - Assessing readiness (health literacy skills and knowledge)
  - Mapping the journey (knowing what to expect)
  - Effective handover (warm referrals, trouble-shooting)

The goal is to support people with IDD to plan for the future – not just respond to a health crisis

# Managing health conditions

- **Connection to a General Practitioner**
  - Management of ambulatory care sensitive conditions
  - Ability to provide more frequent appointments
  - Develop long term relationship to support engagement/transitions
  - Conduct regular preventative care (annual health checks, vaccination, screening, etc.)
  - Potential for 'in reach' appointments
- **The role of the caregiver**
  - Empowering the person with IDD to understand the condition
  - Facilitate social support for the condition
  - Support treatment/management of the condition
    - Identify pain
    - Identify change in health status
    - Communicate with health professional
    - Communicate about follow-up care post health appointment

## Managing health conditions (cont.)

- Recognition of mental health
  - Understanding behaviour as a form of communication
  - Recognising change in behaviour
  - Effective communication with a mental health professional
- Change in health status
  - Identifying 'pain'
  - Understanding the soft signs
  - Taking observations
  - Communicating to health professionals to inform clinical decision-making
- Palliative care
  - Supporting the person with IDD in palliative care
  - Supporting the person with IDD if someone close to them is dying

# Using health services

- Primary care
  - Supporting engagement (choosing a doctor, preparing for appointments, communication)
  - Advocating for person-centred care
  - Modelling effective communication
- Hospital-based care
  - Support needs
    - Feeding, self-care, communication, mobility
    - Behavioural support
  - Planning, planning, planning
    - Pre-admission
    - Admission
    - Planning for discharge
    - Easy Read

# Building health literacy skills and knowledge

- Communicating about health
  - Being a communication partner
  - Developing a communication profile
  - Structured communication tools
  - Health passport
  - Care plans
- Decision-making in health
  - The 'process' of decision-making
  - Dignity of risk
  - Informed consent
  - Role in supporting decision-making
  - Tools to support decision-making

# More health literacy skills...

- Setting health-related goals
  - What could be changed
  - SMART goals
  - Making an action plan
- Coping skills
  - Improving the 'waiting'
  - Social stories
  - Safety plans
  - Managing traumatic experiences
  - Desensitisation
- Finding credible information
  - Assessing whether information reliable and trustworthy

# Understanding the health system

- The health system
  - Health care rights
  - Health sector governance
  - Disability sector governance
  - Structure of the health system
  - How health care is paid for
- The health care team
  - Roles in the health care team
  - Person centred care
- Making complaints

## And finally...

The appendices:

- Healthy living checklist
- Medication pathway (psychotropic medication)
- National Early Warning Score (NEWS)2 system
- Legal framework for decision-making
- Health passports

## In summary...

A focus on the health literacy of caregivers is an opportunity to improve health outcomes of people with IDD.

The health literacy guide is available for free from:

[https://www.notredame.edu.au/\\_data/assets/pdf\\_file/0025/327463/Health-Care-Guide.pdf](https://www.notredame.edu.au/_data/assets/pdf_file/0025/327463/Health-Care-Guide.pdf)

## Next steps:

- Development of best practice resources for disability service providers
- Development of resources/training for caregivers
- Development of a health literacy curriculum for people with IDD



Thank you

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