# Disability and Health Literacy in the ACT

**Project Report**

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# Executive Summary

Health literacy is a critical skill to maintaining good health and accessing safe, high-quality care. Good health literacy helps people stay healthy, find the right health care when they need it, recover well from an injury or illness and live well with chronic health conditions and disability.

However, people with disability disproportionately experience lower levels of health literacy compared to the rest of the population. Some of the factors contributing to these low literacy levels include:

- Cognitive and communication impairments (e.g., intellectual disability, aphasia).

- Limited access to accessible health information (e.g., plain language, braille, sign language).

- Health worker biases or lack of training.

- Environmental and systemic challenges, such as inaccessible facilities or digital platforms.

- Impacts of intersectionality (e.g., when factors such as race, socioeconomic status, and geographic location create more complexity).

Many issues raised by people with disability in this project are also issues for the population more broadly[1], including communication skills of health workers, confusing health systems which are hard to navigate, and difficulty finding and identifying reputable health information.

This report explores the health literacy needs of people with disability using health services in the ACT. Additionally, this report also investigates the knowledge and confidence of health workers in supporting the health literacy of people with disability.

The project was guided by a reference group made up of people with disability, carers, disability advocates and disability service providers to advise on the project methods and provide lived experience perspectives on the data.

Data for this project was collect using a combination of surveys and qualitative interviews to explore the health literacy needs of people with disability and understand the confidence and knowledge of health workers.

## Understanding the health literacy needs of people with disability

Participants reported using a wide range of sources to find health information, but still reported having difficulty finding and using health information.

Participants however, reported preferring to get health information from their health workers to ensure the information was reliable, and that they were able to ask questions. Some of the challenges to finding health information identified by people with disability included not being able to find appropriate information that related to the intersections between their disability and their health conditions. They also

identified that their health workers also did not always have enough knowledge or information to support them.

When they found health information, participants reported that the information was often not available in accessible formats or presented in language that was not easily understood.

Participants also identified that when trying to communicate their health information needs with their health workers, they most commonly faced issues around not having enough time to be able to discuss their health care and communication needs met within an appointment.

## Understanding the knowledge and confidence of health workers in supporting people with disability

Health workers were mostly confident in their ability to apply and adapt their communication methods to meet the needs of consumers. They also reported including families and carers in care and leveraging their knowledge in supporting communication and health literacy.

The barriers to supporting health literacy reported by health workers included:

- Not having enough time during appointments to be able to learn about and adapt their communication to meet the needs of people with disability all of the time.
- Not having enough resources and knowledge of the supports and tools that may be available to them to support the needs of people with disability.
- Not having adequate training to support people with disability, and most often reported needing additional training particularly around how to identify and cater to additional support needs for people with disability.

The findings of the survey and interviews were used to develop key recommendations for improving the health literacy of people with disability.

## Recommendations

**Individual health literacy**

1. Co-design targeted health promotion campaigns with people with disability as part of population health programs.
2. Provide digital literacy training and support for people with disability and carers to learn to use digital health platforms and access technology to participate in digital health care.

3. Create and maintain an accessible platform for health service information and health literacy resources for people with disability, carers, support workers and health workers. Build on existing platforms to avoid duplication.

4. Scope and implement a health navigation service for people with disability and carers.

5.  Provide funding for community organisations to develop or extend social supports for health literacy, including support groups and peer education.

## Health literacy environment

6.  Co-design and deliver training on supporting health literacy of people with disability for health workers in all health settings.
7.  Provide training for disability support workers to enable them to better support their clients to navigate the health system and partner in their own health care
8.  Develop and build staff within public health services to champion health literacy.
9.  Conduct an audit of all resources and tools that can aid and support communication available across Canberra Health Services, and use internal training and platforms to increase the awareness and use of these resources during appointments across all services and specialties.
10. Conduct an audit and improvement process to ensure all ACT Government health apps are fully accessible and user tested.
11. Health and Community Services Directorate to develop and implement policy changes and scope/support funding to extend the length of health appointments for people with disability.
12. Develop, implement and evaluate clear guidelines and policies for working with carers and support workers within public health services, and share best practice policy guidance with other services.

## Further research

13. Support and fund research into the intersection between disabilities and health conditions where research does not exist.

14. Fund specific research into understanding and application of health literacy concepts and needs of people with intellectual and cognitive disability and their supporters, including supported decision making.

15. Provide funding for action research projects that investigate and address the health literacy needs of people with disability from multicultural

16. Provide funding for action research projects that investigate and address the health literacy needs of carers of people with disability.

## Acronyms and Definitions

**ACSQHC** - Australian Commission on Safety and Quality in Health Care

**ACT** – Australian Capital Territory

**ACTCOSS** – ACT Council of Social Services

**ADACAS** – ACT Disability, Aged and Carer Advocacy Service

**Auslan** – Australian Sign Language

**Carer** – a person who provides unpaid care to another person who needs support due to a disability, medical condition, mental health condition or ageing.

**GP** – General Practitioner

**Health worker** – any worker in a health service, including registered professionals like doctors, nurses and allied health, as well as reception and administration support staff.

**HCCA** – Health Care Consumers' Association

**DHR** – Digital Health Record

**MyDHR** – The patient portal for the ACT Digital Health Record

**NCH** – North Canberra Hospital

**NDIS** – National Disability Insurance Scheme

**NSW** – New South Wales

**RACGP** - Royal Australian College for General Practice

**Support worker** – a person who provides paid support to a person with disability with practical, social or emotional support.

# Background

## Definition of Health Literacy

The Australian Commission on Safety and Quality in Health Care (ACSQHC) defines health literacy in two parts, *individual health literacy* and the *health literacy environment*. It defines these as[2]:

> ***Individual health literacy** is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action.*

> ***Health literacy environment** is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way that people access, understand, appraise and apply health-related information and services.*

Good health literacy is the outcome of these components working together, that is, individuals having the ability to interact with an environment that meets their needs for information, access and action. Addressing health literacy requires actions that embed health literacy into systems, ensure effective communication between consumers and health workers, and integrate health literacy into education for both consumers and health workers.

For the purpose of this report, HCCA will use this definition of health literacy. All outcomes of this report will address both components of health literacy together.

Nutbeam[3] categorises health literacy into three levels: functional, communicative/ interactive, and critical. Functional health literacy involves basic reading and writing skills to function effectively in everyday health contexts. Communicative health literacy includes more advanced cognitive and literacy skills for active participation in health care, while critical health literacy involves higher-order skills for critical analysis and control over health-related decisions.

Health literacy is critical to maintaining good health and accessing safe, high-quality care. Good health literacy helps people stay healthy, find the right health care when they need it, recover well from an injury or illness and live well with chronic health conditions and disability.

Low health literacy puts people at risk of poor health outcomes, including longer and more frequent stays in hospital, poor recovery from illness or injury, medication errors, acquiring long-term health conditions and higher costs for health care. People with lower health literacy are more likely to have difficulty accessing health care services, following health management plans and managing chronic conditions[4]. Poor health outcomes from lower health literacy accumulate over a lifetime, meaning that people are more unwell as they age and less able to live independently.

## Health service use by people with disability

In 2022, there were approximately 86,800 people living with disability in the ACT. These make up just under 20% of the population of the ACT[5].

People with disability are more likely to have frequent interactions with the health system. The Australian health care system is very complex and fragmented, so individuals need a high degree of health literacy to navigate this system. In addition, people with disability are more likely to need support to manage their health day-to-day, and need to understand and navigate the National Disability Insurance Scheme (NDIS) and other disability sector-based support.

People with disability in the ACT may use health services such as:

- Public hospital-based services

- Public community-based services

- Private hospitals

- Private GP, specialist and allied health services

- NDIS funded health services including allied health

- Social and community services to support them to maintain health and wellbeing (NDIS funded and not).

## Health literacy of people with disability

Health care systems often place demands, expectations and barriers on consumers and carers that they cannot meet or overcome. Systems and services rely on complex written and oral health information to communicate, and this is not always useable for consumers and carers. This is compounded by health service staff lacking the skills to recognise and address the needs of people who are having difficulty understanding.

Much of the research into health literacy of people with disability focuses on people with intellectual disability, leaving significant gaps in research for other disability types[6]. However, studies consistently show that people with disability generally experience disproportionately low levels of health literacy[6,7].

Barriers contributing to this include:

- cognitive and communication impairments (e.g. intellectual disability, aphasia) with unmet support needs

- limited access to accessible health information (e.g. plain language, braille, sign language).

- health care provider biases or lack of training.

- environmental and systemic challenges, such as inaccessible facilities or digital platforms.

Some reviews have examined access of people with intellectual disability to health care that included factors related to health literacy[8,9]. These found that people with intellectual disability in Australia:

- may have lower health literacy due to generally lower literacy levels

- may have reduced knowledge of common illnesses and when to access a GP for care

- may be fearful or anxious attending the GP, making them less likely to seek care

- are more likely to access GP care when they have confidence and support to interact independently with health workers, manage their own health information and make their own decision about care

GPs have difficulties meeting the health literacy needs of people with intellectual disability due to:

- Lack of targeted health promotion for people with intellectual disability, including for regular preventative health checks.

- Limited intellectual disability specific education or experience.

- Communication difficulty between health workers and people with intellectual disability, including unmet needs for communication aids

- Insufficient time in consultations.

- Incomplete medical records held by the person or their family, carer or support worker.

- Inadequate continuity of care and coordination of services.

- Confusion among GPs around their responsibility to provide health care to people with intellectual disability.

Carers and support workers play a major role in supporting access to health services and communication with health care providers for people with intellectual disability[8,9]. Generally lower health literacy among carers, family and support workers also contributed to lower rates of accessing care as people with intellectual disability are often reliant on others to alert them when they should seek health care[8].

Where support workers and families had increased knowledge of services and have capacity to manage information and appointments, this improved their ability to assist people with intellectual disability to access care[8].

Research by Drum et al.[10] highlights that many people with disability report feeling excluded from public health campaigns, with materials often lacking accommodations for visual, auditory, or cognitive impairments.

**Intersectionality and Vulnerability**

Health literacy challenges are further exacerbated by intersecting factors like race, socioeconomic status, and geographic location. Socioeconomic disadvantage is associated with lower health literacy and poorer health outcomes[11].

For people with disability from marginalised communities, barriers are often compounded due to factors such as structural racism and poverty[12].

**Digital health literacy**

The growth of digital health tools and virtual care, accelerated by the COVID-19 pandemic, has introduced new opportunities and challenges for people with disability. For some people, virtual care improves access by reducing travel and offering flexibility in how they access care. For other people with disability however, the reliance on digital tools increases the barriers they face in accessing care and risks exclusion due to the digital divide.

Studies show that people with disability are less likely to have internet access or digital literacy, particularly older adults, those in rural areas, or individuals with lower income [13]. Telehealth platforms are also often not designed with accessibility in mind and often lack features like captioning, keyboard navigation, or compatibility with assistive technology.

## Health literacy interventions for people with disability

Despite recognised inequities and exclusion from health care, people with disability are rarely mentioned in health literacy research both internationally[14] and in Australia.

To date few studies have addressed low health literacy for people with disability[1]. The Ophelia approach (OPtimising HEalth LIteracy and Access)[15] uses assessment of health literacy needs, collaboration and co-design with communities to find and test health literacy interventions and service improvements that address the needs of the communities involved.

Improving health literacy for people with disability requires a shift from an individual approach to a systematic approach that encompasses inclusive practice. Some strategies include:

- universal design of health communication materials (e.g. plain language, pictograms, captioned videos)
- community navigators or peer mentors to support people with disability to understand and access health services
- cross-sector collaboration between health, disability and social services to create integrated support pathways
- training for health care workers on disability and health and accessible communication

Health literacy is a critical yet often overlooked factor influencing equitable health care for people with disability. Health literacy for people with disability exists at the intersection of individual needs, social inequality, systemic complexity, and technological access.

Addressing disparity and supporting health literacy requires a multisector approach that recognises the interdependence between health, disability, and broader social

structures. As health and social systems become more siloed, and the use of digital tools and platforms in health care becomes more mainstream, ensuring inclusive design and cross-sector collaboration is essential to ensuring that people with disability are not left behind in health literacy.

Addressing health literacy in this population is not just a clinical or educational issue but a matter of human rights and social justice. Future efforts must ensure all individuals, regardless of ability, have the tools and support to make informed health decisions.

## Project aims

This project was funded by the ACT Health and Community Services Directorate. This project sought to:

1. Provide an understanding of the health literacy needs of the ACT disability communities, including their strengths and weaknesses, and identify areas for action;
2. Provide advice on approaches and resources which may be suitable for adaptation in the ACT;
3. Identify future projects and resources to improve how health workers support the health literacy of people with disability; and
4. Identify specific services in the ACT for future co-design research.

The environmental scan (Appendix A), as well as the lived experience and knowledge of the participants, informed advice on approaches and resources which could be adapted in the ACT, and existing services which could be partners for future health literacy projects with disability communities.

The survey and interview components of this project informed our understanding of the health literacy skills and knowledge of the disability communities and their carers, and the barriers they experience in accessing health care.

The surveys and interviews also focussed on understanding the knowledge and confidence of health workers in supporting the health literacy of people with disability, in order to identify future projects which could meet the gaps.

## Methods

A mixed methods approach was used for this project. The project began with an Environmental Scan of existing consultations, guidelines and research, along with interviews with representatives from health services, community organisations and disability advocates. We then used a combination of surveys and qualitative interviews to explore the health literacy needs of people with disability and carers (See Appendix B for full methods), and understand the confidence and knowledge of health workers (See Appendix C for full methods).

HCCA recruited a reference group made up of people with disability, carers, disability advocates and disability service providers to advise on the project methods and provide lived experience perspectives on the data. Further detail about their

participation and impact is at [Consumer, carer and advocate involvement in this project](#).

Invitations to participate in this project was shared widely through HCCA networks, HCCA social media, radio and newsletters and bulletins issued by community organisations that provide supports or care for people with disability. These included:

- Advocacy for Inclusion
- ADACAS
- Women* with Disabilities ACT
- ACT Down Syndrome and Intellectual Disability Association
- Carers ACT
- ACT Mental Health Consumer Network
- ACT Office for Disability
- Radio 1RPH
- National Disability Services
- Hartley Lifecare
- JBCare and,
- HCCA's Chronic Conditions Network.

Invitations to participate were also shared through ACT healthcare networks such as, Capital Health Network, Health and Community Services Directorate (nee ACT Health Directorate), Canberra Health Services, and direct contact with GP practices.

## Limitations

This research seeks to understand the health literacy needs of people with disability and carers and knowledge and confidence of health workers broadly. The findings should not be considered representative of specific groups within these communities.

A key limitation of this study is the low number of participants recruited. Reasons for this included:

- consultation fatigue due to multiple related consultations in recent years

- not considering health literacy as a priority among other issues like physical access to health services and NDIS reforms

- length of the survey and/or interviews

- fear of consequences from speaking up about poor experiences

- lack of support to participate from service providers

- caring responsibilities limiting time and capacity to participate

- high pressure work environment for health workers leading to lack of time and capacity.

Particularly low numbers of responses were received from people with cognitive disability, d/Deaf or Hard of Hearing people and Blind or vision impaired people, despite options to participate in a range of formats.

Over half of the participants who indicated they were carers indicated they live with disability themselves, making it difficult to identify the specific health literacy needs of carers.

Recruitment of people from multicultural backgrounds was limited despite wide promotion of the project. We found that members of these communities may not be comfortable participating in surveys and one-on-one interviews, and group consultation methods such as focus groups may be more successful.

Another limitation of this research is that there are currently no validated tools for measuring health literacy of people with intellectual disability. Early discussions with researchers, advocates and a project advisor with intellectual disability indicated that the research methods chosen may not be appropriate for this group. No survey responses were received which identified that a participant had intellectual disability.

Further research is needed to develop or adapt an appropriate model of health literacy with people with intellectual disability and their chosen supporters. Despite this limitation, HCCA spoke to advocates for people with intellectual disability and reviewed existing research as part of the environmental scan, however this does not capture the lived experience of these consumers.

Health worker results may not be broadly representative due to the low response rate to both the survey and callout for interviews. Participants who self-selected or were approached by HCCA due to existing relationships may be more likely to have existing knowledge and confidence in working with people with disability and/or health literate practice.

# Understanding the health literacy needs of people with disability

40 participants completed the survey. Participants completed the survey online, on paper or over the phone.

23 (57.5%) identified as a person with disability and not a carer, 8 (20%) identified as carers and 9 (22.5%) identified as both a person with disability and a carer.

**Types of disability**

Participants who identified as a person with disability reported living with a range of disabilities (Appendix B, Table 1), with 87% of participants indicating they live with more than one type of disability. The most commonly chosen categories were:

- Physical disability (69%)
- Chronic health conditions (66%)
- Invisible disability (66%)
- Psychosocial disability/mental illness (47%) and,
- Neurodivergence (31%).

Carers who did not have a disability themselves identified they cared for people who had disabilities in all of the available categories except blindness/vision impairment and cognitive disability. The most common conditions identified by carers (of the people they care for) were chronic health conditions and intellectual disability.

**Demographics**

Participants' ages were relatively evenly distributed between 18-71+ (Appendix B, Figure 2). Participants' genders were:

- 67.5% women

- 20%  men

- 10% non-binary

- 2.5% preferred not to say

Participants also identified across a number of diverse backgrounds:

- 35% of participants identified as LGBTQIA+

- 5% identified as Aboriginal or Torres Strait Islander

- 10% identified as being from a multicultural background

- 10% identified as a migrant or refugee

- 93% of participants only spoke English at home

Appendix B, *Disability and Carer Survey Responses* provide more detailed demographics and survey responses.

**Current health status**

Participants were asked to rate their health as poor, fair, good or excellent. No participants reported their health as excellent.
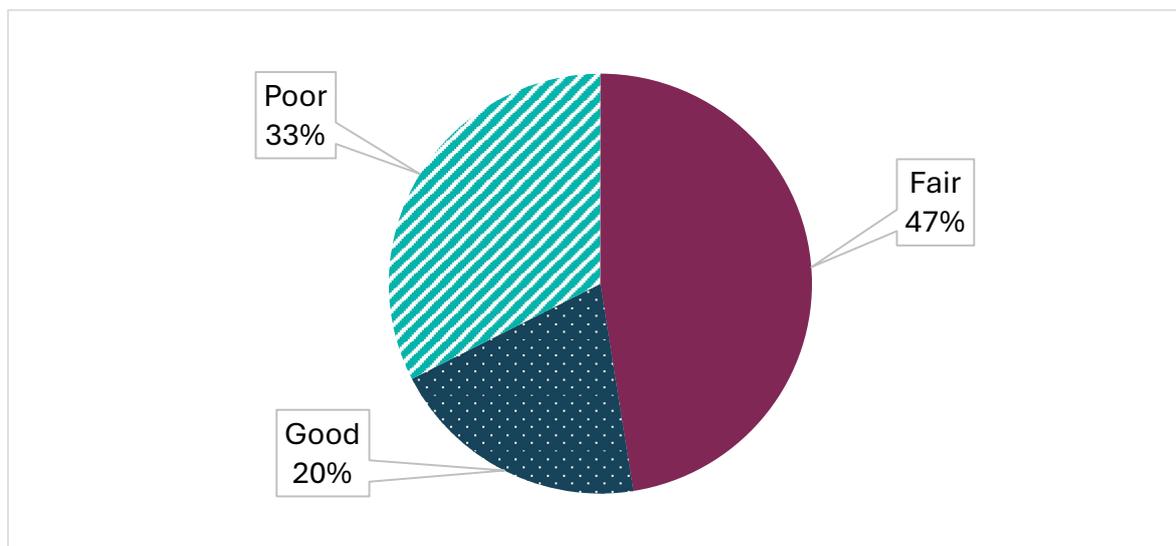


*Figure 1 Participants' self-rated health*

**Health service use**

The most commonly used health services identified by participants included GPs, Public Hospitals including the Emergency Departments, and Walk-in Centres.

All participants said they had visited a GP in the past 2 years. The next most used services were Public Hospitals (75%), Walk-in Centres (70%), Emergency Departments (70%) and Private Specialists (68%) (Appendix B, Table 2 for full results).

## Finding health information

In the health literacy questionnaire (Appendix B, Table 3) domain 8: *Ability to find good health information,* survey participants scored a total of 3.44 out of 5. The overall ACT population scored 4.07 out of 5[1]. This score indicates that on average, most participants found it difficult to find health information.

Participants used a wide range of sources to get information about health and health care (Appendix B, Table 4). Sources used by most participants included:

- GP or family doctor (88%)

- Health specific website e.g. ACT Government Health, Healthdirect (68%)

- Condition-specific organisations e.g. Arthritis Australia, the Cancer Council (65%)

- Online search e.g. Google, Bing, DuckDuckGo (65%)

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[1] Health Literacy Questionnaire domains are compared to the ACT adult population's results in the Australian Bureau of Statistics' 2018 Health Literacy Survey.

- A specialist doctor (63%)

Social supports were also significant sources of information, including social media (35%), friends and family (33%), support groups or peer networks (30%) and support workers (10%).

Some participants noted they preferred to get information from their health workers, particularly GPs and specialist doctors. This allowed them to discuss the information and ask questions and make sure they understand the information. However, they also noted getting information this way was challenging as health workers often didn't have the time to have those discussions.

**Finding credible sources**

Participants highlighted the importance of finding credible and reliable information. While many participants found health information online, they discussed the challenges of being able to identify what is accurate and reliable information.

53% of participants said they agreed or strongly agreed with the statement "*I can find the health information I need on the internet*". However, only 20% of participants said they agreed or strongly agreed with the statement "*I can trust health information I find on the internet*" (Appendix B, Figure 5).

Under the health literacy questionnaire domain 5: *Appraisal of health information*, participants scored an average 2.95 out of 4, better than the ACT population's 2.90 out of 4. However, these scores indicate that on average, adults in the ACT find it difficult to judge the quality of health information regardless of their disability or carer status.

For participants, the challenges to finding information can be addressed by having information about health services and organisations that support people with disability in one place that is easy for people and health workers to access, as one participant suggested:

*"A one-stop-shop for key service information and basic info about health conditions specific to the ACT and covering more than just public services. You need to know about 7 different sites to get this right now. Longer and/or cheaper appointments with a GP or specialists would also mean I can actually ask for the information I can't find elsewhere."*

**Appropriateness and relevance of health information**

Participants discussed challenges in finding information that is appropriate and relevant to them. Participants explained the challenges in finding health information and health workers who understand how some disabilities may impact health conditions and vice versa.

*"I am often looking for the connection between multiple co-morbid conditions, [like] how they interact and what symptoms are from what condition. I find most health information is about one specific condition only or one medication only. It's not often about the connection between autoimmune, gut health, hormone imbalance etc."*

Participants spoke of the need to improve access to health workers like GPs, specialists and allied health workers to be able to find, understand and discuss information.

## Understanding and Using Health information

Participants scored and average of 2.56 in domain 2: *Having sufficient information to manage my health*, which is lower than the ACT population score of (3.13). On average, participant scores (3.61) indicated that they found it easy to understand health information well enough to know what to do (domain 9), though not as well as the ACT as a whole (4.25).

Participants scored the same as the ACT population (3.07) in domain 3: *Actively managing my health*, indicating that they agree that they are actively engaged in their health care and recognise the importance of taking responsibility for their health.

Comments from participants suggest that accessibility of information is critical. While a lot of information may be available on the internet, they may not always be presented in a way that is accessible. As a participant explained, having information presented in ways that are accessible to them would include:

- using other forms of communicating and presenting information that is not just online, for example, audio media such as radio and television, braille, printed information

- having information online where the website is clear and uncluttered making it easy to find the information

- having information printed in large format

- having people take time to explain information or read information which is in print or otherwise not easily accessible

- using language that is less technical.

The issues described above regarding the relevance and appropriateness of information also indicate that not getting information tailored to their specific health needs is a barrier to health literacy.

### Acting on health information

Participants also indicated that they did not have enough social support for their health, scoring lower than the general population in health literacy domain 4, *social support for health* (2.35 compared to 3.19 out of 4). This indicates that most people did not have enough social support to help them maintain their health and act on health information.

## Communication with health workers

The survey also asked participants about the enablers and barriers to being able to communicate with their health workers (Appendix B, p11-12).

Overwhelmingly most of the participants identified that the main barrier and enabler to being able to communicate with their health workers is 'being listened to'. The need to be listened to was raised in many ways when discussing communicating with health workers. This included:

- not having enough time during appointments for consumers to be able to discuss/understand information

- the use of health and medical jargon during appointments doesn't support understanding

- health workers' attitudes and biases towards disability and people with disability impact how they are supported

*"People make assumptions about my son's capabilities because he has Down Syndrome. He has his own voice, and questions should be directed to him in first instance. I can add to help out, but this is his health care."*

- needing a holistic approach to care.

## Use of digital health platforms

We asked participants about whether they had used digital health platforms on a phone or computer to do health related tasks (Appendix B, Figure 4):

- 65% had used a health or wellness app

- 70% had checked test results, a further 5% with help from someone else

- 73% had made an appointment with a health care provider, a further 3% with help

- 63% had an appointment using a video conferencing program or website, a further 3% with help

- 70% had an appointment over the phone, a further 3% with help

Participants were also asked about their confidence with technology (Appendix B, Figure 5):

- 70% agreed they found it easy to learn new technology

- 62% agreed that it was easy for them to see their own health information using the internet

- 18% said they need help to use applications on their phone or computer.

The survey asked participants to identify the barriers they faced when using digital resources to find and understand health information and how to reduce these barriers (Appendix B, p13-14). The findings identified three key themes:

- Having the skills to use different digital platforms/tools/resources.

- User friendly and accessible digital tools and platforms.

- Security and privacy of digital platforms.

Across the three themes the participants identified clear solutions and strategies to enable the use of digital tools and platforms to access information. These are:

- Having consistency across digital platforms and tools so people do not need to learn how to use something new each time.

- Providing support so people can use digital platforms and tools. This includes having dedicated support or help lines to teach people how to use different systems and Frequently Asked Questions (FAQs) sections to allow people to get help when they need it.

- Ensuring that platforms like MyDHR and My Health Record are able to link to each other to allow information to be recorded, maintained and shared easily.

- Building and user testing new tools/platforms and resources with the disability community to ensure they are user friendly and accessible to everyone.

## Health literacy of carers

More than half of the carers who responded to the survey were people with disability themselves and these experienced similar barriers to people with disability who were not carers. On average, carers scored lower in all health literacy domains except 5: *Appraisal of health information* when compared the ACT population and other participants (see Appendix B, Table 3). Carers were somewhat less likely to use digital health platforms and more likely to need help with digital health platforms than other participants.

## Understanding the knowledge and confidence of health workers in supporting the health literacy of people with disability

A total of 19 health workers participated working in the ACT participated in this project. 17 health workers working in the ACT completed the survey. Five health workers participated in semi-structured interviews with the research team, three of whom had also completed the survey. Appendix C: Health Worker Survey Responses provides more detailed information.

The health workers represented a range of specialties from allied health professionals, GPs, health administrators, and specialists.

| Profession | Number of participants |
|---|---|
| GP | 4 |
| Social Worker | 3 |
| Nurse | 2 |
| Reception/Admin | 2 |
| Psychiatrist | 1 |
| Physiotherapist | 2 |
| Dietician | 2 |
| Occupational Therapist | 1 |
| Pharmacist | 2 |

The health workers worked in a range of health care settings across the ACT, including GP clinics, public hospital and community health settings.

| Workplace | Number of participants |
|---|---|
| GP clinic | 6 |
| Public Hospital | 7 |
| Public community health service | 3 |
| Mental health service | 2 |
| Disability Support Provider | 1 |

*Figure 2: Map of locations of participants' workplaces within the ACT*



2 Gungahlin
6 Belconnen
3 Inner North
2 Inner South
1 Weston Creek/ Molonglo
4 Woden Valley
1 Tuggeranong
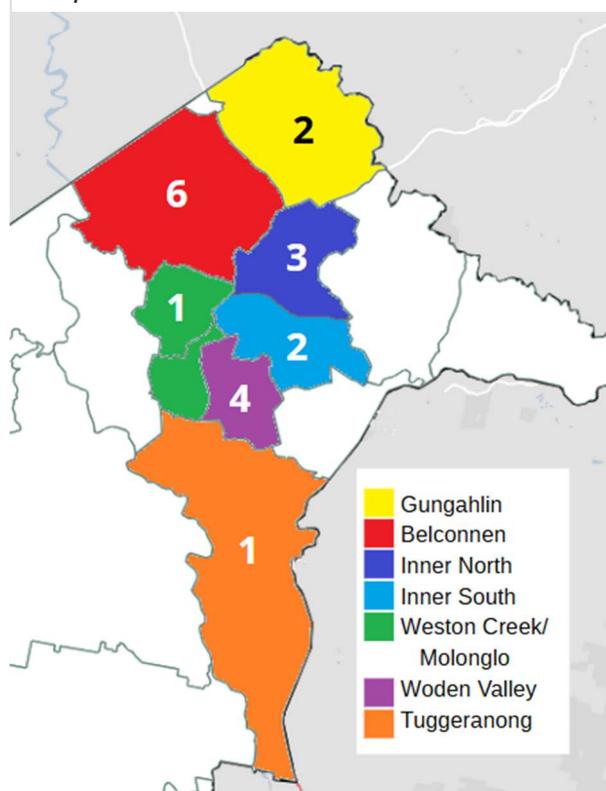
## Confidence in supporting people with disability

Participants were asked to identify their confidence in communicating with people with disability and supporting health literacy (Appendix C, Figure 6).

Over 65% of health workers identified they were confident or very confident in applying and adapting how they communicate to meet the needs of their patients.

When discussing sensitive topics such as reproductive health with people with disability, 57% of participants identified they were confident or very confident and 47% identified that they were confident of very confident when communicating and supporting people with disability who had intersecting needs (e.g. LGBTQIA+, non-English speaking background).

Participants were the least confident in knowing where to find and access the right resources to support the communication needs of people with disability, with 65% participants identifying they were either not at all confident or only somewhat confident.

**Training**

Participants were asked about the training they had previously received when it came to providing care for people with disability. Participants indicated they had received the most training around cultural competency with 77% of participants having received between 1-8 hours of training (Appendix C, Figure 7). 41% of participants had received between 1-4 hours of training on trauma informed care, working with interpreters and health literacy training.

Participants received the least amount of training on disability awareness and using specific communication aids or techniques, with 59% and 65% of participants indicating they had either not received any training on these topics, did not see it as applicable to their role or did not know if they had received any training previously.

Almost all the participants indicated they and their colleagues needed more training to fully understand and meet the needs of people with disability.

The additional training needs identified by the participants included:

- basic Auslan

- trauma informed care

- knowing how to ask questions about people's disabilities and how to address them

- knowing what supports/aids are available and how to access them

- health literacy training around understanding how to support communication and ensure patients have enough information that can be understood without overwhelming them or not providing enough information.

## Knowledge and experience supporting people with disability

**Knowledge and understanding of challenges faced by people with disability in accessing health care**

Participants were asked what they perceived to be barriers for people with disability when trying to access health care. The most common barriers identified included:

- cost of accessing health care
- accessibility of health care
- long wait times to see GPs or specialists
- clinicians using complex language when talking to patients
- the lack of time available in appointments to provide care in a way that meets the needs of their patient
- a lack of resources available to support communication and care needs
- health worker attitudes to caring for people with disability.

The attitudes of other health workers when caring for people with disability was raised by the health workers who participated in a variety of ways. It included stigma and discrimination around people with disability, as well as stereotyping and making assumptions about the decision-making capacity of people with disability.

**Supporting people with disability**

Health workers were asked how they support people with disability.

Most participants (94%) felt that they supported their patients to make their own decisions about their health (Appendix C, Figure 4). 73% said that they referred their patients to disability support services when they needed it.

Only 47% of health workers felt that they had the right resources to support the communication needs of their patients. 70% of participants indicated that they encouraged their patients to provide feedback on their communication preferences and made adjustments to meet their needs. 83% felt that their patients understood what they were telling them about their health and health care.

**Supporting communication needs**

When caring for people with disability, more participants indicated they either always or usually:

- used plain non-medical language
- made adjustments in how they communicated as needed
- collaborated with other health workers to coordinate health care
- provided information in a non-verbal way for example, writing things down and drawing diagrams.

Strategies such as checking for understanding (e.g. using the Teach-Back technique) and collecting and acting on feedback on supporting communication needs were least used by participants (Appendix C, Figure 5).

Participants were asked to identify the resources and tools they use to support communication with their patients. The supports most commonly used by survey and interview participants included using:

- large print material
- information written in Easy English
- supported decision-making tools
- communication boards and apps,
- interpreters.

Some participants also described allowing patients to record appointments or transcribing appointments and emailing a summary of the appointment to patients after their visit (See Appendix C, Table 1).

Interview participants also discussed seeking support from carers and support workers who are present during the appointment in supporting communication by using them to understand health communication needs and check for understanding.

**Involving carers and support workers**

When asked about involving carers and support workers in the care of people with disability most participants reported including them when providing care. For many interview participants, carers and support workers played a critical role in supporting understanding as they were able to identify communication needs, and are able to hold information for the patient if needed. Being able to hold information for the patient played a greater role in acute care settings where participants identified that patients who are unwell may not remember or understand all of the information they receive.

However, the perceptions of participants varied when it came to understanding how well carers and support workers know the patient and are able to support them.

Only 47% of survey participants reported that they felt a person's carer understood their patients' health background and information needs well (Appendix C, Figure 9). In contrast, participants felt that 44% of support workers had a good understanding of the health background and needs of their patient and 38% would have a good understanding of the health information needs of their patients (Appendix C, Figure 10).

While both survey and interview participants included carers and support workers in the care of people with disability, the majority of participants did not know if their organisation had policies around working with carers and support workers. 73% of survey participants indicated they did not know if their organisation had a policy on working with carers, and 59% of participants indicated they did not know if policies existed around involving support workers in the care of people with disability.

Additionally, of the participants who worked in public health services, 88% indicated not knowing if policies were in place around involving carers, and all participants indicated not knowing if policies were in place around involving support workers.

## Barriers to supporting people with disability

Participants were asked to identify any barriers or challenges they faced when caring for people with disability.

The key barriers identified by both survey and interview participants included:

- Existing written resources are often too complex and not easy to understand and there is a lack of resources in other accessible formats.
- Not having enough time with patients during an appointment to ensure that the patient has been able to communicate their needs and that the information being shared by the health worker has been understood.
- Not being able to see patients more often to ensure they have been able to understand and implement what has been discussed during their appointments.

### Resources

Participants discussed difficulties in being able to provide people with disability with health information in more accessible formats. They described written resources as being lengthy and often used medical jargon that patients did not understand.

They also identified a lack of resources being available in audio-visual formats, translated formats or large print or easy to read.

Some participants also identified that where information resources did exist it was not easy to be able to adapt them to suit the communication needs of people with disability. As one participant explained, it took two years to adapt an existing resource into Easy Read format due to needing to go through administrative processes.

Additionally, another participant explained that information resources around medications need to be approved by the Therapeutics Goods Administration of Australia. This means that pharmacists are unable to adapt information relating to medication or share information in more accessible formats if they have not been approved by the TGA.

Participants also described challenges in knowing where to find appropriate resources and communication aides to support people with disability. Participants described having access to resources and tools from a range of areas however, they felt they did not know about many tools and resources that were available to them. Participants within large health settings like the public health services described as sharing resources with their teams or their specialties but often did not know if there were resources or tools supports available to them that were being used by other specialties.

### Time

Time was a key barrier in being able to support people with disability. Both survey and interview participants described not having enough time during an appointment

to be able to fully adapt and meet the communication needs of their patients whilst also providing care.

As one participant explained, pharmacists in a hospital setting are able to dispense medication with instructions printed in large print to support patients with reading adjustments. However, they could not do this all the time as this process took time and the ability to do this was limited during busy periods.

Participants described that where possible they would encourage patients to book a longer appointment where communication needs had already been established, or they took more time during an appointment to ask about their communication needs to be able to support these.

# Summary of findings

The findings of this project have identified key factors that impact the health literacy and the health literacy needs of people with disability. These factors align neatly with the definition of health literacy outlined at the beginning of this report in which both individual health literacy and the health literacy environment play a role in supporting the health literacy of people.

For the purposes of this report, we will summarise the main findings and present the recommendations in the components of individual health literacy and the health literacy environment.

**Individual health literacy**

*"Individual health literacy is the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action [2]."*

This project has highlighted that people with disability are motivated to find, review and use health information to make informed decisions about their health and health care. However, their ability to do so can be limited by their individual skills and knowledge on how to find appropriate and relevant health information that meets their needs.

The findings identified that people with disability have difficulty finding information that is accessible to them. The specific challenges to finding health information include:

- Not knowing where to find information as information about health services and health conditions is spread across many websites and may not be localised for the ACT.
- Information may not be appropriate or applicable to their lives as it is written for a general audience and does not consider the intersection of their disability with their health care needs.

An additional challenge in finding and using health information for people with disability was that information is not often presented in a format that is accessible to them. The participants noted that information available online was often incompatible with screen readers. This is consistent with previous research conducted in the ACT by ACTCOSS[16], Women's Health Matters[16] and HCCA[17]. These reports highlighted the lack of information in accessible formats, particularly Easy English, Auslan, large print, and screen-reader friendly information. Additionally, health workers in both public and private services told us that they could not necessarily get appropriate and accessible health information to share with consumers.

Participants also experienced difficulty with finding information presented digitally, as it assumes that everyone has the digital tools and digital literacy to use technology and navigate digital media to find health information.

Where participants had reported being able to find health information, they identified having difficulties in appraising it for reliability, as they did not always have the skills

to identify the reliability of sources. This was made more difficult when they needed to find information across multiple different sources including websites, 'navigators' or family and friends.

Another finding from this project has been that people with disability and their carers did not feel they had adequate social supports to manage their health and wellbeing. Additionally, carers who participated in this study had lower scores in all of the domains of health literacy than those participants who did not identify as being carers. The results did not show clear reasons for this, however it is clear that unpaid carers face significant demands on their health literacy, and their health and social support needs are often overlooked[1]. Poor health literacy for carers impacts both the health outcomes of the person they care for[8] and their own health outcomes. Health literacy interventions need to consider supporting the health literacy and wellbeing of carers as well as supporting the health literacy of people with disability.

**The health literacy environment**

*"Health literacy environment is the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way that people access, understand, appraise and apply health-related information and services.[2]"*

The findings of this project have identified that process and policies that currently exist within the health system create additional barriers for supporting the health literacy of people with disability.

In particular, this project identified that the current structure and models of health appointments create critical barriers for people with disability. The participants identified that the existing approach of short 15-minute appointments that are often used by GPs, creates challenges for people with disability, who identified that they often need additional time to be able to communicate their needs with their health workers. The short appointment times also limit the time available to health workers to meet the needs of people with disability and carers. It takes time to establish and meet communication needs, provide information, check for understanding and support informed consent.

Discussions with health workers and the findings of the environmental scan identified that existing data systems within health services either do not support recording or requesting reasonable adjustments that can support communication and health literacy. Health services and health workers noted that either the appropriate platforms did not exist to be able to record this information, or that once recorded the information was difficult to find and that many did not know how or where to access the information if it existed.

Health workers also identified that they made efforts to accommodate communication needs and support people with disability to understand and engage in their health. However, they reported feeling limited in the adjustments and the supports they were able to provide due to a lack of knowledge and training of the different supports and services available to them and how to access and use them. Similarly, the key information interviews (Appendix A), identified that social workers

also did not receive any training to be able to support the health literacy needs of their clients or their own health literacy needs. Additionally, some health workers identified that the health information that was available to share with people with disability were often not available in formats that were accessible or easy to understand and did not know where to find more appropriate information. To address this, some reported needing to create new information resources which took a lot of time and effort and needed to go through many approval processes before being used.

Health workers reported including carers and support workers in the care of people with disability to support communication and understanding of health information. The findings indicated that some may have an over-reliance on carer or support workers to support the communication and care of people with disability or have little understanding on how carers and support workers can support the health literacy of people with disability. However, some health workers also reported limited confidence in disability support workers to be able to support people with disability.

Additionally, the findings highlighted that health services across the ACT either did not have policies in place to guide how health workers include carers and support workers in the care of people with disability, or health workers were unaware of them. This was consistent in both public and private health care settings.

Another challenge identified by people with disability in this project was the lack of health information available that considered the intersection of their disability and health conditions. This is consistent with the findings of the 2022 report by Women's Health Matters [17], which found that very little information existed around the interactions of pregnancy and menopause on people with disability.

Participants also identified their health workers also lacked this knowledge and that further research was needed to help bridge the information and care gap when it came to disability and health care.

Many issues raised by people with disability in this project are also issues for the population more broadly[1], including communication skills of health workers, confusing health systems, and difficulty finding and identifying reputable health information. The Community Health Literacy in the ACT Environmental Scan[1] found a number of gaps that are also relevant for the health literacy of people with disability and carers, including:

- Limited coordination of work led by diverse organisations, and few opportunities for the organisations, staff and volunteers involved to share and learn from each other's experiences.

- Limited focus on the connection between health literacy and patient safety, and low community awareness of this connection, and

- Unmet consumer demand for health literacy skills development opportunities, including in the context of self-managing one or more chronic conditions.

A draft framework was developed in 2019 as part of HCCA's Community Health Literacy Project, which could be updated and implemented. Other jurisdictions such as New South Wales have implemented health literacy strategies, leading to initiatives like the [Statewide Health Literacy Hub](#), which embeds disability inclusion into a number of its activities so that it becomes standard practice for health literate services.

# Recommendations

## Individual health literacy

1. **Co-design targeted health promotion campaigns with people with disability as part of population health programs.**

People with disability have said that while they can find information about health and wellbeing, they cannot implement the actions suggested because of access barriers or a lack of tailored advice. This would be improved by co-designing health promotion campaigns with people with disability, with a focus on:

- Accessibility of information, including resources on preventative health activities
- Ways to adjust broad health advice for your ability and capacity. e.g. different ways to increase physical activity
- Where to find community-based services for people who need tailored advice
- How to access screening programs if general options are inaccessible (e.g. bowel screening if at-home testing is not possible)

This co-design process should be embedded into Territory-wide population health strategies.

2. **Provide digital literacy training and support for people with disability and carers to learn to use digital health platforms and access technology to participate in digital health care.**

While most participants had used digital health tools, nearly 1 in 5 said they needed help to use them. A digital health literacy program could address some of these issues by providing accessible training and resources including:

- Sessions on how to use key health applications (e.g. my health app and MyDHR) and how to use them
- Privacy and security of health applications
- Skill workshops on how to find good quality health information online
- Support for carers to manage information about the person they care for, e.g. setting up proxy access in MyDHR, carer mode in medicine apps.
- Video and pictorial tutorials on how to use applications

The national Be Connected program provides funding to enable digital literacy, however there are few initiatives aimed specifically at people with disability and carers. Libraries ACT is a Be Connected partner organisation and has locations throughout the ACT and are well placed to partner with Health and Community Services Directorate and community organisations to run digital health literacy programs for people with disability and carers.

This research reinforced previous findings[16,17] that the cost of up-to-date technology was a barrier to accessing information and making use of digital health tools. Small grants or loans of devices for individuals should be provided alongside digital literacy

training to support participation in health care and self-management, particularly for individuals who are caring for someone else or would benefit from virtual care.

3. **Create and maintain an accessible platform for health service information and health literacy resources for people with disability, carers, support workers and health workers. Build on existing platforms to avoid duplication.**

   *"A one-stop-shop for key service information and basic info about health conditions specific to the ACT and covering more than just public services. You need to know about 7 different sites to get this right now"*

A single platform that holds health information, resources and information about health services and supports is key to addressing the challenges around finding reliable, accessible health information for consumers, carers, support workers and health workers.

This platform should be co-designed with people with disability, carers, community organisations and health services and with ongoing funding to continue consumer involvement in updates and development of new resources. The platform should aim to consolidate resources that exist across health services and settings across the territory. Ideally, an existing platform should be expanded to prevent duplication. Some priority health information topics for this platform include:

- Mental health
- Sexual and reproductive health
- Decision-making and rights in health care
- Screening tests and preventative health
- Navigating health, disability and aged care services in the ACT

The platform could also provide:

- Templates and guidance for services to create accessible information
- Practical guidance for health workers on making reasonable adjustments
- Guidance for health services on how to consider diverse communication needs in policy
- Examples of best practice

Some examples of platforms include:

- [Women with Disabilities Australia's Our Site](): This platform includes a range of resource formats, information for supporters and a site-wide Easy Read mode.
- [NSW Multicultural Health Communication Service](): provides multilingual resources on a range of health topics as well as guidance and tools for health workers, alongside a translation service.

An accessible health information service for the ACT could similarly include dedicated staffing to produce accessible resources and skill up health organisations. There could be an opportunity for the ACT service to expand into multicultural resources as part of an integrated ACT-wide approach to health literacy (Recommendation 14).

4. **Scope and implement a health navigation service for people with disability and carers.**

The complexity of the health system is a significant barrier to access, and individuals need a high degree of health literacy to understand and use the NDIS to maintain their everyday wellbeing[1]. Further confusion is added when a person with disability becomes eligible for aged care, as their eligibility for NDIS and health services may change. Even when consumers have strong individual health literacy skills, the competing demands of multiple fragmented systems can make it very difficult to understand and access the right support – whether that is health care or community-based supports that are needed for self-management and wellbeing.

One-to-one personalised support is needed to help people with disability and carers to find appropriate health and wellbeing services across the disparate support systems. This support could also include capacity building with individuals to navigate these systems in future. This service needs to integrate navigation of health services, community supports, formalised disability supports and aged care if it is to meet the needs of people with disability holistically. This would be best delivered through a cross-sector partnership including Government and community organisations that are already embedded in these spaces.

5. **Provide funding for community organisations to develop or extend social supports for health literacy, including support groups and peer education.**

Both people with disability and carers indicated that they did not have enough social support for their health and wellbeing. There is an opportunity to support new peer-led programs and strengthen existing ones to support health and wellbeing, like Women with Disabilities ACT's [Our Autonomy project](#). This could be done through a funding stream for community groups to undertake activities like:

- running health education events and workshops
- sharing health literacy information at community centres
- training people with disability to become peer health educators and navigators
- expanding existing social groups to build skills such as self-advocacy and cooking healthy meals.

Cross-sector support may be needed to reduce the barriers to participation in these activities, such as support for transport[16] Funded activities should include community led-solutions to support underserved communities like LGBTQIA+ people with disability, women with disability and people with disability from multicultural backgrounds.

## Health literacy environment

6. **Co-design and deliver training on supporting health literacy of people with disability for health workers in all health settings.**

Minimum training in disability competence and inclusive communication should be mandatory for health workers across the ACT, including reception, administration

and management staff. Consumers and disability representative organisations have emphasised that people with disability and carers must be involved in co-designing and co-delivering training in health services to centre lived experience and build trust in health services.

Further training for clinicians needs to include:

- Communication techniques and aids
- Trauma informed communication
- Shared decision making, particularly for people with intellectual disability and cognitive impairment
- Communicating about sensitive topics such as reproductive health care and mental health
- How to involve carers and support their health literacy
- The role of support workers and appropriate ways to involve them.

A successful model like the Down Syndrome Australia Health Ambassadors[18] could be adapted for the ACT context and would develop a workforce of lived experience trainers and advisors that can support change across the health system.

Training needs to be supported by policy and resources, like guidelines for involving carers and support workers (Recommendation 13) and promotion of communication tools (Recommendation 11).

7. **Provide training for disability support workers to enable them to better support their clients to navigate the health system and partner in their own health care**

Support workers may provide significant support for a person' interactions with the health system and in managing their health day-to-day. However, training for support workers does not include health system navigation as standard, and involvement of support workers by some health workers breaches the consent and autonomy of the consumer. Health literacy of support workers themselves may also be low, as this workforce includes a high proportion of recent migrants who may not be familiar with the Australian health care system. Consistent training is needed in:

- knowledge of ACT health services
- supporting the participation of clients in health care
- respecting client's capacity in communication and decision making
- awareness of a client's health care rights

National Disability Services has been doing work to identify key competencies for workers and [share resources about disability health](). This should be supported by ACT-specific information and templates to support continuity of care. Training for health workers (Recommendation 6) is also needed to ensure mutual understanding of roles in person-centred care.

8. **Develop and build staff within public health services to champion health literacy.**

Advocates and health workers told us that improving support for people with disability within mainstream health services is often reliant on passionate staff who bring prior experience and training. These clinicians are able to provide practical expertise to their colleagues and support the development of policies and procedures within health services.

Health and Community Services Directorate and Canberra Health Services should aim to attract staff with expertise in disability and consider such experience as an asset in recruitment. They should identify and develop 'champions' through further training and knowledge sharing opportunities such as a community of practice.

To further promote cultural change and embed more accessible practices across public health services consistently, it is also important to create identified roles within health services. These staff could facilitate tailored training to clinical areas (in collaboration with lived experience trainers per Recommendation 6), advise on practical ways to address barriers to care and practically promote ongoing awareness of reasonable adjustments, accessibility resources and services.

9. **Conduct an audit of all resources and tools that can aid and support communication available across Canberra Health Services, and use internal training and platforms to increase the awareness and use of these resources during appointments across all services and specialties**.
Reasonable adjustments have been identified as an area for improvement in a number of previous consultations (See Appendix A Environmental Scan). Adjustments to support communication were identified as a particular barrier for people with disability in this project as communication is a fundamental part of health literacy. Without equitable access to communication, consumers are not able to:
- ask questions about their health
- voice their decisions about treatment and care
- alert health workers potential safety issues
- tell health workers about other accessibility needs

We found that workers within health services had highly variable awareness of reasonable adjustments, particularly the tools and aids that the service has available and how to request them.

Internal platforms need to be improved to enable staff to understand what is available to support communication and request resources when not readily available. Likewise, consumers and carers need information about how to request what they need and assurance that health workers know how to work with consumers who need communication aids, alternate formats for information, support for decision-making and other adjustments.

10. **Conduct an audit and improvement process to ensure all ACT Government health apps are fully accessible and user tested.**

People with disability and carers identified that many health apps were clunky, difficult to use and not accessible, particularly for people with vision impairment. Consumers also said that design of digital platforms was inconsistent which made it difficult to learn a new app each time.

All ACT Government health apps should be designed to meet accessibility standards and tested with people with disability to ensure equitable access to health information. The ACT Government should develop guidelines to ensure consistency of operation across their apps and mobile versions of their websites.

11. **Health and Community Services Directorate to develop and implement policy changes and scope/support funding to extend the length of health appointments for people with disability.**

Time was a significant factor in health workers ability to meet the health literacy needs of consumers. In public settings, consumers may not know how to request more time and additional time may not be factored into clinic bookings. In private settings such as GPs, longer appointments come with increased cost, which is a barrier for people on low incomes.

Health and Community Services Directorate should review and develop and implement policies and procedures that ensure that people with disability who have identified as needing reasonable accommodations during health appointments be supported to have longer appointments as the standard. This will ensure that people with disability and their carers or support workers aren't having to repeat or request a longer appointment each time and ensure that their appointments allow adequate time to ensure their health and care needs are met.

Health and Community Services Directorate should further scope a funding program which provides longer appointments for people with disability who have identified needing reasonable adjusts in public health settings. They could collaborate with the Capital Health Network on initiatives in primary care such as:

- providing consumers and carers with clear information about Medicare items that can support longer appointments, like MyMedicare, Chronic Condition Management Plans and annual health checks
- educating GPs and practice managers about items to support longer appointments
- scoping pilot programs that enable a multi-funded approach to primary care for people with disability that enable longer appointments and multidisciplinary care such as the ACT Primary Care Pilot program.

12. **Develop, implement and evaluate clear guidelines and policies for working with carers and support workers within public health services, and share best practice policy guidance with other services.**

It is recommended that Health and Community Services Directorate develop clear policies and guidance on involving carers and support workers in the care of people with disability. The policy should include guidelines on:

- Seeking consent before involving carers or support workers
- How to share information with carers and support workers that meets their health literacy needs so they are able to support the consumer.

These policies should form the baseline standards that need to be met by health and community services that operate within the ACT, for example Canberra Health Services and Capital Health Network and private health services. This ensures a minimum standard is set on working with carers and support workers across all health settings.

## Further research

The outcomes of this project have highlighted that there is still a considerable need for further research to create knowledge and understanding on health, health care and disability to be able to improve health literacy and care for people with disability. The following recommendation focus on the research and next steps that need to be taken to support the health literacy and health care and outcomes for people with disability.

13. **Support and fund research into the intersection between disabilities and health conditions where research does not exist.**

Research on the intersection of disability and health should be prioritised within the ACT. Research partnerships and co-designed research with academic institutions, ACT health services and ACT Disabled Persons' Organisations will help to:

- Increase the information and supports that exist for people with disability
- Strengthen the evidence base for health care for people with disability
- Improve the quality and safety of care for people with disability
- Increase the reputation of the ACT research landscape

Prioritising research into disability and health supports the progress of the ACT Government into achieving the objectives and commitments laid out in the strategic plan for research by the ACT Government[19] and Canberra Health Services[20].

14. **Fund specific research into understanding and application of health literacy concepts and needs of people with intellectual and cognitive disability and their supporters, including supported decision making.**

As noted in the Environmental Scan, while there has been research into health literacy interventions for people with intellectual disability, there is limited research into what health literacy means to this population and how it can be measured meaningfully. Existing tools like the Health Literacy Questionnaire pose issues

because they have not been translated and validated in Easy English, and some of the concepts are difficult to apply to their experience as they may be reliant on the support of others to find, understand and act on health information.

Research into health literacy with people with intellectual disability needs to be tailored, trauma informed and done in partnership with organisations trusted by people with intellectual disability, their families and carers. Health and Community Services Directorate should build on the established knowledge and networks of organisations such as ACT Down Syndrome and Intellectual Disability and collaborate with experts such as the National Centre for Excellence in Intellectual Disability Health to co-design further research in the ACT context. This would support the ACT's implementation and evaluation of actions under the National Roadmap for Intellectual Disability Health.

15. **Provide funding for action research projects that investigate and address the health literacy needs of people with disability from multicultural communities**.

The limited response rate from people with disability and carers who are from multicultural backgrounds in this project suggests a need to use an alternative approach to engage with people from these communities. Engaging with people from multicultural communities often takes more times and requires more relationship and trust building. Action research approaches have been used to engage with multicultural communities and tailor health communications to meet their needs[21].

It is recommended that Health and Community Services Directorate partner with multicultural community groups and leaders to develop and conduct specific action research projects to understand and target the health literacy needs of people with disability and carers from diverse cultural backgrounds.

16. **Provide funding for action research projects that investigate and address the health literacy needs of carers of people with disability**.

The findings of this project have highlighted that carers of people with disability, including people with disability who identify as being carers as well, experienced the lowest levels of health literacy when compared to people with disability or the general ACT population. These findings indicate that there are additional challenges and barriers to health literacy when acting in the role of a carer that need to be understood and addressed. However, the specific challenges for carers were not clear from these findings.

Health and Community Services Directorate should partner with organisations such as Carers ACT to understand additional barriers that need to be addressed to support carer health literacy, like the time, cost and social barriers identified in the 2024 Carer Wellbeing Report[22].

# Consumer, carer and advocate involvement in this project

HCCA recruited a reference group to guide the project with perspectives from consumers, carers, advocates and support organisations. The project also recruited two project advisors who did not participate in reference group meetings as it was more accessible for them to meet with researchers directly early in the project.

**Example 1: Articulating the role of support workers**

Interviewing and surveying disability support workers was outside the scope of this project, however consumers, advocates and support organisations all raised issues around the interaction between support services and health services. Some of the issues raised were:

- Lack of clear guidance for health workers and support workers about their roles leads to confusion. This may lead to doctors directing communication to the support worker rather than the consumer, or conversely, excluding support workers when they are needed to support communication by the consumer. Support workers may not view it as part of their role to support communication in health care but may hold valuable information about the day-to-day health of their clients.

- Support worker curriculum does not include adequate information about supporting consumers in a health care setting, such as how to bridge communication gaps and advocate for the consumers' needs and rights.

- Registered support providers may keep quite detailed day-to-day information on health for their clients, but it can be unclear when this can be shared with health services and when it is, it may not be used due to the format of documents.

This prompted questions around support worker involvement in the environmental scan, and questions being included in the health worker surveys and interviews.

**Example 2: Shaping recommendations**

Members of the reference group help with sensemaking of the survey and interview results by adding context from their experiences and pointing out where issues may not have been captured. Areas highlighted by the Project Reference Group included:

- Low response rate to surveys from multicultural communities. Consumers said that other methods, such as focus groups, might be more appropriate, and future research should be led by these communities.

- The importance of consent by the person with disability in the involvement of carers and support workers in health care. While mentioned in some interviews, this was not mentioned by health workers in the survey when asked about how they work with a person's supporters.

- Members from support organisations pointed out that NDIS support coordinators had played an unofficial role in health care navigation, but this was not a billable activity, and support co-ordination was being phased out in

many people's plans. This highlighted a gap created by structural changes to the NDIS.

- Members told us about specific issues in sexual and reproductive health for women with disability including limited information about the interactions between certain conditions and menopause or pregnancy.

Insights from the reference group helped make recommendations coming from the research more specific and practical.

# Appendices

A. Environmental Scan
B. People with Disability and Carers Survey Methods and Results
C. Health Worker Survey Methods and Results
D. People with Disability and Carers Survey Questions
E. Health Worker Survey Questions

# References

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# Appendix A: Environmental Scan

This Environmental Scan was conducted by HCCA to better understand how ACT-based health and disability services are currently supporting the health literacy of people with disability and their carers.

## Review of mainstream health services and disability support services

HCCA interviewed representatives from 6 health and support services across the ACT to gain an understanding of the initiatives and strategies they have in place to support the health literacy of people with disability.

These organisations included:

- Canberra Health Services
- Down Syndrome Association
- ADACAS
- North Canberra Hospital
- National Disability Services
- Women* with Disabilities ACT (WWDACT)

HCCA also interviewed 3 disability advocates to leverage their knowledge and understanding of the supports available to people with disability.

These discussions were focused around understanding what health literacy supports exist within the ACT for people with disability, as well as understanding how health literacy can be further supported and barriers to health literacy be addressed.

Consistent with previous research, our discussions highlighted key components that support health literacy for people with disability. These include:

- Time to build and support health literacy
- Health workers' knowledge of services and supports for people with disability
- Training for health workers

These components together provide a base for supporting health literacy for people with disability. Advocates also raised that generally inaccessible health services removed opportunities to develop health literacy, so broader access issues must be addressed for support to be effective.

### *Time to build and support health literacy*

During the discussions, advocates and representatives from services that support people with disability often spoke about how building health literacy takes time. They discussed that for people with disability time is needed to communicate their needs and understand what is being told to them. However, people with disability are often left at a disadvantage, as their health workers don't have time to learn about and adapt their communication based on the needs of their patients. This was also a barrier to building trust between consumers and health workers.

*Health workers' knowledge of services and supports for people with disability*

Our discussions highlighted a key barrier in improving the health literacy of people with disability often stemmed from health workers not knowing about or having access to information on services and supports that exist for people with disability. This included supports within the health system and social/community supports.

The discussions with the health services highlighted the range of supports and resources available to clinicians and patients to support health literacy. Some tools and resources, however, are often either not used, not used to their best capacity or only used by staff in certain specialties.

The reasons for resources not being used often were that clinicians may be unaware of available communication tools, lack training on their use, or are constrained by time pressures during service delivery.

The most commonly used information within health services were often consumer information sheets that had been translated into Easy Read or into other languages, or interpreters.

The discussions also touched on issues with recording and sharing patients' needs, including reasonable adjustments for communication. Even where a patient's needs are recorded in a care plan, they may not be visible in different areas of public health services or shared across services.

*Training for health workers*

During the discussions, we asked our participants about the training staff receive on working with people with disability as well as supporting health literacy. Within health services, there is mandatory training on diversity and inclusion when staff join the health service. However, participants noted a critical gap in ongoing or refresher training for staff on effectively engaging with people with disability. Additionally, there is no specific training that exists on how to build health literacy for their patients and their families/carers.

Similarly, while disability support workers often support their clients during health appointments or to manage their health, they often do not receive any training on how to support health literacy for themselves or their clients.

## Previous consultations and projects on understanding and supporting health literacy for people with disability

*What has been said in previous government consultations*

Consultation for the ACT Disability Strategy found that access to health care was consistently one of the biggest issues for people with disability[1]. Of the themes covered in the listening report, those relevant to health literacy were:

- health care providers don't know how to communicate with people with intellectual disability or people who don't communicate verbally
- health care providers did not make reasonable adjustments to support better communication or understanding of patients
- assumptions that people with disability don't have the capacity to understand and make decisions about their own health so health workers speak to family carers or support workers instead of their patient
- health workers often did not engage translators, or let patients know free translation services are available
- medical staff not knowing how to book an Auslan interpreter
- the health system is hard to navigate, and that systems are siloed rather than connected

Participants in the consultation said that they would like:

- disability awareness training for all health workers
- health workers to incorporate transcription apps or other communication technology into consultations with patients who might find it useful.
- increased numbers of Auslan interpreters and training for health workers to work with them.

*Community sector research and advocacy*

**Community Health Literacy in the ACT: Environmental Scan, HCCA, November 2020**

In 2019, HCCA conducted an Environmental Scan on Community Health Literacy in the ACT[2]. The report identified key gaps that are still relevant for the health literacy of people with disability in the ACT, including:

- The absence of a jurisdiction-level framework to guide health literacy improvement in the ACT.
- Limited coordination of work led by diverse organisations, and few opportunities for the organisations, staff and volunteers involved to share and learn from each other's experiences.
- Limited focus on the connection between health literacy and patient safety, and low community awareness of this connection, and
- Unmet consumer demand for health literacy skills development opportunities, including in the context of self-managing one or more chronic conditions.

This project also examined issues for people with disability, highlighting that:

- People who have National Disability Insurance Scheme (NDIS) plans must have high health literacy to manage their plans and negotiate NDIS requirements.

- Those ineligible for the NDIS or who have chosen not to participate in the NDIS can face challenges finding information about what services are available and accessing services.

- Health facilities are often designed in ways that are not accessible for people with physical disabilities.

- People with vision impairments may require information in alternative formats

- People with intellectual disability may need support and time to participate in supported decision making

- Some people with disability need to use communication tools such as communication board, however those consulted for this report advised that health service staff are not always familiar with these tools, and services do not always have clear processes in place to support their use.

For carers, this report found that:

- Unpaid carers face significant demands on their health literacy, and their health and social support needs are often overlooked.

- Carers' role in safeguarding the health and wellbeing of the people they support is often undervalued or overlooked in care planning and health service delivery.

Participants in consultation for the report advised that better identification of family carers, recognition of the needs of carers, and involvement of carers and family members in decision-making would support the role that carers play in patient safety.

**Imagining Better: Reflections on access, choice and control in ACT health services for people with disability, ACTCOSS, August 2019**

In ACTOSS's 2019 report, *Imagining Better*[3], people with disability raised several issues and recommendations relevant to health literacy, namely:

- Gaps in knowledge of services and supports available in the ACT for people with disability

"There are gaps in knowledge about critical services and supports experienced by both practitioners and people with disability, their families and carers. People with disability, their families and carers lack awareness of low-cost health services and options, such as the nurse walk-in centres. Practitioners lack knowledge about disabilities and non-health system supports which could assist people experiencing those disabilities to better monitor their health status and service access."

- Clinicians skills and understanding around communication have impacts on the health outcomes on people with disability.

Some participants in this report described clinicians modifying their communication style to accommodate their needs such as: speaking clearly and calmly, using non-technical language and taking their time to explain things. In contrast, one participant also described experiencing a critical incident that could have been avoided if clinicians had spoken to him.

- Information sharing is essential and must be accessible

The report highlighted that accessing information digitally is challenging, particularly for people with vision impairment. Participants also described the need to provide information in multiple formats across digital and hard copy versions to support people to access information in formats that best suit them.

"Every person with a disability should have access to an information resource that lists all of the bulk billing clinics in the city, ancillary services such as the walk-in centres, and provides joined up contacts for health and disability advocacy as well as illness-specific self-help services and resources. Every doctor and health practitioner should have electronic and hard copy information about ways to support, interact with and provide accommodations to people with disability. This should include information on non-health-based disability supports and service."

The report also named some specific initiatives that would support health literacy for people with disability, including:

- Publish and maintain a list of disability friendly bulk billing clinics in Canberra

- Ensure that all screening kits and preventative health information and devices are reviewed by people with disability prior to being issued

- Allow people with disability to take more NDIS supports into clinical settings

- Provide plain-English medical and systems documentation

- Provide funding and training in the access and use of communication boards, facilitated communication, learning of Auslan and easy English within all publicly funded and regulated health settings.

- Maintain and strengthen alternatives that cater to people with barriers to accessing digital devices and technology (i.e. people who cannot access online health information or who need to communicate by phone to access health information)

Note: this report also highlighted that issues such as costs and transport are significant barriers even where people are very health literate.

**"I have to ask to be included…", Women's Health Matters, February 2022**

In 2022, Women's Health Matters sought to understand the views of women in the ACT living with disability on their health and health needs, support and information

and access and barriers to maintaining health[4]. The report found that women with disability often faced barriers around:

- Accessing information
- Health workers knowledge and skills around the intersection of disability and other health conditions
- Inflexibility around communication and contacting people with disability.
- Assumptions that everyone has a computer and know how to use it.
- Affordability

The report found that women with disability faced particular difficulties in finding information about specific health conditions, how specific conditions may affect their reproductive health and how different health conditions may impact each other.

The respondents also identified having difficulty finding reputable health information, particularly for rare conditions. And when information did exist, the information provided was not provided in easily accessible formats. The report highlighted that most often information was presented online and was not always accessible to everyone.

*"Information is one thing, I'm very knowledgeable and can find almost anything I need online. However, information does not correlate with wellbeing for me. It doesn't result in implementation of good advice and strategies for me".*

Respondents highlighted that health workers did not always have information about a condition or disability and did not consider their existing conditions/disability when recommending treatments or lifestyle changes.

Affordability was a further barrier to health information as many women relied on their GP/specialist for information about their health as relevant information was not available for managing their health independently.

A cross-analysis of these reports reveals several consistently raised issues and actionable themes in their findings and recommendations:

- There is a need for a system-wide health literacy strategy tailored to people with disability.
- Access to health information must be accessible, i.e. information is easy to understand, multi-format, non-digital when needed.
- Training for health workers is critical to improve communication and support inclusive care.
- Carers and support workers must be acknowledged in health literacy frameworks.

## Policy, organisational and legislative frameworks

### ACT Policy and frameworks

Within the ACT, there are several policy frameworks that recognise and support the need for action on health literacy for people with disability.

The ACT Government Disability Strategy 2024-2033[5] shows a commitment from the ACT government to support the right of people with disability to full and equal participation in all aspects of community life.

Additionally, The ACT Health Directorate Strategic Plan 2020-2025[6], Healthy Community Strategy 1.5 is to 'Engage with communities and enable healthier choices and protective behaviours through improved health literacy and health promotion'

Additionally, the following strategies also identify health literacy as playing a role in enabling the success of ACT government plans to improve the health and wellbeing of Canberrans

- ACT Health Services Plan 2022-2030[7]
- Accessible, Accountable, Sustainable: A Framework for the ACT Public Health System 2020–2030[8]
- ACT health quality strategy 2018-2028: person-centred, safe and effective care[9]

Encompassed within these are:

- ACT Preventive Health Plan 2020-2025[10]
- ACT Digital Health Strategy 2019-2029[11]
- ACT Carers Strategy 2018-2028[12]
- ACT Health Workforce Strategy 2023-2032[13]
- ACT Mental Health and Suicide Prevention Plan (ACT Plan) 2019-2024[14]
- Position Statement on Improving Mental Health and Wellbeing Outcomes for People with Intellectual Disability[15]

More specifically, the ACT Disability Health Strategy[16] has a key focus area on health information and health literacy. This focus area sets out specific goals around ensuring health accessible information is available in accessible formats and supporting health literacy to improve informed decision-making and capacity to take action to manage health.

### National Policies and Frameworks

Nationally, the federal government has also identified the importance of health literacy in supporting positive health outcomes for people.

The National Statement on Health Literacy: Taking Action to improve safety and quality[17], identifies the importance of health literacy in ensuring people accessing safe and high-quality care. The Statement also provides a table of actions that can support health literacy. These include actions for: consumers, healthcare providers, organisations that provide healthcare services, organisations that support healthcare providers and governments, health regulators and health advisory bodies.

Additionally, the National Preventative Health Strategy 2021-2030[18], identifies health literacy as an immediate priority to achieve its aims. As an action of this priority, in 2022, the Australian Government commenced a body of work to develop a National Health Literacy Strategy.

While these strategies, focus on improving health literacy for all Australians, the National Roadmap for improving the health of people with intellectual disability[19] also highlights the importance of health literacy for people with intellectual disability. The roadmap provides more specific actions and outcomes to support health literacy over the short and long term for people with intellectual disability.

### *National Standards for Safety and Quality in Healthcare*

Health literacy is an identified action area in *Standard 2: Partnering with Consumers* in the *National Standards for Safety and Quality in Healthcare*[20] and several actions within the standard oblige health services to provide information that is accessible, meets the needs of consumer and their carers and families, and is tailored to the diversity of consumers.

| Standard | Action |
|---|---|
| 2.03 | The health service organisation uses a charter of rights that is:<br>a. Consistent with the Australian Charter of Healthcare Rights<br>a. Easily accessible for patients, carers, families and consumers |
| 2.06 | The health service organisation has processes for clinicians to partner with patients and/or their substitute decision-maker to plan, communicate, set goals, and make decisions about their current and future care |
| 2.08 | The health service organisation uses communication mechanisms that are tailored to the diversity of the consumers who use its services and, where relevant, the diversity of the local community |
| 2.09 | Where information for patients, carers, families and consumers about health and health services is developed internally, the organisation involves consumers in its development and review |
| 2.10 | The health service organisation supports clinicians to communicate with patients, carers, families and consumers about health and health care so that:<br>a. Information is provided in a way that meets the needs of patients, carers, families and consumers<br>b. Information provided is easy to understand and use<br>c. The clinical needs of patients are addressed while they are in the health service organisation<br>d. Information needs for ongoing care are provided on discharge |

These actions are aligned across other national standards including the National Safety and Quality Primary and Community Healthcare Standards[21] and the Australian Community Pharmacy Standard.

Additionally, the Australian Charter of Health Care Rights[22] includes the rights to Access, Partnership, and Information. These include:

- The right to health care services that meet the needs of the consumer
- The right to ask questions and be involved in open and honest communication
- The right to make decisions to the extent they are able
- The right to include the people that they want in planning and decision making
- The right to clear information about conditions, tests and treatments to facilitate informed consent
- The right to assistance to help them understand and use health information

*Professional standards and Codes of conduct for health workers*
**Royal Australian College for General Practice (RACGP)**

The RACGP Standards for General Practices[23] have standards that focus on communicating with and involving patients in their care.

The standards outline the need for GPs to build health literacy by:

- recognising the patient's needs and preferences and tailoring communication accordingly
- assuming that most people will have difficulty understanding complex health information and concepts
- providing health information in an unrushed manner using words that the patient understands
- using multiple forms of communication to confirm that information has been delivered and received effectively
- giving the patient targeted information (e.g. leaflets) and telling them where they can access targeted information (e.g. websites and online support groups)
- encouraging the patient, carer and other relevant parties to say if they have difficulty understanding the information
- using proven methods of informing patients about the risks of treatment options.

The standards also require GPs to support communication with patients by:

- using communication strategies to engage with patients who have difficulty accessing the service due to a communication impairment
- supporting access to resources that are culturally appropriate, translated, and/or in plain English
- using an interpreter with patients who do not speak the primary language of our practice team

The standards also address accessibility of services for patients, however has a primary focus on physical accessibility.

**Medical Board of Australia**

The Code of Conduct for the Medical Board of Australia covers all doctors who practice medicine in Australia[24]. The codes does not explicitly mention health literacy, however it contains sections relevant to health literacy.

Section 4 on Working with patients includes a section on effective communication which says that involves:

> "*Taking all practical steps to ensure that arrangements are made to meet patients' specific language, cultural and communication needs, and being aware of how these needs affect patients' understanding.*" (Item 4.3.7)

Under the section on informed consent, it says Good medical practice involves:

> "*Providing information to patients in a way they can understand before asking for their consent.*" (Item 4.5.1).

These items are both relevant to how doctors must communicate with patients in a way that meets their needs and supports their understanding, which is crucial to health literacy.

The code of conduct does not specifically comment on the needs of people with disability, but does contain a section on supporting people with additional needs that mainly focuses on assessing capacity, paying attention to communication and recognising that other people, such as family and carers may be involved in a patient's care.

**Codes of Conduct for other health workers**

**Disability and Health Literacy in the ACT**

The Nurses[25], Midwives[26] and shared codes of conduct for health workers (covering 12 other professions) all include health literacy as an obligation for workers:

In the section on Effective Communication, this says that good practice includes that [health workers]:

> *"c. are aware of health literacy issues, and take health literacy into account when communicating with people*
>
> *d. take all practical steps to meet the specific language, cultural, and communication needs of patients and their families, including by using translating and interpreting services where necessary, and being aware of how these needs affect understanding*
>
> *e. endeavour to confirm a patient understands any information communicated to them"*

The section on informed consent is also relevant as it states that good practice includes that [health workers]:

> *"a. provide information to patients in a way they can understand before asking for their consent […]*
>
> *b. give the patient enough time to ask questions and make informed decisions"*

## Conclusions

National and ACT government frameworks support actions on health literacy that would support people with disability. Whilst there are explicit strategies to address the needs of people with disability in health care, it is crucial to consider the needs of this population as core to quality improvement throughout all aspects of health service delivery.

There is a clear opportunity to develop and disseminate practical guidance and training for health workers, aligned with professional standards and codes of conduct, to strengthen inclusive practice and health literacy support for people with disability.

## Current initiatives in health literacy for people with disability in the ACT

During our discussions, we asked our participants to share with us the programs and resources that exist within their organisations to support health literacy for people with disability.

The list below is a summary of the services and supports that exist for people with disability that can support health literacy. This list is not exhaustive, and a more comprehensive mapping activity may need to be undertaken.

### *Work led by health care organisations*

Some of the programs and resources that exist within the health services in the ACT include:

| Program/Resource | Description |
|---|---|
| CHS Diversity and Inclusion training | Mandatory training for staff on working with people from diverse backgrounds |
| CHS and ACTHS Easy English translation projects | Specific projects for translating existing consumer handouts and information into Easy English. CHS aim to create an easily accessible webpage for translated documents on their website |
| VIP Vision Impaired Person Hospital kit | In 2023, CHS launched the use of a 'Vision Impaired Persons Hospital Kit' (VIP Kit). The kit has been designed by Canberra Blind Society and is designed to make hospital stays for patients who are blind, or vision impaired, more comfortable and allow them to maintain a degree of control of their situation. The Kit includes admission check lists, bedside notices, ID stickers and sighted guide information for their stay. |
| 'Know where to go for your healthcare' | This online tool designed by CHS allows, individuals in the ACT region to answer simple questions about their health needs and find out where to go for the most appropriate care. |
| ADACAS Support Decision Making toolkits | NCH use supported decision making toolkits with clients with cognitive impairments where needed |
| NCH communication resources | NCH have a range of communication tools and aides such as: robotic tools, communication cards, personal amplifiers |
| Marathon Health | NCH provide funding to Marathon health to support out of hours health supports for people on the NDIS. They provide hospital, police and other supports such as helping find emergency accommodation for someone escaping domestic violence. |
| Use of a modified call bell | This is available to use for people with upper limb issues who are unable to press a button. |
| Sharing resources and tools on HealthPathways | Capital Health Network will often share resources and guidance information through their news |
| Information and navigation supports | In partnership with the National Capital Hospital, ADACAS provide information for people with disability, their families |

| | |
|---|---|
| at National Capital Hospital | and support networks. They also support them in connecting with services and provide education sessions |
| Care Finder Program | Funded by Capital Health Network, the Care Finder Program is a trial providing support for older people with to navigate aged care. |

North Canberra Hospital has also conducted a discrete project around communication aides. The first is called the Speak Easy Project. This project was a discrete point-in-time audit to identify the communication aides patients have identified they have needed. The project identified if these needs had noted in their medical records and if these notes and aides had been accessed. The project also sought to identify the barriers to using the notes and requested aides.

*Work led by consumer and community organisations*

Some of the programs and resources that exist within the community services in the ACT include:

| Program/Resource | Description |
|---|---|
| Advocacy services for people with disability | ADACAS and Advocacy for Inclusion provide single issue advocacy services for people with disability who are living in the ACT |
| Our Autonomy project | Women* with Disabilities ACT's Our Autonomy project runs peer events and skill building workshops that include health-themed sessions |
| Canberra Health Literacy Hub | The Canberra Health Literacy Hub, while not specific for people with disability, has a range of resources to support health literacy for consumers, carers, community workers and health workers. |

The community-based organisations we spoke to, also often include a range of resources on their websites to support people with disability, their families and supports and the health care workers to be able to appropriately communicate with, and support the health literacy and health of people with disability. Some of these include:

- ACT Down Syndrome & Intellectual Disability's website integrates Down Syndrome Australia's Easy Read resource hub
- The ACT Nutrition Support Service has information on living with a disability and eating well, as well as cooking classes for those with NDIS funding.
- ADACAS consolidates information and links on health services and coronavirus from multiple sources on their website.

Some condition-specific organisations publish plain language information, however this is not tailored to people with disability, the accessibility of documents is variable and there are very few resources in formats like Auslan, audio or large print.

*National*

**Down Syndrome Australia's Health Ambassador Program**

The Health Ambassadors Program is a group of people with Down Syndrome who teach others how to communicate and include people with Down Syndrome in health communications. There are members from each state and territory, including the ACT. These health ambassadors co-design and deliver training to health workers. Evaluation of this model indicates the vast majority of health workers felt their understanding of communication strategies, including use of communication aids, respectful communication and giving time and support for decision making were all significantly increased by this training[27].

### National Disability Services (NDS)

- The NDS has a Disability Health Hub with information for disability support workers and service providers.
- The NDS Skills Project aims to identify the skills needed by disability support workers and frontline supervisors to perform their roles effectively. The project also aims to identify training pathways, and their effectiveness at supporting worker to perform their roles.
- The NDS have also partnered with Victorian TAFEs in Skills Solutions Partnerships to design and pilot short courses to innovative short training approaches to rapidly address workforce skills gaps in priority sectors. The NDS have partnered with Gordon TAFE to design and deliver micro-credentialing for support workers in improving health outcomes. The modules will tie into foundational supports to address gaps in services and support.

### Disability Gateway

The Disability Gateway is a federally funded service to support people with disability and, their families and carers to find the information, services and supports they need. The gateway's website provides information and links to services on health services and supports available to people, however little information is tailored to the ACT. The phone service provides more tailored advice to people with disability, carers and professionals like health workers.

### The National Centre of Excellence in Intellectual Disability Health

NCEIDH, now including UNSW's Department of Developmental Disability Neuropsychiatry (3DN) has published resources for people with intellectual disability and carers on topics like mental health and preventative health care. They also provide training, e-Learning and toolkits for health workers. They are currently co-designing a knowledge exchange hub with people with intellectual disability, families and supporters.

### Health Care For People Who Need Extra Support: A health literacy guide to support the health of people with a cognitive impairment or intellectual disability

This guide was developed by Dr Rachel Skoss at Notre Dame University. It is for anyone supporting a person with intellectual disability, cognitive impairment or who needs support to understand and navigate the health system. It is a guide to health literacy which includes practical information and links to resources to build the

person's knowledge and skills in managing their own health and support them to navigate the health system.

**Health Information Resources**

These are some examples of accessible health information and health literacy tools available nationally.

- Inclusion Australia's 'It's Doctor Time!' conversation cards and checklists for people with intellectual disability, their families and carers and their healthcare workers.
- Council for Intellectual Disability publishes a library of Easy Read health resources
- Jean Hailes has information on women's health topics in several accessible formats including Easy Read, audio, and translated and captioned videos.
- Deaf Connect has an Auslan resource library that includes some health videos.
- Women with Disabilities Australia's Our Site includes information about a number of health topics in plain English, Easy Read and video. The entire website can be switched into 'Easy Read'.

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# Appendix B: People with Disability and Carers Survey Methods & Results

## Methods

Participants were eligible to complete the survey or participate in an interview if they:

- Identified as having a disability

- Were aged 18 years or older

- Accessed health care in the ACT in the last two years

OR

- Were caring for a person with disability

Data was collected using a survey that was administered online, on paper or through an interview.

The survey included questions from:

- the Health Literacy Questionnaire, and

- questions designed with the project reference group

The Health Literacy Questionnaire is a validated tool created by the Swinburne University Centre for Global Health and Equity. The questionnaire measures how individuals feel about their individual level of health literacy, their confidence in accessing and understanding health information and their ability to engage with their health care providers and take action on health information that has been provided. It is measured across 9 domains.

The additional survey questions explored factors that enable or hinder access to health care or health information for people with disability.

To ensure the survey was accessible, the survey could be completed online, in paper format, over the phone or in-person interview.

Survey data was collected using Microsoft Forms and analysed using mixed methods. Free text responses were analysed for themes based on the pre-determined research questions. Categorical and multiple-choice responses were tabulated in Microsoft Excel. Health Literacy Questionnaire data was analysed in Microsoft Excel using a template and interpretation guidance provided by the Centre for Global Health and Equity to ensure consistency.

## Participants

There were 40 respondents to the survey. Participants were asked to respond thinking about their own experiences in health services, meaning that carers were reflecting on their own information needs rather than those of the person they care for.

*Disability/carer status*

32 (80%) identified as a person with disability, 17 (42.5%) identified as carers. 9 (22.5%) identified as both a person with disability and a carer.

Participants with disability were asked to identify their type/s of disability a list or in their own words.

*Table 1: Types of disability identified by participants*

| | |
|---|---|
| **Physical disability** | 69% |
| **Psychosocial disability/mental illness** | 47% |
| **Neurodivergence** | 31% |
| **Invisible disability** | 66% |
| **d/Deaf or hard of hearing** | 16% |
| **Blind or vision impaired** | 10% |
| **Chronic health condition** | 66% |
| **Intellectual disability** | 0 |
| **Cognitive disability** | 6% |
| **Other…** | 12% |

Other included:

- Neurological

- Social Phobia/Depression/Anxiety

- Genetic, facial difference

- Specific Learning Disorders

- Arthritis, Lymphoedema, Multi nodular goitre, Kidney disease, High blood pressure;

- IBS, PTSD, chronic pain and memory loss

87% of participants identified with multiple categories.

Low numbers of responses were received from people with cognitive disability, d/Deaf or Hard of Hearing people and Blind or vision impaired people. Further consultation is needed with these groups.

No people with intellectual disability responded and further investigation is needed using alternate methodologies to meet the participation needs of this cohort.

*Demographic profile*

While respondents had a broad range of life circumstances, the majority of respondents were women, aged over 50 and the vast majority of respondents spoke only English at home.
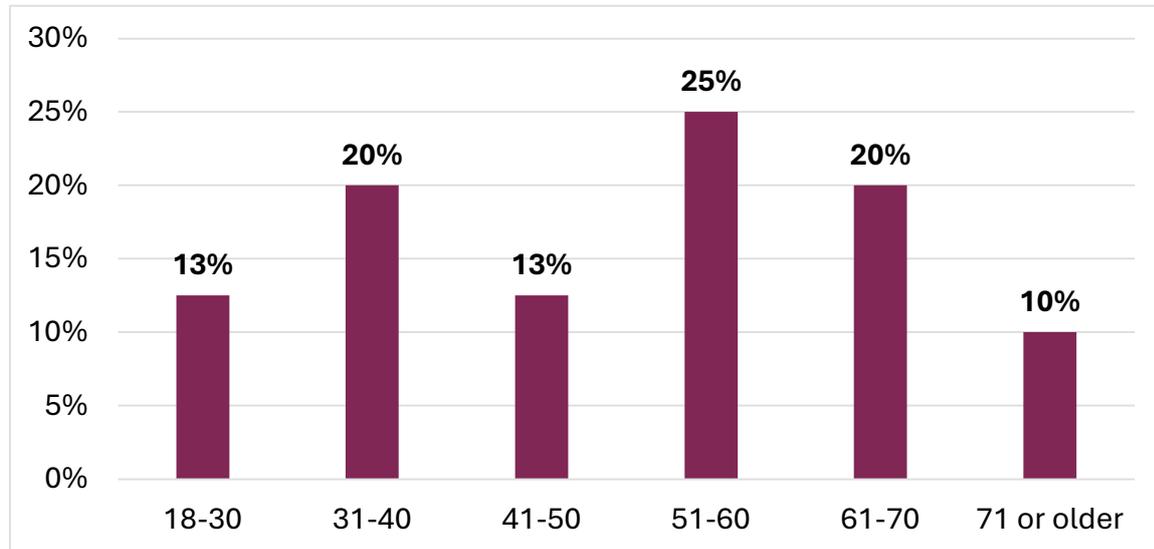


*Figure 3 Age of Participants*

The ages of people with disability were relatively evenly spread, however people with disability who were also carers were more likely to be over 51. 47% of carers were aged 31-40.
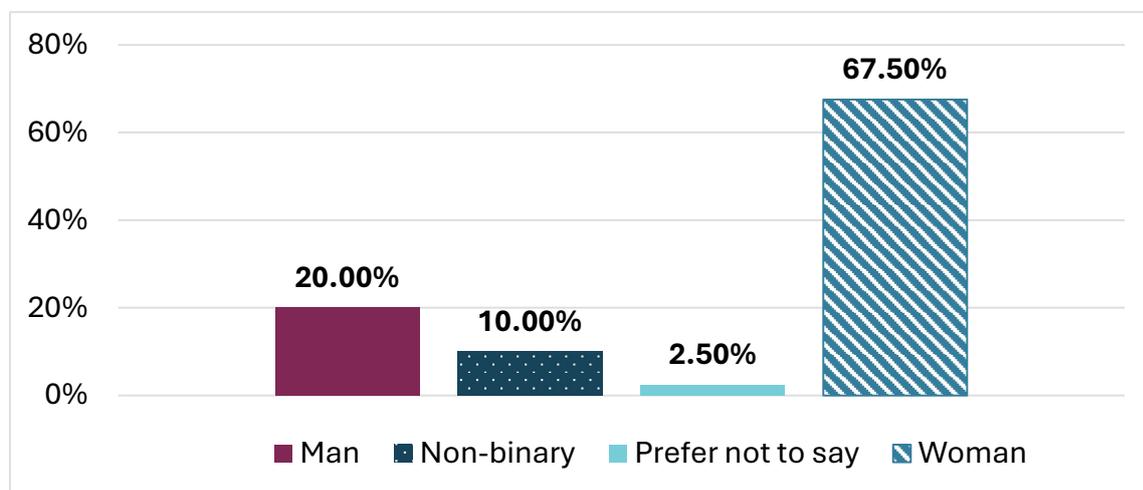


*Figure 4 Gender of participants*

No carers identified as non-binary.

*Other characteristics*

- 35% identified as LGBTQIA+

- 5% identified as Aboriginal or Torres Strait Islander

- 10% of respondents identified as being from a multicultural background

- 10% respondents identified as a migrant or refugee.

93% of respondents indicated that English was the main language used at home. Other languages used were:

- Tamil/Sri Lankan Tamil (5%)

- Hindi (3%)

- Auslan (3%)

Men were underrepresented in the sample, as were people from multicultural backgrounds. Only 2 respondents identified as Aboriginal or Torres Strait Islander. Further research is needed to examine the needs of these groups.

*Health status and service use*
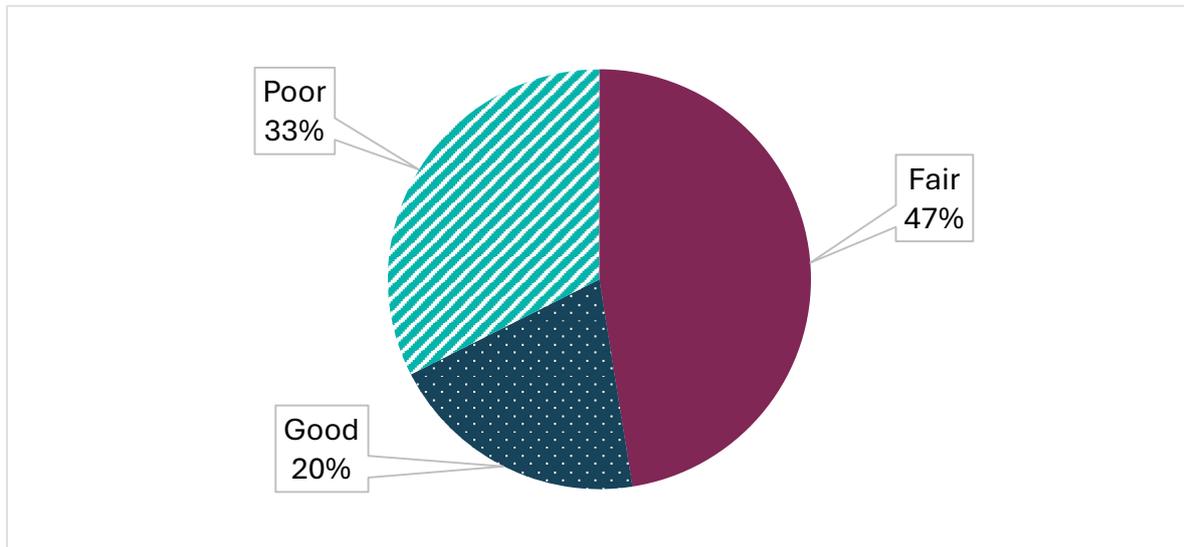


*Figure 5 Participants' self-rated health*

No respondents rated their health as 'Excellent'. Just under half of respondents rated their health as 'Fair' and one-third of participants rated their health as poor.

Respondents were asked to select which health services they had used in the past 2 years. All participants had engaged with General Practitioners.

*Table 2: Health services used by participants in the past 2 years*

| General Practitioner (GP) | 100% |
|---|---|
| Public Hospital | 75% |
| Walk-In Centres | 70% |
| Emergency Department | 70% |
| Private specialist | 68% |

| | |
|---|---|
| Private Allied Health (including NDIS providers) | 55% |
| Community health centre | 53% |
| Private mental health service | 38% |
| Specialist in a public hospital or community health centre | 38% |
| Public Allied Health | 30% |
| Private Hospital | 28% |
| Public mental health service | 23% |
| Other | 8% |

Other included:

- Community mental health service (Meridian)

*Health Literacy Questionnaire*

The health literacy questionnaire scores across 9 domains. Domains 1-5 are scored out of 4 and domains 5-9 are scored out of 5[2].

The domains are:

1. Feeling understood and supported by healthcare providers

2. Having sufficient information to manage my health

3. Actively managing my 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

The table below includes the results for adults in the ACT in the 2018 Health Literacy Survey (ABS) as a reference.

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[2] For 4-point scales, scores below 2.5 indicate that respondents, on average, tend to disagree with the statements within a scale. For 5-point scales, scores below 3.5 indicate that respondents, on average, find the task within a scale difficult to do.

*Table 3: Health Literacy Questionnaire average scores of survey respondents, compared to ACT adults*

| HLQ Domain | People with disability | Carers* | Total | 2018 ACT HLS |
|---|---|---|---|---|
| 1 (score out of 4) | 3.12 | 2.74 | 2.96 | 3.16 |
| 2 (score out of 4) | 2.64 | 2.46 | 2.56 | 3.13 |
| 3 (score out of 4) | 3.16 | 2.96 | 3.07 | 3.07 |
| 4 (score out of 4) | 2.41 | 2.28 | 2.35 | 3.19 |
| 5 (score out of 5) | 2.95 | 2.95 | 2.95 | 2.90 |
| 6 (score out of 5) | 3.12 | 2.94 | 3.05 | 4.11 |
| 7 (score out of 5) | 2.93 | 2.69 | 2.83 | 3.92 |
| 8 (score out of 5) | 3.54 | 3.31 | 3.44 | 4.07 |
| 9 (score out of 5) | 3.63 | 3.56 | 3.61 | 4.25 |

*including carers with disability

These results indicate that on average, participants:

- agreed that they felt understood and supported by health care providers, but less so than the broader ACT population (domain 1)

- agreed that they had sufficient information to manage their health, but much less so than the broader ACT population (domain 2)

- agreed that they took an active role in managing their health, similar to the broader ACT population (domain 3)

- disagreed that they had a social system that supported their health (domain 4)

- found it difficult to appraise health information, to a similar degree to the ACT population (domain 5)

- found it difficult to actively engage with health providers, much more than the broader ACT population (domain 6)

- found it difficult to navigate the health system, much more than the broader ACT population (domain 7)

- found it difficult to find good health information, more than the broader ACT population (domain 8)

- found it easy to understand information well enough to know what to do, but much less so than the broader ACT population (domain 9)

*Information sources and digital health literacy*

*Table 4: Sources of health information used by participants*

| | |
|---|---|
| My GP or family doctor | 88% |
| Health specific website | 68% |
| Online search | 65% |
| Condition-specific organisations | 65% |
| A specialist doctor | 63% |
| Disability organisations | 43% |
| Social media | 35% |
| Friends and family | 33% |
| Support group or peer network | 30% |
| Digital or AI assistant | 18% |
| Radio | 13% |
| Support worker/s | 10% |
| Newspaper | 10% |
| Online forums | 10% |
| Other | 8% |
| Online messaging groups | 3% |

Other included:

- Community centres

- Other health facilities e.g. allied health providers

- Occasionally noticeboards at shops etc (particularly for things like remedial massage or alternative medicine)

- Academic journals

- Government health websites

- Library

- ACT government programs e.g. Pain clinic + support group

- Mental health organisations

- Insight timer app

*Use of digital health services/platforms in past 2 years*

Respondents were asked to indicate if they had used digital health tools like apps, checking results online or telehealth services.
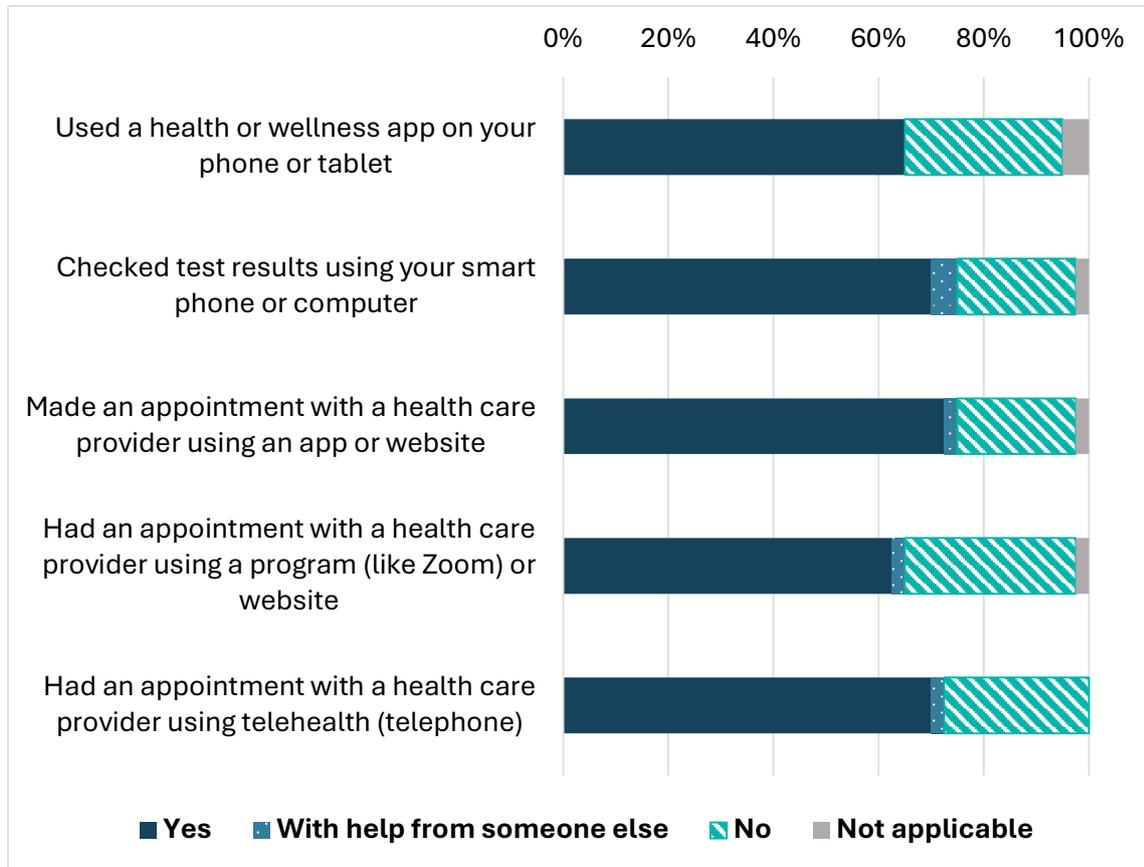


*Figure 6: Digital health services/platforms used in past 2 years. View as a table.*

Carers were less likely to use digital health tools and more likely to need help.
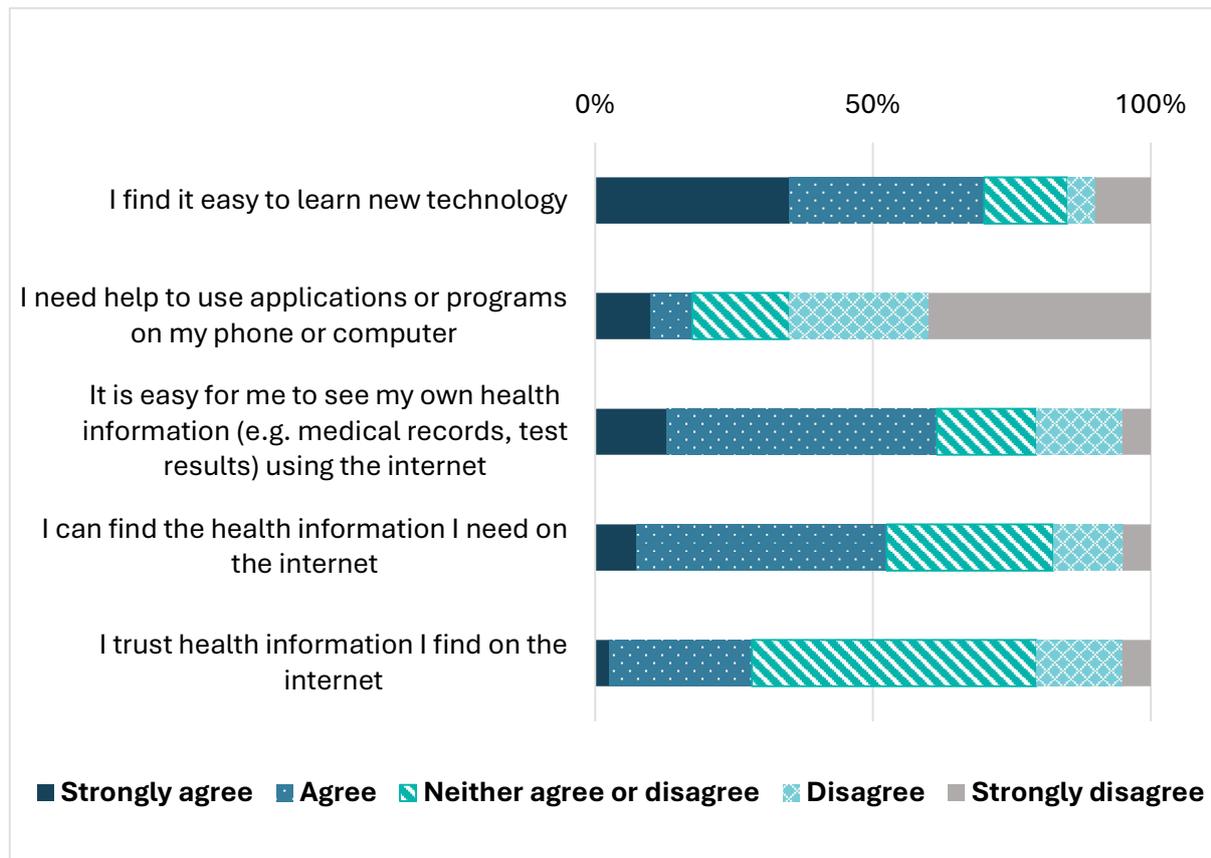
Ease of technology use



*Figure 7: Comfort with digital health tools/platforms. View as a table.*

Respondents were asked to rank how much they agreed or disagreed with each statement about their use of technology.

## Qualitative analysis of free-text questions

### Finding health information

When it came to finding health information, participants mostly sought their information from their health care providers or online. Finding information from these sources were both enabling and challenging. However, when it came to finding information participants talked about:

- The importance of finding reliable and credible information
- Finding relevant and appropriate information
- Finding information in a format that is accessible

### Finding appropriate and reliable information

Participants highlighted the importance of finding credible and reliable information. While many participants found health information online, they discussed the challenges of being able to identify what is accurate and reliable information. As a result, some participants noted they preferred to get information from their health professionals. This allowed them to discuss the information and ask questions and

make sure they understand the information. However, they also noted getting information from their health professionals was challenging as they often didn't have the time to have those discussions.

Some participants also discussed the challenges around finding information that is appropriate and relevant to them. Participants explained the challenges in finding health information and health professionals who understand how some disabilities may impact health conditions and vice versa.

*I am often looking for the connection between multiple co-morbid conditions, [like] how they interact and what symptoms are from what condition. I find most health information is about one specific condition only or one medication only. It's not often about the connection between autoimmune, gut health, hormone imbalance etc.*

Participants also spoke about health care professionals in the ACT not having enough knowledge or specialty expertise about certain health conditions or disabilities. As one participant explained that having a rare condition meant they often knew more about their condition than their health professionals.

For participants, the challenges to finding information can be addressed by having information about services and organisations that support people with disability in one place that is easy for people and health professionals to access

*A one-stop-shop for key service information and basic info about health conditions specific to the ACT and covering more than just public services. You need to know about 7 different sites to get this right now. Longer and/or cheaper appointments with a GP or specialists would also mean I can actually ask for the information I can't find elsewhere.*

Participants also spoke of the need to improve access to health professionals like GPs, specialists and allied health professionals to be able to find, understand and discuss information. For the participant this looked like:

- Having more bulk billing GPs to reduce the costs of going to seek care and information
- Having access to more publicly available specialists who have knowledge and understanding on the interactions of disabilities and health conditions.
- Having longer appointments with health professionals as a standard

**Finding information in a format that is accessible**

Participants also discussed having access to information in ways that are accessible is critical. While a lot of information may be available on the internet, they may not always be presented in a way that is accessible. As participant explained, having information presented in ways that are accessible to them would include:

- Using other forms of communicating and presenting information that is not just online. For example, audio media such as radio and television, braille, printed information
- Having information online where the website is clear and uncluttered making it easy to find the information

- Having information printed in large format
- Having people take time to explain information or read information which is in print or otherwise not easily accessible
- Using language that is less technical

*Communicating with health professionals*

The survey also asked participants about the enablers and barriers to being able to communicate with their health professionals.

Overwhelmingly most of the participants identified that the main barrier and enabler to being able to communicate with their health professionals is 'being listened to'. The need to be listened to was raised in many ways when discussing communicating with health professionals. This included:

- Not having enough time during appointments for participants to be able to discuss/understand information
- The use of health and medical jargon during appointments doesn't support understanding
- Health professionals attitudes and biases towards disabilities and people with disability impact how they are supported
- Needing a holistic approach to care

**Time**

For participants, time was the most common barrier and enabler to supporting communication with health professionals. They identified that that they often don't have enough time during the appointment to be able to identify their needs and concerns properly.

*It's hard when they are too rushed and I feel like I can't ask all the questions I'd planned to. It's easy when they allow me to record the session using Otter AI, which transcribes and summarises what's been said.*

Other participants explained, their disability may make it hard to hear and understand information, and for others it makes it more difficult to communicate their needs and they need a little more time and patience to be able to communicate. However, the short time limits for appointments often make it difficult to do this.

*I'm autistic, and I find it really hard to verbally explain what's happening, especially when I'm stressed or in pain. Quite often I've realised after the appointment etc what I needed to say which frustrates me.*

They also identified that health professionals often don't have enough time to be able to communicate health information with them in a way that they can understand.

*They're too busy and have too much work to be really present and spend the time with you.*

Participants identified that having more time for appointments would allow them to be able to communicate better with their health professionals and allow health

professionals time to be able to communicate and explain things in ways that people with disability can understand.

**Jargon**

Participants also highlighted that many health professionals use a lot of technical jargon which makes it difficult to understand.

> *They speak in medical terms that I struggle to understand*

Participants explained that communicating with health professionals can be made easier, if they were asked at the beginning of an appointment how they would like information to be shared and communicated.

Some successful communication methods suggested by participants included: drawing diagram, having instructions printed out or written down to support remembering them, using apps for exercise programs.

*Health professional attitudes and bias*

Some participants felt that their concerns and questions weren't listened to or taken seriously because they had a disability, which had an impact how they were able to communicate during their appointments

Some identified that they aren't included in the process of making decisions about their health and conditions as a result of their disability.

> *People make assumptions about my son's capabilities because he has Down Syndrome. He has his own voice, and questions should be directed to him in first instance. I can add to help out, but this is his health care.*

> *They tend to make assumptions about capacity of my daughter or her future decisions and choices. It is damaging to relationships and disrespectful which reduces my confidence in their ability as a professional.*

One participant also described that even though they had clearly stated their needs and asked to see a practitioner with experience in their condition and disability, they were allocated to a different practitioner who had no experience and was not able to provide them with appropriate care.

**A holistic approach to care**

Participants described that health professionals often had a lack of understanding of how their disability can impact their health and how they manage their health conditions.

As one participant noted:

> *[It is] hard when they don't actually read my history so the appointment time is wasted on background they already have and they give me general advice that I can't follow due to my other conditions.*

Participants explained that increasing health professionals awareness of other services and supports that are available to people with disability is also important in caring for a person holistically.

*Digital Health Literacy*

The survey also aimed to understand the use of digital tools and platforms amongst people with disability.

The survey asked participants to identify the barriers they faced when using digital resources to find and understand health information and how to reduce these barriers.

The findings identified three key themes:

- Having the skills to use different digital platforms/tools /resources
- User friendly and accessible digital tools and platforms
- Security and privacy of digital platforms

**Having the skills to use different digital platforms/tools /resources**

A key barrier to using digital tools and platforms for participants was having the skills to use the myriad of platforms and tools that are available. Participants identified that every tool and platform is different and learning how to use them all takes time.

Participants also discussed challenges in identifying reputable resources and which information sources can be trusted.

One participant also raised the issue of not having access to appropriate technology to be able to use digital tools and platforms.

*I can't afford a new laptop but I no longer have a pension card so I don't believe I qualify for any subsidised refurbished computer schemes. My current phone manages OK but it's now very old.*

**User friendly and accessible digital tools and platforms**

The second significant challenge that participants identified when using digital tools and platforms was in their accessibility. Participants described platforms as being 'clunky' and not easy to navigate around.

Participants also identified that for many people with disability, digital platforms are not accessible. One participant identified that many sites and platforms are not accessible to people with vision impairments.

Additionally, participants also identified that many of the tools and platforms that are available work individually and don't allow users to connect their information. For example, one participant described not being able to synchronise their information from the myDHR app to the My Health Record so that all their health information was in one place and consistent.

**Security and privacy of digital platforms**

Participants also raised concerns about not knowing about the security measures in place on the tools that they use. This led to concerns about the security and privacy of their health information and a reluctance to use it.

One participant also identified that individuals should have the option to not use digital platforms where they did not feel comfortable using it or had concerns using it.

**Supporting digital health literacy**

Across the three themes the participants identified clear solutions and strategies to enable the use of digital tools and platforms to access information. These are:

- Having consistency across digital platforms and tools so people do not need to learn how to use something new each time.
- Providing support so people can use digital platforms and tools. This includes having dedicated support or help lines to teach people how to use different systems and Frequently Asked Questions (FAQs) sections to allow people to get help when they need it.
- Ensuring that platforms like myDHR and My Health Record are able to link to each other to allow information to be recorded, maintained and shared easily.
- Building and user testing new tools/platforms and resources with the disability community to ensure they are user friendly and accessible to everyone.

## Table versions of charts

*Figure 7 Digital health services/platforms used in past 2 years*

|  | Yes | With Help | No | Not Applicable |
|---|---|---|---|---|
| Used a health or wellness app on your phone or tablet | 65% | 0% | 30% | 5% |
| Checked test results using your smart phone or computer | 70% | 5% | 23% | 3% |
| Made an appointment with a health care provider using an app or website | 73% | 3% | 23% | 3% |
| Had an appointment with a health care provider using a program (like Zoom) or website | 63% | 3% | 33% | 3% |
| Had an appointment with a health care provider using telehealth (telephone) | 70% | 3% | 38% | 0% |

*Figure 8: Comfort with digital health tools/platforms*

|  | Strongly Agree | Agree | Neither agree or disagree | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| I find it easy to learn new technology | 35% | 35% | 15% | 5% | 10% |
| I need help to use applications or programs on my phone or computer | 10% | 8% | 18% | 25% | 40% |
| It is easy for me to see my own health information (e.g. medical records, test results) using the internet | 13% | 49% | 18% | 15% | 5% |
| I can find the health information I need on the internet | 8% | 45% | 30% | 13% | 5% |
| I trust health information I find on the internet | 3% | 26% | 51% | 15% | 5% |

# Appendix C: Health Worker Survey Methods and Results

## Methods

To be eligible to take part in the project, participants had to:

- Be a health professional or administrative staff who work for a health care service in the ACT (i.e. a health worker)

Data was collected using a survey and semi-structured interviews.

The survey included questions focused on:

- identifying tools and techniques health workers used to communicate/support health literacy with people with disability

- their confidence levels in supporting consumer and carer health literacy

- the amount of training they had received to support health literacy and their additional training needs (if any)

- their involvement of carers and support workers when caring for people with disability

Survey participants were also invited to participate in semi-structured interviews to gain a deeper understanding of their responses. Five health workers participated in interviews, three of whom had completed the survey.

The interviews with participants were conducted from November 2024 to May 2025 and were conducted by members of the project team. Based on participant preference the interviews were conducted either in-person, via telephone or online via Microsoft Teams.

With participant permission interviews were recorded for notetaking purposes and notes were taken during the interviews. The notes were analysed using NVivo™ software.

Survey data was collected using Microsoft Forms and analysed using mixed methods. Free text responses were analysed for themes based on the pre-determined research questions. Categorical and multiple-choice responses were tabulated in Microsoft Excel.

Interviews were analysed using the themes that emerged from the surveys which included:

- Finding, appraising and using health information.

- Communication with health workers.

- Barriers/enablers to finding, appraising and using health information.

Barriers/enablers to communicating with health workers.

## Participants

A total of 17 health professionals working in the ACT completed the survey. The health professionals represented a range of specialties from allied health professionals, G.P.s, health administrators, and specialists. The majority of participants worked in public hospitals, followed by GP clinics. Responses were spread across all regions of the ACT with the majority in Belconnen. Most public health services were in Belconnen. GP clinics were located in Inner North, Inner South, Molonglo Valley/Weston Creek and the Woden Valley.

*Figure 9 Professions of health worker participants*



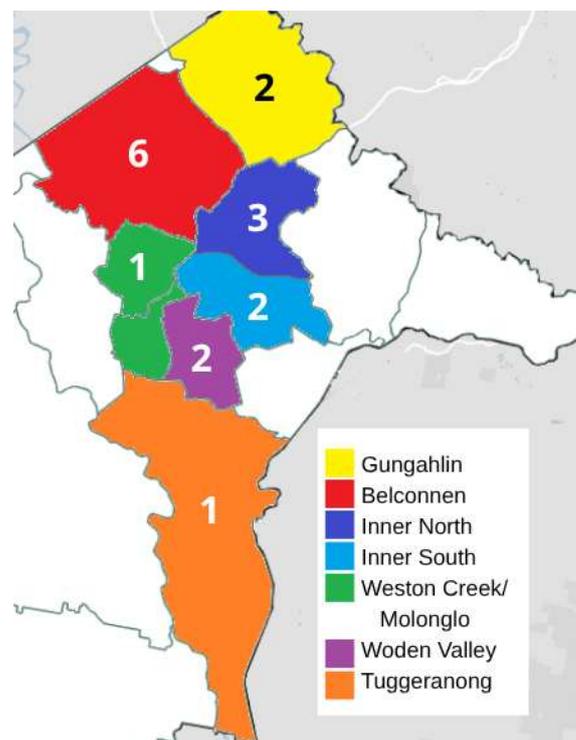*Figure 8 Types of settings where respondents worked*
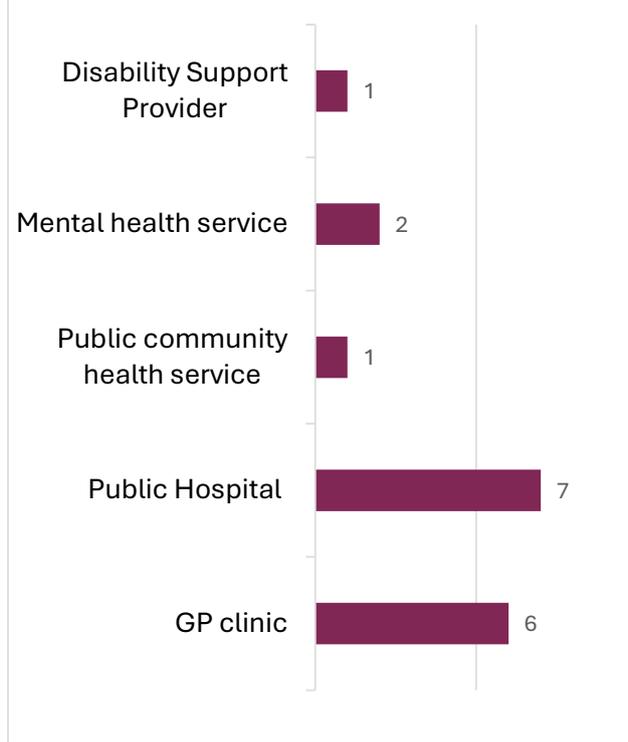


*Figure 10 Map of respondents' workplaces in the ACT*

## Beliefs and Actions

Health workers were asked to how strongly they agreed with statements about their interactions with people with disability
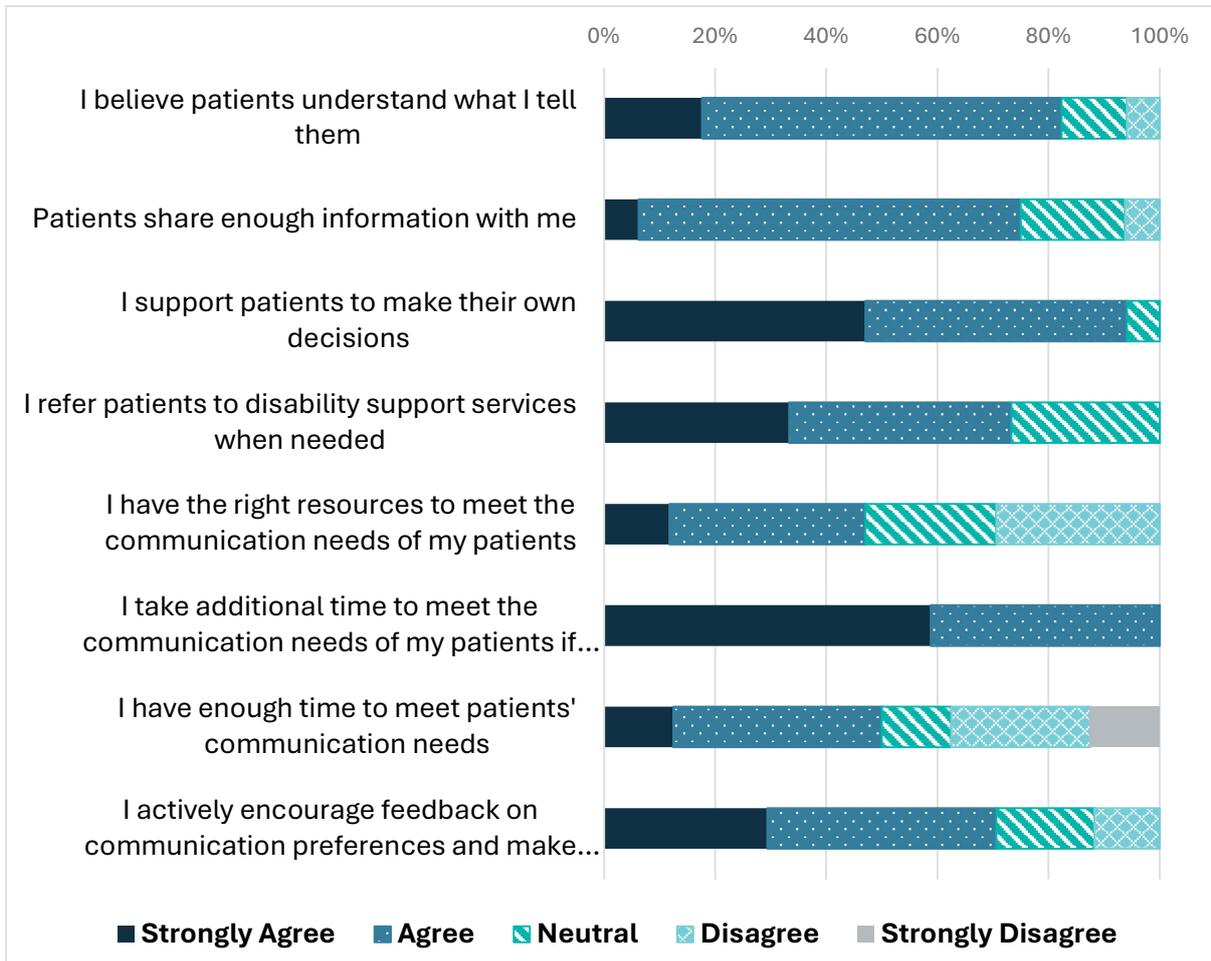


*Figure 11 Agreement with statements about working with people with disability. View as a table.*

The majority of respondents agreed or strongly agreed that patients understood what they told them, were able to share enough information with them, that they supported people to make their own decisions, however less than 50% agreed or strongly agreed that they had enough resources to support communication needs.

All respondents agreed or strongly agreed that they took additional time to meet the needs of patients, however only 50% responded that they had enough time to do so. For respondents based in GP practices, only 40% responded that they had enough time to meet the communication needs of their patients.

70% of respondents encouraged feedback and made adjustments in their communication style.

## Communication support and techniques used to support patients

Respondents were asked how often they used different techniques to support communication.
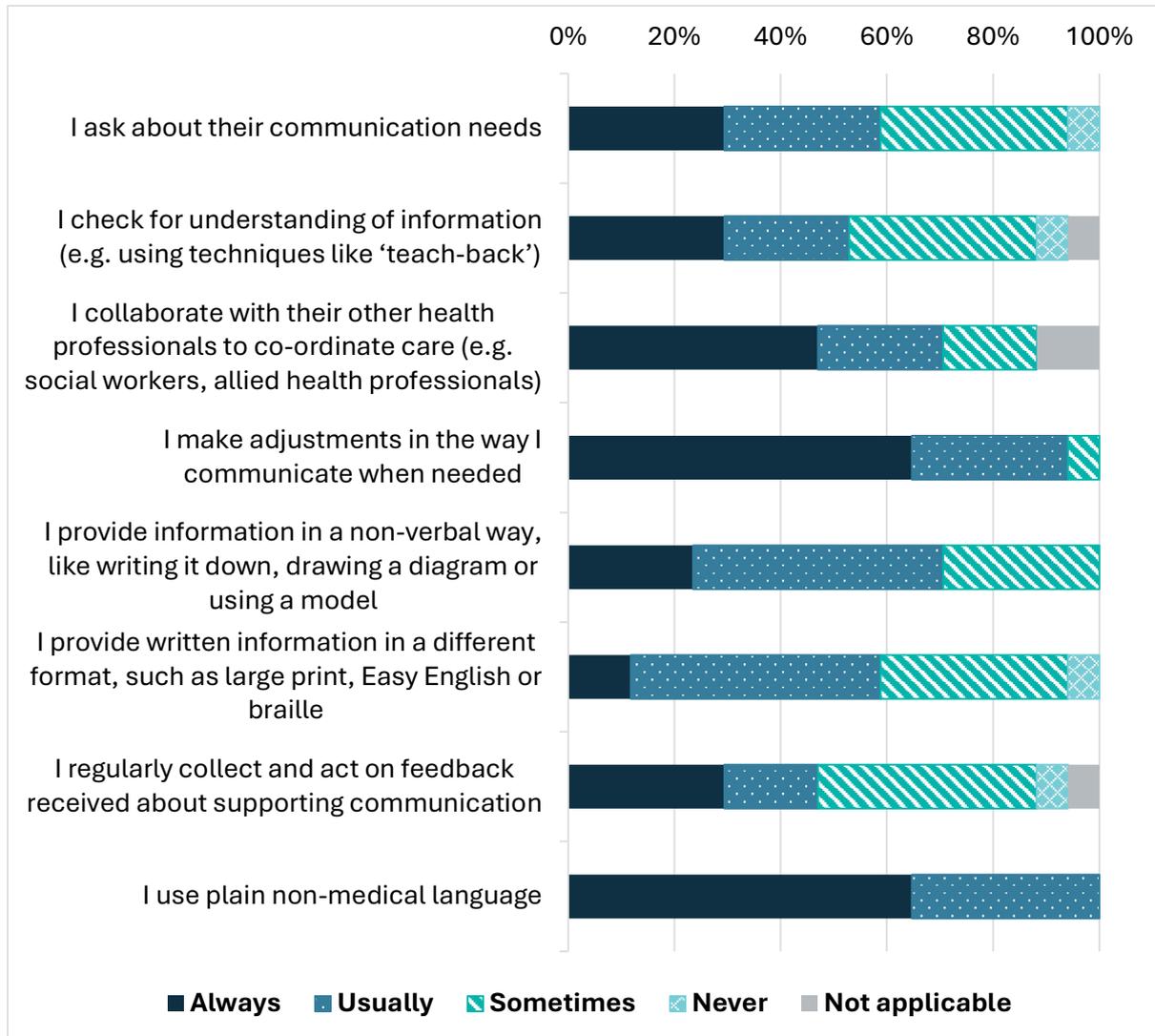


*Figure 12 Actions taken to support communication. View as a table*

Only 58% of workers always or usually asked about a person's communication needs and even fewer (53%) checked for understanding of the information they communicated. 47% of respondents always or usually collected and acted on feedback about supporting communication.

All respondents believed that they always or usually used plain non-medical language and over 90% said that they made adjustments in they way they communicated when needed.

### Specific support for communication

The survey respondents were asked to identify the supports they use to support communication with their patients. The most commonly used supports included using large print material, and information written in Easy English.

Survey participants also used supported decision-making tools, communication boards and apps, having interpreters and allowing patients to record appointments or transcribing appointments.

*Table 5 Communication tools used by respondents*

| | |
|---|---:|
| Easy English | 76% |
| Large print | 76% |
| Supported decision making tools | 41% |
| Allowing patients to record appointments | 35% |
| Communication boards | 29% |
| Trasncribing appointments | 29% |
| Communication apps | 24% |
| Sign language interpreting | 24% |
| Hearing loop or personal amplifiers | 12% |
| Completing or reading a health 'passport' | 6% |
| Braille | 0% |

Survey participants were also asked to share techniques that they use when communicating with people with disability. The most common techniques included:

- Using teach back techniques to check for understanding
- Making sure they speak clearly and slowly without jargon.
- Using diagrams and drawings
- Creating individualised handouts or programmes.
- Having resources available in written, video and audio form, and/or in multiple languages
- Trying to communicate health information in ways that connects to and relates to their everyday lives and interests
- Ensuring that they allow for additional time for appointments if additional support needs have already been identified
- Ensuring that patients are able bring a support person with them to their appointments, if they need it.

Other tools and strategies used by respondents included, emailing a summary of the appointment to patients after their visit as well as speaking and consulting with other members of their care team including families and carers.
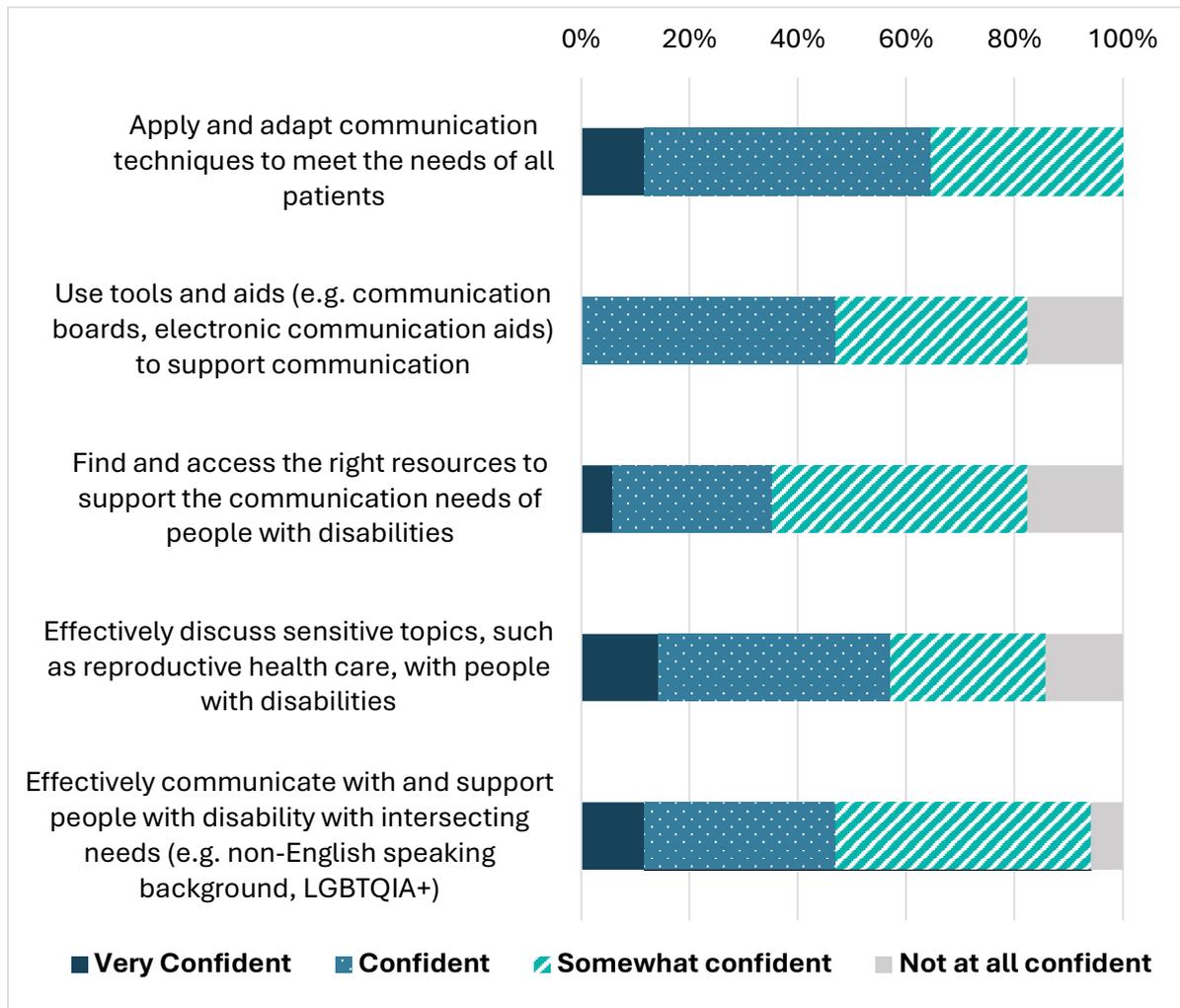
## Confidence



*Figure 13 Confidence in supporting communication and health literacy. View as a table*

## Enablers and Barriers

Respondents were asked to identify what would be needed to support better communication with people with disabilities. The most common responses were:

- Additional training

- Knowing what resources are available to support communication

- Having more time with patients

Survey respondents were also asked to identify the barriers to communication with people with disabilities. The key barriers they identified included:

- Existing written resources are often too complex and not easy to understand and there is a lack of resources in other accessible formats.

- Not having enough time with patients during an appointment to ensure that the patient has been able to communicate their needs and that the information being shared by the health professional has been understood.

- Not being able to see patients more often to ensure they have been able to understand and implement what has been discussed during their appointments.

Some respondents also identified they faced difficulties in ensuring the way they communicate with patients is appropriate. They identified that it can be difficult to gauge how much information to communicate as well as finding it difficult to communicate in simple language.
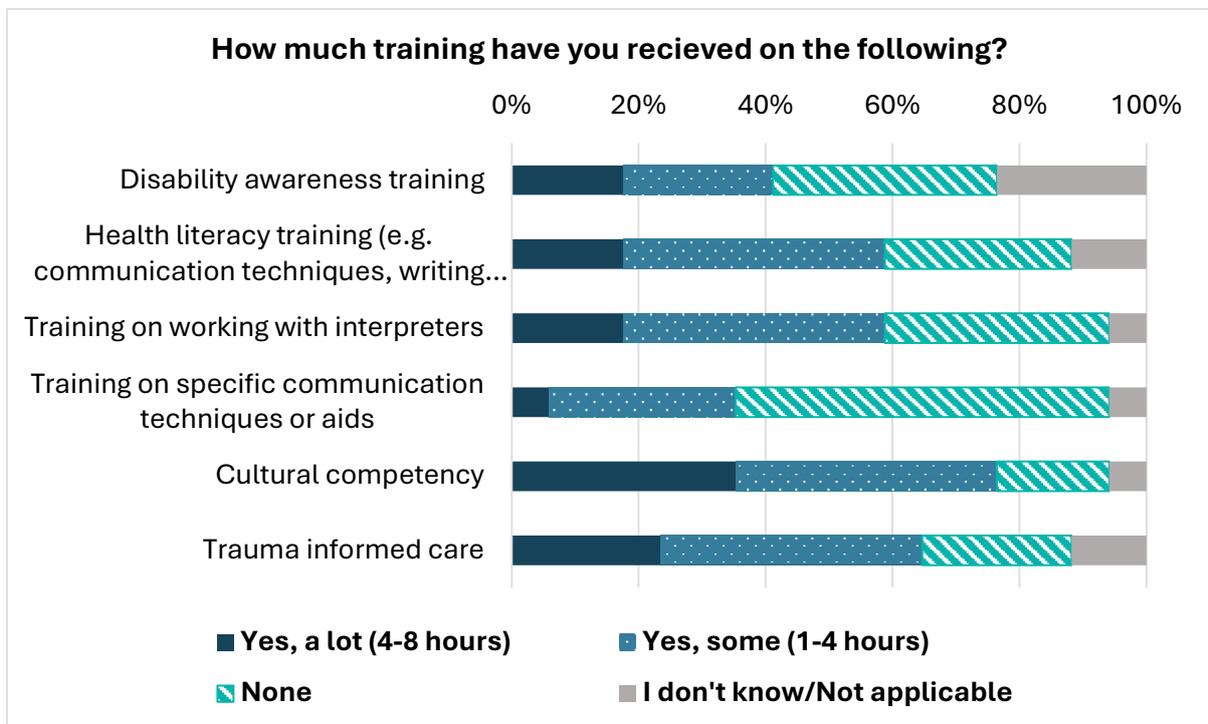
## Training



*Figure 14 Amount of training received. View as a table.*

24% of respondents said they were unsure if they had completed disability awareness training or did not consider it applicable to their role. More than 50% or respondents had received no training in specific communication techniques or aids. 35% had received no training in interpreter use. Most respondent had received at least some training in health literacy, cultural competency and trauma informed care.

**How much further training do you think is needed to fully understand and meet the needs of people with disability?**

Lots more
23%

I'm not sure
6%

Somewhat more
71%

Legend:
- I'm not sure
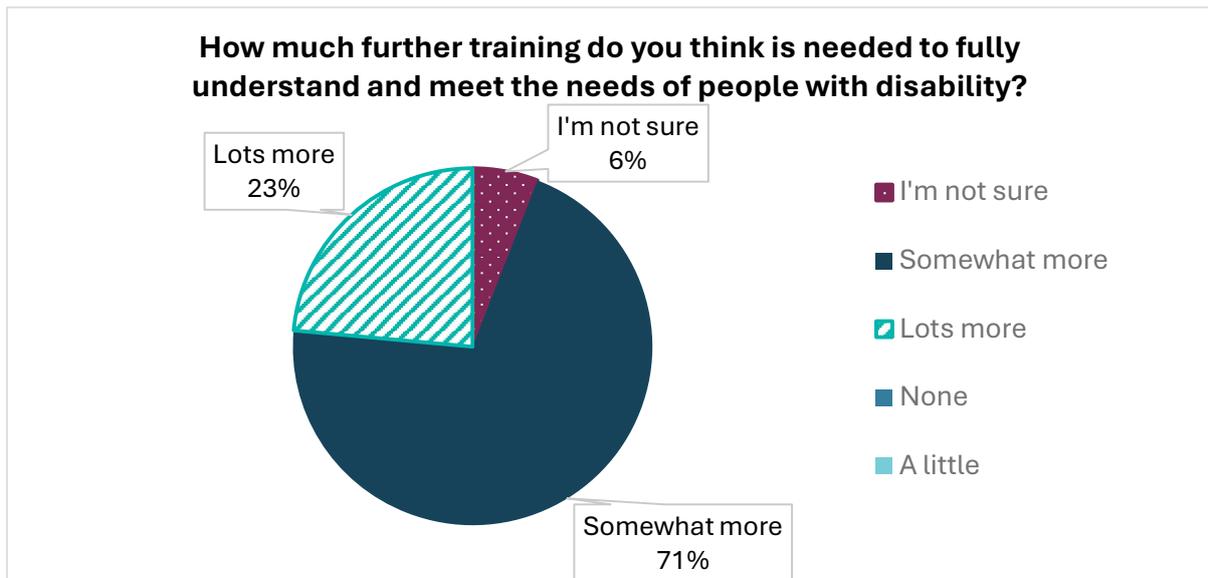- Somewhat more
- Lots more
- None
- A little

*Figure 15 Health worker views on further training needs*

95% of respondents said they and their colleagues needed somewhat more or lots more training to meet the needs of people with disability.

When asked what training they believed themselves or their colleagues would benefit from, respondents said:

- Basic AUSLAN

- Trauma informed care

- Knowing how to ask questions about people's disabilities and how to address them

- Knowing what supports/aids are available and how to access them

Respondents also indicated needing training and support to understand how to support health literacy particularly around knowing how much information to provide patients without overwhelming them or not providing enough information.

One respondent also indicated that needing training around how to identify mental health presentations and how to provide care for people with intellectual disabilities.

## Involvement of carers and support workers

Survey respondents were asked how well they felt their patients carers and support workers understood the person they were supporting's health background and needs, essential health information for their care and how to support the person navigating the health system.
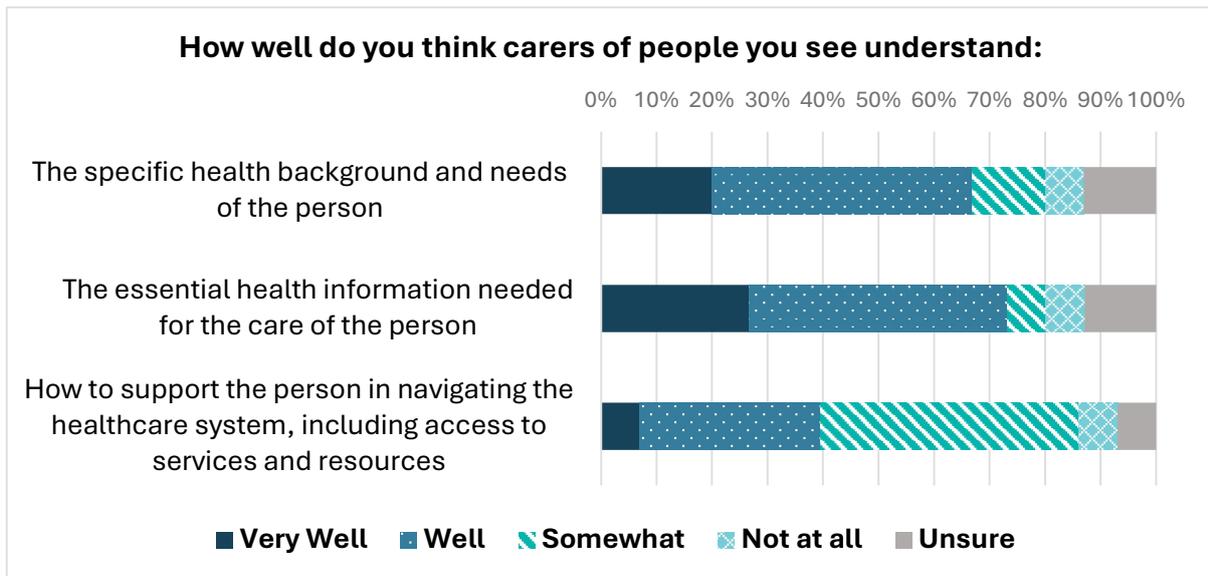
*Figure 16 Perception of carer understanding of health information. View as a table.*

The majority of health workers said that they believed that carers understood the health background, needs and essential health information of the person they are caring for well or very well. However, more than 50% believed that carers only somewhat or not at all understood how to support the person to navigate the health system.
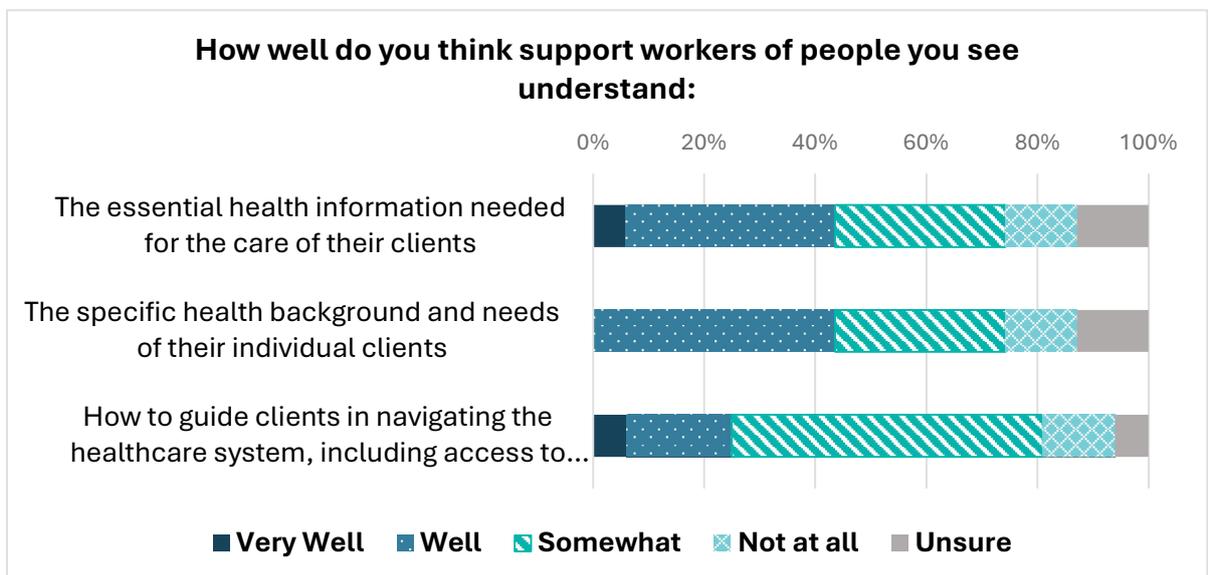


*Figure 17 Perception of support worker understanding of health information. View as a table.*

44% of health workers believed that support workers did not understand or only somewhat understood the health background, needs and essential health information of their client. The same proportion believed support workers understood

this information well or very well. 69% of respondents believed support workers only somewhat or not at all understood how to support their clients navigating the health care system.

Health workers were asked if their organisations had policies around involvement of carers and support workers.
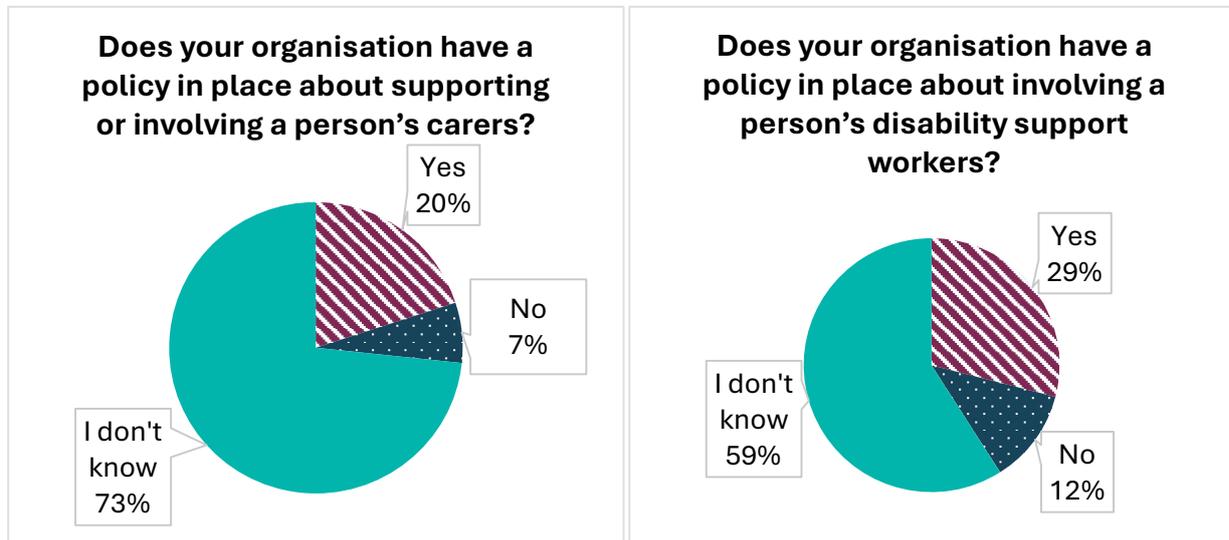


*Figure 18 Health worker awareness of carer and support worker related policies*

All public health service staff said they did not know if there was a policy around involving a persons support workers. 88% of the respondents who worked in a public health service indicated that they did not know if there was a policy around supporting or involving a persons carer.

## Table versions of charts

*Figure 4 Agreement with statements about how they work with people with disability*

| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| **I believe patients understand what I tell them** | 18% | 65% | 12% | 6% | 0% |
| **Patients share enough information with me** | 6% | 69% | 19% | 6% | 0% |
| **I support patients to make their own decisions** | 47% | 47% | 6% | 0% | 0% |
| **I refer patients to disability support services when needed** | 33% | 40% | 27% | 0% | 0% |
| **I have the right resources to meet the communication needs of my patients** | 12% | 35% | 24% | 29% | 0% |
| **I take additional time to meet the communication needs of my patients if needed** | 59% | 41% | 0% | 0% | 0% |

| | | | | | |
|---|---|---|---|---|---|
| I have enough time to meet patients' communication needs | 13% | 38% | 13% | 25% | 13% |
| I actively encourage feedback on communication preferences and make adjustments accordingly | 29% | 41% | 18% | 12% | 0% |

*Figure 5 Actions taken to support communication*

| | Never | Sometimes | Usually | Always |
|---|---|---|---|---|
| I ask about their communication needs | 6% | 35% | 30% | 30% |
| I make adjustments in the way I communicate when needed | 0% | 6% | 29% | 65% |
| I collaborate with their other health professionals to co-ordinate care (e.g. social workers, allied health professionals) | 0% | 18% | 24% | 48% |
| I use plain non-medical language | 0% | 0% | 35% | 65% |
| I provide information in a non-verbal way, like writing it down, drawing a diagram or using a model | 0% | 29% | 47% | 24% |
| I provide written information in a different format, such as large print, Easy English or braille | 6% | 35% | 47% | 12% |
| I check for understanding of information (e.g. using techniques like 'teach-back') | 6% | 35% | 24% | 30% |
| I regularly collect and act on feedback received about supporting communication | 6% | 41% | 18% | 30% |

*Figure 6 Confidence in supporting communication and health literacy*

| | Not at all confident | Somewhat confident | Confident | Very Confident |
|---|---|---|---|---|
| Apply and adapt communication techniques to meet the needs of all patients | 0% | 35% | 53% | 12% |
| Use tools and aids (e.g. communication boards, electronic communication aids) to support communication | 18% | 35% | 47% | 0% |

| | | | | |
|---|---|---|---|---|
| **Find and access the right resources to support the communication needs of people with disabilities** | 18% | 47% | 29% | 6% |
| **Effectively discuss sensitive topics, such as reproductive health care, with people with disabilities** | 14% | 29% | 43% | 14% |
| **Effectively communicate with and support people with disability with intersecting needs (e.g. non-English speaking background, LGBTQIA+)** | 6% | 47% | 35% | 12% |

*Figure 7 Amount of Training Received*

| | Yes, a lot (4-8 hours) | Yes, some (1-4 hours) | None | I don't know/Not applicable |
|---|---|---|---|---|
| **Disability awareness training** | 18% | 24% | 35% | 24% |
| **Health literacy training (e.g. communication techniques, writing consumer friendly information)** | 18% | 41% | 29% | 12% |
| **Training on working with interpreters** | 18% | 41% | 35% | 6% |
| **Training on specific communication techniques or aids** | 6% | 29% | 59% | 6% |
| **Cultural competency** | 35% | 41% | 18% | 6% |
| **Trauma informed care** | 24% | 41% | 24% | 12% |

*Figure 9 Perception of how well carers understand health information*

| | Very Well | Well | Somewhat | Not at all | Unsure |
|---|---|---|---|---|---|
| **The specific health background and needs of the person** | 20% | 47% | 13% | 7% | 13% |
| **The essential health information needed for the care of the person** | 27% | 47% | 7% | 7% | 13% |
| **How to support the person in navigating the healthcare system, including access to services and resources** | 7% | 33% | 47% | 7% | 7% |

*Figure 10 Perception of how well support workers understand health information*

| | Very Well | Well | Somewhat | Not at all | Unsure |
|---|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| **The essential health information needed for the care of their clients** | 6% | 38% | 31% | 13% | 13% |
| **The specific health background and needs of their individual clients** | 0% | 44% | 31% | 13% | 13% |
| **How to guide clients in navigating the healthcare system, including access to services and resources** | 6% | 19% | 56% | 13% | 6% |

# Appendix D: Survey of people with disability and carers

1. I am a…

   a. Person with disability

   b. A carer

2. (if answered a. above) How are you completing this survey?

   a. By myself

   b. With help from a family member or carer

   c. With help from a support worker

## Part 1. Health Literacy Questionnaire (44 scales)

**About this section:** The Health Literacy Questionnaire is a set of questions designed to measure different parts of health literacy in individuals[3]. Each section or 'domain' has 3-4 scales of how much you agree with a statement or how easy or hard it is to do something. The questions ask about:

1. Feeling understood and supported by healthcare providers (Domain 1)

2. Having sufficient information to manage my health (Domain 2)

3. Actively managing my health (Domain 3)

4. Social support for health (Domain 4)

5. Appraisal of health information (Domain 5)

6. Ability to actively engage with healthcare providers (Domain 6)

7. Navigating the healthcare system (Domain 7)

8. Ability to find good health information (Domain 8)

9. Understand health information well enough to know what to do (Domain 9)

## Part 2. About how you find and use health information

**About this section:** These questions are about your individual experience with health information and health services.

1. How would you rate your overall health? (poor/fair/good/excellent)

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[3] The health literacy questionnaire is used under license from Swinburne University of Technology and cannot be published here. Further information: ghe-licences@swin.edu.au or see: Osborne RH, Batterham RW, Elsworth GR, Hawkins M, & Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health 13, 658 (2013). https://doi.org/10.1186/1471-2458-13-658

2. Where do you get information about health and health services? (select all that apply)

    a. My GP or family doctor

    b. A specialist doctor

    c. Support worker/s

    d. Friends and family

    e. Social media (including Facebook, Instagram or TikTok)

    f. Health service website

    g. Newspaper

    h. Radio

    i. Online search (including Google, DuckDuckGo)

    j. Online forums (such as Reddit, Yahoo Answers)

    k. Digital or AI assistant (such as Google Assistant, Amazon Alexa, Chat GPT, Siri, Cortana)

    l. Condition-specific organisations (e.g. Arthritis Australia, the Cancer Council)

    m. Disability organisations (e.g. Women with Disabilities ACT, Down Syndrome Australia)

    n. Other ____

3. What makes it easy or hard for you to find the health information you need? (free text)

4. What would make it easier for you to find the health information you need? (free text)

5. What health services have you used in the last 2 years? (select all that apply)

    a. Walk-In Centres

    b. Emergency Department

    c. Public Hospital

    d. Private Hospital

    e. General Practitioner (GP)

    f. Public Allied Health

    g. Private Allied Health (including NDIS providers)

    h. Public mental health service

    i.   Private mental health service

    j.   Private specialist

    k.   Specialist in a public hospital or community health centre

    l.   Community health centre

    m.  Other ___

6. What makes it easy or hard for you to communicate with health services and health care workers? (free text)

7. What would make it easier for you to communicate with health services and health care workers? (free text)

8. In the past 2 years, have you: (options: Yes/No/With help from someone else)

    a.   Used a health or wellness app on your phone or tablet

    b.   Checked test results using your smart phone or computer

    c.   Made an appointment with a health care provider using an app or website

    d.   Had an appointment with a health care provider using a program (like Zoom) or a website

    e.   Had an appointment with a health care provider using telehealth (telephone)

9. How much do you agree/disagree with the following statements: (strongly disagree/disagree/agree/strongly agree)

    a.   I find it easy to learn to use new technology

    b.   I need help to use applications/programs on my phone or computer

    c.   It is easy for me to see my own health information (e.g. medical records, test results) using the internet

    d.   I can find the health information I need on the internet

    e.   I trust health information I find on the internet

10. What do you like or dislike about using digital health tools like apps and websites? (free text)

11. What would make it easier for you to use digital health tools like apps and websites? (free text)

## Part 3. About you

1. How would you describe your disability? (select all that apply)

    a. Physical disability

    b. Psychosocial disability/mental illness

    c. Neurodivergence

    d. Invisible disability

    e. d/Deaf or hard of hearing

    f. Blind or vision impaired

    g. Chronic health condition

    h. Intellectual disability

    i. Cognitive disability

    j. Other…

2. How old are you?

    a. 18-30

    b. 31-40

    c. 41-50

    d. 51-60

    e. 61-70

    f. 71 or older

3. What is your gender? (man/woman/non-binary/other)

4. Do you identify as any of the following (multi-select):

    a. Aboriginal or Torres Strait Islander

    b. LGBTQIA+ (Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, or other)

    c. From a multicultural background

    d. Migrant or refugee

5. What is the main language/s do you use at home? (free text)

## Appendix E: Health worker survey questions
**About you**

1. What is your role? (free text)

2. Where is your primary location of work? (Postcode or suburb)

3. What kind of service do you work in?

   a. General Practice

   b. Public community health service

   c. Public hospital

   d. Private hospital

   e. Non-government community health organisation

   f. Disability service provider

   g. Other private practice (e.g. specialist centre)

   h. Aged care facility

   i. Indigenous health service

   j. Community pharmacy

   k. Other _____


**Confidence and knowledge**

4. Rate how much you agree with the following statements in regard to patients/clients you see who are people with disability:

   (Options: Strongly disagree, disagree, neutral, agree, strongly agree, not applicable)

   a. I believe patients/clients understand what I tell them

   b. Patients share enough information with me.

   c. I support my patients to make their own decisions.

   d. I refer my patients to disability support services when needed.

   e. I have the right resources to meet the communication needs of patients.

   f. I take additional time to meet the communication needs of patients if needed.

   g. I have enough time to meet patients communication needs

    h. I actively encourage feedback on communication preferences and make adjustments accordingly

5. Rate how often you do the following with people with disability and their supporters
(Options: Never, Sometimes, Usually, Always, Not Applicable)

    a. I ask about their communication needs

    b. I make adjustments in the way you communicate when needed

    c. I use plain non-medical language

    d. I collaborate with their other health professionals to co-ordinate care (e.g. social workers, allied health professionals)

    e. I provide information in a non-verbal way, like writing it down, drawing a diagram or using a model

    f. I provide written information in a different format, such as large print, Easy English or braille.

    g. I check for understanding of information using techniques like 'teach-back'

    h. I regularly collect and act on feedback received about supporting communication

6. What other kind of adjustments/techniques do you use to support communication and understanding? (free text)

7. How confident are you in your ability to: (Options: Not at all confident, somewhat confident, confident, very confident, Not applicable)

    a. Apply and adapt communication techniques to meet the needs of all patients.

    b. Use tools and aids (e.g. communication boards, electronic communication aids) to support communication.

    c. Find and access the right resources to meet the communication needs of people with disability

    d. Effectively discuss sensitive topics, such as reproductive health care, with people with disabilities

    e. Effectively communicate with and support people with disability with intersecting needs (e.g. non-English speaking background, LGBTQIA+)

8. Have you completed training in any of the following?
(Options: Yes, some (1-4 hours). Yes, a lot (4-8 hours). No. and I don't know)

    a. Disability awareness training

b. Health literacy training (e.g. communication techniques, writing consumer friendly information)

c. Training on working with interpreters

d. Training on specific communication techniques or aids

9. How much further training do you think is needed to fully understand and meet the needs of people with disability you see? (Options: None, A little, Somewhat more, Lots more)

10. What specific topics or skills do you think you or your colleagues need more training in to better support people with disabilities? (free text)

## Barriers, enablers and resources

11. What do you think are the main barriers people with disabilities face when accessing healthcare? How do you ensure that those barriers are minimised in your practice? (free text)

12. What techniques or resources do you find helpful when communicating health information to people with disability? (free text)

13. What are some barriers or limitations for you when communicating health information to people with disability? (free text)

14. Have you used any of the following tools or resources to support communication? (multi-select)

a. Communication boards

b. Communication apps

c. Sign language interpreting

d. Hearing loop or personal amplifiers

e. Large print

f. Braille

g. Easy English

h. Completing or reading a health 'passport'

i. Supported decision making tools

j. Allowing patients to record appointments

k. Transcribing appointments

15. What resources do you think would help yourself and your colleagues meet the health literacy needs of people with disability? (free text)

## Working with support workers

1. Do you involve support workers who accompany patients to appointments where appropriate? If yes, how? If you do not involve them, why? (free text)

2. What role do you believe support workers play in assisting clients with their healthcare needs, and how can they collaborate effectively with healthcare professionals? (free text)

3. How well do you think disability support workers you have worked with understand:

   (Not at all, somewhat, well, very well, unsure)

   a. the essential health information needed for the care of their clients

   b. the specific health background and needs of their individual clients

   c. how to guide clients in navigating the healthcare system, including access to services and resources

4. Does your organisation have a policy in place about involving a person's disability support workers? (yes/no/I don't know)


## Working with informal carers (e.g. family and friend carers)

5. Do you involve carers who accompany patients to appointments where appropriate? If yes, how? If you do not involve them, why? (free text)

6. How well do you think carers you have worked with understand:

## (Not at all, somewhat, well, very well, unsure)

   a. the specific health background and needs of the person

   b. the essential health information needed for the care of the person

   c. how to support the person in navigating the healthcare system, including access to services and resources

7. Does your organisation have a policy in place about supporting or involving a person's carers? (yes/no/I don't know)