Report on Barriers and Issues in Health Advocacy for People with Disability

Long Term Health Advocacy Working Group

Contents

Acknowledgements

Acknowledgement of Country

The Working Group acknowledges the traditional owners of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present. We pay our respects to all First Nations people with disability and acknowledge the higher prevalence of disability among First Nations peoples and the distinct challenges they face, along with the contributions they make to society.

Acknowledgement of people with disability and their support networks

The Working Group acknowledges people with disability and the people who support them who have fought and advocated for improved health care for people with disability. We acknowledge Working Group members who generously shared their lived experience expertise and people with disability and their support networks who informed this report.

Acronyms

ADS: Australia’s Disability Strategy

AAC: Augmentative and Alternative Communication

AHPRA: Australian Health Practitioner Regulation Agency

APTOS: Applied Principles and Tables of Support – determines responsibility of NDIS and other service systems

CHAP: Comprehensive Health Assessment Program (for people with intellectual disability)

DHDA: Australian Government Department of Health, Disability and Ageing

DHSCC: Disability and Health Sector Consultation Committee

DRC: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

HITH: Hospital in the Home

NDIA: National Disability Insurance Agency – Agency that manages the National Disability Insurance Scheme (NDIS)

NDIS: National Disability Insurance Scheme

NSQHS: National Safety and Quality Health Service Standards

PHN: Primary Health Network

PTSD: Post Traumatic Stress Disorder

RACGP: Royal Australian College of General Practice

UNCRPD: United Nation’s Convention on the Rights of Persons with Disability

Executive Summary

The Long-Term Health Advocacy Working Group (the Working Group), established by the Disability and Health Sector Consultation Committee (DHSCC), was tasked with identifying the key issues relating to health advocacy for people with disability.

This report draws on evidence from Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC), national reviews, stakeholder input, and lived experience to inform DHSCC members and relevant stakeholders about the key advocacy barriers affecting people with disability across all health settings. It distinguishes between individual and systemic advocacy issues and outlines opportunities for improvements.

The report does not make policy or budget recommendations but identifies areas for influence and action by DHSCC member organisations.

It is a human right for people with disability to have quality health care

The United Nations Convention on the Rights of People with a Disability states in Article 25 that *'**Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability**.'* While Australia ratified the convention in 2008, the Working Group noted that the fundamental rights under the convention have not yet been achieved across Australian health systems as a result of health advocacy barriers faced by people with disability.

Health advocacy is critical for health equity

People with disability continue to face significant barriers to receiving appropriate and quality health care, as highlighted in the DRC. These barriers are deeply embedded in both individual and systemic factors, requiring coordinated, cross-sectoral responses. While substantial work has been done to dismantle these barriers across the federal and jurisdictional health systems, there is significant work to be done until health equity is achieved on a national scale. In the meantime, health advocacy plays a crucial role in creating opportunities for people with disability to be an active participant in their own health care.

The Working Group calls on DHSCC members to use their influence to drive change, support sustainable advocacy models, and ensure that people with disability can access the health care they are entitled to under the UN Convention on the Rights of Persons with Disabilities.

Key health advocacy themes and barriers

The Working Group identified four overarching themes in relation to health advocacy for people with disability, as shown below.

- Workforce knowledge and practice
- Health and disability system interface
- Access and autonomy for people with disability
- Communication

The key issues surrounding these themes relate to **individual self-advocacy** and **systemic advocacy barriers**.

Self-advocacy relates to a person's capacity to determine their own health needs at all stages, communicate their health and support needs, and participate in health treatment decisions autonomously. **Individual advocacy** is when a person uses one-on-one advocacy supports such as a professional advocate, relative, friend or volunteer to help them advocate for their own health needs.

System advocacy relates to the broader health and disability systems and their capacity to enable people with disability to determine their own health needs at all stages, communicate their health and support needs, and participate in their health treatment decisions.

This report identifies several health advocacy barriers at both the individual and system levels across the key themes.

Health and disability system interface

NDIS concurrent supports are not available for people with complex needs while in hospital. Removing access to a person's usual disability supports while in hospital can also remove access to advocacy support, as well as other essential day to day supports for people with complex needs. This is viewed as an urgent issue by the Working Group.

Lack of clarity around shared responsibilities and funding arrangements between the NDIS and hospitals is a system barrier that prevents individuals accessing appropriate disability supports when they are admitted to hospital.

This service gap between NDIS-funded supports and hospital care poses several risks to individuals with disability and complex needs. This includes an increased risk of medical and clinical hazards, lack of correct mobility and feeding supports, lack of communication and consent, elevated risk of triggering behaviours of concern, and increased chance of traumatic experiences for the patient.

Workforce knowledge and practice

The health and disability workforces lack foundational knowledge and practice as it relates to the wider health care of people with disability. The health workforce lacks appropriate disability knowledge, such as knowing how to identify person-centred needs like communication formation, required functional-disability supports, and understanding of supported decision-making. Without appropriate training, staff may have low confidence in treating people with disability and complex needs. Unless appropriate health advocacy options are available, this can lead to diagnostic overshadowing, misdiagnosis, unnecessary restrictive interventions, and repeated presentations to hospital.

The disability workforce often has poor health literacy which can limit their capacity for health advocacy. Health literacy training is not mandatory for disability support workers, and the disability workforce does not receive consistent training to set themselves up as effective health advocates.

Access, autonomy and communication

Communication, access and autonomy barriers are found across all touchpoints of the health system in various health settings. People with disability often require a trusted and trained communication partner to help them understand the reasoning for specific health procedures, facilitate supported decision-making, and help an individual understand health information and instructions. Access barriers can also include high private fees for NDIS-required assessments or being declined treatment due to perceived risk or complexity of health care needs.

System barriers to communication, access and autonomy were also identified. There is systemic lack of inclusion of people with disability in health policies and procedures, as well as a lack of accessible health information. Health professionals often have limited awareness of communication formats or needs and low confidence treating people with disability. Telehealth appointments or Hospital in the Home care are underutilised, there are long wait-times for disability-specific services, and high out-of-pocket costs for appropriate services.

Mainstream health services often lack appropriate supports or adjustments to provide care for people with disability. Many health services have short appointment times, lack physical access adjustments such as ramp access, height-adjustable examination beds or hoists, and are often high sensory overload environments in facilities that are inaccessible to people with low health literacy.

Opportunities for further action

To address these health system issues and their impacts on the health advocacy of people with disability, the Working Group proposes the following **next steps for consideration**.

Immediate action to address NDIS-funded disability support workers in hospitals

This includes opportunities to improve access to concurrent supports for people with disability while in hospital as part of their NDIS plan review process, including reviewing current rules, principles and processes. There is also an opportunity to continue work to clarify shared roles and responsibilities between Commonwealth government portfolios and states and territories. This would help to provide consistent and appropriate care across mainstream health services, disability settings, and hospitals.

Long-term solutions to improve health advocacy support for people with disability

This includes opportunities to facilitate access to health advocacy programs websites and support government policy for these to be available at no costs to population groups identified at highest risk. There is also an opportunity to undertake a scoping review of nation-wide capacity building initiatives and fund disability advocacy programs targeting improved health literacy and navigation.

Promote and develop external advocacy solutions

This includes opportunities to review the hospital liaison model process to identify improved linkages with most at risk people admitted to hospital including multiple identification pathways. Consideration could also be given to hospital resourcing and cost benefits related to the hospital liaison officer or disability navigator roles that specialise in disability advocacy and support for most at risk population groups.

Increase capacity in the health system to better understand the health needs of people with disability

There could be an opportunity to review standards and requirements for disability baseline knowledge as part of workforce/service standards review. Better integration of health information across systems is needed so that information follows an individual across health systems.

Introduction

Long-Term Health Advocacy Working Group

The Long-Term Health Advocacy Working Group (the "Working Group") was established in August 2024 by the Disability and Health Sector Consultation Committee (DHSCC). The Working Group was created as a time-limited group to define the key advocacy barriers experienced by people with disability in health settings in relation to:

- Opportunities for people with disability to increase their own individual health advocacy and health literacy.
- Systemic barriers within health settings that impact opportunities for short and long-term health advocacy of people with disability.

Membership of the Working Group:
- Co-Chair – Heather McMinn, National Disability Service
- Co-Chair – Jayne Lehmann, EdHealth
- Donna Gillies, NDIS Quality and Safeguards Commission
- Tracey Martell, Office of the Public Advocate Queensland
- Dariane McLean, Inclusion Australia
- Jaquie Mills, Microboards Australia
- George Taleporos, Consumer Advocate
- Samantha Connor, People with Disability Australia
- Secretariat - Department of Health, Disability and Ageing

Purpose and use of the report

This report has been prepared for the DHSCC to further its consideration of how to address, facilitate and strengthen health advocacy for people with disability.

This report provides an overview of the key barriers faced by people with disability in advocating for their health rights and needs across health settings. This report also highlights key concerns at a system level that contribute to health advocacy barriers.

Definition of health

The World Health Organisation defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”[1]. The health system, when working optimally, facilitates the pursuit of good health for all through inclusive and accessible access to a range health services, including:

- Primary care services, such General Practice, oral health, allied health, and sexual and reproductive health services.
- Mental health services
- Other specialist medical services for specific and/or complex conditions
- Hospitals

This report identifies the advocacy barriers experienced by people with disability across a broad range of health services such as those listed above. It is also acknowledged that specific mainstream health services may present additional health risks and barriers to people with disability.

Definition of health advocacy

For the purposes of this report, the Working Group defines health advocacy as enabling an individual to:

- determine their own health needs at all stages
- communicate their person-centred needs, health history, and home and living settings and supports
- access health services to meet their health needs
- request reasonable accommodations to ensure their access needs are met
- raise and protest discriminatory approaches which prevent their health needs being met
- participate in planning prior to hospitalisation, health treatment decisions, recovery planning and implementation of health plans.

The Working Group found there were challenges in distinguishing the individual and system advocacy barriers from wider health care issues affecting people with disability, such as service delivery and access. While this report acknowledges the importance and relevance of these broader health system issues to many organisations represented on the DHSCC, they are considered out of scope for this report.

This report does not make policy or budget recommendations. Instead, organisations with policy ownership across government and non-government sectors are identified against each advocacy barrier. Individual DHSCC member representatives can consider the report’s findings from their own organisational perspectives and areas of influence, to address local needs and opportunities within the health and disability interface.

In developing this report, the Working Group considered evidence from the Royal Commission into Violence Abuse, Neglect and Exploitation of People with Disability (DRC), recent review and reform reports, government policy and strategies (listed in Appendix 1), key stakeholder disability focused reports and anecdotal evidence from people with disability, family or carers and disability providers.

Working Group members also acknowledge the additional advocacy barriers experienced by First Nations people with disability. First Nations people with disability face intensified marginalisation when accessing health care, with increased challenges in their ability to access services and support. Working Group members note that, beyond health advocacy barriers for people with disability, mainstream services do not always provide culturally safe care for First Nations people. The health advocacy barriers described in this report present increased negative consequences on the health outcomes of First Nations people with disability.

The Working Group also acknowledges the continuing negative effects of COVID-19 on the disability community across Australia. The heightened risk of severe COVID-19 symptoms in the disability community underscores the urgent need to address health advocacy barriers for those who require frequent access to health care services as a result of COVID-19 diagnosis.

The importance of health advocacy

The United Nation's Convention on the Rights of People with a Disability identifies key human rights that people with disability are entitled to expect, including autonomy, respect and freedom to make their own choices and decisions and this applies to all aspects of life. Article 25 states *'**Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability**.'* Australia ratified the UNCRPD convention in 2008, and the convention came into effect in 2009. However, people with disability continue to report barriers are impacting their ability to advocate for their individual health needs, supports and services.

People with disability have a right to advocate for their health care needs, information and support.

Equitable health care access for people with disability, as identified in Article 25 of the UNCRPD, includes:

a) providing persons with disability with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including sexual and reproductive health and population-based public health programmes.

d) removing health system barriers to ensure that health professionals can provide care of the same quality to persons with disabilities as those without disabilities. This includes facilitating free and informed consent through training and enforcing ethical standards for public and private health care[2].

Federal, state and territory governments all share responsibility for protecting the rights of people with disability, as enshrined in the ratified UNCRPD Article 25. While the convention underpins government policies and strategies, the system barriers highlight significant gaps in how this is currently applied to workforce training and service requirements as previously identified by evidence given to the DRC during the public hearings on health[3].

The report *'System changes to enable optimal health outcomes for people with disability'*[4] noted that the equitable health care obligations are not being met despite Australia's commitment to the UNCRPD. This is identified as a result of systemic issues including socio-economic disadvantage and lack of access to quality and affordable health care, health promotion and prevention and suggests an overarching disability and health strategy should be considered.

The Working Group noted that substantial progress on achieving the fundamental rights under the convention has not yet been achieved across Australian health systems, in part due to broader health advocacy barriers. These barriers impact awareness, access, prevention, early intervention and treatment of people with disability.

There is urgent need for appropriate health advocacy channels and supports to ensure people with disability attain their fundamental right to health as outlined in the UNCRPD.

Achieving the UNCRPD ratified rights can only occur when both individual and system barriers impacting a person's ability to advocate for their immediate and long-term health needs are addressed.

People with disability continue to face health care barriers and poor support within Australia's health system[5]. Barriers include unacceptable or lengthy waiting times, cost, inaccessibility of buildings, discrimination by health professionals, and issues caused by lack of communication between the health professionals treating them. These issues severely impact access to quality health services and the attainment of good health by people with disability. While there are reforms underway that may eventually help to overcome these barriers, we know that any changes to the health system, and particularly the health and disability interface, are complex and will take time to achieve. In the meantime, people with disability need to be able to advocate for their health needs where they are not being met. The right to self-advocacy is fundamental to a person's health and wellbeing.

The DRC Final Report underscores the importance of advocacy for people with disability and their supporters as needed. Witnesses to the report describe that there is a risk of patients falling between the gaps in health services if they do not have advocacy support[6].

To review where advocacy barriers occur for people with disability across the health system, the Working Group developed two process maps:

- the health journey of a person with disability within primary health services (See Appendix 2: Primary Health Journey: Person with disability)
- the hospital journey (Appendix 3: Hospital Journey: Person with disability).

This process confirmed members' understanding of the reality people with disability face when interacting with Australian acute and primary care health services. The process also highlighted the complexity of touchpoints between the individual and health system where barriers were identified.

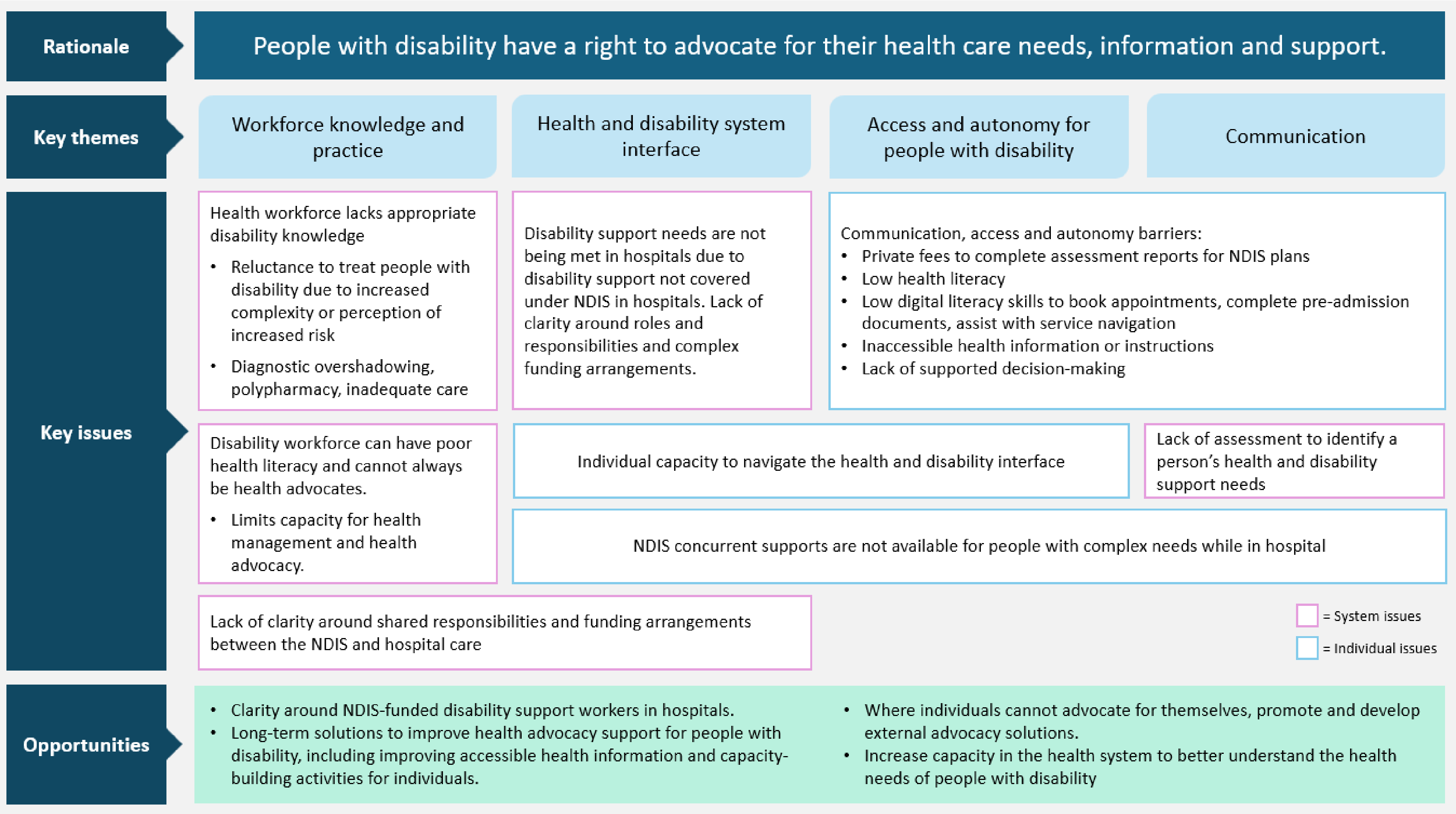
Overarching Themes

The Working Group identified four overarching themes relating to health advocacy:

- Workforce knowledge and practice
- Health and disability system interface
- Access and autonomy for people with disability
- Communication

The themes, issues and opportunities discussed in this report are outlined in **Figure 1**.

Figure 1: Overview of key themes, issues and opportunities relating to health advocacy



Rationale

People with disability have a right to advocate for their health care needs, information and support.

Key themes

- Workforce knowledge and practice
- Health and disability system interface
- Access and autonomy for people with disability
- Communication

Key issues

Health workforce lacks appropriate disability knowledge
- Reluctance to treat people with disability due to increased complexity or perception of increased risk
- Diagnostic overshadowing, polypharmacy, inadequate care

Disability support needs are not being met in hospitals due to disability support not covered under NDIS in hospitals. Lack of clarity around roles and responsibilities and complex funding arrangements.

Communication, access and autonomy barriers:
- Private fees to complete assessment reports for NDIS plans
- Low health literacy
- Low digital literacy skills to book appointments, complete pre-admission documents, assist with service navigation
- Inaccessible health information or instructions
- Lack of supported decision-making

Disability workforce can have poor health literacy and cannot always be health advocates.
- Limits capacity for health management and health advocacy.

Individual capacity to navigate the health and disability interface

Lack of assessment to identify a person's health and disability support needs

NDIS concurrent supports are not available for people with complex needs while in hospital

Lack of clarity around shared responsibilities and funding arrangements between the NDIS and hospital care

🟪 = System issues
🟦 = Individual issues

Opportunities

- Clarity around NDIS-funded disability support workers in hospitals.
- Long-term solutions to improve health advocacy support for people with disability, including improving accessible health information and capacity-building activities for individuals.
- Where individuals cannot advocate for themselves, promote and develop external advocacy solutions.
- Increase capacity in the health system to better understand the health needs of people with disability

Advocacy barrier types

Advocacy barriers have been grouped into two main categories:

1. Self-advocacy and individual advocacy barriers

Self-advocacy relates to a person's capacity to determine their own health needs at all stages, communicate their health and support needs, and participate in health treatment decisions autonomously. However, some people with disability may have limited capability to self-advocate. This could be due to personal circumstances or complex support and communication needs, and they may require independent advocacy support.

Individual advocacy is when a person uses one-on-one advocacy supports such as a professional advocate, relative, friend or volunteer to help them advocate for their own health needs.

The report will discuss the individual advocacy barriers and considerations relating to:

- increasing one's own **health literacy** to navigate the health and disability system interface.
- the ability of a person with disability to **communicate** their health needs, **access** appropriate health care and exercise **autonomy** over their health treatment decisions.

The Working Group noted that most of the barriers identified for urgent consideration were associated with health services and systems outside of the individual's control. As a result, the individual advocacy barriers for consideration, such as health literacy capacity building and health system navigation, while important, would only achieve limited impact on their own.

2. System advocacy barriers

System advocacy relates to the broader health and disability systems and their capacity to enable people with disability to determine their own health needs at all stages, communicate their health and support needs, and participate in their health treatment decisions.

The report will discuss the system advocacy barriers and considerations relating to:

- addressing the support gaps created as a result of the **health and disability funding interface**, specifically as it relates to functional support in hospitals.
- **health and disability workforce knowledge, practice, and training**
- system barriers that impact the **communication, access, and autonomy needs** for people with disability.

The Working Group noted that system advocacy barriers present the most serious impact on health outcomes for people with disability. System advocacy barriers can lead to delayed health management access for people with a disability, misdiagnosis, avoidable hospitalisation, ineffective models of care and avoidable use of restrictive interventions. This, in turn, adds to increased health related trauma for individuals with disability, and family or carers.

System barriers also affect health service budgets, avoidable use of emergency transport and hospital admissions, and operational requirements in both health and disability service sectors. The system advocacy barriers are a contributing factor to inappropriate service delivery and priorities. Opportunities to address system barriers will benefit both people with a disability and health systems.

Individual advocacy barriers

Individual capacity to navigate the health and disability interface

The interface between health and disability systems at the Commonwealth, state and territory level is complex. Service fragmentation, lack of care coordination, lack of appropriate services, information that is not accessible nor consistent across services, and separate funding systems all contribute to the complexity of how the health and disability systems interact. For an individual with both health care needs and disability support needs, this can impact a person's ability to navigate the health system, and their ability to advocate for their health and disability needs.

As a result, in order to navigate the complex health and disability interface across state and federal jurisdictions, including the NDIS, people with disability require high levels of health literacy, or access to individual supports to provide health literacy expertise. A lack of appropriate health literacy and health advocacy supports can result in serious health outcomes, particularly in hospital systems.

This issue corresponds directly with the following:

NDIS Review (2023) Action 1.4: National Cabinet should agree to jointly invest in navigation support for people with disability outside the NDIS.

NDIS concurrent supports are not available for people with complex needs while in hospital

One example of a barrier due to the complexity of the health and disability interface is that there is a lack of shared understanding between the NDIS and the health system as to which agency is responsible for funding disability workers to support the functional needs of people with disability while in hospital (see System Barriers: Health and Disability Interface for more information). The result of this is that people with disability often have inconsistent, delayed or, in some instances, no access to their NDIS-funded disability support workers while they are in hospital.

When admitted to hospital, people with disability are often required to understand and effectively communicate their disability and co-occurring health needs at a time when they are unwell. If a person with disability has limited capacity to self-advocate and they require independent advocacy support, removing access to concurrent NDIS supports while in hospital may also remove access to advocacy support.

This issue corresponds directly with the following:

NDIS Review (2023) Recommendation 2: Increase the scale and pace of change in mainstream and community inclusion and accessibility and improve the connection between mainstream services and the NDIS

While hospitals are responsible for managing the health care needs of admitted patients, it may not be possible for an individual’s disability support needs to be met by hospital staff. People with high support needs require disability related support when in hospital for functions such as:

- maintaining effective communication and supporting the health care team to understand how a person exhibits pain
- support in regard to body positioning and movement to prevent pressure sores, identification of falls risks, and ensuring a person is positioned to eat safely
- expert support for feeding
- coregulation support from a trusted person who knows them well to support their sense of safety, prevent escalation, help identify potential triggers and respond appropriately to behaviours of concern
- support to engage with specific treatments or procedures, including regulation support and co-design of adjustments
- maintaining functions of daily life such as social connection, online work or entertainment.

Communication, access and autonomy barriers

Advocacy relies on the ability of a person to communicate their health needs. Communication and advocacy are essential for asserting autonomy over health choices, including selecting providers, consenting to treatments, or agreeing to medications.

> “People with disability face a range of barriers to accessing quality health care. These must be removed by … identifying adaptations and supports required for a person-centred approach.”
>
> *- Disability Royal Commission, Final Report, Executive Summary*

Barriers to a person's right to communication, access and autonomy are found across all touchpoints of the health system, from General Practice, allied health, and oral health services through to specialist professionals.

Examples of individual barriers include:

- the need to pay private fees to ensure assessment reports can be completed for NDIS plans.
- requirement for digital literacy skills to make appointments, complete hospital pre-admission documents, assist with health service navigation, or manage contact systems with multiple digital options.
- inaccessible health information or instructions.
- lack of supported decision-making.

Supported decision-making is decision-making with the support of others. It starts from the premise that everyone is able to make decisions and should be supported to do so. Article 12 of the CRPD recognises the right to support for decision making.

Communication and supported decision making are not a one size fits all practice, and many people require a skilled communication partner trained in their specific needs in these areas.

Lived experience input from the Working Group indicates that some health professionals are reported to be declining appointments for people with disability due to complexity of needs, burden of health support documentation, and NDIS assessment requirements that are not cost effective to the practice.

These autonomy and access barriers reflect opportunities for system improvements. They are also important to consider from an individual advocacy lens as they highlight how people with disability are discriminated against as result of their disability due to perceived complexities outside of their control.

Current opportunities and limitations

The individual health literacy, communication, access and autonomy barriers highlight the need for sustained capability-building initiatives for people with disability.

Programs with existing capacity to increase individual advocacy capability may address health-related barriers in some cases. For example, Inclusion Australia's *It's Doctor Time!* campaign includes resources to make the annual health assessment easier and more accessible for people with intellectual disability, their supporters and families.

However, capability-building initiatives rely on funding being available to support the development and running of the program. Without them, individuals must seek independent access or become dependent on others for their advocacy. The Working Group identified that capability-building initiatives were limited, especially for people with disability requiring support to advocate for their health needs and functional requirements. Many initiatives are only short-term projects.

Organisations or advocacy groups with both health knowledge and disability expertise could achieve long-term effectiveness, especially when people with a disability are actively involved in all parts of the project. The Working Group noted that family and carers would also benefit from being able to increase their health literacy and service navigation capability-building programs to support people with disability more effectively when required.

System advocacy barriers

Health and disability interface

As previously discussed in the *Individual advocacy barriers* section, the interface between health and disability systems at the Commonwealth, state and territory level is complex. It follows that there are also complex funding arrangements and there are often shared responsibilities across different government agencies.

Lack of clarity around shared responsibilities and funding arrangements between the NDIS and hospital care

The NDIS Review recommendations highlight a failure of government agencies to agree on shared responsibilities under the current *Applied Principles and Tables of Support to Determine Responsibilities of the NDIS and other service systems* (APTOS)[7].

> "The framework which governs the relationship between the NDIS and other service systems — the Applied Principles and Tables of Support (APTOS) — has failed. It is based on the idea that there is a hard line between the NDIS and other systems. Despite its intent, it has led to seemingly endless arguments about who does what and who pays for it."
>
> *- NDIS Review: Working together to deliver the NDIS Final Report*

Specifically, there is no common understanding between the NDIS and the health system as to which agency is responsible for funding disability workers to support the functional needs of people with disability while in hospital. This is despite functional supports being recognised as reasonable and necessary within NDIS funding more broadly.

The 2024 NDIS Transitional Rules state that the NDIS is responsible for "*funding of [disability-related health supports] for people with complex communication access needs or behaviours when accessing health services, including hospitals and in-patient facilities*"[8]. Despite this, anecdotal evidence and lived experience indicates that the delivery of disability-related health supports is being referred to hospital staff when a person with disability is admitted to hospital, and that NDIS-funded support workers are not a central part of the care team.

This issue corresponds directly with the following:

NDIS Review (2023) – Recommendation 2: Increase the scale and pace of change in community inclusion and accessibility and improve the connection between mainstream services and the NDIS[9].

Disability support needs are not being met in hospitals without disability support

While support needs vary between individuals, people with high support needs still need disability related support when in hospital.

Many supports require general health staff to have specialist disability knowledge. However, this specialist knowledge has been identified as lacking in health services due to the low levels of disability support training among health professionals. While existing strategies for initial and ongoing learning for health professionals are being developed, these will take time for the workforce to complete their training.[10] Even if this does occur, many people with disability require supporters with specific individualised understanding of how to meet these needs which rarely conform to a one size fits all approach, meaning that the safest option for people with disability is to have their correctly trained and experienced support workers (referred in this report as disability-functional support) with them in hospital and other health settings.

The people most at risk of health advocacy barriers in hospital are people with disability who are unable to advocate for their own specific needs or face barriers to communicating their health needs effectively with health workers. This includes people:

- with intellectual disability
- with developmental delay, cognitive or neurological conditions
- who require support with communication or Augmentative and Alternative Communication (AAC) methods
- who have a history of trauma associated with health-related treatments, environments or experiences
- who struggle to self-regulate for a range of reasons, including pain or being unwell, resulting in difficulties engaging with diagnosis or treatment processes
- who do not have family or carer support available or involved and are reliant on familiar and trained disability support workers to assist functional advocacy needs
- who have specialised physical health, equipment or mobility requirements.

Risks resulting from gaps in the health and disability funding interface

The gap in disability-functional support created by the health and disability funding interface can result in greater health risks for people with disability.

Increased risk of medical and clinical hazards

The gap of disability-functional support created as a result of the health and disability funding interface can result in serious risk to health for people with disability. Without disability-functional support, people with complex needs are generally unable to recognise clinical risks or hazards and communicate that to their care team.

Pressure sores and body positioning issues

People with high physical support needs may require additional support with body positioning and movement. This may include the need for regular repositioning to prevent pressure sores, identification of falls risks, and ensuring a person is positioned to eat safely. These supports require the presence of disability-functional support workers who know the patient.

Lack of feeding support

People with complex needs may need expert support for feeding. People with difficulty swallowing (dysphagia) are at a greater risk of choking or aspiration without appropriate trained support and supervision, which may beyond the capacity of hospital staff.

Elevated risk of triggering 'behaviours of concern'

When a person with disability cannot advocate for their supports and health needs, behavioural responses can be triggered. While they may be interpreted by hospital staff as 'concerning' or posing potential danger, the behaviour is often a form of communication or the result of previous trauma experienced within health services. Often, hospital workers lack the skills required to identify and support people when they are showing signs of distress. Regardless of the training hospital staff may have, many individuals require the presence of a trusted person – who knows them well – to facilitate coregulation and assist in processing the stress and disorientation associated with illness, pain, and unfamiliar environments. The lack of support can lead to the use of unnecessary restrictive practices or a failure to diagnose.

Lack of communication and consent

People with complex communication needs require an effective communication partner available, preferably a disability-functional support worker who knows the patient's communication needs well. Communication partners can ensure the patient has a voice and support the health care team to understand how a person exhibits pain. Communication partners also support the person's processing and decision-making ability, i.e. to be able to understand what is happening and to give consent. The risks of assault escalate where there are no skilled communication partners present and hospital staff are left to guess if a person is giving consent or not.

Difficulties in receiving treatment

Some people may require additional support to comply with specific treatments or procedures, such as scans, blood draws, or taking medications. The person's usual support worker is well placed to know what the patient needs to ensure those necessary procedures can be completed. If procedures are unable to be completed, then opportunities for diagnosis and/or treatment are lost.

Increased risk of poor mental health

People with high support needs still need disability related support when in hospital to do the usual things they might do in daily life, for example, maintaining social connections, or engaging with the broader world (e.g., work, entertainment) online. Staying in hospital without access to the kinds of distractions and activities which would generally be available is a violation of human rights and likely to negatively impact mental health.

Increased cost to the health system

As a result of the increased risk of inadequate health treatment for people with disability in hospital, the Working Group noted the high prevalence of people with disability who are readmitted to hospital with the same untreated health conditions. The presence of disability-functional support workers or communication partners can ensure that health treatment and communication needs of the person with disability are addressed in the first instance. The absence of these support workers increases the risk of miscommunication and readmission, which can lead to additional and unnecessary costs incurred by hospitals.

To address the gap of disability supports in hospital, close contacts of people with disability have reported to take extreme measures to provide care. This includes instances where elderly parents have stayed in hospital with their family member with disability, despite their own health needs.

Current opportunities and limitations

Currently, there is a mechanism to gain approval for NDIS concurrent supports, enabling the person’s usual support to be provided while the person is in hospital. However, this mechanism is applied inconsistently across Australia. For example, in NSW it is possible for a physician to request the supports for a person with complex needs with approval granted for up to a 12-month period, potentially covering multiple hospital admissions. In contrast, in WA the request is only made once the person has already been admitted and covers only that admission. Approval can take up to 48 hours, resulting in uncertainty regarding whether disability organisations will be recompensed for providing the support.

Disability hospital liaison officer (HLO) models who specialise in disability advocacy may be able to support a person advocating for their health management. The hospital liaison officer model varies in scope for advocacy requirements across Australia. Reports indicate the model relies on the person with disability being identified by hospital staff as needing the HLO, with referral to the HLO initiating the connection with the individual. This process often leads to advocacy delays and cannot easily be initiated by family or disability support workers.

Other models of support are disability liaison officers (DLOs) or specialist teams established in hospital services with varying levels of engagement related to the scope of work set by the health service. Despite positive reports of the Victorian DLO program, multi-site requirements and staff shortages may still result in advocacy gaps across health systems.

Workforce knowledge and practice

The Working Group identified a lack of foundational knowledge and practice within the health and disability workforce as it relates to the wider health care of people with disability. Workforce knowledge and skill gaps relate to disability-functional support, disability-specific health concerns, management of chronic health conditions in people with disability and the capacity of the disability system to accommodate health support.

This issue corresponds directly with the following:

Australia’s Disability Strategy - Health and Wellbeing Policy Priority 1 to ensure all health service providers have the capabilities to meet the health needs of people with disability[11].

Health workforce lacks appropriate disability knowledge

Witnesses to the DRC noted a systemic lack of training about the health of people with disability (and specifically cognitive disability) for health professionals in all health disciplines throughout their careers and across health services.

The Working Group identified the health workforce as having limited knowledge of disability health, particularly in relation to understanding intersecting lifespan health conditions and the settings and support systems that may be required by people with disability. This presents a significant barrier to health advocacy for people with disability. The lack of disability-related knowledge and skills affects health professionals’ ability to identify person-centred needs, such as appropriate communication formats, settings adjustments, and required disability-functional supports. This can negatively impact a person’s health outcomes and lifespan.

Other health workforce knowledge gaps exist in relation to:

- how co-occurring health conditions impact their disability, or may not be in relation to their disability (for example, the Working Group noted high prevalence of diagnostic overshadowing by health professionals in their interactions with people with disability)
- incorrectly attributing behaviour exhibited by people with disability as a symptom of mental health conditions
- disability-related day-to-day health needs
- the importance of preventive health care for people with disability
- AAC options for people with disability
- how to identify, design and implement reasonable adjustments for people with disability to access health care

Example: Oral health services

A lack of health workforce knowledge can impact the health risks of people with disability in particular health services. For example, the Working Group noted that oral health services face an underrepresentation of special needs dentistry specialisation, and a lack of disability knowledge amongst generalist dentists. People with disability often require sedation for dental care, including for simple dental checkups or cleaning.

This can lead to long waiting times for special needs dentistry services, and increased costs to people with disability for additional adjustments. There is also a higher risk of complications from general anaesthetic among people with disability in mainstream oral health settings.

In addition, medical practitioners are not trained in oral health assessment, which can lead to a risk of overlooked oral health issues medical assessment and diagnoses.

Lack of workforce knowledge and appropriate treatment options result in fewer people with disability receiving oral health care, which can lead to significant health complications (such as difficulty eating and communicating with others).

Impact of knowledge gaps

A lack of consistent baseline knowledge across health services can result in people with disability presenting to hospitals more frequently due to a lack of available health care options. The Working Group noted that re-admissions can often occur due to ineffective assessment and diagnosis of health concerns. Some members of the Working Group shared anecdotal reports from disability workers who are supporting people with disability, who, on discharge from hospital settings, are returning home with:

- reduced mobility status
- severe constipation or loss of weight from lack of functional support for mealtime management or lack of understanding of the specific dietary needs
- pressure sores due to lack of appropriate knowledge or understanding of disability and mobility constraints

Lived experience evidence shared with the Working Group indicated other consequences caused by a lack of appropriate disability knowledge in the health workforce, including:

- reports of people with disability being discharged from hospitals or emergency departments without thorough assessments
- misdiagnosed health needs
- diagnostic overshadowing associated with disability
- polypharmacy.

These consequences are reported as occurring across community and hospital health services. Further reports shared with the DRC highlight a need for improved knowledge and understanding of a person’s specific advocacy requirements and support to address the barriers impacting health outcomes[12].

The Working Group highlighted that inadequate health workforce training can also lead to continued use of restrictive practices due to insufficient communication or advocacy for the health needs of people with disability. Restrictive interventions are often used in health settings in lieu of consistent baseline workforce knowledge and practice in identifying person-centred risk mitigation strategies. Restrictive practice intervention instead of preventative actions can lead to additional physical and psychological risks for people with disability who are nonverbal, who have intellectual, cognitive or neurological disability, or have developed PTSD from previous negative experiences in health settings.

Health workforce knowledge gaps and real-world effects on health advocacy

Anecdotal reports describe how people with disability are left isolated in hospital rooms or emergency areas for extended time periods without appropriate support or communication by staff. Some reasons for this might include:

- staff feeling inadequate in their ability to communicate with and make assessments with the individual
- not having consistent systems to access health history or information on appropriate adjustments or supports
- the expectation from health workforce that disability support workers would be onsite for the support and advocacy needs where family or carers are not available or involved.

Instances where anxiety and distress resulted in behavioural protests, interventions included the use of security guards to intervene, the application of bed restraints and delivery of sedation. At times, this can result in a failure to provide diagnostic or treatment options at all.

Disability workforce lacks appropriate health literacy

The Working Group also noted that health knowledge gaps in the disability workforce present advocacy barriers to addressing the health needs of people with disability within health settings.

The disability workforce receives inconsistent training to equip them with the knowledge and skills to provide a baseline level of health literacy and health system navigation. The lack of adequate health training among disability workforce and support workers can lead to lack of confidence in advocating for the health needs of the people they are supporting within the health system. Additionally, health navigation knowledge gaps also impact the ability of the disability workforce to advocate for and organise critical health appointments, such as regular GP appointments to monitor an acute or chronic health conditions, annual health assessments, and preventative screening and tests. It is also important to understand the intersectionality of how disability support workers are learning and implementing their health literacy skills. The Working Group noted a gap in cross-system collaboration between the health and disability workforces. This in itself poses a communication barrier, and contributes to the complexities experienced by support workers in navigating the health system.

The casual workforce was highlighted by the Working Group as a particular concern, with reduced opportunities to access professional development or engage in discussions around disability health needs with colleagues.

Current opportunities and limitations

The lack of disability awareness in health systems can cause an overall distrust among people with disability and their supporters in the ability of health professionals to listen to and act upon their health needs. This is compounded when disability support workers have low health literacy and the disconnect can further impede a person’s ability to advocate for their health needs and requirements.

While many health disciplines have qualification frameworks and professional accreditation requirements for course curricula, they are impacted by various constraints. Constraints impacting workforce understanding of disability health includes a lack of mandated education. Specific disability health training often depends on the interest of individual workers wanting to improve their understanding of the needs and requirements of people with disability.

Current government initiatives and policies aimed at increasing workforce disability knowledge and practice were identified as important steps towards facilitating the health advocacy of people with disability in health systems. However, the Working Group highlighted concerns that the momentum to embed non-mandatory baseline knowledge is low. Evidence for this includes feedback from PHNs noting intellectual disability health training is a low priority compared to other continuing professional development programs, low awareness of the Comprehensive Health Assessment Program for people with intellectual disability (CHAP), and optional disability initiatives provided by the RACGP and the National Safety and Quality Health Standards.[13]

The Working Group acknowledges these education and training initiatives are a positive step towards improving access to quality and safe health services, but it does not reduce the current advocacy barriers experienced by people with disability and their supporters.

Improving health literacy and baseline health system navigation knowledge for disability workers is another opportunity to address some of the workforce barriers. Upskilling the disability workforce, particularly disability support workers, is one opportunity to improve health advocacy capability. This would, in turn, improve confidence for both the person with disability and their support workers during the patient journey and to advocate for their health and disability-functional support needs as required. Upskilling of disability workers may require changes to current infrastructure and training programs to ensure disability workers have access to appropriate resources so that long-term improvements to baseline knowledge can be achieved.

System barriers to communication, access and autonomy

Health service environments and settings vary in relation to how they embed accessibility and inclusion for people with disability. This variation impacts how a person with disability can exercise autonomy to advocate for appropriate health support, information, diagnosis and treatment.

The Working Group identified several barriers experienced by people with disability when accessing and interacting with primary health professionals and their services, as exemplified in Appendix 1 and 2 of this report.

This issue corresponds directly with the following:

DRC recommendation 6.1 to establish a national plan to promote accessible information and communications

DRC Recommendation 6.10 to ensure that people with disability are presumed to be able to make their own decisions

DRC recommendation 6.14 to improve systemic advocacy to promote supported decision-making[14]

A key system barrier identified by the Working Group is the difficulty in health systems to identify and record the health advocacy needs of people with disability. This recordkeeping barrier hinders the ability of people with disability to access primary care services and can impact the quality and safety of the care provided[15].

Lived experience feedback provided via the Working Group reported:

- lack of assessment to identify a person's health and disability support needs, preventing early access to health services due to ineffective and/or unnecessary health assessments, misdiagnosis and diagnostic overshadowing.
- delays in early intervention, screening and diagnostic procedures (such as identification of late-stage cancers)
- delays in access to appointments were reported as impacting treatment for emerging or existing health needs, leading to further health deterioration.

Delays in assessment also impacted an individual's ability to provide adequate information for NDIS funding decisions for residential and in-home supports. This delay can result in some people exiting the service due to lack of funding while waiting for plan reviews, increasing hospital admissions as a last resort to receive the care options they need.

Additionally, clinical information systems vary across health services, with limited and inconsistent identification of people with disability. Inconsistent data across health systems impacts how individual advocacy needs, supports and health history are captured. This impacts how information is shared between health services and professionals, and how this information is communicated with a person's family, carers or support workers.

Other barriers to health autonomy and access identified across health systems by the Working Group include:

- limited availability of cost-effective services for people with disability, including general practice billing models, and expensive oral health, allied health, psychology, psychiatry and other specialist assessment costs.
- short appointment times under the Medicare Benefit Scheme are not suitable for people with disability, leading to health advocacy barriers when health needs are misdiagnosed, unrecognised or overlooked.
- limited access to Hospital in the Home (HITH) care to reduce unnecessary hospital visits and allow people with disability to have procedures done at home, as highlighted during the COVID-19 pandemic. For example, this could include treatments such as chemotherapy or iron infusions.
- telehealth options are not always appropriate to achieve the same effectiveness of a face-to-face assessment or to address all acute care needs for people with disability.
- limited access to specialist disability health services support models such as Centre for Developmental Disability and Health Victoria.
- long waiting times for disability specific services e.g. psychiatrists, specialist disability health services with rural regional and remote locations increasing risk of delays.

These access and autonomy barriers lead to a lack of ability to communicate for needs and health concerns is continuing to be reported resulting in:

- delays in admission or emergency assessment processes
- poor meal and health management support delivering during admissions
- mobility deterioration, wound and pressure complexities
- discharges delays or inappropriate discharges leading to subsequent avoidable readmissions and use of emergency transport.

A note on physical access

Health service settings have improved over time with increasing awareness of the needs of people from diverse population groups, including people with disability. However, many health care centres are located in older buildings or small private service settings which are not physically accessible. Other access barriers include inappropriate hoists (if available at all), examination couches that cannot be height adjusted, and inaccessible information materials that use complex health terms. Support and availability of AAC devices and resources can be limited and often relies on the individual having the required skills or bringing their equipment with them.

Other environmental and health setting barriers include:

- inconsistency of implementation and understanding of the breadth of accessibility needs, requirements and how to identify these for people attending services
- high sensory overload environments and complex navigation in facilities that are inaccessible for people with low health literacy.
- limited access to home-based appointments where primary care services can be provided in a safe environment using home-based physical supports and equipment e.g. vaccinations.

Current opportunities and limitations

The Working Group identified that, to mitigate the risks within the health system, increased advocacy in relation to health literacy and service navigation is critical to support the needs of people with disability. People with complex communication, health and disability needs were noted to benefit greatly from increased health advocacy. Government allocations of funding for initiatives such as the National Roadmap for Improving the Health of People with Intellectual Disability[16] and the National Roadmap to Improve the Health and Mental Health of Autistic People[17] provide welcome opportunities to improve health advocacy for people with disability.

Overall, these system barriers have previously been identified in reports and papers, including DRC public hearing report on health care for people with intellectual disability[18]. Microboards Australia also published a report on how health services can deliver better health outcomes for people with intellectual disability[19], and in 2018 Latrobe University produced a report on improving inclusivity for people with an intellectual disability in mainstream services[20]. While these report findings address the needs of people with intellectual disability, these considerations can also impact other disability population groups.

Next Steps for Consideration

The Working Group recommends the following key steps to promote action across DHSCC member organisations.

Immediate action to provide clarity around NDIS-funded disability support workers in hospitals

Immediate action is required to allow people with disability to have access to NDIS-funded support workers and/or concurrent disability-functional supports while in hospitals as part of their NDIS plan. This will allow people with disability to have their health care needs met by hospital staff, while continuing to have their disability-functional support needs met by a known disability support worker when in hospital.

Clear responsibilities, enduring funding rules and guidance are needed to clarify funding arrangements between hospitals and NDIS, and ensure appropriate management of this arrangement, such as specifying criteria for having complex needs, and specifying the level of support required. This will help to prevent people with disability experiencing worse health outcomes when admitted to hospital where high risk health advocacy needs exist. Increased transparency is required around the process of ensuring these needs are met in hospital would help decision-makers better understand system advocacy barriers.

Opportunities:

The NDIS Rules are currently being negotiated between state, territory and Commonwealth governments. This provides an opportunity for consideration of the impact and resourcing costs on state and territory hospital services regarding disability-functional support needs a person with complex disability requires when admitted to hospital.

DHSCC member influence and consideration:

NDIA and states and territories to consider how best to enable concurrent supports for people with disability while in hospital to align with an individual's NDIS plan. This may include consideration of the following conditions:

- The person meets the criteria for having complex needs, such as:
    - High physical support needs and/or
    - Complex communication needs and/or
    - Behaviours of concern
- The approval is for continuation of support at the level they receive in their plan, rather than additional support hours.
  (Note: a mechanism is required to request additional support hours if there has been a change in disability-related support needs)

NDIA to consider principles and processes for identifying how identified APTOS[21] rules related to disability-functional support responsibilities can be applied to groups identified at as having complex needs.

NDIA to discuss shared responsibility with mainstream health services to provide health supports in disability settings for high-risk patients with clinical health needs.

State and territory health government to consider hospital resourcing and cost-benefit of delivering health support services within disability settings for high-risk patients with clinical health needs.

Long-term solutions to improve health advocacy support for people with disability

Accessible health information and improved health literacy

Health information across all health settings should be provided in accessible and appropriate formats to support a person with disability. There is opportunity to increase health literacy, including how to actively participate in management of treatment and recovery. Seek to improve health literacy for individuals with disability where possible, and for their support workers and advocates.

There is a need for ongoing capability-building for individuals, their families, supporters and disability organisations to create individual and systemised health advocacy models for people with disability.

Opportunities:

Advocacy organisations such as CID, Inclusion Australia, Cerebral Palsy Alliance, Summer Foundation, Autism Australia and Microboards Australia to share and promote good examples of existing or previous health literacy activities, accessible health information, and activities to increase individual capacity for health advocacy.

Under the National Disability Advocacy Program, the government funds disability advocacy providers to deliver advocacy support across Australia. The program provides ‘people with disability with access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation’.[22]

Funded campaigns can help to target specific audiences and improve health literacy, access to health information and enable people with disability to advocate for their health needs. “It’s Doctor Time” is one example of a campaign targeted to people with intellectual disability[23]. If we are to sustain and develop health advocacy skills, then programs require ongoing funding and sustainability to increase their impact across systems and individuals. There is a need to identify what is working and provide funding to continue their impact.

DHSCC member influence and consideration:

NDIS Commission - to support access to programs via links on commission website and supporting government advocacy for these to be available at no costs to cohorts identified at highest risk.

State and territory government consideration of the cost benefit of (1) undertaking a scoping review of nation-wide capability-building initiatives and (2) funding disability advocacy programs targeting improved health literacy and navigation.

Where individuals cannot advocate for themselves, promote and develop external advocacy solutions

Family and carers are not always available, equipped or interested in being involved in the health advocacy of a person with disability. This includes people with ageing or deceased parents or siblings, deceased partners, people whose parents have intellectual or learning disabilities, or people who are estranged from family. Other examples include people who have families or networks who work or are burnt out from their caring role. The person with disability may have also been relinquished to the care of disability support providers at some point in their life. Even parents who do have capability to advocate for their family members report frequent failure to do so when navigating complex health systems. Health advocacy services are required for individuals and families in these circumstances. External advocacy organisations do exist and can be accessed by people with disability and their families, but there is a lack of awareness of their availability and capability can be limited, especially with the loss of some advocacy services as the sector transitioned to the NDIS. Additionally, many advocacy services do not have the capability or training to meet the health-specific advocacy needs of people with disability.

Opportunities:

There is a critical issue with the current model of disability support in hospitals. To address this, a review of the current models of disability liaison is required within each state and territory health system. Much like the Aboriginal and Torres Strait Islander Liaisons model, something similar needs to be embedded within hospital services. This recognises there are specific needs in this population group that requires people with the knowledge, skills and attitudes to facilitate their health advocacy and resultant health care and requires a consistent embedded approach across all states and territories.

DHSCC member influence and consideration:

NDIA to consider processes for improved linkages with most at risk people admitted to hospital including multiple identification pathways.

State and territory government health services to consider hospital resourcing and cost benefits related to the hospital liaison officer or navigator roles that specialise in disability advocacy and support for most at risk population groups.

Increase capacity in the health system to better understand the health needs of people with disability

Strategies to increase the capacity of the health system to address the needs of people with disability include workforce training, accessible communication and improving the health and disability sector’s understanding of the role of support workers. Improved communication of individual support needs across health settings, greater access to home-based health services and access to communication partners while in hospital would also help to reduce system barriers for people with disability.

Understanding how to care for people with disability is essential for workers in both the health and disability sectors. When this knowledge is built into everyday practice, it helps people with disability to speak up for their health needs—either on their own or with support. Embedding a baseline knowledge amongst the health and disability workforce will be fundamental to overcome health literacy barriers.

Opportunities:

The Working Group recommends that all areas of the health workforce consider improving baseline disability health knowledge. Disability health capability improvement should be included in professional standards for accreditation. These initiatives must be recognised as a cost benefit to the health system and based on the Intellectual Disability Health Capability Framework[24] .

Better integration of health information across systems is needed so that information follows an individual across health systems.

This opportunity can explore current policies, standards and activities and how they can increase capacity of information systems, such as My Health Record uptake.

Greater understanding is needed to explore how My Health Record can support the person with disability and the health workforce to understand their history and existing health management needs to inform discussion of emerging conditions, planning and early intervention.

DHSCC member influence and consideration:

DHDA to review My Health Record use and its capacity to capture the health and support needs of people with disability.

DHDA, NSQHSS, RACGP and other health professional bodies to review standards and requirements for disability baseline knowledge as part of workforce/service standards.

Appendix 1

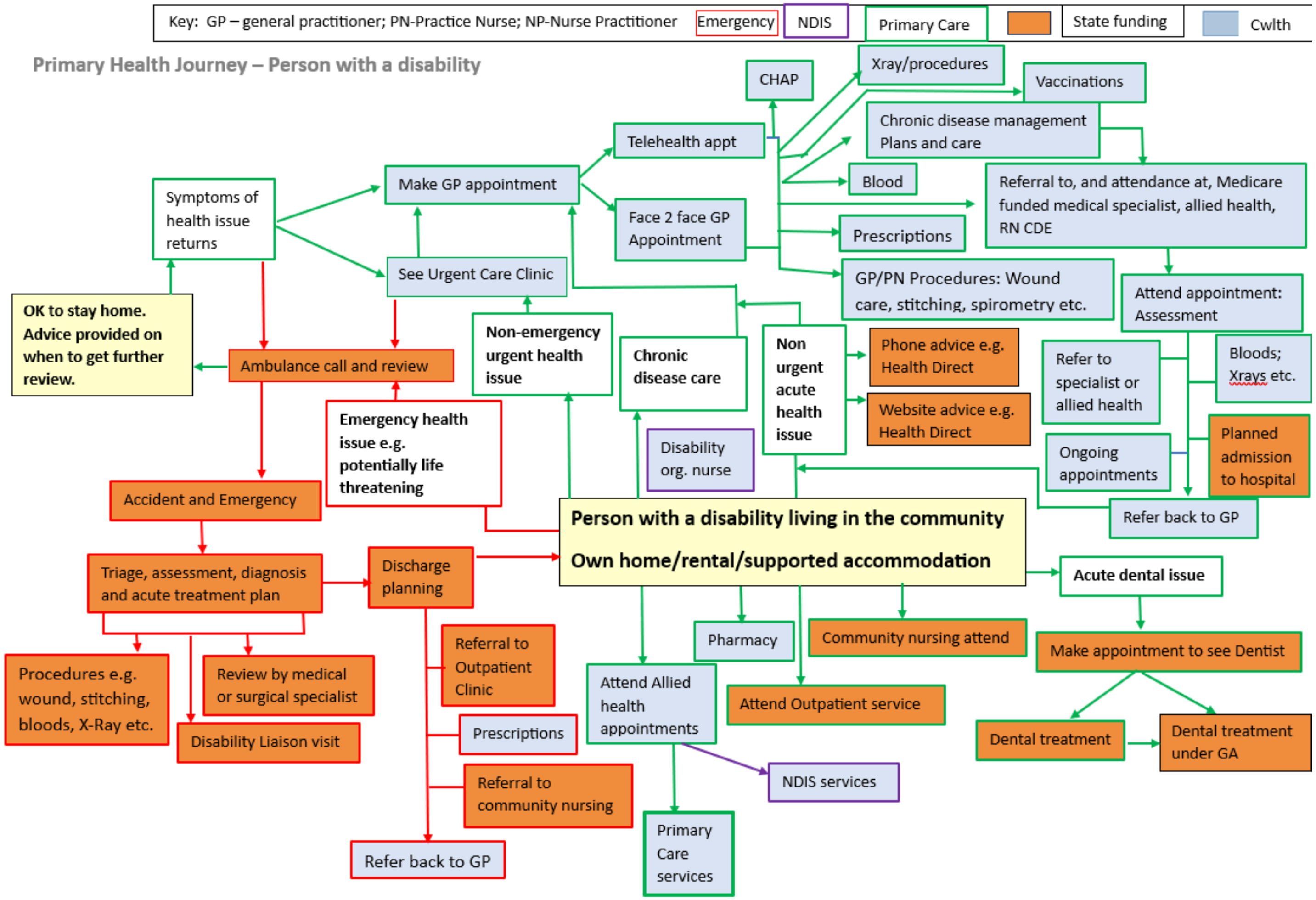
Standards and rules that are either mandated or recommended across the health system interfacing with disability health advocacy needs, barriers and opportunities.

Standard/Rules	Who it applies to	Mandated or recommended	Notes
UN Convention on Rights of Persons with Disabilities (UNCRPD) Article 25.	Australian Government ratified	Principle Reporting evidence not listed on UN Committee list March 2025.	A UN committee meets regularly to review matters associated with countries who are signatories to the convention. Australia provides reports and representation to the committee
National Safety and Quality Health Service (NSQHS) Standards updated in May 2021.	Health services	Mandated	– Health service - A service unit involves a group of clinicians and others working in a systematic way to deliver health care to patients. It can be in any location or setting, including pharmacies, clinics, outpatient facilities, hospitals, patients' homes, community settings, practices and clinicians' rooms
NSQHS User guide for health care of people with an intellectual disability	Health services	Recommended	Refer above
RACGP Standards for GP Practice Accreditation	RACGP accredited General Practice	Mandated	
RACGP Disability modules and resources	RACGP accredited General Practice	Recommended	
National Disability Insurance Scheme (Getting the NDIS Back on Track No. 1) (NDIS Supports) Transitional Rules 2024	All NDIS Providers	Mandated	

Standard/Rules	Who it applies to	Mandated or recommended	Notes
NDIS Quality and Safeguards Commission Practice Standards	All NDIS registered providers Un-registered providers	Mandated Some mandated and some recommended	
NDIS Quality and Safeguards Commission Practice Standards HISSD's	All NDIS registered providers identified for audit under e NDIS Practice Standards, Supplementary Module 1: High Intensity Daily Personal Activities (HIDPA	Mandated	
Applied Principles and Tables of Support (APTOS) to determine responsibilities of NDIS and other funded systems	Commonwealth, State and Territory Governments sign the agreement related to APTOS	Mandated -with new APTOS pending	Rules identify scope of responsibilities /funding sources

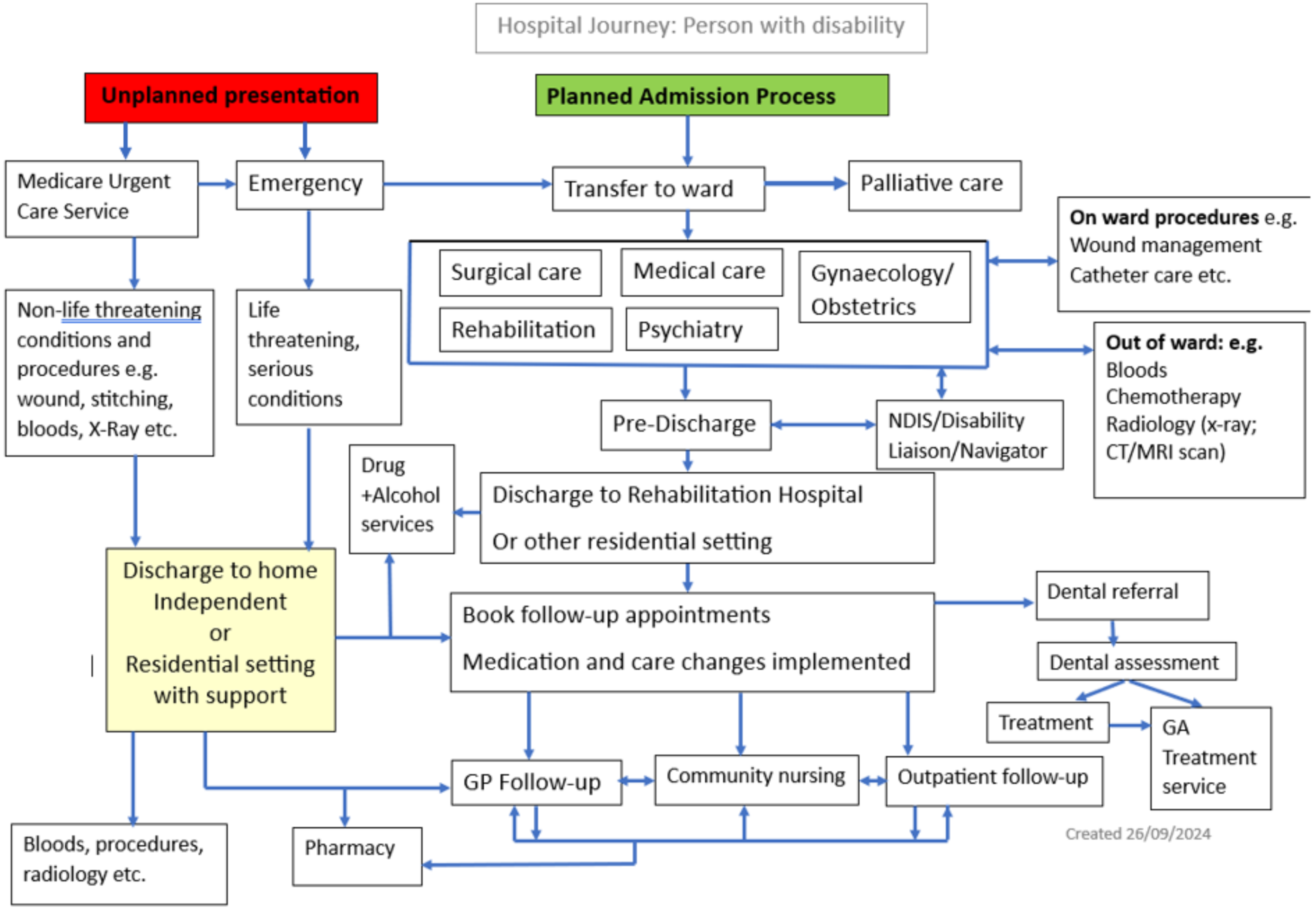
Appendix 2

Primary health map



Appendix 3

Hospital Journey



Hospital Journey: Person with disability

Created 26/09/2024

References

---

[1] Constitution of the World Health Organization

[2] United Nations Convention on the Rights of Persons with Disabilities, Article 25 – Health, https://social.desa.un.org/issues/disability/crpd/article-25-health

[3] DRC Report on Public hearing 4 – Health care and services for people with cognitive disability, pp41, 55

[4] Kavanagh, A. & Badji, S. (2024). System changes to enable optimal health outcomes for people with disability. Melbourne: Centre of Research Excellence in Disability and Health. https://doi.org/10.26188/24171750 pp7,8,15

[5] Australian Institute for Health and Welfare (AIHW), People with disability in Australia, 2024, https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/health/access-to-health-services#Difficulties

[6] Final Report, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Volume 6, page 351.

[7] NDIS Review: Final Report, page 66, https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/

[8] National Disability Insurance Scheme (Getting the NDIS Back on Track No. 1) (NDIS Supports) Transitional Rules 2024, Schedule 1, pp 13.

[9] NDIS Review: Final Report, page 35, https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/

[10] Intellectual Disability Health Capability Framework pp. 21-25

[11] Australia's Disability Strategy 2021-2031, page 36, https://www.disabilitygateway.gov.au/document/11081

[12] DRC Report on Public hearing 4 – Health care and services for people with cognitive disability, pp104 – 109, 115-123.

[13] SPIDAH Project | Western Victoria Primary Health Network Final report pp23

[14] Disability Royal Commission: Final Report – Volume 6, Enabling Autonomy and Access, https://disability.royalcommission.gov.au/publications/final-report-volume-6-enabling-autonomy-and-access

[15] https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/health/access-to-health-services

[16] National Roadmap for Improving the Health of People with Intellectual Disability | Australian Government Department of Health and Aged Care, pp 4-7, 9-11.

[17] National Roadmap to Improve the Health and Mental Health of Autistic People 2025–2035 | Australian Government Department of Health and Aged Care, pp12,19,23

[18] Final Report, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Executive Summary, page 77.

[19] Medical and Health Access Planning - Microboards Australia pp 37-39, 48

[20] Enabling Mainstream Systems to Be More Inclusive and Responsive to People with Disabilities: Hospital Encounters of Adults with Cognitive Disabilities,pp7, 64, 80-81, 85

[21] The Applied Principles and Tables of Support to Determine the Responsibilities of the NDIS and other Service Systems | Department of Social Services

[22] Submissions of Counsel Assisting the Royal Commission following Public hearing 30, 25 January 2023, p 90 [241]; Transcript, John O'Donnell, Public hearing 30, 23 November 2022, P-283 [23–40].

[23] It's Doctor Time! for people with intellectual disability – Inclusion Australia

[24] Intellectual Disability Health Capability Framework | Australian Government Department of Health and Aged Care