



ACT
Government

ACT Health

DISABILITY HEALTH STRATEGY 2023-2033

**PUBLIC
CONSULTATION
DRAFT**



MINISTERIAL FOREWORD

[to be developed]

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DISABILITY HEALTH STRATEGY 2023-2033

INTRODUCTION

WHAT IS THE DISABILITY HEALTH STRATEGY?

The Disability Health Strategy is a ten-year plan which aims to ensure people with disability have equitable and appropriate access to healthcare in the ACT. It is part of the ACT Government's vision for an inclusive society that gives everyone the chance to participate in community life and leaves no-one behind.

This strategy seeks to be inclusive of all people with disability in the ACT. People with disability of all ages (including those over the age of 65), people with disability regardless of National Disability Insurance Scheme (NDIS) status, and people with disability in the full array of life and life circumstances.

The Disability Health Strategy compliments *Australia's Disability Strategy 2021-2031* and the *ACT Disability Strategy 2023-2033*.



Figure 1: ACT Strategic Structure

[Size, colours, and design of structure to be updated]

We are committed to making information available in multiple accessible formats, including Easy English. If you require information in a format that is not yet available, please email us on acthdisabilityandcommunity@act.gov.au.

The definition of key terms and concepts can be found in the [Glossary](#) at the end of this document.

WHO IS THE STRATEGY FOR?

The Disability Health Strategy is for:

- **people with disability** to support the right to access healthcare in the ACT – free from discrimination and on equal terms with all people in the ACT.
- **families, carers, and advocates of people with disability** to support the person with disability on their healthcare journey.
- **healthcare services in the ACT** to help services to build capability to provide better healthcare services and responses to people with disability.

The United Nations *Convention on the Rights of Persons with Disabilities* (CPRD) was ratified by the Australian Government in 2008 and defines people with disability as:

... those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

WHY IS THE STRATEGY NEEDED?

People with disability have inherent rights to life and access to equitable and tailored healthcare. These rights are set out in the CPRD, the *Disability Discrimination Act 1992*, and the *Human Rights Act 2004 (ACT)*. The ACT was the first Australian jurisdiction to enact a human rights act.

In 2018, the Australian Bureau of Statistics reported one in five people in the ACT reported as living with disability. The Australian Institute of Health and Welfare's *People with Disability in Australia 2020* report states health outcomes for people with disability are poorer than for those without disability.

People with disability have specific needs, priorities, and perspectives based on their individual identities including their gender, age, sexuality, race, and cultural background, and can face additional barriers and inequities.

In its 2019 report, *Imagining Better: Reflections on access, choice and control in ACT health services for people with disability*, the ACT Council of Social Service found that people with disability in the ACT self-reported poor health outcomes as a result of:

- economic disadvantage
- diagnostic overshadowing (where a person's disability is treated as the problem rather than a person's presenting medical condition)
- poor attitudes, including a lack of a social model for responding to disability or health within clinical settings
- inappropriate digital and physical infrastructure leading to access barriers and poor communications, and
- services gaps including a lack of tailored services to help manage diagnostic conditions (i.e., to understand, treat and manage the primary and secondary health impacts of different kinds of disabilities)

In 2020, the ACT Government committed to develop and implement an ACT Disability Health Strategy to help address these issues, and to improve health outcomes for people with disability.

HOW HAS THE STRATEGY BEEN DEVELOPED?

The development of the Disability Health Strategy was supported by a significant evidence base, including feedback from the Health and Wellbeing consultations undertaken by Community

Services Directorate for the ACT Disability Strategy, along with national and local legislation, policy, and research.

The ACT Health Directorate commissioned research and consultation in order to scope and inform the development of the Disability Health Strategy, delivering:

- a scoping paper, *Future Directions of Disability Health in the ACT: Phase One of the ACT Disability Health Strategy Project*, and
- a listening report, *ACT Disability Health Strategy Roundtable: Listening Report – Phase One of the of the ACT Disability Health Strategy Project*.

In addition, disability health-related research commissioned by Community Services Directorate to inform development of the ACT Disability Strategy was provided to the ACT Health Directorate to supplement the scoping paper.

A draft of the Disability Health Strategy was considered at a roundtable in March 2023. A high-level capture of the key insights in the form of a listening report, *ACT Disability Health Strategy: Listening Report – Phase Two of the ACT Disability Health Strategy Project*, informed the next draft of the strategy.

These documents are available on the ACT Health Directorate [website](#).

A list of legislation, policy, and research used in the development of the Disability Health Strategy can be found at the [end](#) of this document.

HOW HAS THE DEVELOPMENT OF THE STRATEGY BEEN GOVERNED?

The Disability Health Strategy was guided by and developed in conjunction with the Disability Health Strategy Steering Committee. Members of the committee included people with disability, carers of people with disability, service providers, advocacy groups, and key ACT Government Directorate representatives.

The roundtable in March 2023 brought together additional people with disability, carers of people with disability, service providers, advocacy groups, and representatives from ACT Government Directorates to consider a draft of the Disability Health Strategy and provide feedback for the next draft of the strategy. The roundtable included two conversations:

- **Question 1:** How satisfied are you with what is covered in the Strategy?
 - What is missing from the Strategy?
 - Are there any focus areas, key issues or concerns that have been overlooked?
 - What would you like to change about the Strategy?
- **Question 2:** How do you feel about the overall structure of the Strategy?
 - What do you think about the flow of the Strategy?
 - Are there any sections you feel need to move or change?
 - Do you have any concerns about language or terms used in the Strategy?

[Information about the public consultation to be included in the final version]

THE STRATEGY – AN OVERVIEW

*People with disability attain the highest possible healthcare
– free from discrimination and on equal terms with all people in the ACT*

The Disability Health Strategy is a 10-year overarching plan to improve health outcomes for people with disability in the ACT. The strategy will inform and guide the development of subsequent action plans.

GOALS	GUIDING PRINCIPLES	FOCUS AREAS
Goal 1 People with disability have autonomy and their rights are respected	United Nations Convention of the Rights of Persons with Disabilities	Focus Area 1 Health information and literacy
	‘Noting About Us Without Us’	
	Social model of disability	Focus Area 2 Service access, design, and delivery
Goal 2 People with disability have access to appropriate healthcare services	Intersectionality	
	Diagnostic overshadowing	Focus Area 3 Emergency planning, preparedness, and management
	Social determinants of health	
Goal 3 Change is achievable, measurable, and reported back to the community	Trauma-informed practice	Focus Area 4 Workforce
	Universal Design	Focus Area 5 Data and research
	Reasonable adjustments	

Figure 2: The Disability Health Strategy Overview
[Size, colours, and design of overview to be updated]

HEALTHCARE IN THE ACT

Healthcare in the ACT is provided by both public and private services. The services map below places people at the centre of a three-pronged healthcare service delivery landscape in the ACT – preventative health, care in the hospital, and care in the community.

This ‘person-centred’ approach to conceptualising healthcare services also assumes that by shifting the culture from ‘doing to’ to ‘doing with’, significant clinical improvements can be made.

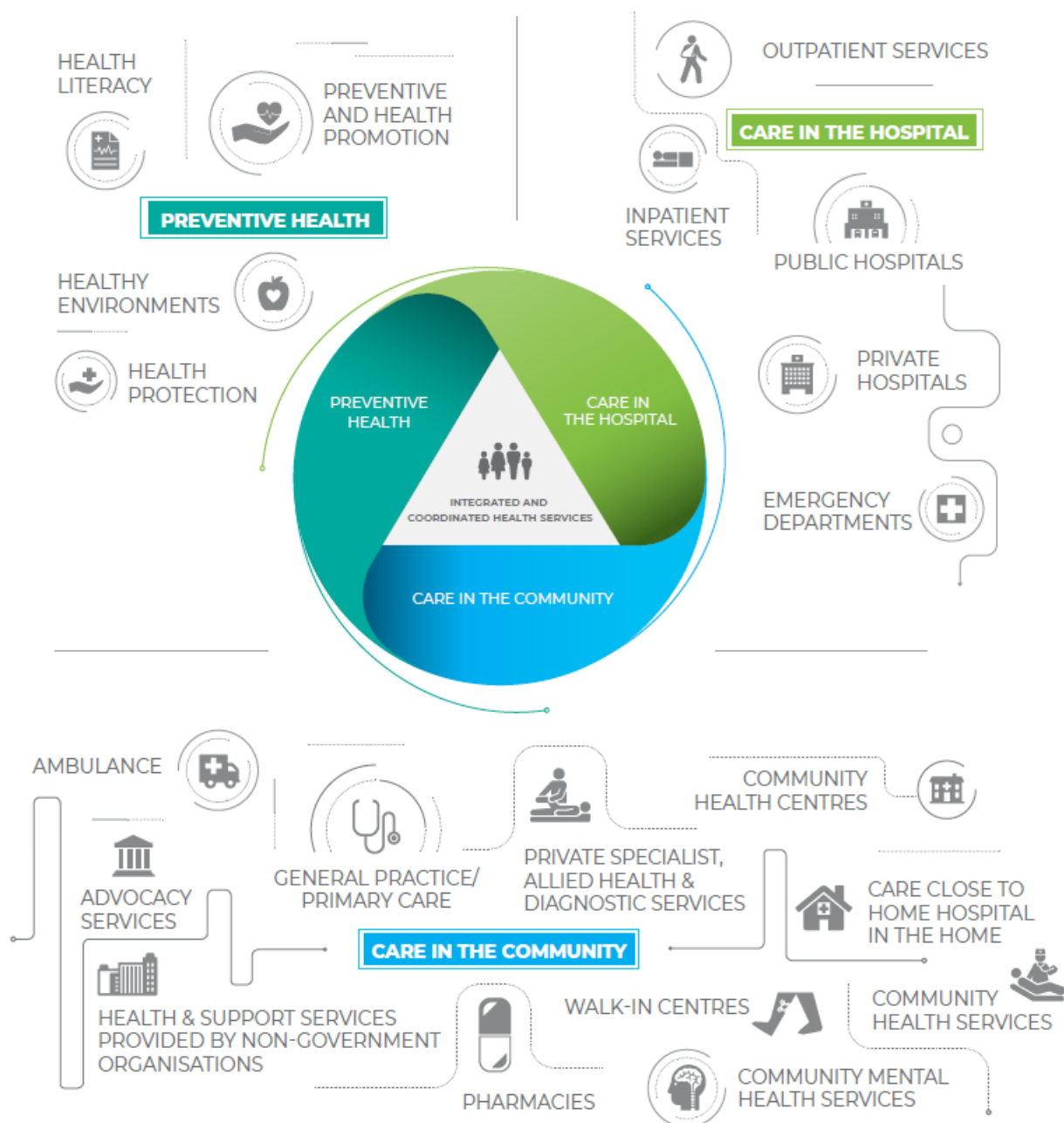


Figure 3: Healthcare in the ACT Map
[Size and colours of services map to be updated for readability]

The services map includes:

Preventive Health

- *Health Literacy* – providing and helping people to understand health information
- *Preventive and Health Promotion* – programs to prevent disease and promote good health
- *Healthy Environments* – creating surroundings that support public healthcare
- *Health Protection* – prevention of public health incidents, monitoring and enforcing healthcare regulations

Care in the Hospital

- *Inpatient Services* – treatment provided when admitted to hospital
- *Outpatient Services* – treatment provided without being admitted to hospital
- *Emergency Department Services* – diagnosis and treatment of urgent health issues

- *Public Hospitals* – government funded comprehensive healthcare facilities
- *Private Hospitals* – privately funded comprehensive healthcare facilities

Care in the Community

- *Ambulance* – on-site emergency care and transport to hospital
- *General Practice/Primary Care* – the first contact between people and the healthcare system provided through general practices, community nursing, and allied health practice.
- *Private Specialist Allied Health & Diagnostic Services* – various diagnostic, technical, therapeutic, and direct healthcare services
- *Community Health Centres* – facilities that provide primary care, health promotion, and allied services
- *Care Close to Home Hospital in the Home* – a hospital replacement service providing hospital level care in the home
- *Community Health Services* – services delivered by the community sector
- *Community Mental Health Services* – government or community sector mental health programs delivered in the community
- *Walk-in-Centres* – nurse-led facilities that provide free primary healthcare to anyone who is over one year of age without a need for appointments
- *Pharmacies* – facilities where people can buy prescription and over-the-counter medicines
- *Health & Support Services Provided by Non-Government Organisations* – tailored services delivered by the community sector
- *Advocacy Services* – services that promote and protect the rights of people and empower people to protect their own rights

ACTION PLANS

Action Plans will sit under the Disability Health Strategy describing the work and the commitments made by stakeholders to ensure people with disability have equitable and appropriate access to healthcare in the ACT.

While the action plans will contain specific activities which fulfill the requirements of the three goals, nine principles, and five focus areas presented in this strategy; the plans will also have a focus on priority populations identified in current national and local legislation, policy, and research. Priority populations for the First Action Plan will include:

- women with disability
- older people with disability
- people with an intellectual disability
- Aboriginal and Torres Strait Islander People with disability
- culturally and linguistically diverse people with disability
- LGBTIQ+ people with disability
- detainees with disability
- carers of people with disability

The development of the Disability Health Strategy's First Action Plan will be guided and developed in conjunction with the Disability Health Strategy Steering Committee and activity stakeholders.

Future action plans will be developed under the guidance of the to-be-established ACT Disability Health Reference Group.

IMPLEMENTATION AND GOVERNANCE

The implementation of the Disability Health Strategy and its action plans will be overseen by the Director-General, ACT Health Directorate through the Strategic Board Human Services Committee. This committee comprises of Director-Generals from ACT Health Directorate, Community Services, Education, Justice and Community Safety, and Chief Minister, Treasury and Economic Development.

The ACT Disability Health Strategy Steering Committee will govern the establishment of an ACT Disability Health Reference Group, handing over responsibility of the Disability Health Strategy and its action plans to the reference group after the strategy and first action plan are launched.

The ACT Disability Health Reference Group will provide high-level strategic monitoring of the implementation of the Disability Health Strategy and Canberra Health Services' *Disability Action and Inclusion Plan* (DAIP). The reference group will primarily consist of people with disability and carers of people with disability, with minimal ACT Government Directorate representatives. The reference group will be chaired by a person with disability.

Terms of Reference and position descriptions will be developed by the ACT Disability Health Strategy Steering Committee. People with disability and carers of people with disability will get the opportunity to apply for a position on the reference group, with terms to be set by the steering committee.

ACT Health Directorate will undertake annual reviews of the action plans and report on progress to the ACT Disability Health Reference Group and the Strategic Board Human Services Committee through ACT Health Directorate's Director-General. These reviews will be publicly published for access by the ACT community.

GOALS AND PRINCIPLES

The Disability Health Strategy has a set of Goals and Principles. The three Goals set out the outcomes the strategy aims to achieve over the 10 years, while the nine Principles provide foundational standards to lead systemic change across healthcare in the ACT for people with disability.

GOALS

1. People with disability have autonomy and their rights respected:

- People with disability have equitable access to health information and healthcare services.
- People with disability, including those supported by carers, formal or informal advocates, or others, have the right and capability to make informed healthcare decisions.
- People with disability have a right to be treated with dignity and respect.
- People with disability will not face physical, sensory, stereotyping, and diagnostic overshadowing discriminatory barriers to healthcare.
- People with disability have their cultural backgrounds, traditions as well as their individual life choices, relationships, and foundational values respected by healthcare services.
- People with disability, their family members, carers, and advocates of people with disability are meaningfully involved in healthcare service consultations and governance.

2. People with disability have access to appropriate healthcare services:

- Prevention and early intervention healthcare services are timely, comprehensive, appropriate, and effective.
- Healthcare services are accessible to people with disability, with barrier-free and inclusive physical spaces, reasonable adjustments, and affordability.
- Healthcare professionals and services understand the social model of disability and have the capability to meet the needs of people with disability, inclusive of their relationships and community.
- People with disability of all genders are able to access appropriate, safe healthcare.
- Aboriginal and Torres Strait Islander People with disability healthcare needs will be met through community-lead, culturally appropriate practices.
- Mental health supports and services are appropriate, effective, and accessible for people with disability.
- Emergency preparedness, risk management plans, and public responses are inclusive of people with disability, and support their physical and mental health, and wellbeing.
- Family members, carers, and advocates of people with disability are included in healthcare conversations and decisions where appropriate.

3. Change is achievable, measurable, and reported back to the community:

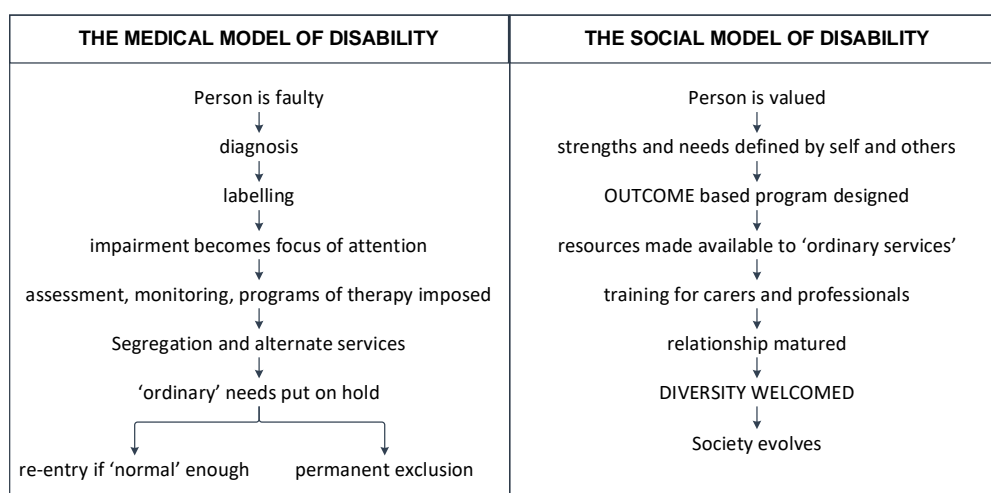
- Data on the experiences and health outcomes of people with disability is collected, used to plan and improve healthcare services, and reported back to the community.
- Disability Health Strategy actions are tracked, evaluated, and reported on.

PRINCIPLES

United Nations Convention of the Rights of Persons with Disabilities	People with disability have the right to access and participate in the whole healthcare system in the ACT. For further information see the Glossary .
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‘Nothing About Us Without Us’	People with disability in the ACT will have full and direct participation in healthcare strategies, policies, and service planning that affect their lives. For further information see the Glossary .
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Social model of disability	The healthcare system in the ACT will move from a medical model of disability towards a social model of disability, removing any barriers that hinder the full participation of people with disability. The social model of disability views people with disability as a ‘whole’ person.
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Adapted from: Mason, R & Rieser, M, 1994, *The Struggle for Inclusion: The Growth of a Movement* in Stanford, D, 2021, *Future Directions of Disability Health in the ACT: Phase One of the ACT Disability Health Strategy Project*

For further information see the [Glossary](#).

Intersectionality	The healthcare system in the ACT will view healthcare from an intersectional perspective and is committed to acknowledging, respecting, and responding to people with disability holistically as diverse individuals.
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For further information see the [Glossary](#).

Diagnostic overshadowing	The healthcare system in the ACT will work towards lowering instances of diagnostic overshadowing.
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For further information see the [Glossary](#).

Social determinants of health	The healthcare system in the ACT will work towards addressing the social determinants of health influencing the health outcomes and inequities imposed on people with disability.
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	For further information see the Glossary .
Trauma informed practice	The healthcare system in the ACT will acknowledge the profound impact of past and/or current trauma and violence can have on the healthcare needs and healthcare access of people with disability.
	For further information see the Glossary .
Universal Design	The healthcare system in the ACT will adopt Universal Design to guide the planning, design and delivery of facilities, equipment or services in order to maximise accessibility and also to reduce the need for ongoing 'reasonable adjustment' responses.
	For further information see the Glossary .
Reasonable adjustments	The healthcare system in the ACT will accommodate people with disability with reasonable adjustments; it will not seek to change people with disability to accommodate the healthcare system.
	For further information see the Glossary .

FOCUS AREAS

The Disability Health Strategy has five Focus Areas. The Focus Areas identified are critical to achieve the Goals and Principles of the strategy, and provide a platform for change to enable people with disability to attain the highest possible healthcare, free from discrimination and on equal terms with all people in the ACT.

FOCUS AREA 1 – HEALTH INFORMATION AND LITERACY

Accessible health-related information is important for supporting the best health outcomes for people with disability

Information helps people to make decisions and choices about their lives and enables them to live independently and take part fully in society. For many people with disability, accessible health information is not readily and easily available. Accessible information is information that people can understand. For people with disability, it can mean different things to different people. For some people it is information in Easy English, large print, Auslan, or Braille. For others it might be information translated into their first language.

All people have the right to accessible health information. Providing accessible information for people with disability, their family members, carers, and advocates is a reasonable adjustment. Under an intersectional lens, the development of accessible information should foremost target those with intersecting barriers and what their information needs are. This can include Aboriginal and Torres Strait Islander People with disability, culturally and linguistically diverse people with disability, and people with an intellectual disability.

Under the principle of ‘nothing about us without us’, people with disability, their family members, carers, and advocates should have full and direct participation in the development of disability-health related information. They are the experts. They know what works for them and what does not.

Health literacy helps people with disability, their family members, carers, and advocates to make informed healthcare decisions

Inaccessibility of health information and low levels of health literacy prevent people with disability, their family members, carers, and advocates accessing and understanding the information they need to make informed healthcare decisions. Health literacy is the degree to which a person has the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

With a disability-related lens, health literacy is important for:

- **People with disability**, to make informed decisions and take action to manage their health and healthcare.
- **Family members, carers, and advocates of people with disability**, to support people with disability to access healthcare and make informed healthcare decisions.
- **Community support organisations**, to provide informed care for people with disability.
- **Healthcare workforce**, to manage their communication and understand the diversity and complexity of healthcare needs for people with disability.
- **Healthcare services**, to ensure people with disability, their family members, carers, and advocates are able to access and navigate the services provided and engage in their own care.

FOCUS AREA 2 – SERVICE ACCESS, DESIGN, AND DELIVERY

Healthcare is accessible for people with disability

People with disability often have poorer health and wellbeing outcomes than the general population. In the past, these differences were viewed as an inevitable consequence of disability, but it is increasingly recognised it may actually be the result of inequalities and inequities in access to healthcare.

Accessibility is when the needs of people with disability are considered, and healthcare facilities and services are designed or modified so that they can be used by all people. Physical access to healthcare facilities is now widely accepted as a basic right for all people, regardless of disability, and is now embedded into national legislation, *Disability (Access to Premises – Buildings) Standards 2010* (updated in September 2020) made under the *Disability Discrimination Act 1992*.

As with all members of the general population, the healthcare needs of people with disability can vary broadly. The range of healthcare services available to the general population must also be accessible to people with all types of disability. It is important both to enhance the capacity of people with disability to access the healthcare system and also to ensure that the system is able to respond in an appropriate and timely manner to their needs.

The inclusion of people with disability, their family members, and carers – along with the principles in this strategy – in the planning, design, and review of healthcare facilities, policies, and services helps to reduce barriers and promote equitable accessibility.

Appropriate healthcare services are available to people with disability

While people with disability need access to general healthcare services, specialist services are also required. Australia is facing healthcare workforce shortages, leading to reduced availability of healthcare services, especially specialist services. This includes reduced availability of specialist services for people with disability.

Healthcare services may also be unavailable to people with disability due to financial barriers. There are significant differences in the availability of healthcare services between those who are able to pay for services and those who do not have the resources to do so. People with disability are less likely than people without disability to have a high level of income and more likely to rely on government income support payments.

Appropriate healthcare services for people with disability also encompasses intersectionality, with those with intersecting barriers requiring reasonable adjustments to meet their healthcare needs. This includes having culturally appropriate and gender appropriate healthcare services for people with disability. Care must also be taken to meet the healthcare service availability of those with psychosocial or other mental health conditions. Ensuring optimal psychosocial and mental health and wellbeing is an integral part of healthcare service provision for people with disability.

People with disability, their family members, or carers are empowered to make informed, supported decisions about healthcare

It should not be assumed that people with disability are unable to participate in healthcare decisions and give informed consent. Informed consent means a person understands their condition and its proposed treatment. People usually give their own consent to treatment.

Without information about their condition and its proposed treatment, a person can't make a fully informed decision and give valid consent. Every person has the right to participate in decisions about their own healthcare. On occasion, some people with disability will seek support which may be from family, carers, advocates, or the healthcare provider to understand the options available

and make healthcare decisions. This is a reasonable adjustment, to allow supported decision-making where indicated and preferred. Support might include more time, a quiet space, or the information in a different format.

In circumstances where people with disability nominate, or has appointed, a substitute decision maker an informed consent may be sought from that person. This may be through appointment of a health attorney, by an attorney appointed for personal and health matters under an enduring instrument or through orders issued by the ACT Civil and Administrative Tribunal appointing a Guardian for medical and health matters.

People with disability are afforded healthcare navigation and integration

Services within a healthcare system are often siloed, with limited to no coordination of the healthcare services provided. For people with disability, who are often accessing multiple healthcare services and community supports, this can lead to poorer health outcomes. People with disability could achieve better continuity of care through healthcare navigation and integration supports.

Healthcare navigation guides people through the healthcare system and helps them to overcome barriers that prevent them from getting the care they need. People with disability may face many barriers to healthcare, and navigation enables access to, and coordination of, healthcare services they need to be as healthy as possible.

Integrated healthcare provides seamless, coordinated, efficient, and effective care that reflects the whole of the person's healthcare needs. At the core of integrated care is the delivery of person-centred care within a system that is easy to navigate and access, is responsive and adaptive to specific healthcare needs, provides choice and greater opportunities to actively engage with the healthcare system, and supports providers to collaborate more effectively across health and social care to improve health outcomes and experience.

Integrated healthcare involves the collaboration and cooperation across primary, secondary, and tertiary healthcare, along with government and non-government services. Integrated healthcare can extend to include the co-location of healthcare services and community supports.

Integrated healthcare coupled with healthcare navigation enables people with disability to access timely and targeted healthcare and community supports, decreasing the risks of avoidable adverse events that might otherwise occur with the lack of coordination across the healthcare system and community supports.

FOCUS AREA 3 – EMERGENCY PLANNING, PREPAREDNESS, AND MANAGEMENT

The healthcare system is prepared to meet the needs of people with disability and their support system in a public emergency

The 2019-2020 Australian bushfires and the COVID-19 pandemic emphasised the need for specific emergency planning, preparedness, and management of public emergencies – fire, floods, and pandemics – for people with a disability and their support system (family members, carers, advocates, and service providers).

A health response for people with disability before, during, and after public emergencies should be planned, prepared, and managed in accordance with their needs, and the needs of their support system. The healthcare system, along with the larger disability sector, needs to be equipped to respond to these needs during public emergencies.

A successful health response includes people with disability and their support system in the development, execution, and evaluation of public emergency planning, preparedness, and management.

Health-related communication and information is appropriate and accessible for people with disability and their support system in a public emergency

During a public emergency, appropriate and accessible communication and information are key. Well-informed plans and strategies can ensure health advice reaches the targeted population quickly, while misinformation can be mitigated. Good communication and information is presented in a way the targeted population can understand.

For people with disability and their support system, a variety of modes and formats can be used. Modes include television, radio, electronic (telephone, text messages, emails, websites), and hardcopy written material (information sheets, flyers, letters); while formats include, audio, written, Australian Sign Language (Auslan) and captioning, plain language, Easy English, different languages, and large print.

Forming community partnerships with the disability sector can ensure the right information, in the right mode and format, is accessible to people with a disability and their support system at the right time during a public emergency.

Healthcare services are accessible for people with disability in a public emergency

Accessible healthcare services in a public emergency are those that adapt to change. Recent history has shown how adaptable the healthcare system can be when required, it has also shown where the healthcare system can improve to ensure healthcare services are truly accessible in a public emergency. For people with disability, who may be at increased risk of health-related complications during a public emergency due to complex and chronic health conditions, an accessible and adaptive healthcare system is key.

A public emergency increases the everyday barriers people face in accessing healthcare. For people with disability, who already face barriers to healthcare, these barriers can be overwhelming and risk poor health outcomes and increased adverse events. These risks can be isolated and mitigated by planning and preparing the healthcare system to ensure the accessibility of healthcare services during a public emergency.

FOCUS AREA 4 – WORKFORCE

Disability training builds the healthcare workforce's capabilities to meet the needs of people with disability, their family, carers, and advocates

A lower level of disability health literacy across the healthcare workforce can present unfamiliar challenges and can result in adverse outcomes if those challenges are not anticipated and met. Disability awareness and disability-specific knowledge assists to ensure the needs of people with disability are safely and adequately met by the healthcare workforce.

The attitudes and actions of the healthcare workforce are critical contributors to the experiences of people with disability, their family, carers, and advocates across the healthcare system. This includes treating people with dignity and respect.

It is important that disability-related healthcare training is co-designed with people with disability, their family members, carers, and advocates. It is key that training consider the foundational principles outlined in this strategy – the rights of people with disability, 'Nothing About Us Without

Us', the social model of disability, intersectionality, diagnostic overshadowing, the social determinants of health, trauma-informed practice, Universal Design, and reasonable adjustments.

People with disability are a part of the healthcare workforce

People with disability bring a range of skills, talents, and abilities to the healthcare workforce. They can have a unique perspective and empathy for the needs of people with disability, their family members, and carers.

Ensuring that genuine employment opportunities, free from barriers, are available within the healthcare system for people with disability provides opportunity for people with disability to realise their potential and make advances in their healthcare career, including advancing to leadership roles.

According to the *Australia's Disability Strategy 2021-2031*, employment and financial security are central to improving outcomes for people with disability. This includes providing jobs and career opportunities, greater autonomy, and having adequate income for people to meet their needs.

FOCUS AREA 5 – DATA AND RESEARCH

Data provides healthcare services with knowledge and evidence for change

Data plays a pivotal role in policy-making, and in each and every stage from development and implementation, to monitoring and assessment of effectiveness, to the analysis of cost-effectiveness. Good data, data that is valid and reliable, is evidence, and evidence drives change.

Data provides a platform to identify gaps, barriers, and challenges that people with disability encounter, and is key to creating a clearer picture of the healthcare system for people with disability. Data provides a mechanism for the quality assurance and quality improvement of healthcare services. This leads to improved healthcare services and better health outcomes for people with disability.

The disaggregation of disability data, in line with the *Health Records (Privacy and Access) Act 1997 (ACT)*, will allow for targeted reform in the healthcare system in the ACT. In addition, the feedback and complaints mechanisms can provide evidentiary data to make targeted or systemic change for people with disability.

Research drives healthcare innovation and improvements

Research is a process of seeking out answers to a specific problem. Along with data, research will develop the evidence base for future policies, interventions and other initiatives to improve the health outcomes for people with disability.

Targeted research drives the development of evidence-based tools, models of care, and other initiatives to improve the health of people with disability and the health services provided to them. Research includes people with disability during design and implementation.

Over the past five years, disability-focused data and research has been undertaken, providing an evidence base for change and innovation in disability healthcare in the ACT. Relevant research used in the development of the Disability Health Strategy can be found in the [References](#) section at the end of this document.

GLOSSARY

Carers

According to the [Carer Recognition Act 2010](#), a person who gives care and support to a relative or friend who has a disability is considered a carer. Carers can be any age, including children and young adults.

In the ACT, the [Carers Recognition Act 2021 \(ACT\)](#) formally recognises the vital contribution carers make to the Canberra community. There are more than 50,000 carers in the ACT, including carers of people with disability.

People who are employed to look after someone, work as a volunteer for an organisation, or doing work experience are not considered carers.

Diagnostic overshadowing

Diagnostic overshadowing occurs when a healthcare professional inadvertently attributes symptoms to a person's disability rather than a health issue. This creates a risk the health issue may go undiagnosed or undertreated.

In literature, diagnostic overshadowing is often linked to people with an intellectual or cognitive disability, but it is relevant to any person with disability accessing the healthcare system.

According to Li-Ve Tasmania:

... diagnostic overshadowing is not caused by a lack of care or willingness to help. It can, however, be associated with a lack of knowledge or experience treating or supporting someone with an (intellectual) disability.

See the [Australian Primary Health Care Nurses Association \(APNA\) website](#) for further information.

Intersectionality

Intersectionality is a concept that helps us understand that people's identities are complex and multidimensional, including aspects such as race, ethnicity, indigeneity, gender, class, sexuality, geography, age, disability/ability, migration status, and religion. The term 'intersectional' refers to the fact these aspects of identity should not be considered in isolation, since they interact in specific and unique ways, including for people with disability.

These aspects of identity exist within social relations and structures of power that create relative privilege and disadvantage. Because identity is complex and multifaceted, the privilege and disadvantage experienced by any single person is complex and multifaceted as well.

These structures of power often perpetuate discrimination, disadvantage, and unequal treatment, particularly against people whose identity includes more than one marginalised or devalued attribute. An 'intersectional lens' recognises people as complex individuals and groups, and progress over time to more equitable outcomes for all.

An intersectional lens aims to achieve:

- genuine recognition of the diversity of experiences and identity of each person with disability and within marginalised groups to provide a framework for delivering better health outcomes for all, and to avoid reducing these complex needs, identities, and life experiences exclusively to deficits and disability,
- substantive equality that leaves no one behind,
- more inclusive and responsive policy making and service delivery, and

- a better understanding of the context, resource priorities, access and equity needs, and solutions, required to improve all health services in the ACT for all people with disability.

Medical model of disability

According to the medical model (of *disability*):

‘disability’ is a health condition dealt with by medical professionals. People with disability are thought to be different to ‘what is normal’ or abnormal. ‘Disability’ is seen ‘to be a problem of the individual.

From the medical model, a person with disability is in need of being fixed or cured. From this point of view, disability is a tragedy and people with disability are to be pitied. The medical model of disability is all about what a person cannot do and cannot be.

The medical model of disability contrasts with the [social model of disability](#).

See [People with Disability Australia website](#) for further information.

‘Nothing About Us Without Us’

According to the United Nations (UN):

The motto ‘Nothing About Us Without Us’ relies on a principle of participation, and it has been used by Disabled Peoples Organizations throughout the years as part of the global movement to achieve the full participation and equalization of opportunities for, by and with persons with disabilities.

See the [United Nations website](#) for further information.

Reasonable adjustments

The United Nations (UN) [Convention of the Rights of Persons with Disabilities](#) defines reasonable adjustments (or commonly used term ‘reasonable accommodations’) as the:

... necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Reasonable adjustments are person-centred and respond to the particular needs of the person with disability. The adjustments do not have to be costly and can be provided by anyone involved in the health care of the person with disability.

See the [Australian Human Rights Commission website](#) for further information.

Social determinants of health

The World Health Organization (WHO) describes social determinants as

the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.

The social determinants can influence health equity in positive and negative ways, and can include:

- income and social protection
- education
- unemployment and job insecurity

- working life conditions
- food insecurity
- housing, basic amenities and the environment
- early childhood development
- social inclusion and non-discrimination
- structural conflict
- access to affordable health services of decent quality.

The social determinants associated with improving the health of people with disability point to key known barriers:

- prohibitive costs
- limited availability of services
- physical barriers
- inadequate skills and knowledge of health workers.

See [Australian Institute of Health and Welfare \(AIHW\) website](#) for further information.

Social model of disability

According to the social model of disability:

‘disability’ is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others.

A social model perspective does not deny the reality of impairment nor its impact on the individual. However, it does challenge the physical, attitudinal, communication and social environment to accommodate impairment as an expected incident of human diversity.

Under the social model, people with disability are not ‘objects’ of medical treatment, they are ‘patients’ with rights, capable of claiming those rights, able to make decisions for their own lives based on their free and informed consent and be active members in treatment decisions.

In context, impairment is a medical condition that leads to disability; while disability is the result of the interaction between people living with impairments and barriers in the physical, attitudinal, communication, and social environment. It’s not the inability to walk that keeps a person entering a building by themselves, but the stairs that are inaccessible that keeps a wheelchair user from entering the building.

The social model of disability contrasts with the [medical model of disability](#).

See [People with Disability Australia website](#) for further information.

Trauma

Blue Knot Foundation describes trauma as:

a state of high arousal. It is an event or events in which a person is threatened or feels threatened. The experience of trauma overwhelms the person’s capacity to cope. Trauma also describes the impacts of the event or events.

Different people experience different traumas differently. Certain experiences are traumatic for some people and not for others. The impacts of trauma depend on your age/s, your previous experience/s of trauma, how long the trauma lasts, how often it happens, and

how extreme it is. They also depend on your culture, background, and the social context of your life.

Trauma also describes physical injury or harm, and can include the impacts of healthcare treatment. Trauma responses can be triggered again when a person who has previously had physical, mental, or emotional traumatic experiences is in a situation of threat, high stress, or is reminded of those previous experiences in some way. Some people with disabilities have experienced trauma due to inappropriate medical care or discrimination within the healthcare system and this may impact the way they engage with healthcare.

See [Blue Knot Foundation website](#) for further information.

Trauma-informed practice

According to Blue Knot Foundation, trauma-informed practice:

- *Rests on the foundation principle of ‘do no harm’.*
- *Does not require clinical knowledge and is not ‘treatment’.*
- *Understands the effects of stress on the brain and body.*
- *Considers what has happened to the person (not what is ‘wrong’ with the person).*
- *Regards ‘symptoms’ as outgrowths of coping strategies.*
- *Is sensitive to client comfort levels and to THE WAY IN WHICH a service is delivered (not just WHAT the service is).*
- *Works with (rather than ‘doing to’) the client”*

Trauma-informed practice recognises and acknowledges trauma and its prevalence, alongside awareness and sensitivity of its dynamics. Key trauma-informed practice principles include safety, trustworthiness, choice, collaboration, empowerment, and respect for diversity. This orientation recognises the impact of power differentials in healthcare service settings, maximises self-determination, supports autonomy, and empowers individuals to learn about the nature of their injuries and to take responsibility in their own recovery.

See [Blue Knot Foundation website](#) for further information.

United Nations Convention of the Rights of Persons with Disabilities

The United Nations *Convention of the Rights of Persons with Disabilities* (CRPD), ratified by Australia in 2008, recognises that:

persons with disability have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

In particular, healthcare services shall:

- Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;*
- Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;*
- Provide these health services as close as possible to people’s own communities, including in rural areas;*
- Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with*

disabilities through training and the promulgation of ethical standards for public and private health care;

- e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*
- f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*

See [United Nations website](#) for further information.

Universal Design

The Centre for Excellence in Universal Design, defines Universal Design as:

... design that's usable by all people, to the greatest extent possible, without the need for adaptation or specialised design.

Universal Design can apply to service delivery design as well as the physical products, environment, and infrastructure. When universal design is applied (in conjunction with co-design methodology), the consequence is that fewer requests and requirements for specific access considerations, reasonable adjustments and accommodations, as more people (and ideally everyone) is able to use the same spaces, products, and services.

See the [Centre for Excellence in Universal Design website](#) for further information.

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WEBSITES

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[Australian Institute of Health and Welfare \(AIHW\) website](#)

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[Blue Knot Foundation website](#)

[Centre for Excellence in Universal Design website](#)

[People with Disability Australia website](#)

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ACT Health acknowledges the Traditional Custodians of the land, the Ngunnawal people. ACT Health respects their continuing culture and connections to the land and the unique contributions they make to the life of this area. ACT Health also acknowledges and welcomes Aboriginal and Torres Strait Islander peoples who are part of the community we serve.

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