

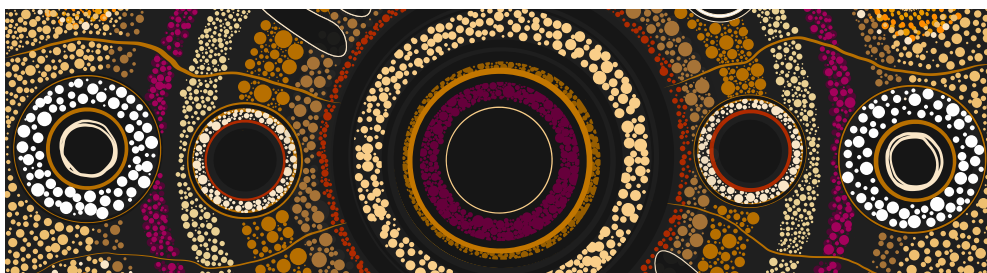
DISABILITY HEALTH STRATEGY 2024-2033



ACT
Government

ACT Health

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Acknowledgement of Country

We acknowledge the Ngunnawal people as traditional custodians of the ACT and recognise any other people or families with connection to the lands of the ACT and region. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region.

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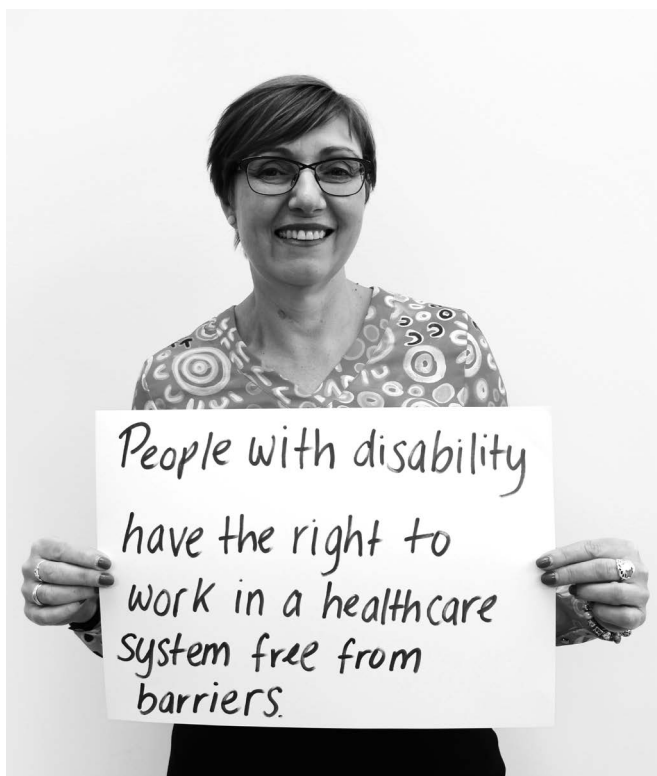
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CONTENTS

Ministerial Foreword.....	1
Introduction.....	2
What is the Disability Health Strategy?	2
Who is the strategy for?	4
Why is the strategy needed?	4
How has the strategy been developed?	5
The strategy – an overview.....	6
Goals	6
Principles.....	8
Healthcare in the ACT.....	10
Commitment for change – focus areas.....	11
Focus area 1 – Health information and literacy.....	12
Focus area 2 – Service access, design, and delivery	14
Focus area 3 – Emergency planning, preparedness and management.....	17
Focus area 4 – Workforce.....	19
Focus area 5 – Data and Research.....	21
Implementing the strategy – action and governance.....	23
Implementation and governance.....	23
Action plans.....	24

MINISTERIAL FOREWORD



Minister for Health, Rachel Stephen-Smith MLA

The ACT Government is committed to improving the health and wellbeing of all people with disability in the ACT. This is key to our commitment to make Canberra the most inclusive and welcoming city in Australia.

Every Canberran should be able to access healthcare that meets their needs, without fear of experiencing prejudice or discrimination. Unfortunately, we know that this is not always the case for people with disability in the ACT. This has resulted in Canberrans with disability experiencing poorer health outcomes compared to the rest of the community.

The Disability Health Strategy is a transformational document that sets out the direction and priorities for the ACT Government as we build a more accessible and inclusive healthcare system in the ACT.

It is underpinned by extensive research, data and consultation, as well as legislation at the international, national and ACT levels.

This document provides an invitation and foundation for healthcare services in the ACT to join together with people with disability, their families, carers and advocates to create a healthcare system that is free from discrimination and in which all people in the ACT can access high quality healthcare, on equal terms, regardless of disability.

In developing the Strategy, the Government committed to the principle of 'nothing about us without us'. People with disability are the experts in their own lives and ensuring their voices are heard has been central to the work. The ACT Health Directorate has worked in close partnership with the disability community through each stage of the development process.

I would like to thank everyone who partnered with the Government in developing the Disability Health Strategy, and those who took the time to share their experiences. I acknowledge and thank the people with disability, their families, carers, advocates and community stakeholders who participated in consultations. I would also like to acknowledge the members of the ACT Disability Health Strategy Steering Committee who played a critical role in providing feedback and insights into the work undertaken.

It is a pleasure to provide the Disability Health Strategy to the Canberra community. I look forward to continuing to work with the disability community to improve health outcomes and strengthened engagement with Canberrans with disabilities as we continue to build the most accessible and inclusive city in Australia.



*Renée Heaton, member of
ACT Disability Health Strategy
Steering Committee and
Chair of the ACT Disability
Reference Group*

INTRODUCTION

WHAT IS THE DISABILITY HEALTH STRATEGY?

The Disability Health Strategy is a 10-year plan that 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, where everyone has 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 2024-2035*.

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 at acthdisabilityandcommunity@act.gov.au.



Australia's Disability Strategy 2021-2031

The national strategy to increase inclusion for people with disability across all life domains.



ACT Disability Strategy 2024 – 2034

A strategy to build more accessible and inclusive ACT, where people with disability can fully participate in all aspects of community life.



ACT Disability
Justice Strategy
2019-2029

ACT Disability
Health Strategy
2024-2033

ACT Inclusive
Education
Strategy 2024-2034



Disability Access and Inclusion Plans (DAIPs)

Figure 1: ACT Strategic Structure



WHO IS THE STRATEGY FOR?

The Disability Health Strategy is for:

- **people with disability** to support their right to access healthcare in the ACT – free from discrimination and on equal terms with all people in the ACT.
- **Family members, carers, and advocates of people with disability** to support the person with disability on their healthcare journey.
- **healthcare services in the ACT** to support 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 (Cth), 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 2022: in brief* states:

In general, people with disability report poorer general health and higher levels of psychological distress than people 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 Disability Health Strategy was guided by and developed in conjunction with the ACT 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 content of the strategy was supported by a significant evidence base, including feedback from the Health and Wellbeing consultations undertaken by the Community Services Directorate for the ACT Disability Strategy, along with national and local legislation, policy and research.

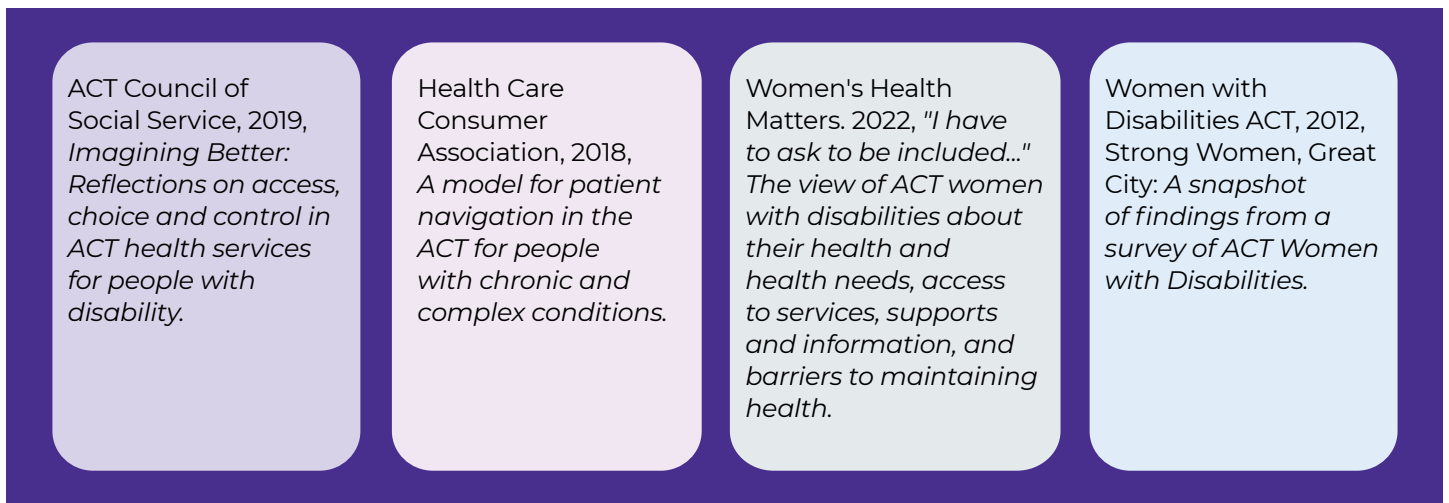


Figure 2: Community-based organisation research

The ACT Health Directorate commissioned research to scope and inform the development of the Disability Health Strategy. This resulted in the 2021 scoping paper, *Future Directions of Disability Health in the ACT: Phase One of the ACT Disability Health Strategy Project*. In addition, the Community Services Directorate commissioned disability health-related research to supplement the scoping paper.

Two consultation roundtables with key stakeholders were undertaken, one in November 2021 and the other in March 2023. The first roundtable brought together key stakeholders to discuss the governance of the development of the strategy and lessons learned from COVID-19, while the second brought together key stakeholders

to consider a draft of the Disability health Strategy. Subsequently, listening reports based on the conversations at the roundtables resulted in two listening reports.

The draft Disability Health Strategy was released for six-weeks public consultation in June and July 2023 on the ACT Government's YourSay platform. Key insights and feedback from this consultation was captured in a listening report, *ACT Disability Health Strategy YourSay Public Consultation Listening Report*, and informed the final version of the strategy.

The research and listening reports are available on the [ACT Health Directorate ACT Disability Health Strategy website](https://www.health.act.gov.au/act-disability-health-strategy).



C Moore, member of the ACT Disability Health Strategy Steering Committee and Health Literacy Officer, Health Care Consumers' Association

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 an overarching plan to ensure people with disability have equitable and appropriate access to healthcare in the ACT and improved health outcomes. The strategy will inform and guide the development of subsequent action plans.

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

Three goals, developed by the ACT Disability Health Strategy Steering Committee, set out the outcomes the strategy aims to achieve over the 10 years.



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



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



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



Goal 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, make informed healthcare decisions and have their decisions respected.
- People with disability are treated with dignity and respect.
- People with disability will not face discriminatory barriers to healthcare, including physical, sensory, stereotyping, and diagnostic overshadowing.
- 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 have the choice to include family members, carers, and advocates in healthcare conversations and decisions in order to support their healthcare rights and needs.
- People with disability, their family members, carers, and advocates of people with disability are meaningfully involved in healthcare service consultations and governance.



Goal 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 and sexualities 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



Goal 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

Nine principles provide foundational standards to lead systemic change across healthcare system in the ACT for people with disability.

1. Healthcare as a human right

People with disability have the right to access and participate in the whole healthcare system in the ACT. There are international, Australian and ACT laws that protect and advance the human rights of people with disability, including the *United Nations Convention on the Rights of Persons with Disabilities and the Human Rights Act (2004)* (ACT).

2. '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. 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 Organisations 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.

3. Social model of disability

The social model of disability recognises 'disability' as the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. Under the social model, people with disability are not subjects of medical treatment. Rather, 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.

4. Intersectionality

The healthcare system in the ACT will view healthcare from an intersectional perspective and commit to acknowledging, respecting and responding to people with disability holistically as diverse individuals. 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.

5. Person-centred care

Person-centred care ensures that a person receiving healthcare is treated with dignity and that their individual differences and preferences are responded to and respected.

Patient-centred care is supported by information, systems and services that meet patient needs. It assists to reduce instances of diagnostic overshadowing - when a healthcare professional inadvertently attributes symptoms to a person's disability rather than a health issue.

6. Social determinants of health

The healthcare system in the ACT will address the social determinants of health influencing the health outcomes and inequities imposed on people with disability.

The World Health Organization (WHO) describes social determinants as the *non-medical factors that influence health outcomes*.

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; and
- inadequate skills and knowledge of health workers.

7. Trauma informed practice

The healthcare system in the ACT will be trauma informed and acknowledge the profound impact that past and/or current trauma and violence can have on the healthcare needs and healthcare access of people with disability.

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.

8. 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.

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.

9. 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 reduce the need for ongoing 'reasonable adjustment' responses.

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.

When Universal Design is applied (in conjunction with co-design methodology), the result is fewer requests and requirements for specific access considerations, reasonable adjustments and accommodations, as more people (and ideally everyone) are able to use the same spaces, products and services.

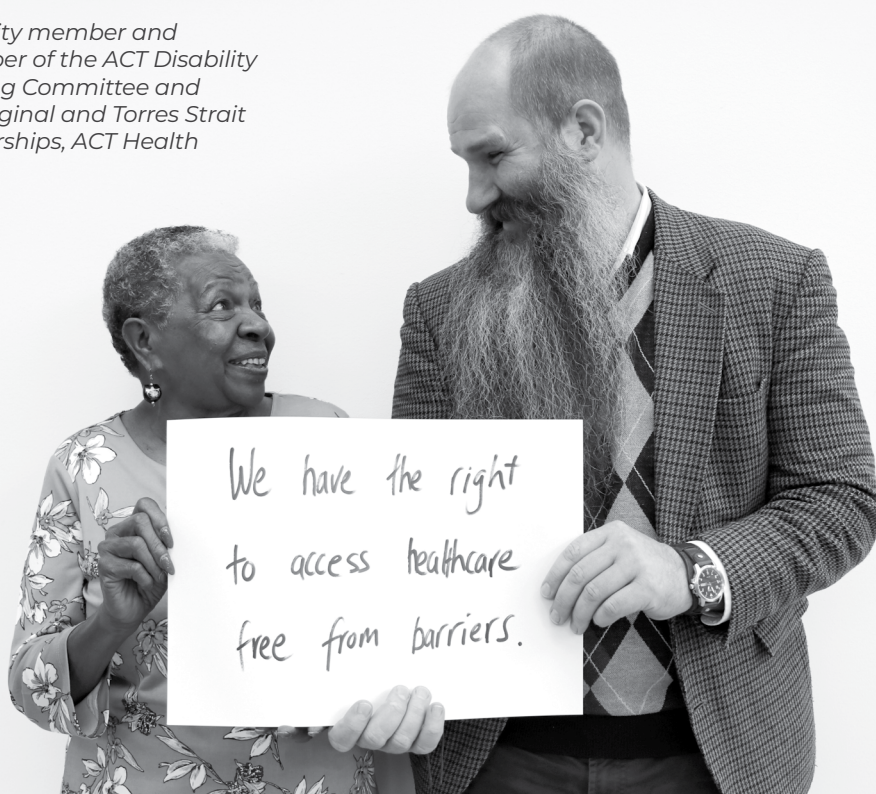
HEALTHCARE IN THE ACT

In the ACT, people are at the centre of a three-pronged service delivery landscape, with preventive health, care in the hospital, and care in the community provided by both public and private services. This 'person-centred' approach to conceptualising healthcare services focuses on shifting the culture from 'doing to' to 'doing with', with the potential to improve clinical outcomes.



Figure 3: Healthcare in the ACT delivery landscape

Louisa Sailor, community member and Yehuwdiy Dillon, member of the ACT Disability Health Strategy Steering Committee and Senior Director of Aboriginal and Torres Strait Islander Health Partnerships, ACT Health Directorate



COMMITMENT FOR CHANGE – FOCUS AREAS

Identified as critical to achieving the goals and principles of the strategy, these five focus areas provide a platform for change to enable people with disability to attain the highest possible quality of healthcare, free from discrimination and on equal terms with all people in the ACT.


Focus area 1 – Health information and literacy

Focus area 2 – Service access, design, and delivery

Focus area 3 – Emergency planning, preparedness and management

Focus area 4 – Workforce

Focus area – 5 Data and Research



Kim Adams, member of the ACT Disability Health Strategy Steering Committee and Health Ambassador, Down Syndrome Australia

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, Australian Sign Language (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

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.

Accessible health information and increased levels of health literacy enable people with disability, their family members, carers, and advocates to access and understand the information they need to make informed healthcare decisions.

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.



Jamie Garner,
community member



Tess Yvanovich,
community member

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* (Cth).

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 nation-wide 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 healthcare services that are safe and appropriate for people with disability of diverse cultures, genders, sexualities and backgrounds. 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 have 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 and is responsive and adaptive to specific healthcare needs.

It should provide choice and greater opportunities to actively engage with the healthcare system and support providers to collaborate more effectively across health and social care to improve health outcomes and experience.

Integrated healthcare involves 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



*Crystal Bevan,
community member*

FOCUS AREA 3

EMERGENCY PLANNING, PREPAREDNESS AND MANAGEMENT

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

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

A health response for people with disability before, during and after 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 emergencies.

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

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

During an 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, Auslan, 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 disability and their support system at the right time during an emergency.

Healthcare services are accessible for people with disability in an emergency

Accessible healthcare services in an 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 an emergency. For people with disability, who may be at increased risk of health-related complications during an emergency due to complex and chronic health conditions, an accessible and adaptive healthcare system is key.

An 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 an emergency.

*Jake Docker, Maria Travers,
Kat Guerin Spijkers and Lisa Spencer,
ACT Disability Health Strategy Project
team, ACT Health Directorate
(missing - Yas Barrington-Knight)*



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, person-centred care, 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.



*Sharon Ding,
community member*



*Maria French,
community member*

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 5 years, disability-focused data and research has been undertaken, providing an evidence base for change and innovation in disability healthcare in the ACT.



*Ben Zarew,
community member*



Patricia Songoro,
community member

IMPLEMENTING THE STRATEGY – ACTION AND GOVERNANCE

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 2022-2025 (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.

An evaluation framework will be developed in the first year of the strategy. This will provide a structure for reporting on the progress of the action plans and outcomes of the strategy. This will include annual reviews of the action plans and reporting 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 so that they can be accessed by the ACT community.

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.

The action plans will contain specific actions and 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.

Any disability health-related recommendations or policy changes within the 10-year timeline of the strategy will be included in supplementary or future action plans.

