ACT
Government

Towards a 10-year ACT Disability Strategy

Listening Report 2022

Ministerial foreword

Yuma. I am Emma Davidson, the Minister for Disability in the ACT. Firstly, thank you for taking an interest in how the ACT can become a better place for people with disability and their families and therefore for everyone.

Thank you to all the people who contributed to the conversations outlined in the Listening Report. Your views have been heard and will form the core of the new 10-year ACT Disability Strategy.

I am delighted that the consultation reached into so many diverse parts of the ACT community, with conversations with the LGBTIQA+ community, the culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people, older Canberrans, young people, women and family carers. It was important to learn how the experience of disability can affect people differently.

Thank you to the ACT Disability Reference Group who led and co-designed the consultation process to ensure the voices of people with disability and their allies shape the ACT Disability Strategy. I am excited about a future where the ACT sees every person with disability as a creative, innovative, insightful, talented and vital part of our community.

Thank you to everyone who has had their say in the consultation to develop a new 10-year ACT Disability Strategy. These conversations require courage and require the ACT Government to hear your truth, to address the cracks in the system and grow our understanding of disability to make Canberra a more inclusive, accessible and equitable place for all. I hope the Listening Report demonstrates that you have been heard and your views considered.

Emma Davidson MLA
Minister for Disability

Chair, ACT Disability Reference Group foreword

As Chair of the ACT Disability Reference Group, I reflect on the experience of planning and delivering this consultation. All members of the Disability Reference Group have been closely involved for over a year now.

Disability is not a niche issue; it is about everyone. One in 5 Canberrans identify as having a disability. It is almost a certainty that everyone will experience disability in some way in their lifetime.

I am thrilled at the number of people who took part in this consultation from so many parts of the ACT community. Thank you to everyone in the community who gave us their insights and expertise, who trusted us enough to be vulnerable and speak their truth. I am very pleased to say that the Listening Report reflects the voices of everyone who came along to a session, who filled in a survey, who contributed artwork, who had a conversation or sent in a submission.

What would I like to see in the new 10-year ACT Disability Strategy? In the first 4-year Action Plan I would like to see mandated Disability Action and Inclusion Plans. I would like to see a focus on transport because we want it to be as easy to get out and about for people with disability as it is for everyone else.

I would like to see changes in workplace cultures with initiatives such as reasonable adjustment passports becoming everyday tools.

Thanks again to all who contributed to the conversation. We will use this contribution generously given to us by the community to build a strategy that works in tandem with *Australia's Disability Strategy 2021–2031* but is uniquely Canberran. We are excited about the opportunity that a 10-year ACT Disability Strategy presents to make a difference in our lives and the lives of all Canberrans with disability.

Renée Heaton
Chair, ACT Disability Reference Group

Abbreviations and acronyms

Acronym	Full title
ABS	Australian Bureau of Statistics
ACAT	ACT Civil and Administrative Tribunal
ACCAN	Australian Communications Consumer Action Network
ACOLA	Australian Council of Learned Academies
ACTPS	ACT Public Service
ADACAS	ACT Disability Aged and Carer Advocacy Service
ADS	*Australia's Disability Strategy 2021–2031*
AEDC	Australian Early Development Census
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Welfare
ASD	Autism Spectrum Disorder
Auslan	Australian Sign Language
CALD	Culturally and Linguistically Diverse
CHAP	Comprehensive Health Assessment Program
CYPS	Child and Youth Protection Services
DAIPs	Disability Action and Inclusion Plans
DRG	ACT Disability Reference Group
DSP	Disability Support Pension
FASD	Foetal Alcohol Spectrum Disorder
GP	General Practitioner

Acronym	Full title
ILC	Information Linkages and Capacity Building
LGBTIQA+	Lesbian, Gay Bisexual, Transgender, Intersex, Queer, Asexual + Allies
LHDG	Liveable Housing Design Guidelines
NCVER	National Centre for Vocational Education Research
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGO	Non-government organisation
NRS	National Relay Service
OOSH	Out of School Hours
P-CEP	Person-centred Emergency Preparedness
SCAN	Student-centred Apprasial of Need
SDAC	Survey of Disability, Ageing and Carers
SDM	Supported Decision-Making
SES	Student Experience Survey
SLES	School Leavers Employment Supports
SLP	Socio-Legal Practice
SME	Small and medium sized enterprise
TAPs	Targeted Action Plans
UN	United Nations
UNCRPD	UN Convention on the Rights of Persons with Disabilities

Accessibility statement

The ACT Government is committed to making its information, services, events and venues as accessible as possible. This document has been written in plain English and is accompanied by an Easy English summary available at **https://yoursayconversations.act.gov.au/act-disability-strategy**.

If you have difficulty reading a standard printed document and would like to receive this publication in another format (such as large print), please email the Office for Disability at **officefordisability@act.gov.au** or call us on **6207 1086**.

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Executive summary

We are developing a new 10-year ACT Disability Strategy to create a more welcoming and accessible community to improve the lives of the 80,000 Canberrans with disability.

The Australian Government launched *Australia's Disability Strategy 2021–2031*[1] on 3 December 2021. This commits all Australian Governments to work together to bring about an inclusive society for people with disability. The ACT has obligations under Australia's Disability Strategy and has committed to developing a 10-year whole-of-government ACT Disability Strategy. The ACT Disability Strategy will consolidate the ACT's commitment to *Australia's Disability Strategy 2021–2031* and create actions and outcomes in our local community.

Across the ACT Government there are a range of commitments in action to create better outcomes for people with disability and their families. These commitments include the development of an Inclusive Education Strategy, a Disability Health Strategy a Disability Employment Strategy and the second action plan for the *Disability Justice Strategy 2019–2029*.

The ACT Disability Strategy will align these initiatives under a holistic framework and develop systemic actions across government.

Our conversation with you

An open consultation on the ACT Disability Strategy took place from April to August 2022. This consultation was co-designed and led by the ACT Disability Reference Group. The voices of people with disability were at the forefront of planning and activities.

We held 33 public consultation events which were attended by 415 people. We received 397 completed responses to the online survey. Thirty-five (35) children and young people entered the student voice competition. We received 36 submissions from organisations and individuals. At the 2022 Canberra Disability Expo, 130 people voted for their top 3 actions. Of the events held, 31 were facilitated by people with disability and 2 were facilitated by family carers.

Consultation activities included:

- focused conversations on identified themes (in person and online)
- open forums
- kitchen table conversation kits
- submissions, both written and video
- an online survey through the YourSay platform
- a ‘Student Voice’ creative competition
- one-on-one conversations
- a voting activity at the 2022 Canberra Disability Expo.

The focused conversations reached into diverse parts of the community with shared experience. We engaged with women, young people, people who are ageing, carers, culturally diverse people, LGBTIQA+ and Aboriginal and Torres Strait Islander people.

Many community organisations supported the coordination of these events, which helped to reach people with disability and their supporters from many parts of the ACT community. We thank those organisations for their involvement.

Who we engaged

Of the 397 people that completed the survey:

- 57% were people with disability
- 46% were family members of carers
- 20% were service providers or advocates.

Many people identified with more than one role: 33% of people with disability responding to the survey also cared for and/or had a family member with disability; and 17% of people with disability also had a role as a service provider or advocate.

Of the survey respondents:

- 74% were female, 18% male and 4% non-binary
- 51% were aged between 35 and 64 years old
- 24% were over 55 years old
- 18% were 25–34 years old
- 7% were under 24 years old
- 63% of respondents with disability were currently in employment.

Many community organisations had their say through submissions or kitchen table conversations including:

- Canberra Blind Society
- Deaf ACT
- ACT Down Syndrome Association
- Speaking Out for Autism ACT
- Indigenous Allied Health Australia
- ACT Council of Social Services
- ACT Disability Aged and Carer Advocacy Service
- Advocacy for Inclusion
- Focus ACT
- Imagine More
- Meridian ACT
- Missing School
- Occupational Therapy Australia
- Radio 1 RPH
- Volunteering ACT
- Women’s Centre for Health Matters
- ACT Council of Parents and Citizens (disability working group)
- ACT Inclusion Council.

The focus topics

The consultation was co-designed with the ACT Disability Reference Group. The Disability Reference Group worked with the ACT Government to select the following focus topics that are of importance to people with disability in the ACT. These topics can also be mapped to the outcome areas of *Australia's Disability Strategy 2021–2031*. The focus topics are:

- Lifelong learning
- Early childhood
- Health and wellbeing
- Supported decision-making
- Experience of Aboriginal and Torres Strait Islander people with disability
- Having a home
- Supports and services
- Safety
- Employment
- Accessible communities
- Justice
- Emergency and disaster management.

How we analysed the qualitative data

There were 8 open text questions in the survey and we received 1,391 open text answers. In addition, we received detailed records of all conversations held with the 415 people that attended events and the one-on-one conversations.

Once the consultation was complete, qualitative responses from event notes, survey questions and submissions were allocated to focus topics and key themes were identified.

Key community insights

Quantitative data from the survey

The average life satisfaction for people with disability is 5.5 out of 10, compared to 7.1 out of 10 for the general community (general community data from a 2020 YourSay Survey).

87% of survey respondents felt the broader community do not consider the needs of people with disability and 84% agreed that the broader community are unsure how to act towards people with disability.

The **top 5 challenges** identified through the quantitative survey were:

1. Having control over things which affect your life/ the life of people with disability.
2. Finding and using health care services that are needed.
3. Finding and getting good quality paid supports and services.
4. Finding opportunities to connect or socialise with other people.
5. Having enough money for everyday things.

The **top 5 areas for action** were:

1. Health care provision.
2. Disability supports and services.
3. Having a safe and accessible home.
4. Having a voice.
5. Employment.

The **top 5 specific activities** people would like to see included in the ACT Disability Strategy were:

1. Having individual advocacy to support people with disability.
2. Mandatory Disability Action and Inclusion Plans for organisations.
3. More support in educational settings.
4. Employment targets for employing people with disability.
5. Increasing the confidence of employers to engage with people with disability.

Systemic issues identified through the consultation

A number of systemic issues were raised repeatedly across many focus topic conversations; and through the survey and submissions.

These issues have a profound impact on the lives of people with disability and their families. They are all interconnected and there is no single solution to overcoming them.

People told us that the strategy should aim to address the systemic issues by:

- making it easier for people with disability to navigate mainstream systems
- reducing social isolation and lack of inclusion
- ensuring people with disability have more of a voice in policies and decisions
- overcoming negative community attitudes, stigma and discrimination
- addressing the lack of disability awareness and knowledge across many sectors
- putting actions in place to reduce financial hardship for people with disability.

The structure of this report

The report includes a chapter on each of the 12 focus topics. Each chapter includes what we heard from the community, an overview of evidence and best practise, as well as initiatives currently underway in the ACT that relate to that focus topic.

What's next?

We are now talking to many parts of the ACT Government about what we have heard and what we can do to address the challenges raised by the community.

We are sharing the community's ideas with influencers and decision makers across government to make plans to address these issues as one government.

We are continuing to work closely with the ACT Disability Reference Group to guide the creation of the 10-year *ACT Disability Strategy 2023–2033* and the first 4-year Action Plan.

To find out more about the ACT Disability Strategy and other initiatives, policies and projects in Canberra visit **www.yoursay.act.gov.au**.

If you have feedback to share you can send it to **officefordisability@act.gov.au**.

Overview of the consultation

Why an ACT disability strategy, and why now?

The *ACT Disability Strategy 2023–2033* will demonstrate our commitment to supporting the ACT community with fit for purpose services based on lived experience aligned with broader national strategy.

The Australian Government *Australia's Disability Strategy 2021–2031*[2], launched on 3 December 2021, is the national framework that commits all Australian governments to work together to bring about an inclusive society for people with disability. It was developed by all levels of government with people with disability, their families, carers and supporters.

The outcome areas of Australia's Disability Strategy are:

- Employment and financial security
- Inclusive homes and communities
- Safety, rights and justice
- Personal and community support
- Education and learning
- Health and wellbeing
- Community attitudes.

The National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) was introduced in 2016 as a new way of providing support to Australians with disability.

The NDIS aims to provide people with a permanent and significant disability, and who are younger than 65, with flexibility and choice of supports and services to meet their individual needs, giving people direct control over the funding they receive. The NDIS is not means-tested and has no impact on income support such as the Disability Support Pension or Carer Allowance.

Not all people with disability are eligible for the NDIS. The NDIS does not fund supports that are meant to be available through other mainstream government and community services, even if that service system does not actually provide it.

We know people with disability and their families often struggle to access and navigate the NDIS and face barriers to securing the funded supports and services they need.[3] We also know some people with disability and their families are not accessing the supports and services they need because they are not eligible for the NDIS.

The Australian Government recently announced an Independent Review of the NDIS. The ACT Government is optimistic that this review will reposition people with disability to be at the centre of the Scheme and deliver the reforms required to bring about a sustainable NDIS that meets the diverse needs of people with disability, in keeping with the original intention and values of the Scheme, as set out in the *NDIS Act 2013*.

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

The Disability Royal Commission was established in 2019 in response to community concern about widespread reports of violence against, and the neglect, abuse and exploitation of, people with disability. The Royal Commission is gathering information through research, public hearings, submissions and private sessions and is expected to deliver a final report, with recommendations, to the Australian Government in September 2023. The Disability Royal Commission is investigating many settings including schools, workplaces, jails and detention centres, forensic units and secure mental health facilities, group homes or boarding houses, family homes, hospitals and day programs.

At the ACT level there are several strategies under development by areas of government to build supportive environments for people with disability. These include the development of an Inclusive Education Strategy, a Disability Health Strategy, a Disability Employment Strategy and the next action plan for the *Disability Justice Strategy 2019–2029*.

The ACT Disability Strategy will maximise the benefit of this momentum and complement directorate-specific actions by aligning initiatives under a holistic framework and developing systemic actions across government.

Consultation to develop an ACT Disability Strategy

The open consultation on the ACT Disability Strategy took place from April to August 2022. This consultation was co-designed and led by the ACT Disability Reference Group, an advisory group to the ACT Government and the Minister for Disability working to ensure the ACT Government is aware of issues of impact for people with disability in the ACT. The ACT Disability Reference Group worked with the Office for Disability and the Minister for Disability to shape the consultation activities and to determine the questions to put to the community through events and a survey.

One important decision was that every event would be facilitated by a person with disability from the community, not by ACT Public Service employees. This was to ensure people with disability led discussions and engagement around issues that impact the lives of people with disability. This aided our goal of providing a safe space where people felt heard and listened too and were respectful of listening to others' experiences and ideas.

To prepare for the consultation, members of the Disability Reference Group and key community members undertook training in public facilitation and public speaking.

Consultation methods

1. 2-hour focused conversations on identified themes (in person and online).
2. 2-hour open public forums.
3. Kitchen table conversation kits.
4. Submissions, both written and video.
5. An online survey through the www.act.gov.au/YourSay platform.

During the consultation, the following additional options were added:

1. **More focused conversations:** In order to reach into more parts of the ACT community, more events were added,many co-hosted by partner organisations.
2. **Student Voice competition:** The team recognised the need to engage more children and young people so added this competition, inviting children and young people to provide a creative response to the question: “How do we make Canberra more inclusive for all?”.
3. **One-on-one conversations:** In July 2022, most events were moved online due to a surge in COVID-19 cases. One-on-one conversations were offered to accommodate participants who were not able to use online platforms.
4. **The Canberra Disability Expo:** In August 2022 we took 20 of the most proposed actions from the wider consultation and asked people at the Canberra Disability Expo to vote on the 3 they believed would have the most positive impact on people with disability.

Who participated in the consultation?

In total, 33 consultation events were held and attended by 415 people and 397 people completed the online survey. Additionally:

- 35 children and young people entered the student voice competition
- 36 organisations and individuals provided submissions to the consultation
- 130 people participated in voting for their top 3 actions at the ACT Disability Expo.

33
events with themed conversations

415
people attended consultation events

397
online survey responses

36
written submissions from individuals & organisations

35
creative responses received from students

130
people voted for ideas at the Canberra Disability Expo

The consultation events and facilitators

Focused conversations were held with members of community with lived experience. We sought to engage with people with disability, family and supporters from many diverse parts of the ACT community. We heard how diverse identities combined with disability can add to the complexities and potential disadvantage experienced by people. The Student Voice competition received an impressive and diverse array of responses, from poems and essays to drawings and songs. Some of the visual art has been included in this report, and offers unique insights into how children and young people approach inclusion. We are very grateful for their thoughtful contribution, which has enriched conversation and thinking about the future.

Each event went for 2 hours. People sat on tables of up to 8. Some activities included the whole room, and some were deep conversations at tables. The same was replicated for online events with breakout rooms. In addition to the main facilitator, each table or breakout room had a table facilitator with disability, and a scribe to capture what was said at each table.

Various community organisations supported the coordination of these events, which helped to engage with people with disability and their supporters from many parts of the ACT community. Many thanks to the following organisations for assisting to host conversations:

- Women with Disabilities ACT
- Health Care Consumers Association
- Rights and Inclusion Australia
- National Disability Services
- Meridian ACT
- Canberra Blind Society
- ACT Council on the Ageing
- Mental Health Community Coalition
- National Ethnic Disability Alliance
- Carers ACT
- Belconnen Arts Centre.

We heard from Aboriginal and Torres Strait Islander community members with disability during 2 yarning circles. These discussions focused on the unique experiences, challenges and ideas in community, and consider ways of improving supports for people with disability in the Aboriginal and Torres Strait Islander community.

We thank the 16 people with disability and 3 carers who facilitated consultation events. This was a valuable activity to elevate the voices of people with disability. Many thanks to the facilitators:

- Alarna Moscaritolo
- Ben Zarew
- C Moore
- Deborah Eades
- Dominic Golding
- Dougie Herd
- Erika Lyons
- Graham Downie
- Kat Reed
- Kerry Snell
- Louise Bannister
- Lyn Wu
- Nic Stuart
- Patrice Soward
- Renée Heaton
- Ruth O'Brien
- Sharon Ding
- Wayne Herbert
- Yenn Purkis.

About this listening report

Focus topics

Following is a list of focus topics for this report:

- Reoccurring issues and themes
- The experiences of Aboriginal and Torres Strait Islander people with disability
- Lifelong learning
- Early childhood
- Health and wellbeing
- Decision-making
- Having a home
- Supports and services
- Safety
- Employment
- Accessible communities
- Justice
- Emergency and disaster management.

Who contributed to this report

Many thanks to all that helped to create the Listening Report. Graham Downie from the Disability Reference Group was a proofreader for the report for flow and consistent voice. Alarna Moscaritolo from the Disability Reference Group contributed to the focus chapter of the experiences of Aboriginal and Torres Strait Islander people with disability.

The ACT Disability Reference Group members have been integral to the consultation and the Listening Report. Many thanks for their dedication and passion, including: Renée Heaton (Chair), C Moore (Deputy Chair), Ajar Sana, Ben Zarew, Craig Wallace, Alarna Moscaritolo, Erika Lyons, Graham Downie, Katie Shoemack, Kerry Snell, Nic Stuart and Patrice Soward. Thanks also to former ACT Disability Reference Group members Sharon Ding, Deborah Eades and Louise Bannister for their intensive involvement.

Thanks also extend to the many partners across the community and the ACT Government who supported the consultation and the Listening Report development, including the researchers and subject matter experts that provided evidence for the focus chapters within this report.

ACT Wellbeing Domains

What is the ACT Wellbeing Framework?

The *ACT Wellbeing Framework* is helping the ACT Government and community work in partnership to lift the quality of life of all Canberrans, particularly those with lower wellbeing than average.

Wellbeing is about how we are doing, as individuals, as a community. It is about having the opportunity and ability to lead lives of personal and community value — with qualities such as good health and time to enjoy the things in life that matter, in an environment that promotes personal growth and is sustainable.

The *ACT Wellbeing Framework* provides high-level indicator outcomes for Canberra. Measuring wellbeing will help us understand how we can improve the lives of all Canberrans and support those who need it most.

The ACT Government is using the wellbeing framework and the information it provides to inform government priorities, policies and investment decisions.

What does the framework mean for the ACT Disability Strategy?

The vision of the wellbeing framework is for the ACT to be an inclusive, welcoming society where everyone can reach their full potential.

The experiences of people with disability in the ACT are not always equal to others. They may face discrimination, fewer job opportunities, higher levels of underemployment and greater difficulty accessing health services. *The Living Well in the ACT Region* survey (2020) shows people with disability experience lower than average personal wellbeing in the many areas of life such as:

- social connection
- community participation
- overall health and mental health
- feeling that their voices and perspectives matter
- housing suitability
- sense of belonging and inclusion.

The ACT Disability Strategy will have an evaluation framework to track progress over the 10 years of the Strategy. The ACT wellbeing data for people with disability will be an important source of information for the evaluation of the Strategy.

The Listening Report links each of the focus topics to the most relevant wellbeing domains.

The 13 focus chapters in the Listening Report are based on issues that people have identified as important. Throughout this report, each focus chapter will refer to the most closely matched Wellbeing Domains to what we have heard.

Wellbeing domains

Access & connectivity
Getting around to places we value and accessing the services we need.

Economy
We share in our city's economy.

Education & lifelong learning
Gaining the skills and education needed at all stages of life.

Environment & climate
The environment sustains all life now and into the future.

Governance & institutions
Having a say, being heard, and working together for better outcomes.

Health
Being healthy and supported with the right care.

Housing & home
Having a place to call home.

Identity & belonging
Being able to express identity, feel a sense of belonging, and participate fully in society.

Living standards
Having the financial resources to live life well.

Safety
Feeling safe and being safe.

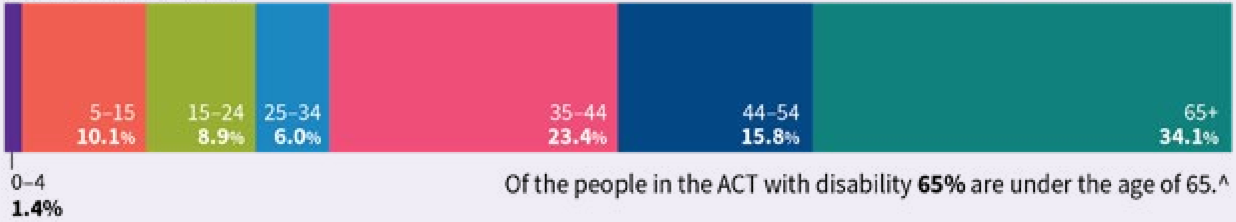
Social connection
Being connected with family, friends and community.

Time
Having time to live life well.

People with disability in the ACT

In the ACT there are 80,000 people with disability. This is **19.4%** of the ACT population, which is around **1 in 5** people.^

AGE BREAKDOWN



Of the people in the ACT with disability **65%** are under the age of 65.^

Many people with disability work, volunteer and take part in the community.

27.7% have volunteered within the past 12 months.*

36.8% regularly attend events, festivals and community groups & take part in hobbies.*

18.7% are a carer for another person.*

40.7% are employed in paid work.*

Despite this positive contribution, negative community attitudes impact people with disability.

59.6% of people with disability are economically disadvantaged. The average income of a person with disability is **$700** a week compared to **$1,343** a week for people without disability.*

When asked their satisfaction with feeling a part of the community people with disability reported an average of **5.1** out of **10** on the wellbeing index.*

52.0% of people with disability report poor health compared to 19.6% of people with no disability.

36.3% of people with disability experience financial distress compared with 16.0% with no diability.

40.7% of people with disability have high levels of psychological distress compared to 7.6% of people with no disability.

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^ Data from Australian Bureau of Statistics (ABS) 2016 Census and 2018 ABS Survey of Disability, Ageing and Carers

* Data from 2021 Regional Wellbeing Survey

Housing

Nationally, 35.9% of households include a person with disability.

In the ACT:

- 53% of households living in public housing include a person with disability
- 29% of households in social housing include a person with disability
- more than 1,730 (12%) of income units receiving Commonwealth Rent Assistance received the Disability Support Pension as their primary payment type. *An income unit is a person or group of people with shared income within a household, or a person living in a non-private household with individual income. A parent and dependent children, a married couple, or a person living in a shared non-private house are all examples of an income unit.*

University degree

Nationally, people with disability over the age of 20 are less likely to hold a bachelor’s degree (17%) compared to people without disability (35%).[5]

Employment

Nationally, people with disability of working age:

- have lower rates of labour force participation (53%), compared to people without disability (84%)
- are twice as likely to be unemployed (10%) than people without disability (5%).[6]

Graduates with disability take 61.5% longer to gain full-time employment than other graduates.[7]

Public transport

Nationally, 14% of people with disability aged 5 years and over who leave home are unable to use any form of public transport.

Taking an intersectional approach

‘Intersectionality’ refers to how different aspects of a person’s identity interact to shape their experiences. Intersectional discrimination ‘not only impacts on how groups are viewed, understood, and treated, but it also impacts on how groups access, or are unable to access, resources, services, and supports’.[4]

To develop the Disability Strategy the ACT Government has proactively engaged with diverse groups of people with disability, their families, and communities, on the key issues for consideration in the development of the next 10-year Disability Strategy.

People with disability can have multiple (shared and distinct) experiences, characteristics, and identities. People with disability may be simultaneously affected by multiple forms of discrimination and disadvantage arising from culture, gender, sexuality, class, religion, age, social origin, and other experiences.

In order to hear the diverse of views and experiences of people with disability, we engaged with:

- women and girls
- people from culturally and linguistically diverse communities
- Aboriginal and Torres Strait Islander communities
- carers
- people who are ageing
- young people
- LGBTIQA+ identifying people
- people with intellectual disability, psychosocial disability, neurodiversity, complex health conditions and invisible disability.

Survey results

A publicly available online survey was hosted on the ACT Government YourSay website and was open from 31 March to 10 August 2022.

The survey was developed under guidance from the ACT Disability Reference Group as a collaboration between the Community Services Directorate and the Chief Minister, Treasury and Economic Development Directorate within the ACT Government. The survey was strength-based, meaning questions emphasised the autonomy and capability of respondents. Respondents were allowed to answer both for themselves and on behalf of the adult or child that they cared for.

The survey had 5 parts:

1. About you
2. Living with disability
3. Challenges
4. Community attitudes
5. Priorities and actions.

In the survey, we asked people to think about:

- What helps create a welcoming community for people with disability?
- What are the barriers and challenges facing people with disability?
- What actions should be taken to make it easier for people with disability to live the kind of life they want to live?

Following is a report on the community responses to the above 5 sections.

Part 1: **About you**

397 people completed the survey.

57% people with disability

46% family members or carers

20% service providers or advocates

Many people identified with more than one role:

- 33% of people with disability responding to the survey also cared for and/or had a family member with disability
- 17% of people with disability also had a role as a service provider or advocate.

Respondents represented a cross-section of the community:

- 74% of the people that completed the survey were female, 18% male and 4% non-binary
- 51% of people were aged between 35 and 64 years old; 7% were under 24; 18% were 25–34 years old; and 24% were over 55 years
- 63% of people with disability who took the survey identified that they were employed
- 47% of all people who completed the survey were working full-time, 21% were working part-time or casually and 11% were retired.

The survey asked family members/carers who they were representing through the survey — 45% of the people with disability represented by a family member were students.

Part 2: **Living with disability**

Of the 397 people that took the survey, 227 identified as a person with disability.

A wide range disability experiences were represented in the survey as identified by both people with disability and family members that care for a person with disability.

Life satisfaction

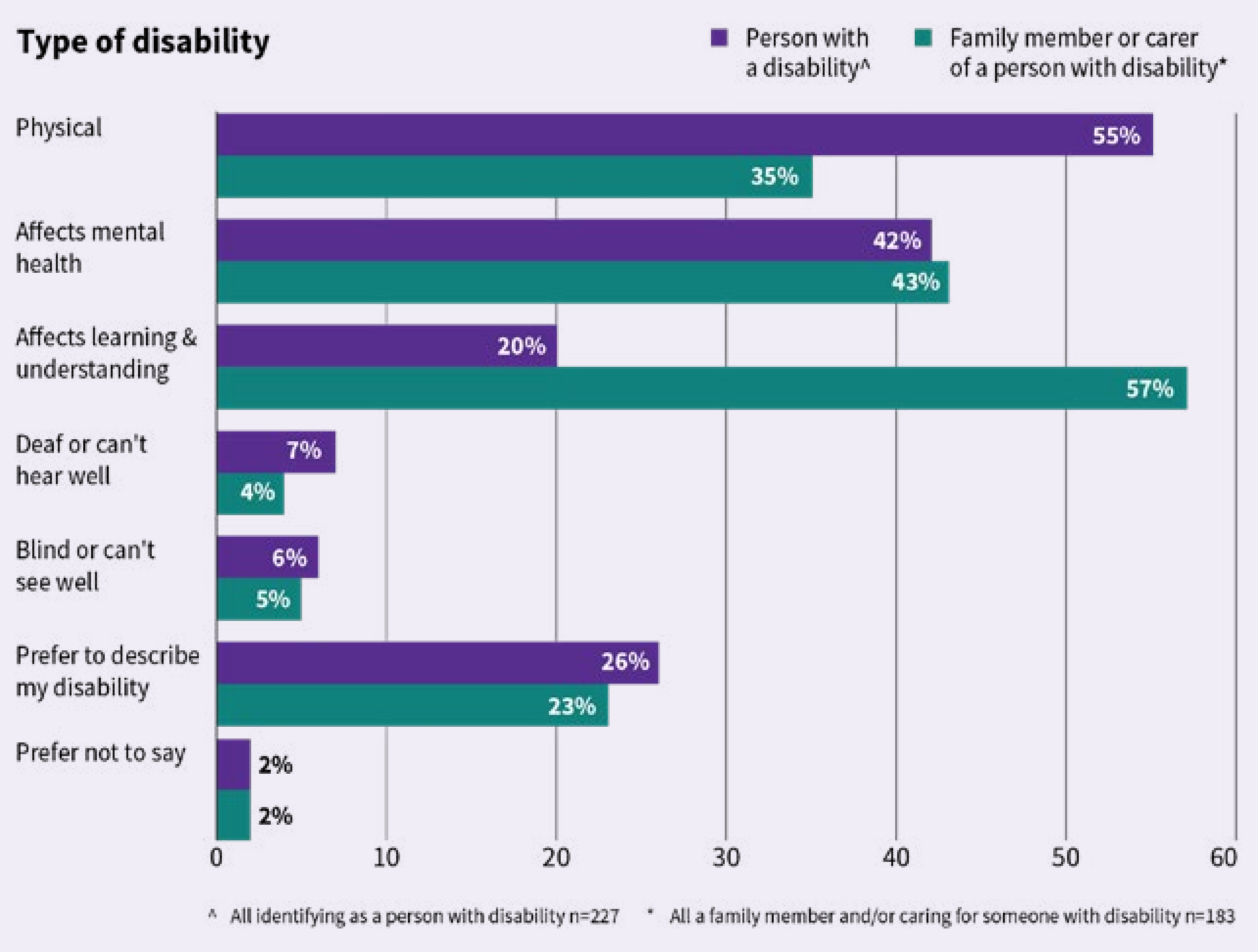
People with disability rated their life satisfaction between zero (completely dissatisfied) and 10 (completely satisfied).

Life satisfaction for people with disability was identified as lower than the wider ACT community.

The average life satisfaction people with disability reported was 5.5 out of 10.

For comparison, a YourSay survey in December 2020 found the average life satisfaction for Canberrans was 7.1 out of 10.

Thirty-four per cent (34%) of people with disability felt that their life had worsened in the past year while 21% reported their life had gotten better.



Part 3: **Challenges**

We asked people to rate challenges to see which were their biggest issues. The top 5 challenges were slightly different for respondents with disability compared with family carers.

Top 5 issues for **people with disability**:

1. Having **control** over things which affect your life / the life of people with disability.
2. Finding and using **health care** services that are needed.
3. Finding and getting good quality paid **supports and services.**
4. Finding opportunities to **connect or socialise** with other people.
5. Having enough **money** for everyday things.

Top 5 issues for **family and carers**:

1. Finding and getting good quality paid **supports and services**.
2. Finding and using **health care** services that are needed.
3. Having **support for carers**.
4. Finding opportunities to **connect or socialise** with other people.
5. Having **control** over things which affect your life / the life of people with disability.

Part 4: **Community attitudes**

Inclusion and being welcome is an issue in the ACT for people with disability.

We asked people whether people not welcoming or including people with disability is an issue.

- 55% of all respondents felt this was a big or very big issue.
- 59% of people with disability felt this was a big or very big issue.
- 53% of family carers felt it was a big or very big issue.

The broader community struggles to know how to interact with people with disability:

- 87% of people agreed that the broader community do not consider the needs of people with disability.
- 84% of people agreed that the broader community are unsure how to act towards people with disability.
- 72% of people feel the broader community are not comfortable asking people with disability what supports they need.

Part 5: **Priorities and actions**

Priorities

We asked people which areas should be a high priority for reform. The top 5 priorities for reform were very closely aligned with each group of respondents noting that health care provision, disability supports and services, access to employment and safe and accessible housing were all priority areas for reform. Accessible buildings and community attitudes also featured as important areas for reform.

Priorities by respondent group

	People with disability	Family or carer	Advocate or provider
1	Health care provision	Disability supports and services	Employment
2	Disability supports and services	Health care provision	Safe and accessible housing
3	Employment	Employment	Disability supports and services
4	Safe and accessible housing	Safe and accessible housing	Health care provision
5	Accessible buildings	Community attitudes	Community attitudes

The following areas were considered a high priority for action by more than two-thirds of respondents, listed in order of priority:

1. Health care provision
2. Disability supports and services
3. Having a safe and accessible home
4. Have a voice
5. Employment
6. Accessible buildings and public amenities
7. Safety from violence.

Actions

We asked people to pick one tangible action they thought would have the most impact on the lives of people with disability. The top 5 were:

1. Having **individual advocacy** to support people with disability.
2. Mandatory **Disability Action and Inclusion Plans** for organisations.
3. More **support in educational settings.**
4. **Employment targets** for employing people with disability.
5. Increasing the **confidence of employers** to engage with people with disability.

Free text comments

The survey included 8 questions that provided an opportunity to add free text responses. There were 1,391 free text responses which we categorised and added to the narratives heard in the focused conversations and public forums. Together, this information is the foundation of the synthesis of ideas in the focus chapters of the Listening Report.

We found that people were slightly more likely to share negative experiences in these free text comments of the survey, rather than in face-to-face focused discussions. The comments and experiences shared were rich and diverse and provided insights into challenges and experiences.

Canberra Disability Expo—testing ideas from the consultation

From 2 to 3 September 2022, the Office for Disability ran an activity at the Canberra Disability Expo at Exhibition Park in Canberra. A list of 20 ideas for change that were frequently suggested at consultation events was created.

Each idea was placed on a board on the wall. People were invited to take 3 stickers and choose 3 ideas they felt would have the most positive impact on people with disability.

The activity attracted 130 participants. Following is a list of the top 10 ideas, with the number of votes received for each.

Idea	Votes
Mental health support for young people with any disability	46
More local supports for people that do not receive NDIS	36
Affordable and accessible homes for people with disability to buy or rent	33
Support to help people understand the service system, where to find supports, what activities and services are available	33
Information on places in the community and how accessible they are, such as restaurants, shopping centres, entertainment venues	25
Help for people to apply for support and funding from NDIS, housing and Centrelink etc	23
More Auslan interpreters available in Canberra	20
Employment targets for employing people with disability	19
A program to help make workplaces more accessible and inclusive	18
A public campaign to promote disability awareness and inclusion	18

FOCUS TOPICS

What we have heard and what we are thinking about

1 Reoccurring issues and themes

Systemic issues

Through all the information we heard in the consultation there were 6 issues that came up over and over. These issues have a profound impact on the lives of people with disability and their families. These issues are:

1. Mainstream systems are too challenging to navigate alone.
2. Social isolation and a lack of inclusion.
3. Not enough of a voice in policy making and decisions that impact lives.
4. Poor community attitudes, stigma and discrimination.
5. Lack of disability awareness and knowledge across many sectors.
6. Financial disadvantage.

These issues are complex and have a variety of causes. They cannot be solved by one action or one part of government. Each systemic issue is explained below with its corresponding link to the ACT Wellbeing Domains.

ISSUE 1 Mainstream systems are too challenging to navigate

ACT WELLBEING DOMAINS

Access & connectivity

Time

What we heard from the community—the challenges

Difficulty finding information, applying for support, knowing where to go for help and finding inclusive activities and programs came up regularly through the consultation. People have told us that trying to work their way through systems is exhausting. This system confusion relates to health, education housing, justice, supports and services, transport, decision-making, employment, social and recreational activities and more.

We heard that many people are not getting the support they need because they find applying for the support, or even knowing what supports are available, too difficult.

> “When you first get a diagnosis, you don’t know what services are available, or what options are out there.”

People told us getting support can be even more confusing for people from culturally and linguistically diverse backgrounds.

Health care providers are often the first point of contact when someone receives a new diagnosis. However, people commented that sometimes health care providers did not have enough knowledge of the whole system to provide advice and help with the next steps.

> “The system doesn’t understand the system. GPs, psychologists and paeds [sic] need to understand their role in diagnosis of ASD the next step, and support groups and benefits. I lost so much money and time navigating the system.”

People told us that sometimes their disability made it difficult for them to fill in forms or apply for supports, and often help was not available.

> “When you are vision impaired, dealing with any kind of form is not easy. My request for support was denied due to privacy legislation and the Centrelink Disability line refused to help.”

Part of the issue is a lack of information, or sometimes information that is too hard to find.

> “Not enough information about access to services including housing, education, health, and transport and being able to use those services.”

People with disability and family carers often need to work their way around many systems all at once, which adds to the difficulty.

> “Parents and carers should not have to reinvent the wheel on how to navigate school and the NDIS on their own.”

Parents told us this challenge affects their ability to support their child to get the most out of their education.

> “If you don’t have access to the right information at the right time to navigate the system — what you need to apply for and where, what words you need and when. If you don’t know this you are less likely to succeed.”

People find the health care system confusing, especially the connection between Medicare and NDIS.

> “Health — it is very complicated navigating being a disabled person with health issues. The NDIA throws us back to Medicare and Medicare refers us back to the NDIA.”

People commented that applying for supports is complicated and that many people do not have the capacity to apply, which means they fall through the gaps. This includes NDIS, housing, the Disability Support Pension and more. People with disability as well as family carers told us there is no one to support them through the process of finding and applying for supports.

Overall, people commented that the many requirements on people with disability and their families to get and maintain support is exhausting.

> “Everyone feels like a beggar, there is a limit to how much you can ask people for help. It gets exhausting having to ask people for help all the time.”

> “You shouldn’t have to tell your story over and over again.”

Apart from supports and services, even finding information about accessibility in the community is difficult. People told us they sometimes had to make many phone calls to find out whether an event, business or place would be accessible.

> “Booking a restaurant or event. My son, who does not have a disability, can go to a website and easily find the information he needs, and it is assumed he will be able to participate. For me it’s the opposite. When I google, I usually can’t find information on accessibility so it’s not obvious whether I can participate or not.”

> “There are some lovely walks and events on offer in Canberra but when you check websites, there is often no mention about accessibility. If you follow up, the response is often tokenistic such as ‘you can probably use this entrance; you can probably do this; we hadn’t really thought about it’. It is very tiring having to be forceful and work your way through things.”

What the evidence says

We know service systems such as health, the NDIS, education, housing, and Centrelink are complex and can be hard to access or navigate for people with disability, their families, and carers.

Evidence[8] tells us service systems often inadequately consider and respond to the diverse access and participation needs of people with disability. For example, the Disability Royal Commission found that ‘people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system’.[9]

A lack of timely access to safe and inclusive disability and mainstream services and supports can:

- deny dignity to people with disability, their families, and carers
- limit independence and social and economic participation of people with disability
- place people with disability at increased risk of harm, mistreatment and other poor experiences which negatively impacts physical and emotional wellbeing.[10]

We know diverse barriers across systems and sectors deny or restrict people with disability from:

- Accessing and securing culturally safe/accessible services and supports in a timely manner, free from all forms of discrimination and bias.
- Accessing and understanding information about what services and supports are available.
- Navigating complex and often interdependent processes within and between programs, systems, and sectors.
- Making informed decisions during interactions with systems, processes, or programs.
- Understanding rights and options and accessing the required support to exercise autonomy.

ISSUE 2 Social isolation and lack of inclusion

ACT WELLBEING DOMAINS

Social connection

Identity & belonging

What we heard from the community—the challenges

“Living with a disability is a lonely life.”

Social isolation was frequently raised in the consultation. People told us about how social isolation impacts the wellbeing of people with disability. Social isolation is the result of many factors.

Lack of transport options and the limits of the taxi subsidy scheme means that getting out and about is sometimes either too expensive, too time consuming or too difficult, which adds to social isolation.

“Lack of affordable transport limits our access to social outings and means getting to and from basic appointments can take hours (e.g. regular public transport is either non-existent or very limited to botanic gardens, zoo, arboretum, ACT Carer activities, Calvary Hospital, UC Hospital). Taxi Subsidy Scheme cost caps haven’t kept pace with inflation, so taxis are a luxury we only use as a last resort. The flexible bus service booking, and zone rules make it too impractical to be useful.”

For some people, their disability makes public transport extremely difficult or impossible.

“I am neurodivergent and at times have had no choice but to use public transport, but I find it totally exhausting, with confusing timetables, sitting with lots of different people, different smells, bus drivers’ taste in music etc. It is literally painful, getting home at the end of the day.”

The shortage of social programs outside of NDIS is another issue. Many people told us that since the introduction of NDIS, the options for community engagement programs have become limited. About 12% of Canberrans with disability currently access NDIS funding. For people that do not receive NDIS funding, there are not many accessible social programs available.

Even for people that do receive NDIS funding, often the package does not allow for money to be spent on social activities or for transport to social activities.

“Lack of friends because of inability to find low cost or free opportunities to meet other people with intellectual disability. There is often not money in NDIS plans to attend social activities.”
Parent of an adult with intellectual disability.

“I have funding support to provide housing, healthcare, basic home care — there is no funding for social inclusion, for recreation…”

Cost is a barrier to getting out and about for people with disability and financial disadvantage is another systemic issue. The cost of activities can add to social isolation.

“Price is an accessibility and disability issue because people with disability are usually low-income recipients. Realistic concessions should be built into pricing for all ACT-funded facilities — maybe 50% of the full price.”

Community attitudes add to social isolation. In the survey, 84% of people felt that the broader community are unsure how to act towards people with disability. We asked people whether they felt the community not welcoming or including people with disability was an issue. This was a big or very big issue for 55% of survey respondents.

Some people told us that encountering the world is tiring when you don’t know how people are going to react to you or whether they will be welcoming towards you.

“Peoples’ attitudes to disability are archaic. Little things chip away at you all day.”

Parents told us community attitudes affect their child’s ability to be socially connected.

“My granddaughter has an intellectual disability and attends mainstream school but is an outsider within the school community. She is made fun of, has no friends… She now spends her leisure time sitting in her room playing video games and only goes out when family members urge her to come. It is heartbreaking…”

Sport could be a good avenue for social connection but **many people with disability told us they found that sport was not inclusive for them.**

“I learned at school a very long time ago that sport was not inclusive for people like me.”

Other recreational activities may also lack accessibility for people with disability.

> “Many social/hobby clubs do not cater for people with disability, for example, I had to leave the Men’s Shed because I felt pushed aside and ignored. The attitude of members needs to change — it seems that the Men’s Sheds are only set up for men who are fit and healthy.”

> “I can’t go to church anymore with autism, no education or inclusive disability programs in … churches. No ongoing support or education for Pastors about psychosocial disability, you are expected to be social in this community setting and go to lots of social events when your autistic brain is not wired for that...”

Social isolation can also be the result of poor health and medical conditions. For people in the community, sometimes health is a barrier to being out and about in the community.

> “…I tend to get stuck alone at home, going nowhere but home and work, because it’s too difficult to navigate the world (with queues, not enough accessible parking and lots of walking and stairs) when I’m not well.”

We heard from families that have children with high support needs or unpredictable behaviour that they often felt very isolated.

The Deaf community told us that **many Auslan using children feel isolated in mainstream schools** as they do not have daily contact with other children they can easily converse with.

> “Parents of children with hearing loss find it difficult to access the community. School students can feel isolated and not included as they are spread out in mainstream schools and cannot create a peer network.”

COVID-19 has of course been another cause of social isolation. Many people have needed to isolate for extended periods due to health concerns and many are still isolating. In addition, a number of social options were paused during the pandemic, and some have still not resumed as before.

> “Since the COVID-19 pandemic and isolation, I am finding it difficult to reintegrate into society.”

> “Feeling socially disconnected with not as many opportunities to meet new people, especially since COVID-19 started.”

What the evidence says

Evidence tells us that people with disability can routinely feel segregated, excluded, marginalised and ignored.[11]

The exclusion of people with disability is driven by negative attitudes, stigma and prejudice and often results in increased vulnerability, social isolation, and loneliness, which are significant issues impacting people with disability and their families and carers.

The Disability Royal Commission noted ‘Attitudes are developed, reaffirmed, and shared within the wider community. Research suggests limited contact between people with disability and the wider community can contribute to a lack of understanding of disability. Negative attitudes can cause a social distance between people with disability and the wider community driven by stigma’.[12]

Nationally, the evidence[13] also tells us:

- People with disability aged 15–64 are twice as likely to experience social isolation compared to people without disability. These rates are consistent across all age groups, with the largest gap being between people with disability aged 15–24 (18%) and those of the same age without disability (6.6%).
- 28% of people with disability aged 15–64 experience loneliness compared to 16% of those without disability.
- Younger groups of people with disability (31% for those aged 15–44) have higher rates of loneliness that older age groups (26% of those aged 45–64, and 21% of those aged 65 and over).
- About 4 in 9 (or 44%) of people with disability aged 15–66 avoided situations, such as visiting family or friends or going to shops and cafes, because of their disability.
- More than 3 in 10 (or 31%) of people with disability aged 5–64 do no leave home as often as they would like to, with the most commons being related to their disability status, or due to anxiety, fear and cost.

A long-term study of 267,000 people in NSW undertaken by the Sax Institute also found that people with disability are significantly lonelier than the general population. Sixty-two per cent (62%) of people with disability are intensely or low/moderately lonely, compared to 50% of the general community.[14]

ISSUE 3 Not enough of a voice in policies and decisions that affect us

ACT WELLBEING DOMAINS

Government & institutions

Identity & belonging

What we heard from the community—the challenges

In the survey, we asked people to tell us about issues that affect people with disability. The second largest issue was: ‘having control over things that affect your life/the life of people with disability’.

We asked survey respondents to rate the priority areas for action. ‘Having a voice’ ranked 4 out of the 17 available options.

Throughout the consultation, people with disability told us they were not usually consulted or invited to contribute to policy decisions. People felt excluded from decision-making, and from representation in decision-making bodies.

> “People doing things to us or for us and not with us.”

People commented that government consultation processes were not accessible and did not ensure people with disability were proportionally reflected in engagement. People feel decisions are often made about them without the voice of lived experience.

We heard people with disability are not given the same educational or professional opportunities, and as a result are far less likely to be in corporate or government leadership positions, or in other positions of influence.

> “Disability has been considered something to hide, so people with disability do not get the same education, jobs, or social inclusion. They are not seen as ‘normal’—they are not in Parliament, on boards.”

What the evidence says

The motto of the disability rights movement, ‘nothing about us without us’ relies on principles of participation, in particular, the active involvement of people with disability in the planning of strategies and policies that affect their lives.[15] Articles 4 and 33 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) outline participation principles and require governments to closely consult and involve people with disability on all matters that affect them.

Including people with disability, and their representative organisations, in important decision-making discussions and policy reform agendas helps to ensure policies and programs are effective, fit for purpose and responsive to the diverse needs of people with disability.[16] On the other hand, we know that excluding people with disability from decision-making processes perpetuates their exclusion from all areas of society as ‘their perspectives are systematically ignored, leading to public policies and programs that are not responsive, not effective and continue to hinder their rights.[17]

Self-advocacy and self-advocacy groups are about empowerment and leadership and help support people with disability to build their skills and confidence to speak up for themselves, understand and assert their rights and have greater control over decisions about their lives.[18]

Self-advocacy works to improve the individual, social and political inclusion of people with disability, particularly people with intellectual disability, in a number of ways, including through ‘building social relationships, fostering participating in civic organisations and engaging in political structures and processes’.[19]

Evidence[20] shows that people with disability engaged in self-advocacy activities are exposed to opportunities that are likely to improve self-confidence allowing for more empowered engagement with the wider community. Furthermore, engagement in self-advocacy often involves greater participation in civil society and political activities, which results in the increased visibility and voice of people with disability.[21]

ISSUE 4 Community attitudes, stigma and discrimination

ACT WELLBEING DOMAINS

Identity & belonging

Safety

What we heard from the community—the challenges

In the survey, more than half of respondents felt ‘community welcome and inclusion of people with disability’ was a big or very big issue.

Fifity-seven per cent (57%) of survey respondents felt that taking action to change community attitudes was a high priority for the ACT Disability Strategy and 31% saw it as a medium priority.

The consultation told us one of the key issues with community attitudes is that people don’t think about disability when they plan services, events and developments.

> “People with disability are either an afterthought or second class citizen.”

Discrimination and mistreatment can be an outcome of negative community attitudes toward people with disability. People in the consultation told us they experience mistreatment which affects their wellbeing.

> “People’ attitudes to disability are archaic. Little things chip away at you all day.”

> “Negative attitudes and stigma from allied health professionals, teachers, parents, students, and community members.”

In the consultation we heard that people in the community have a lot of misconceptions about disability. We heard that people without disability rely on stereotypes and assumptions because they do not see people with disability represented in the media, or in enough parts of their everyday lives. We also heard about how the lack of representation in the media or public life impacts on the way people with disability see themselves.

> “The media does not reflect people like me. There is nobody to set an example of who I can aim to be when I am older. The people reflected in the media do not inspire me as someone who I can learn from and admire.”

People with disability told us they are frustrated when they are treated as ‘heroic’ just for living their lives.

> “I am tired of the social perception of being ‘inspiring’ for just doing everyday stuff.”

We heard that people with disability feel they are seen only as their disability and not as a whole person, with disability only one part of their experience.

> “People underestimating people with disability — we want most of the same things as everyone else. We don’t want people to look away from us, or disappear, because it’s too hard. We want to be valued as people rather than being seen as our disability.”

We heard that people with disability are presumed not to be able to make their own decisions.

> “Instead of asking me they are making decisions on my behalf.”

We heard there are many attitudes toward people with invisible disability, and that people presume they can tell a person’s disability status just by looking at them.

> “Not being believed when you have invisible disabilities such as chronic fatigue, autism etc. People say ‘you look fine to me’.”

People told us they feel there are low expectations about the capabilities of people with disability.

> “Lack of expectations. Because my son is non-verbal, there is the assumption that he can’t do something, and he is not given the opportunity to try, which makes him feel awful.”

Parents feel these low expectations affect their child’s experience at school and their child’s perception of themselves.

> “Teachers tell neurotypical kids ‘you can be anything you want to be’ but then tell us and our kids not to expect too much.”

We heard that students with disability are sometimes not included in mainstream school life which prevents the development of understanding and connection in young ages.

We heard that inclusion in the workforce is more difficult for people with disability. People with disability told us they feel ignored and excluded.

> “People with disability are perceived as not knowing what they are talking about, no matter the topic. They are not respected, not listened to, and not being treated as people worthy of being listened to.”

People told us sometimes professionals speak to their family or carer rather than speaking to them.

> “A doctor I saw recently spoke to my husband the whole time, not to me.”

In addition to overall wellbeing and quality of life, the impact of these negative community attitudes affects health outcomes, social connection, access to employment and financial outcomes for people with disability.

What the evidence says

Australia’s Disability Strategy 2021–2031 acknowledges these disadvantages, noting ‘People with disability continue to experience avoidance, discrimination, violence and abuse, hostility and low expectation, preventing active and meaningful social inclusion and participation in many aspects of society’.[22]

The Attitudes Matter survey, a population level representative survey of community attitudes towards people with disability, found that most people have positive or inclusive attitudes with only a minority reporting overtly negative attitudes.[23] However, it also identified that 78% of respondents were unsure how to act towards people with disability. This suggests that regardless of people’s intentions, uncertainty can drive behaviour that negatively affects people with disability.

We also know that attitudes can differ towards different cohorts of people with disability. Research shows that people without disability are less comfortable with people with psychosocial disability than with people with physical disabilities.[24]

Conscious attitudes and bias can be addressed directly through policy, with evidence showing this can be achieved by identifying specific situations where biased decisions can occur, then developing interventions to address them, which focuses on both ‘changing the attitudes themselves or the behaviours that reflect the attitudes’.[25]

ISSUE 5 Lack of disability awareness and knowledge across many sectors

ACT WELLBEING DOMAINS

Access & connectivity

Education & lifelong learning

Identity & belonging

What we heard from the community—the challenges

Lack of disability awareness came up in survey questions and consultation events on many focus topics, including education, early childhood, health and mental health, justice, safety, accessible community, and employment.

In the health focused conversation, we heard that people feel many health professionals lack disability awareness and as a result do not provide the care that is needed in an appropriate manner.

> “Attitudes from medical professionals who have very outdated information and say things like ‘you don’t look autistic’.”

> “Health care professionals need to speak to me in a way I understand. Speak clearly and ask me if I know what is going on.”

We heard similar comments in conversations about mental health.

> “Relationship counselling for people with disability often don’t have good outcomes. Counsellors don’t understand disability.”

Regarding safety, we heard about experiences with police as well as crisis support services where staff lacked disability awareness.

> “The attitude of police. There should be additional care and service for people with disability.”

> “Family safety and family violence services are not designed to act for people with disability.”

People's experiences in the workforce indicated that it is common to encounter colleagues and managers that lack disability awareness.

> “The attitudes of employers are based on past experiences of people with disability. Comments like ‘Oh! We had an ASD employee once before and it was a nightmare! We don't want someone like that again.’ Perceived barriers also stem from limited education on disability.”

In conversations around accessible communities, people shared experiences of community, recreational and social groups where lack of awareness created a barrier to participation.

> “I think partly it's that people do not have much knowledge about what accessibility means. I am constantly being told that that I am not a priority. If it happened once or twice, maybe, but when it's in almost every group?”

Similar comments were shared when discussing experiences of interactions with the justice system.

> “Lawyers have limited awareness and understanding of disability and, even if they do have some understanding, they are not allocated enough time to cater and adjust.”

What the evidence says

Disability awareness is defined as ‘educating people regarding disability and ensuring people with disability have rights to lead their lives and are seen as equal citizens'.[26] We know that people with disability and the broader community lack awareness of the rights of people with disability. Evidence tells us that lack of disability awareness across numerous sectors—such as justice, education, and health—delivers poor outcomes for people with disability. [27]

An action arising from work under Australia's Disability Strategy is the development of the Disability Best Practice Guide and Action Plan developed by the Australian Council of Learned Academies.[28] This disability confidence training will be incorporated within higher education curriculum and target occupations across the education, health, justice and social services workforce to better respond to the needs of people with disability.[29]

ISSUE 6 Financial disadvantage

ACT WELLBEING DOMAINS

Living standards

Economy

What we heard from the community—the challenges

What does a good life look like?

> “… one crucial thing: the money for disabled people to live a life like other normal people, not in poverty, cut from community and proper health care.”

In the survey we asked the community how much certain challenges affected them. ‘Having enough money for everyday things' was ranked as the fifth biggest challenge.

People told us the Disability Support Pension was not adequate to provide for all expenses, especially when medical expenses and prescriptions were required.

> “I get about $23k pa from the DSP. My absolute minimum expenses are $25k pa none of which are covered by the NDIS as they are ‘everyday expenses'.”

Lack of money affects people's ability to enjoy life and do things they enjoy.

> “I have no energy to do anything but the bare essentials. I cannot afford holidays or fun experiences that aren't free.”

Families told us financial pressures were compounded when there was more than one person with disability in the household.

> “Some days it feels impossible as a person with disability who is also a carer/parent to two children with disability. Making ends meet when medical costs are so high in the ACT is very difficult.”

Parents told us their ability to work, or to work full-time, was impacting on their care commitments for their child/children and this in turn added to the lack of money.

> “As a parent, I haven't been able to go back to work because I need to be available to navigate health support for my child.”

People with complex health conditions find that the health care they require can add to their financial strain.

> “I would like to be able to afford the health care that I need — I have to book my specialists appointments for when my Centrelink comes in, otherwise I won’t have enough money to pay for them.”

Only about 12% of people with disability in the ACT receive NDIS funding. For others, accessing supports, services and health care is very expensive.

> “If I want to access health services or support appropriate to my needs I need to pay for it out of pocket. Diagnostics, treatment, psychotherapy, medication, GP, everything is incredibly expensive. I am not eligible for any government or community support with my disability, and do not have a strong family or community network to support me.”

For some people, their living expenses mean they need to remain full-time in the workforce, even if doing so impacts their health.

> “My particular ‘disabilities’ are no longer or have never been listed on the list to allow me to access any financial support. I am also lucky enough to have a decent full-time job, however as a single person, I pay all my mortgage, utilities and living costs on my own, with no assistance. When you add all my medication costs and specialist visits to that it is difficult to afford it all ….”

Older Canberrans with disability spoke about the challenges of being ineligible for NDIS funding and being unable to access the same level of support through My Aged Care.

> “If you apply for disability funding after the age of 65, you are not eligible through the NDIS. You only qualify for the aged care package and the My Aged Care funding in more limited than the NDIS.”

What the evidence says

In 2021, the Sax Institute 45 and Up study found that people with disability experience much more financial distress than the general population. In that year:

- 53% of people with disability reported that finances control their life, compared to 39% of the general community
- 50% of people with disability reported they worry their money will not last compared to 32% of the general community
- 22% of people with disability reported they rarely have money left over at the end of each month compared to 11% of the general community.[30]

Barriers to education and employment, coupled with other forms of attitudinal and structural disadvantage restrict people with disability from living independently and fully participating in all aspects of society. Low employment and underemployment contribute to financial disadvantage. The labour force participation rates for people with disability has remained unchanged from 2003 (53%) to 2018 (53.4%), and the median income for people with disability is approximately half that of people without disability.[31] Subsequently, people with disability are at increased risk of experiencing poverty and financial disadvantage compared to people without disability.[32]

Nationally the evidence tells us:

- Around 2 out of 5 people living in poverty have a disability (38% of nearly 2 million adults living in poverty).
- one in 6 people with disability live in poverty (compared to one in 10 people without disability).

These figures likely underestimate the true number of people with disability experiencing poverty, as the poverty line does not account for the extra costs of disability. The costs of medical care, personal support, transport, and other expenses mean that people with disability are often worse off than people without disability on the same income. [33]

What we are thinking about

There are actions underway to address some of the systemic challenges outlined above.

To address the issue of confusing systems, as well as people with disability lacking a voice in decisions, the ACT Government funds several Disabled People's Organisations (DPOs) and non-government organisations to deliver self-advocacy, individual advocacy and systemic advocacy services and outcomes for people with disability in the ACT and we are committed to supporting these programs into the future.

To address the lack of disability awareness in many sectors, in October 2022 2 ACT-based organisations were awarded Information Linkages and Capacity Building (ILC) grants from the Australian Government. Canberra Business Chamber was funded to design and deliver a program to change attitudes of business owners towards employing people with disability. The ACT Disability Aged and Carer Advocacy Service (ADACAS) was funded to develop and implement a workplace disability inclusion initiative across the ACT and Queanbeyan. These grants are designed to remove barriers by building disability awareness in a variety of sectors.

To reduce stigma and discrimination towards people with disability, the Community Attitudes Targeted Action Plan sits under *Australia's Disability Strategy 2021–2031*, and sets out Australian, state and territory government commitments to improving community attitudes towards people with disability.

The ACT Government has committed to achieving the objectives of the Targeted Action Plan though key actions. Progress will be monitored and reported against on an annual basis, with a public report published towards the end of each year.

As we shape the ACT Disability Strategy, we are looking at how we can embed change to settings and systems to support inclusion for people with disability.

We are thinking about how we can:

- provide support for government, community, and business organisations to develop and implement plans to improve accessibility and inclusion
- ensure professionals and staff across sectors have disability awareness to provide services and deliver their work in a way that is inclusive
- make sure people with disability can be involved in consultation processes
- understand the existing sources of data across the ACT Government that can inform us about how people with disability are accessing government services and working in the service, with the aim of achieving more consistent and comparable data
- support people with disability and family carers to navigate the many systems they encounter, to help people find and get the support they need, and access services
- consider other options to change behaviour and overcome stigma and discrimination, such as public education and disability awareness campaigns.

2 Experience of **Aboriginal and Torres Strait Islander people with disability**

ACT WELLBEING DOMAINS

Living standards | Identity & belonging | Economy | Social connection

STORIES FROM THE COMMUNITY

> “I cared for my child with disability for 18 years, before he passed away. I was good at advocating for his support needs—better than most people in my community, however, that didn’t mean that he was able to access culturally safe supports. He often missed out on participating in our community events because we didn’t have the right cultural supports. I felt I had to “whitewash” my son, so that he could engage with disability supports because there was, and still is, nothing specifically for Aboriginal and Torres Strait Islander People with disability in the ACT community.”

Aboriginal and Torres Strait Islander people with disability and their family carers were invited to engage in a series of consultations led by Alarna Moscaritolo and Patrice Soward, both Wiradjuri women and Disability Reference Group members.

We held two conversations talked with Aboriginal and Torres Strait Islander people with disability and their carers. We asked what a good life looks like, what challenges they faced, and what ideas they had for change.

A third session was held to share what we had heard and proposed what would be included in this report to check that community members felt their views had been represented.

Image credit: Tanya Chatfield, ‘Aboriginal and Torres Strait islander people with disability, families and carers, young and old, reaching out and connecting in our communities’.

What does a good life look life?

Aboriginal and Torres Strait Islander people would be able to access services that are led and staffed by Aboriginal and Torres Strait Islander people. People told us that they wanted to be able to deliver the services in the way they knew would work for them — 'Mob helping Mob'.

> “If I was in crisis and I walked in and saw one of you fullas, I would know I was going to be alright.”

> “Our own unity within disability units. Our Mob can help ourselves.”

> “Having more Aboriginal People in these services both leading and servicing our community, our Mob helping Mob.”

Community told us they feel culturally safe, have trust, and feel respected when an organisation has Aboriginal and Torres Strait Islander staff.

We heard that cultural safety needs to be embedded in everything an organisation does — not just by having one Aboriginal or Torres Strait Islander staff member.

We heard cultural safety is more than a set of rules, it is understanding and incorporating cultural protocols to ensure organisations are aware of how to respond to the needs and circumstances of Aboriginal and Torres Strait Islander people with disability, their families and carers in the right way.

> “Culturally safe is including the whole family in the network. When one person has a disability and needs help, it impacts many, many people who provide support.”

Services and supports would be responsive and easy to navigate. We heard people want to be able to be able to call a service and speak to a person. They want interactions with service providers to feel like having a human conversation, not going through a series of tick-box questions. They want disability supports and services to never have a 'wrong door'.

> “Easy processes, so we don't have to be waiting and put on hold for long periods of time. Being able to access services fairly quickly and go to places where we can get that support when we need it.”

> “Less red tape. It's about having that one-stop-shop.”

> “When we want or need a service now due to a crisis, those services should be available now. We don't need the added frustration of not being able to speak with a person.”

Carers would be supported. People told us that caring is just part of life — not only for people who are the parent or immediate family member of a child or adult with disability, but for extended family and community members as well. They told us that in a good life, carers would be able to get the information they need, know what supports are available and how to access them. Workplaces would be accommodating to caring responsibilities. Carers would be able to take time off from caring before they experienced burn out and would have opportunities to get together with other carers to support and learn from each other. In a good life, carers would have financial security, and be able to retire comfortably.

> “You love your family but need help and support to look after yourself as well.”

People told us how good health includes physical, mental and spiritual health. Good health care from doctors and hospitals is important, and so are mental health services. But health is not limited to medical settings — health also comes from connection to people and Country.

> “Health means more than just medicine — it means friendship, intimacy, being listened to.”

> “Being able to get together, being able to go bush.”

People would like to know their child with disability is safe at school. This includes knowing that they are safe from physical harm and bullying, and that their school is culturally safe. We heard it is important that cultural safety isn't the responsibility of only one teacher, but the responsibility of everyone involved in the school.

> “Knowing what happens to your kids when you are not there and feeling they are safe at school, that somebody is looking out for them.”

What are the challenges?

It is hard to find culturally safe services and supports. Most people do not have anywhere to go for culturally safe disability support — the exception was people who had built relationships with a specific staff member who was able to deliver culturally safe support. Everyone agreed there is no organisation that could be relied on as culturally safe, in the disability sector.

> “The reality is that the majority of the Aboriginal and Torres Strait Islander community have nowhere safe and supportive to go, outside of their own homes. No official advocates who specialise in the issues surrounding disability in their community.”

We heard about bad experiences with service providers. People felt they were racially profiled, and that service providers were patronising or judgemental, especially when entering their homes.

> “I have always felt dirty. I have had to whitewash myself and my son, having these services coming into our home.”

We heard that providers aren’t prepared to adapt their service to the reality of Aboriginal and Torres Strait Islander family structures and ways of caring. We heard accounts of providers wanting to speak with a single primary carer, or to visit a single place of residence, when there was no single primary carer or place of residence for that person.

> “A lot of the services would come to me and talk to me on my own, but we don’t do it on our own. There is no single primary carer — we have a whole army of primary carers!”

Some families we heard from did have a single primary carer. People emphasised that different families had different structures, and that service providers needed to understand and respond to that reality.

Cultural safety is important for students with disability. People told us that cultural safety can influence the family’s decisions when choosing schooling and education options. People felt the small group units within mainstream schools were not as equipped to support students and their families and did not inform families about the services available through NDIS. We heard a strong message about the need for cultural support staff for Aboriginal and Torres Strait Islander students in specialist schools.

The system is hard to navigate, and supports are not coordinated. People told us that seeking support was exhausting, and they were often told that the service or organisation they were approaching was not the right one to resolve their issue.

> “There are so many different services, how do you know what they are or where to go? There is unclear and inconsistent information.”

There are many different services within the ACT and a lot of Aboriginal and Torres Strait Islander people are told that they need to access multiple services to be able to receive the supports their family need. Community would like to see a one stop shop, a place wherec ommunity could attend and be connected with the different services available in Canberra, without being made to run around all over town, especially if they don’t have the means to travel around Canberra.

Social housing supports are not adequate or fit for purpose. We heard it is hard to get allocated an appropriate home and Aboriginal and Torres Strait Islander family structures are not reflected in the way housing is allocated.

> “Housing supports don’t match the shape of Aboriginal families.”

Caring responsibilities are often shared across extended families and kinship networks, but housing decisions often do not accommodate for this. Many people need homes large enough for extended family to come and stay, to help with caring or for respite. People told us that in their experience, housing allocations are often a long way away from extended family.

> “Eventually when you get an accessible home, it is across town. It costs so much for people to travel to your house you, lose your networks, and an additional stress factor is now placed upon yourself and your support networks. Why can’t we have an accessible house near family.”

We heard funding for home modifications may not reflect Aboriginal and Torres Strait Islander family structures and ways of caring. Both immediate and extended family members often provide care for other family members with disability, and their homes need to be accessible to provide appropriate and safe natural supports.

> “The NDIA wouldn’t pay for the modifications for my [extended] family’s homes, so he [son] was excluded from his family. We had to drag him down the corridor on a mattress. We needed funding to accommodate more than one home, because he had more than one home. We needed my family’s homes to be accessible as well.”

Nobody we heard from had disability support services provided by a First Nations support worker in their lifetime. We heard community-controlled organisations are not involved in the provision of disability supports.

> “During my working career at an Aboriginal community-controlled organisation, I saw that there were a lot of our kids there who were experiencing autism. It frustrated me that we weren’t trained in that area, and I didn’t know a lot about it.”

> “In the ACT there is no First Nations peak body for disability, therefore it is expected that other Aboriginal Community Controlled Organisations should pick up the downfall, when they are not funded or resourced to be able to successfully deliver the specialised services our community with disability need. A First Nations disability peak body is exactly what our Canberra community need.”

There are different understandings of disability in Aboriginal and Torres Strait Islander communities, and the word ‘disability’ is not often used. While that creates less segregation of people with disability, it can also lead to invisibility or dismissal of the experiences of people with disability.

> “My experience as a carer, and my son’s experience as a boy with disability, is invisible in my community. I feel invisible.”

> “The use of the word disability in our community has a lot of intergenerational traumas attached to it, due to a period in time where if our children had a disability, they would be taken from us and placed in homes — sadly this continues to this day.”

People are hesitant to approach government services for support, because of deep distrust. We heard from people who had received advice from family not to seek help from disability support organisations because it might result in their child being removed from their care.

> “You can’t tell these white folks that you are struggling because they’ll take him child, and we won’t see him again.”

People felt asking for help would perpetuate negative stereotypes about First Nations Peoples not being capable of self-reliance. People felt judged by services when they entered their home.

> “We don’t often ask for help. If we do ask for help, there is always stigma around it. We look after our own.”

We heard that people didn’t approach government services because they were disillusioned and didn’t expect real help after being failed many times. We heard distrust of government services was the result of multiple generations being actively harmed by government intervention.

There is so much trauma that we face daily, and people don’t think — they say we ‘should be past it’ but we will never be past it.

> “As a community, we are still talking about the same problems that people have fought for, for 20 to 30 years and there is still no change.”

People feel government doesn’t understand Aboriginal and Torres Strait Islander peoples’ experiences, doesn’t talk with Aboriginal and Torres Strait Islander communities, and isn’t accountable to Aboriginal and Torres Strait Islander communities. People are frustrated about government making decisions without understanding culture. People feel government only interacts with a small number of organisations and doesn’t go out to communities directly.

People community told us that **guardianship guidelines are not culturally appropriate for community**. People felt that they were pushed into making an application for guardianship for finances or health decisions. Understanding the rules about what this involves can be complicated and ‘if you get it wrong then a strange white person takes away your rights to make decisions about your children’. Family carers of people with disability who need support making decisions are concerned about their family member’s welfare if/when they pass away.

Carers face challenges with financial security and employment. Many family carers shared financial difficulties they experienced or anticipated experiencing in future because of caring responsibilities. We heard that everyday expenses, like food and bills, are often difficult to afford on the carer's payment. People also shared concerns about their retirement, as they did not work or had to take time off work to provide care, and as a result had accrued little or no superannuation. People told us they were concerned about their job security because they frequently had to take time off work or ask for flexibility to accommodate caring responsibilities. We heard about the mental health impacts of constant financial stress, and the immense responsibilities of caring.

> “There's that fear of letting the family down by not being able to provide that secure income.”

We heard about challenges finding employment as a First Nations person with disability. We heard that while there are employment supports for people with disability, and private recruitment agencies for Aboriginal and Torres Strait Islander people, there are no culturally safe specialist employment services for Aboriginal and Torres Strait Islander people with disability.

> “How does my son with a disability get job ready? Get a job? We don't get help.”

> “How do our family members with a disability get the opportunity to have a job? Who do we go to? What are the services to support them? What kind of jobs can they apply for? What support will be provided to them in their jobs?”

Trying to navigate the NDIS is challenging. People want an Aboriginal or Torres Strait Islander supports through the NDIS, including culturally appropriate and culturally safe plan managers. We heard people had plan managers who did not understand their culture and way of life and wanted them to change to be able to manage their supports their way, which is culturally inappropriate.

> “Quite often, regarding my son's NDIS package the planners would say ‘in order to give you a break, your mum takes your son’. No, culturally my mum needs to spend time with her grandson on her own. They say ‘we don't fund that, though’ even though she is one of his primary carers. Her home is where he was raised.”

What are the ideas for change?

We consistently heard the best solution is ‘our mob looking after our mob’.

Some ideas were:

- an Aboriginal and Torres Strait Islander-controlled disability support organisation
- an advocacy service for Aboriginal and Torres Strait Islander people
- a community-run program targeting particular cohorts like men, women, elders and youth, to give them a space to talk about their struggles where they feel safe and don't feel shame
- community-controlled supports and services, including detox, rehabilitation, and healing places.
- Aboriginal or Torres Strait Islander NDIS Plan Managers and Local Area Coordinators.

Aboriginal and Torres Strait Islander Community Controlled Organisations being better resourced to be able to employ, train and retain qualified employees to lessen the burden of one or two position that are sometimes funded.

People want to see cooperation and communication between government and Aboriginal and Torres Strait Islander communities at the grassroots level. People suggested it should be easier for small community initiatives to get funding.

> “If I want to organise a yarning circle, and get funding for hiring a room, or printing flyers, or getting catering, I shouldn't have to go through [community-controlled organisation] to do it, or Office for Disability to do it.”

People suggested an advisory group of people from different parts of the Aboriginal and Torres Strait Islander communities in Canberra for all Aboriginal and Torres Strait Islander people within Canberra to come together to ensure consultations include a variety of voices.

People feel government needs to consult more frequently, more widely, and should pay people meaningfully for consultation. Payment for consultation should be simple, and on-the-spot, rather than a long process of filling out forms.

We heard that identified positions have potential to deepen trust and connections with community, but only if the recruitment process is completed properly. Some people feel criteria for an identified position should be more than Aboriginal or Torres Strait Islander ancestry. They suggested employers look for people with genuine and long-standing connections to the local community.

People suggested information about child development and disability support services could be shared with parents via Koori Pre. We heard that for many Aboriginal and Torres Strait Islander children, Koori Pre is their first opportunity for early intervention. We heard that although hearing tests and health checks are a part of the Koori Pre program, extra Allied Health support for children with disability who attend the program would be of value.

People suggested support for system navigation, including mainstream supports, disability supports, and supports specifically for First Nations Peoples. Some people suggested a central place where staff have cultural understanding and knowledge about disability supports, such as a hub or directory service.

Other people suggested better linkages between existing services, and warm referral processes.

We heard through consultation participants and submissions about the importance of making sure Aboriginal and Torres Strait Islander cultural beliefs, knowledges, protocols and understanding of disability are embedded in all services, whether they are provided by government or the community sector. Community members emphasised the need to train non-Indigenous staff about Aboriginal and Torres Strait Islander cultures and practices. This is an extremely important component to ensuring cultural safety is provided when non-Indigenous staff are supporting community.

People suggested more supports for Aboriginal and Torres Strait Islander people with disability to enter the workforce, such as an Aboriginal and Torres Strait Islander Disability Employment Service as well as job-preparedness courses for Aboriginal and Torres Strait Islander people with disability when leaving school.

We heard ideas about more support for carers. We heard about the importance of peer support, for carers to get together with other carers. People suggested that carers have the opportunity to have out-of-home respite, that is inclusive of larger family groups and also includes the person with disability but provides a break from everyday responsibilities. People suggested carers payments include contributions to superannuation, so that carers were able to retire after a lifetime of work, like everyone else is able to.

What the evidence says

The National Agreement on Closing the Gap is a policy framework that establishes goals and commitments for various levels of government to improve life outcomes for Aboriginal and Torres Strait Islander people. There are no targets specifically aimed at improving outcomes for Aboriginal and Torres Strait Islander people with disability, but 7 targets include disaggregation for disability status in baseline indicator data. Gathering disaggregated data about disability status is marked as an area for data development for a further 3 targets.[34] Collecting data about outcomes for people with disability is an essential step to improving outcomes.

Australia's Disability Strategy 2021–2031 acknowledges that Aboriginal or Torres Strait Islander identity impacts the way people are viewed, understood, and treated, as well as how they access, or are unable to access, resources, services and supports. Most of the Targeted Action Plans (TAPs) under the Strategy (including the Employment TAP, the Community Attitudes TAP, the Early Childhood TAP, and the Safety TAP) include specific actions to improve outcomes for Aboriginal and Torres Strait Islander people with disability.

Disability prevalence

Aboriginal and Torres Strait Islander people of all ages are significantly more likely to have disability than other Australians. In the 2018 Survey of Disability, Aging and Carers, about one in 4 (24%) First Nations Peoples were identified as a person with disability.[35] The 2018–19 Aboriginal and Torres Strait Islander health survey[36] which uses a broader definition of disability found prevalence: 38% nationally, and 42% in the ACT.[37]

Both surveys found that disability prevalence is similar between Aboriginal and Torres Strait Islander men and women.[38]

Life outcomes

Aboriginal and Torres Strait Islander people have significantly worse health and social outcomes than non-Indigenous Australians. Colonisation, racial discrimination, trauma and a lack of culturally appropriate services have all contributed to the poor life outcomes of First Nations Peoples.

There is a lack of data on the life outcomes of Aboriginal and Torres Strait Islander people with disability.[39] The lack of data is identified as a focus of work in the Closing the Gap Disability Sector Strengthening Plan.[40]

The *Closing the Gap Data Development Plan* includes actions to expand the amount of data available about life outcomes for Aboriginal and Torres Strait Islander people with disability by making disaggregated data by disability status available.[41] As well as asking about and recording disability status more widely, and better linking existing data, the Closing the Gap Disability Sector Strengthening Plan identifies the need for 'a more culturally inclusive method of research and data, one which is grounded in community',[42] which will amplify the voices of First Nations Peoples, and ultimately and allow a far better understanding of the experiences and perspectives of First Nations Peoples with disability.

Employment

At the time of the 2018 Survey of Disability Aging and Carers, more than half (56.2%) of Aboriginal and Torres Strait Islander people with disability were not in the labour force, compared with 24.3% of Aboriginal and Torres Strait Islander people of the same age with no disability. One-third (33.1%) were employed, compared with 64.5% of Aboriginal and Torres Strait Islander people of the same age with no disability.[43]

Education

Just over half (50.2%) of Aboriginal and Torres Strait Islander people with disability aged 15 years and over have completed year 11 or above. Less than one in 10 (7.2%) have completed a bachelor's degree or above.[44]

Health

In the National Torres Strait Islander Social Survey, last conducted in 2014–15:

- 23% of First Nations Peoples with a disability or restrictive long-term health condition rated their health as excellent or very good, compared to 53% of First Nations Peoples without a disability.
- 45% of First Nations Peoples with a disability or restrictive long-term health condition experienced high or very high psychological distress in the last 4 weeks, compared to 23% of First Nations Peoples without disability.

- 19% of First Nations Peoples with disability or a restrictive long-term health condition reported they had experienced problems accessing healthcare services, compared to 11% of First Nations Peoples without disability.

Justice

We know that disability prevalence is higher among Aboriginal and Torres Strait Islander people. We also know that Aboriginal and Torres Strait Islander people are drastically overrepresented in the justice system; in the ACT, Aboriginal and/or Torres Strait Islander people are imprisoned at 19 times the rate of non-Indigenous people, well above the national average.[45] However, data on the disability prevalence of Aboriginal and Torres Strait Islander people who are imprisoned, or who interact with the justice system in other ways, is scarce.

Towards Disability Justice for the ACT notes the following barriers to the identification of Aboriginal and Torres Strait Islander people with disability in the justice system:

> “To a large extent the justice system relies on people with disability identifying as such and there is evidence of underreporting by Aboriginal and Torres Strait Islander people due to a range of factors including: a cultural conflict between the Western concept of disability and the diverse approaches to recognising and responding to disability within Aboriginal and Torres Strait Islander communities; a lack of trust due to inter-generational trauma; a lack of culturally appropriate disability services; and multiple involvement in service interventions.”[46]

The Disability Royal Commission has provided a comprehensive body of evidence on the experience of Aboriginal and Torres Strait Islander people with disability related to justice. The Royal Commission heard evidence that:

- First Nations women with disability who have experienced sexual abuse and/or domestic and family violence were disbelieved, ignored or no action was taken when they reported the incidents to police
- there is a lack of culturally appropriate screening for First Nations Peoples or cognitive impairment in the criminal justice system
- lack of identification of disability and disability supports for First Nations Peoples in custody leads to greater risk of being subject to restrictive practices or abuse by other prisoners in response to behaviour stemming from undiagnosed disability
- lack of identification of cognitive disability amongst parents of children in the child protection system reduces opportunities to support parents to continue to care for their children in their homes.[47]

Accessing disability supports and services

Between September 2018 and December 2022, the number of Aboriginal and Torres Strait Islander people participating in the NDIS more than quadrupled nationally (10,574 participants to 42,679) but increased by only 61% in the ACT (270 to 435)[48] in the same period. The National Aboriginal and Torres Strait Islander Health Survey 2018–19 found disability prevalence among Aboriginal and Torres Strait Islander people in the ACT to be slightly higher than the national average (42% versus 38%), as was the rate of having a profound/severe core activity limitation (9% versus 8%).[49]

‘Committed support’ describes the financial level of support the NDIA has committed to provide a participant based on their assessed need. As of September 2022, the average committed support for identified Aboriginal and Torres Strait Islander participants in the ACT was $28,813, which is below the average committed support for identified non-Indigenous participants ($33,332) as well as for identified Aboriginal and Torres Strait Islander participants nationally ($34,607).[50]

‘Utilisation rate’ describes how much of those allocated funds are being spent, as a percentage of the committed support. As of September 2022, the average utilisation rate for identified Aboriginal and Torres Strait Islander participants in the ACT is 72%, which is slightly below the average utilisation rate for identified non-Indigenous participants in the ACT of 76%.[51]

The NDIS was raised by more than half of respondents to the Disability Royal Commission’s Experience of First Nations Peoples in Australia Issues paper. The Royal Commission identified ‘a lack of culturally appropriate services, complex application processes, inadequate funding for remote service delivery and an overall lack of cultural capability’ as the main concerns of respondents related to the NDIS.[52]

Cultural and social inclusion

Aboriginal and Torres Strait Islander people with disability participate in cultural events, ceremonies, and activities at the same rate as Aboriginal and Torres Strait Islander people without disability. They are also equally likely to speak an Indigenous language, recognise an area as their traditional Country, and identify with a clan, tribal or language group as Aboriginal and Torres Strait Islander people without disability.[53]

Scott Avery, Worimi scholar and activist comments that the "inclusive participation in cultural and community events has a positive impact on social health and wellbeing and moderates the harm of inequalities experienced in daily life".[54] Based on his research, Dr Avery sees the inclusion of people with disability in Aboriginal and Torres Strait Islander communities as an enduring feature of First Nations cultures that has persisted despite significant disruption to First Nations Peoples' ways of life and practices since colonisation.[55]

Strengthening the community-controlled sector

Submissions to the Disability Royal Commission,[56] and the Closing the Gap National Agreement [57] identify the need to increase and strengthen First Nations community-controlled organisations.

The National Agreement on Closing the Gap identifies the following as key to a strong sector:

- sustained capacity building and investment in Aboriginal and Torres Strait Islander community-controlled organisations
- a dedicated and identified Aboriginal and Torres Strait Islander workforce […] where people working in community-controlled sectors have wage parity based on workforce modelling commensurate with need
- support by a peak body, governed by a majority Aboriginal and Torres Strait Islander Board, which has strong governance and policy development and influencing capacity
- a dedicated, reliable and consistent funding model designed to suit the types of services required by communities, responsive to the needs of those receiving the services, and is developed in consultation with the relevant peak body. [58]

What we are thinking about

As we develop the ACT Disability Strategy, we will continue to collaborate with Aboriginal and Torres Strait Islander people with disability, their families, and carers. We are thinking about how we can:

- Support self-determination of Aboriginal and Torres Strait Islander people with disability in all aspects of planning, service design, service delivery, and data collection.
- Support a disability focused Aboriginal and Torres Strait Islander Community Controlled-Organisation in the ACT.
- Develop strong and trusting relationships between the ACT Government and Aboriginal and Torres Strait islander people and communities.
- Embed culturally safe practices in all services delivered by the ACT Government.
- Improve access to early intervention for Aboriginal and Torres Strait Islander people with disability of all ages, at key life stages.
- Improve data collection to better understand the diverse experiences of Aboriginal and Torres Strait Islander people with disability, while aligning any data development with the principles of Indigenous Data Sovereignty.
- Ensure Aboriginal and Torres Strait Islander people with disability who interact with the justice system are identified and connected with culturally appropriate services.

3 Early **childhood**

ACT WELLBEING DOMAINS

Access & connectivity

Social connection

STORIES FROM THE COMMUNITY

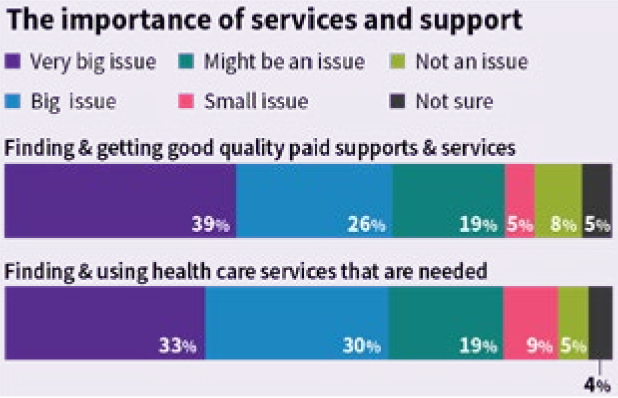
Tas* received an autism diagnosis for her young son from a paediatrician. She was given no information from the paediatrician on what autism was, or on what supports, and help were available to the family. She went to her GP the next day and asked what she should do to 'fix' her son's autism Looking back, having learned a lot more about autism, she realises her diagnosing specialist had not given her any of the information she needed to support her son.

What we learned

Quantitative survey information

We heard that supports and services, healthcare and education were important issues to the community, particularly for family members and carers. These issues relate strongly to the early childhood years.

In the survey we asked people what their biggest challenges were. 'Finding and getting good quality supports' and 'Finding and using health care services' ranked first and third.



For family members and carers, these issues ranked first and second — 73% of family members and carers rated them as big or very big issues.

What we heard

What are the challenges?

We heard that families face challenges trying to get a diagnosis for their child. A diagnosis is important to many families as it provides them with an understanding of the condition, what it means and how they can assist their child. A diagnosis is also essential to access a range of supports that could make a big difference in the life of a small child.

We heard that at the time of the consultation, the wait for a free autism assessment through the Child Development Service can be very long. Families may seek a private assessment if they can afford to, but we heard that there is a shortage of diagnosing professionals in the ACT, meaning long wait times. Many families travel interstate for an assessment, but this is expensive and time consuming.

Families told us the wait for a diagnosis can mean a delay in early intervention therapies and supports for their child.

> “There is a huge gap, parents who are wanting a diagnosis and having to wait 12–18 months. This is a long time in the early intervention window.”

We heard that the system is confusing. Parents find it hard to learn about available supports. In the early childhood years, parents are juggling new parenthood along with trying to navigate support and funding systems such as the NDIS. We heard from families who felt they were not supported by their diagnosing specialist to understand the next steps to finding supports.

We heard that support services often did not refer on to other supports and services that could assist. We heard that families had no one to assist them in through their journey across the service system. Parents of children born with hearing impairment told us they found it difficult to find information on how to learn Auslan and to connect with other families in the Deaf community.

> “New parents who have no experience with disability are juggling all the new parent challenges along with supporting a child with disability.”

People feel the support available has reduced since the introduction of NDIS. They feel there is less community-based group support, and the focus has shifted to individual paid support. People explained that individual support does not always meet all a child’s needs, such as the need for social interaction, nor does this meet their family’s needs to learn, understand how to best support their child and be part of a community. Individualistic support also means many children without an NDIS package have few options available to them.

> “There is a gap after NDIS — once NDIS funding starts, there is no longer a holistic centre to guide families through the process.”

We heard from multicultural communities that across cultures, attitudes toward disability may vary and this can be a barrier to families reaching out for support.

A family’s visa status impacts whether free supports are available. Some people without permanent residency are afraid if they reveal they have a child with disability they will be deported and not be successful in their claims for residency.

We heard that some parents with disability are afraid of asking for additional support as they fear they will be seen as unfit parents and risk having their child removed into care. We heard that they don’t want to make a fuss about housing or supports in case people think they can’t support their child.

Some people felt they had encountered early childhood educators who lacked disability awareness and inclusion training and that more of this training is needed.

We also heard from the community they felt many staff in the school space also lacked disability awareness training.

Some early childhood educators told us they felt their qualifications did not equip them to support children with disability.

> “What damage are we doing to children when we aren’t ready for them? Why should they pay the price of us having to work on the fly?”
> Early childhood educator

We also heard there is a lack of after school care and holiday programs that can accept, include, and cater for children with disability.

What are the ideas for change?

People wanted early childhood education centres and schools to implement Disability Action and Inclusion Plans so they could understand exactly what the commitment was to their child and what to expect. People felt these plans would support families in which a parent has disability and make centres inclusive for staff with disability. People would like to see more training for early childhood educators, teachers, and other school staff on disability awareness, into qualifications and regular professional learning.

People would like to see easier and quicker access to assessments and diagnosis through free child focused services.

They would like to see more free community-based support outside of NDIS so that young children can get early intervention support that is not dependent on a diagnosis or NDIS plan.

Some participants came up with the idea for a one stop holistic centre to support young children with disability and their families. The centre could help connect with available supports, access programs, connect with other families and provide referrals, therapeutic intervention, health care services and check-ups.

People would like to see intensified early support for families with babies with disability and for new parents with disability. This includes extended home visiting programs by experts, such as Maternal and Child Health nurses or social workers.

Community members advised there is a need to find a way to build the knowledge of diagnosing specialists about the support systems available to families and children with disability.

Peer support programs that help share the knowledge of families with older children with disability with families with newborn or young children with disability, were also suggested.

We also heard the need for an improved response to Foetal Alcohol Spectrum Disorder (FASD), including opening a specialist FASD clinic in the ACT and upskilling health practitioners and the community on FASD.

What the evidence says

The Australia Early Development Census (AEDC) measures early childhood development across 5 domains as they enter their first year of full-time school. The census shows a trend of increased developmental vulnerability in ACT children. Since 2009, we have seen increases in developmental vulnerability in all 5 AEDC domains for ACT children:

1. Physical health and wellbeing
2. Social competence
3. Emotional maturity
4. Language and cognitive skills (school-based)
5. Communication skills and general knowledge.

The proportion of children developmentally vulnerable on one more domain(s) has increased from 24.6% in 2018 to 26.7% in 2021.

The percentage of ACT children identified as needing further assessment increased from 14.7% in 2018 to 17.6% in 2021.[59] Children defined as having ‘special needs’ (AEDC terminology) are not included in these overall developmental vulnerability scores.

Best practice actions to achieve change

Parent education

Several effective parental training programs improve parents’ capacity to identify early signs of disability. One example was trialled by the University of the West Indies.[60] Parent training sessions were conducted during routine health checks and immunisations for children (3–18 months). Parent training programs have been shown to improve parenting self-efficacy in parents of children with developmental disability.[61]

For Australian families waiting for diagnostic confirmation of their child’s possible disability, the NDIS Early Childhood Approach allows them to access funding for early intervention without a formal

The Deaf community would like to see easier access to learning Auslan and more connection for families with babies and young children to community. Children are mostly on their own in education settings as the only signer in class. An opportunity for children and families who use Auslan to meet, and connect for a shared purpose, would foster a positive sense of community.

People suggested that Cultural and Linguistically Diverse community organisations could provide supports such as peer programs and information for their communities.

Aboriginal and Torres Strait Islander peoples suggested more information and supports be provided through Koori Pre.

Participants suggested more intervention and support could be provided through preschools— the earlier the support the better.

People suggested increasing disability education in early childhood education and teaching training.

diagnosis. However, many parents are unaware of this option and parents are rarely advised of this option by their primary care physician or healthcare professionals. The NDIS Early Childhood Approach can be accessed with a diagnosis of Global Developmental Delay from a GP, a much simpler process than a formal diagnosis. Promoting this option to parents and to GPs and other health care providers would help families access early intervention sooner.

Supports for families

Peer supports

Studies suggest parental support groups are effective at improving a sense of belonging, parental self-efficacy, confidence, a sense of empowerment,[62] lowered depressed mood, and general wellbeing.[63] One study highlights the potential effectiveness of web-based support programs in facilitating support seeking behaviours in parents.[64] Kindship is a social media app that functions as an online support group.[65] Kindship now has over 2,500 parents.

Peer support can also help families navigate the system. Evidence suggests peer lead advocacy can help combat government complexity. Parents that look to their peers when seeking information about services have better outcomes than those who are socially isolated and unconnected.[66]

Community sector supports

In Western Australia more than 5,500 families raising children with disability are supported by the organisation Kalparrin,[67] primarily funded by state and federal grants. Kalparrin delivers several services such as free one-on-one support; free information resources; peer support programs; and in-hospital support. Organisations such as this can provide affordable support to families unable to access privately funded support or NDIS.

ACT context

The *Best Start for Canberra's Children: The First 1000 Days Strategy* (Best Start)[68] has recently been launched to support a coordinated effort focused on the first 1,000 days in a child's life to enable parents to feel more confident, supported and connected and for services to be accessible.

Set up for Success: An Early Childhood Strategy for the ACT[69] was released in 2020 to ensure all children in the ACT have access to the early learning and development they need.

An Inclusive Education Strategy[70] and the ACT Disability Strategy are being prepared through collaboration across ACT Government directorates.

The ACT Government has announced that the Child Development Service will be recruiting 14 more allied health professionals commencing in 2023 to provide early intervention therapeutic support for children aged 24–36 months who experience developmental delays.

What we are thinking about

As we shape the ACT Disability Strategy, we are thinking about how we can:

- Align actions within the ACT Disability Strategy with Set up for Success, Best Start, as well as the ACT Inclusive Education Strategy and the ACT Disability Health Strategy that are under development, to improve access to early ongoing childhood therapies, services, and support as well as access to quality, disability-informed early childhood education.
- Ensure families can easily access early intervention and support when needed, that is safe and culturally appropriate.
- Assist families to navigate systems to try to achieve great outcomes for their children.
- Improve access to supports for young children without a formal diagnosis or NDIS package.
- Make it easier for children to have their needs identified, assessed, and supported.
- Increase disability awareness amongst early childhood education and school staff and among young children and increase their understanding of early childhood development and the identification and impact of disability.
- Increase supports for parents with disability from maternity through to parenting.

Image credit: Celia, age 11

4 Accessible **communities**

ACT WELLBEING DOMAINS

Access & connectivity

Social connection

Safety

UNCRPD

Article 9 of the UNCRPD requires State Parties to ensure people with disabilities access, on an equal basis with others, transport and the physical environment, both in urban and rural areas. [71]

STORIES FROM THE COMMUNITY

> “I am legally blind and use a white cane to help me when I am out and about. My cane allows me a lot of independence and using it has helped me to feel much safer as my vision has declined. After using a white cane for more than 5 years, I would say I am very good at navigating unfamiliar environments—but since moving to Canberra I often find myself in trouble. There have been many times I have been walking along a footpath, only to find it ends suddenly in the middle of a nature strip. Curbs often drop suddenly onto the road, instead of slowly sloping down. Public art tends to just pop-up in places in the city all of a sudden, without tactile markers around it to indicate that I am about to encounter a hazard. The people I have met since living here have been so warm and welcoming—I can’t say the same about the built environment.”

What we learned

Quantitative survey information

The survey included questions about issues that people with disability experience in the ACT and asked people to consider actions that would make a difference.

The survey asked people to pick one highest priority for action. 'Accessible building and community amenities' were in the top 5 selected.

The survey asked about community attitudes. **In the survey, most respondents agreed that the broader community struggles to know how to interact with people with disability**, with 87% of people feeling the broader community often does not consider the needs of people with disability and 72% feeling the broader community is not comfortable asking people with disability what supports they need. These attitudes create barriers that affect access to many parts of everyday life for people with disability.

What we heard

We heard that access is more than physical access to buildings and places. Access is feeling welcomed and considered.

Access includes attitudes of people in community and providers of services. Access includes people's homes, visiting friends, public spaces, shops and services. Everyone should be in a position to make their way through public spaces with the greatest possible independence and comfort.

Image credit: Phebe, age 16

What are the challenges?

We heard about the challenges people with disability experience moving around public spaces.

A good life is…

> "a world where I do not have to fear the environment."

> "I am not disabled if my environment is designed well — if it is designed well, I don't have a disability and I can do exactly what you do."

People told us that inaccessible design in public spaces is very common, including in newly built infrastructure. We heard that Canberra's urban areas can be difficult to navigate because of walkways being too narrow or obstructed, tactile markers not being used or being used incorrectly, and gradients being too steep. Issues in suburban areas include streets without footpaths or footpaths that end suddenly, and vertical curbs at road crossings.

We heard how accessible environments sometimes become inaccessible because they are not well maintained, or because laws about walkway obstruction aren't followed. People told us how sandwich boards, café furniture, shared e-scooters, and overgrown plants contribute to making public spaces unsafe to move around for people with vision or mobility impairment. Sensory accessibility was raised as a concern. People talked about the way that smells, sounds, light and colour, and other sensory inputs can impact people with sensory sensitivity. We heard that while people who are neurodivergent may be impacted by different sensory inputs, there are some ways that a space or activity can have strong negative impacts on some people while providing no real benefit to others — for example, scented soaps and air fresheners.

The behaviour of other people impacted how safe people with disability feel moving around the community. We heard comments from people who felt unsafe because strangers they interacted with in the community acted in a way that was threatening or inconsiderate.

People told us that they have trouble getting where they need to go. People who use cars as their main form of transport told us that there are often not enough accessible parking spaces, and that accessible parking spaces don't always have an accessible entrance nearby.

We heard the ACT Taxi Subsidy Scheme does not meet everyone's needs. Most people we spoke to were not aware that it is possible to request additional trips on top of the allocated 126 per year. People felt that increases to the subsidy haven't kept up with increases in taxi prices.

People who use public transport told us that while parts of the network are accessible, there needs to be improvements for everyone to have a fully accessible journey, every time. People want more frequent bus services, and for all bus stops and buses to be fully accessible. They also told us that more park and ride services, with plenty of accessible parking spaces, would make using public transport easier and more appealing.

Disability awareness of transport drivers was an issue. People told us that they had faced discrimination from taxi and ride-share drivers refusing to allow their guide or service dog to travel and other examples of mistreatment.

We heard it is difficult and unreliable to get accessible transport in the evenings. We heard accounts of people unable to communicate independently left in extreme weather conditions without transport.

We heard about the challenges people face accessing the services and amenities they need. People told us there are not enough accessible bathrooms in public places like parks and shopping precincts. People told us many other places did not have enough accessible bathrooms, which restricts people from activities like going out with friends. We also heard that the lack of Changing Place bathrooms in Canberra is a problem — there are only two.

We heard that without a changing place, leaving the house for long periods becomes impossible if there is need to change incontinence aids. We heard about people wearing 3 incontinence pads to get through the day, or having to lie on the floor of a public toilet to change.

We heard there are not enough locations in the Canberra city for guide dogs to toilet, and that guide dog toileting locations are often not considered in the design of public spaces.

Fenced and/or accessible playgrounds were a priority among parents and family carers of children with disability. We heard that it is hard to find out which playgrounds are accessible or fenced.

People talked about the difficulty of finding accessible sporting and recreational facilities. We heard from community organisations who struggled to find the funding to upgrade their amenities to improve accessibility. Participants discussed whether it served the community better to focus funding on making a small number of facilities fully accessible or spreading funding across lots of facilities, making each a little more accessible.

We heard that it is hard to find social and recreational activities that are accessible both physically and attitudinally. Community-based clubs and programs told us it is hard to find the funding to make their activities and facilities more accessible, or to give their staff disability-awareness training.

People told us about accessibility problems they encountered at big events or entertainment venues. Based on the experiences of people with disability and family carers, we learned that people with disability are rarely considered or consulted in the planning of events. We heard that it is very difficult to get accessible tickets to major events.

We heard from many people with disability and family carers that they can't afford social and recreational activities and events. For many people, after living and medical costs, there is not much left for pursuing hobbies or going out.

We heard that some people know about programs that provide some concession or support but that applying for each concession is time-consuming. Many concessions need to be requested individually, with different applications and different visits to the GP to support each applications.

People told us finding the information they need to access the community was challenging. People want to be able to find out about accessible parking, get real-time public transport information, find out what services and amenities are accessible, and find out about events and activities they can participate in. We also heard information needs to be available in a variety of formats. If information is available only online, or only in writing, or only via a smartphone app, some people will be excluded. We heard the need for accessibility information relates to all aspects of the community.

What are the ideas for change?

People told us there needs to be more consultation with people with disability earlier in the planning of activities. We heard from many people the idea of forming a large panel of people with disability to be consulted on the development of public precincts, amenities, services, programs and events.

People asked for easier and more responsive ways to report accessibility issues.

People want to see more Disability Action and Inclusion Plans (DAIPs). DAIPs are plans to ensure people with disability have equal access to an organisation's services and amenities. Participants told us they want to see ACT Government take an active role in leading and supporting the implementation of DAIPs across all sectors.

People asked for a clear plan to improve the accessibility of walkways.

People suggested ways the ACT Government could support community organisations to be more accessible. They suggested the ACT Government could provide information, resources and incentives to organisations. They proposed support for community organisations to deliver staff training, infrastructure upgrades, DAIPs, and other improvements.

People wanted more flexible and on-demand transport, including on weekends and evenings. People told us they like services like the Community Bus Service and the Flexible Bus Service but want to see them available at more times.

People suggested that the ACT Government could play a leading role in making information more accessible by making all public-facing ACT Government communications fully accessible. People suggested Easy English training and accessible communication guides could be made available to the community and business sector, to encourage more accessible communications.

We heard ideas about how accessibility information could be made more widely available. Some people suggested a noticeboard or directory for accessible or inclusive events in Canberra. Other people wanted to explore ways that accessibility information could become universally integrated into existing mainstream websites and guides.

People told us they wanted there to be consistent understanding of how to talk about access and how to communicate with people so they can find out what they need to know. It was suggested that the ACT Government create guidelines and advice that government and business can follow to improve accessibility.

What the evidence says

More change needs to happen to ensure people with disability can live in accessible, well-designed communities that enable full participation in social, economic, cultural, and sporting life.

Universal design can be seen as 'a design process that enables and empowers a diverse population by improving human personal, health and wellness, and social participation'.[72] Universal design is based on acceptance and respect for the broad range of human ability and aims to address barriers faced by people with disability, older people, children and other diverse populations that the design process usually overlooks. Universal design goes beyond the concept of 'accessibility' as accessibility often refers to minimum compliance with codes and standards for people with disability. Universal design can be applied to many things such as the built environment, product design, information technology, transport, travel, recreation and sport, education, and policy development.[73]

In regard to public transport, the Disability *Standards for Accessible Public Transport 2002* (Transport Standards) have been in effect for two decades, yet people with disability still experience transport inaccessibility. Nationally, the evidence[74] tells us that 6.3% of people with disability can use some but not all forms of public transport, and 14.3% (or one in 7) people with disability cannot use any form of public transport due to lack of access. The barriers experienced by people who cannot use public transport are:

- access issues due to steps (42.4%)
- difficultly getting to stops or stations (30.6%)
- fear and anxiety (23%)
- lack of seating or difficulty standing (21.3%).[75]

Without access to transport, people with disability experience restrictions on their ability to 'work, study, shop, socialise with family and friends, be engaged in recreational activities, and access vital government services'.[76] Transport inaccessibility requires many people with disability to rely on family or friends, or the taxi system, which restricts independence and autonomy.

The Australian Government is currently reviewing the Transport Standards to ensure they are efficient, effective and fit for purpose to meet the current needs of Australian society.[77] This work is also looking at the alignment between the Transport Standards and the *Disability (Access to Premise-Building) Standards 2010* (Premises Standards) which provide accessibility requirements for public buildings, including public transport premises. This review process is expected to be finalised by 2023.

Like the Transport Standards, the purpose of the Premises Standards is to make sure people with disability have equal access to public buildings, and that building certifiers, developers and managers fulfil their responsibilities to people with disability as set out in the *Disability Discrimination Act 1992*.[78]

Evidence suggests that people with disability have had limited opportunities to understand the Premises Standards, including their practical application. There is a need to ensure the Premises Standards are made accessible to people with disability and 'ongoing training and education for the disability sector to ensure people with disability are aware of their rights under the Standards, including how to exercise their rights through lodging complaints to the appropriate state or Commonwealth body'. [79]

Advocates state there is a 'lack of adequate data on the implementation and effectiveness of the Premises Standards', and that addressing this should include 'rigorous consultation with people with disability on the barriers they face in accessing premises'.[80]

There have been some recent advancements in accessibility for people with disability in the community. In 2020 The Australian Communications Consumer Action Network (ACCAN) developed an Accessible Communications Roadmap, in partnership with people with disability and other experts, focusing on ensuring all people with disability in Australia have full and equal access to communications technologies and services.[81] This Roadmap supports organisations and individuals to create an accessible communications sector. It maps accessibility and inclusion goals for telco providers, the National Relay Service (NRS), emergency services, scam protection and cyber bulling initiatives, and focuses on inclusive online environments (e.g. web accessibility and digital choice), and accessibility and affordability of devices.

Regarding community attitudes and stigma, people with disability are subject to attitudinal discrimination which 'can cause a social distance between people with disability and the wider community driven by stigma'.[82] Such attitudes can be a barrier for people with disability to accessing many parts of the community due to the risk of facing discrimination and feeling unwelcome.

ACT context

Within the ACT context there are some things already happening in this area. The ACT Government supports community groups, organisations and small businesses to be more accessible through the Disability Inclusion Grants program. These grants of up to $20,000 each fund activities to address attitudinal, communication and physical barriers to access and inclusion.

What we are thinking about

As we shape the ACT Disability Strategy, we are thinking about how we can:

- Implement a consistent approach to access and inclusion across ACT Government events, activities, services, and places.
- Support community organisations to deliver more accessible events, activities and services.
- Consult with people with disability when planning precincts, amenities, services and events.
- Commit to universal design principles.
- Improve our public transport network to meet the needs of people with disability.
- Make sure ACT Government communications are accessible.
- Use ACT Government communications to share information about accessible places and activities.

5 Lifelong learning

ACT WELLBEING DOMAINS

Education & lifelong learning

UNCRPD

Article 24 of the UNCRPD requires signatories to recognise "…the right of persons with disabilities to education. With a view to realising this right without discrimination and on the basis of equal opportunity, State Parties shall ensure an inclusive education system at all levels…". [83]

STORIES FROM THE COMMUNITY

What does a good life look like?

Teachers, support staff, parents, community members being open and honest and for parents to be equipped to work together from a place of partnership. Asking what works for your child and figuring it out together, rather than instantly seeing barriers. Or not seeing learning as ongoing and changing. Asking, asking, asking, how can we learn/work together." Parent of a child with Down syndrome.

What is challenging?

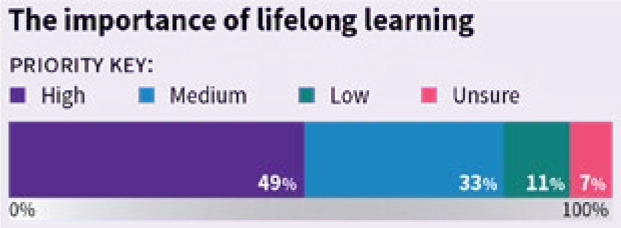
I acquired a physical disability. The ANU is not wheelchair accessible because the systems are not set up for us to be able to go to university. At the moment, I am learning from the internet. I want to learn electronics so that I can make my own assistive devices, but it is hard to learn remotely— it is just not accessible for me to learn at ANU.

SCHOOL-AGED **LEARNING**

What we learned

Quantitative survey information

The survey asked people to prioritise areas for action in the ACT Disability Strategy and 82% of respondents rated lifelong learning as a high or medium priority for action.



Respondents were asked which tangible actions would make a difference in the lives of people with disability. Education ranked third and fourth. ‘More support in educational settings’ was the third top ranked action, with 68% feeling it would have a big impact and 19% it would have some impact. ‘Increasing the confidence of education professionals to engage with people with disability’ was ranked fourth, with 63% feeling this would have a big impact and 24% feeling it would have some impact.

When asked to choose one tangible action that would have the most impact, ‘More support in educational settings’ ranked third. For family carers this ranked first out of all possible actions with 91% of family carers feeling this would have a big impact.

What we heard

What are the challenges?

People told us they would like teaching staff and learning support staff to have more disability awareness and more resources to cater to the needs of students with disability in the classroom.

Many of the parents that participated felt their child had not been given enough opportunities to participate in the mainstream classroom. Other parents felt that when their child was in the mainstream classroom, it was unsuccessful as the classroom teacher did not have the expertise or resources needed to make this a success.

> “The biggest barrier throughout schooling was the assumption that my child belonged elsewhere.”

Some parents felt that in a small group setting, their child had less opportunities than other students in school and that the expectations on what their child could achieve were too low.

> “When she was put into the special unit, they assumed she had a low IQ, she was given boring work, of no relevance to her. My kid ended up hating school her literacy and numeracy skills were shocking when she left.”

Similarly, students with intellectual disability told us that low expectations were frustrating and unfair. They told us teachers and other students often assumed they weren’t capable of things that they had gone on to achieve.

Older students told us about assessment methods they believed lacked universal design. Students would like to see more flexibility in how they could demonstrate their learning especially in Year 11 and 12.

> “The ATAR is system is awful because it is only a reflection of how you do in tests.
> …I can’t do tests — in college I used to have breakdowns at exam time.”

Parents told us the process to get their child the reasonable adjustments needed was difficult. Parents of children with 'invisible' disability such as autism in particular told us they had found this challenging.

Parents told us of challenges accessing supports. They told us the system is confusing and this makes it exhausting to advocate for their children.

> “You need to be a highly capable 'tiger mum' with time on your hands to advocate for your child.”

They told us the current Student-Centred Appraisal of Need (SCAN) process to gain support within a school is a deficit-based approach which is demoralising for the family. Some parents told us their child's disability did not tick enough boxes to make them eligible for support and they felt their child's needs were not catered for.

> “My son had autism, but he doesn't tick enough boxes in the school system to get funding for extra support — so as a single mum if I want him to get support and therapy, I need to fund all of that myself.”

We heard stories from parents whose child/ren had been suspended from school many times. **Parents feel suspensions minimise disruption to other students but do nothing to help the child with disability.**

Parents and students shared experiences of bullying and exclusion, which may come down to a lack of disability understanding and awareness for students.

> “Being bullied — I was punched. People stealing my stuff. Teachers not helping me.”

People also talked about mental health support in schools and found some school mental health services were not disability trained, particularly in regard to supporting students on the autism spectrum.

We also heard there is a lack of after school care options for students with disability. Participants told us the specialist schools do not offer after school care and after school, programs in mainstream schools are not always equipped or trained to support children with disability.

> “Out of school hours (OOSH) providers have not had luck applying for funding to provide support for children with disability.”

Parents of Deaf children told us their children felt isolated in mainstream school communities and suggested more support to enable Auslan in schools would be beneficial for children who are Deaf or hard of hearing. They would like their children to have more, opportunities to make friends with other Deaf children as well as opportunities for them, and their hearing classmates, to learn Auslan.

In the consultation, members of the Deaf community people told us that they felt Auslan is the richest and fullest communication option for many people and that other methods of communication such as lip reading and speaking do not capture as much information as Auslan.

What are the ideas for change?

Parents would like to see more support for families and students to navigate their way through the system, connecting education with therapy and supports, peer groups and other services.

People told us they would like to see explicit statements of welcome and Disability Action and Inclusion Plans in schools. They felt all schools and ACT Government should have an agreed definition of inclusion in schools and to find ways of measuring inclusion to show how schools are improving their outcomes.

People would like to see more disability awareness training, with Teacher Quality Institute accreditation, for all school staff (teachers, learning support staff, student support teams etc) and to have disability training built into degrees and other qualifications.

Students and parents wanted schools to have straight-forward, simple processes to put in place reasonable adjustments. They wanted reasonable adjustment processes that recognised students' needs can change over time.

> “I want my child to have access to the reasonable adjustments she needs in the school setting to help her succeed, such as being able to use a laptop rather than handwriting, flexibility with assignments.”

> “When adjustments are needed — it has to come from us, but often it's on other peoples' terms about what they think we need.”

> “My teachers need to understand that I have barriers that are hard for me, and that making adjustments is good. They often say ‘you don't need it’ but it helps me with my work and my life.”

They would like to see more **experiential disability awareness for students**.

They would like to see **universally designed school infrastructure** and a long-term commitment to make all schools physically accessible by an agreed date.

They would like to see **universal design in learning**, with a variety of options for students to be offered a package of learning to suit them as individuals. This would allow students to learn in a way that suits them and help students work to their strengths and follow their interests. It would also mean that assessment is done flexibly in ways that suit each student.

> “Universal design for learning empowers students to take control of their own learning.”

They would like to see changes to the SCAN school-based assessment process **to be more about strengths than deficits**.

They would like to see **after school options for students with disability in which the students would feel safe and supported**. Students told us about the value of participating in after school activities with other students with disability, that gave them a place where they felt they belonged and could be themselves. They would also like to see more work experience opportunities for students with disability.

They suggested more **transition support** to help students from primary school to high school, from high school to college and from college to after school.

People would like to see **education options for students that miss large amounts of school** due to disability. They would also like to see more support for young carers.

Some members of the Deaf community, and other people in the consultation, would like to see a bilingual Auslan/English school and they would like to **see Auslan offered as a language to learn in mainstream schools**.

What the evidence says

The right to inclusive education

The UNCRPD General Comment No. 4[84] describes the 4 types of educational environments:

1. **Exclusion** — students are directly or indirectly prevented from or denied access to education in any form.
2. **Segregation** — the education of students with disability is provided in separate environments, in isolation from students without disability.
3. **Integration** — placing students with disability in existing mainstream educational institutions, as long as they can adjust to the standardised requirements of those institutions.
4. **Inclusion** — systemic reform to content, teaching methods, approaches, structures and strategies to overcome barriers to provide all students with an equitable and participatory learning experience that best corresponds to their requirements and preferences.

Nationally, the rights of students with disability to access education on an equal basis are protected by the *Disability Discrimination Act 1992*. The Disability Standards for Education clarify the obligations of education and training providers regarding students with disability, including the obligation to make provide access to facilities, provide reasonable adjustments, and to consult with students and their parents and carers about reasonable adjustments. Because the Disability Standards for Education guide educational providers on their obligations to individual students, they are not necessarily a tool for the systemic reform envisioned by the UNCRPD goal of inclusive education.

The Disability Royal Commission has identified the right to inclusive education as a central part of its work, and a priority is to investigate the barriers to inclusive education.[85]

Barriers to inclusive education

The term 'inclusive education' has been employed in Australia for over 2 decades, to describe a wide variety of educational arrangements, including students spending part of their time in a mainstream setting and part in a segregated setting, spending all of their time in a mainstream setting while being individually supported, or learning in a mixed-abilities setting with multiple classroom teachers.[86] Currently in Australia there is no legislated or agreed national definition of 'inclusion' or 'inclusive education'. Jurisdictions have employed broad definitions to encompass culturally diverse students, Aboriginal and Torres Strait Islander students, and LGBTQIA+ students.[87] This does not address the issue of the absence of an agreed model or definition of inclusive education for students with disability. Without a legislated definition or framework, it is difficult to measure progress towards inclusive education in Australia or compare the success of the approaches of different jurisdictions.

The Disability Standards for Education are the means by which students with disability in Australia are protected from discrimination and ensured access and participation in schools. The Senate Standing Committee into current levels of access and attainment for students with disability in the school system heard from multiple submitters that there is widespread ignorance of the Disability Standards for Education 2005 (the Standards) or the right of all children to have access to education. The Inquiry received 'overwhelming evidence regarding the many barriers faced by students with disability and their families'. A major barrier identified by the committee was the practice of 'gatekeeping', where schools refuse or attempt to discourage the enrolment of students on the basis of their disability.[88]

Other barriers identified by the committee include the failure of schools to provide the reasonable adjustments required by students, and exclusion from school activities.

Disability awareness and specialist disability knowledge is frequently cited as a key determinant of inclusion of students with disability. The Disability Royal Commission heard evidence that 'training provided to pre-and in-service teachers in Australia does not adequately prepare them to support students with disability'.[89] A Senate enquiry into current levels of access and attainment for students with disability in the school system found that it is important to ensure that everyone in the school environment is equipped with the best knowledge to meet the needs of students with disability. For that reason, the committee noted 'that there is a clear need for teachers and all school administrators to receive more focused education on the rights and needs of students with disability as part of their qualification process, along with continued professional development throughout their career'.[90] An OECD survey highlighted that 74% of teachers in Australia were trained to teach in mixed ability settings as part of their formal teacher education or training,[91] while 38% of teachers on average felt prepared to teach in such settings when they finished their studies.

Impacts of exclusion from education

Excluding students with disability from education has serious and long-term impacts. Low educational attainment and poor engagement in school is associated with higher levels of unemployment, lower income, and social exclusion.[92] Educational attainment is also a key determinant of health, because of the relationship between education and income, and because education equips people to make more informed health choices.[93]

The exclusion of students from school also impacts on their family carers. When education settings exclude students to the extent they can no longer attend school, or can only attend part time, one parent may be required to give up work to attempt to provide education and supervision at home, excluding them from the workforce.[94]

Specialist settings

There is a wide body of literature examining whether specialist or mainstream settings deliver better educational and social outcomes for students with disability.

Most Australian jurisdictions and the Australian Government are in favour of continuing specialist settings. Tasmania, Western Australia, South Australia and Queensland have reduced the number of specialist schools between 2010 and 2020; the Northern Territory and the ACT have maintained the same number of specialist schools, and NSW and Victoria have increased the number of specialist schools in their states during this time.[95] Continuing or expanding specialist settings nationally is based on the grounds of parental choice.

Non-mainstream settings are also advocated for as a way for students to be immersed in a social environment with similar peers. This is particularly the case in the Deaf and Hard of Hearing community, where the use of Auslan as a primary language forms the basis of a shared culture and identity.

Regardless of the merits or drawbacks of specialist settings, it is important to consider that almost 9 out of 10 of students with disability are educated in mainstream settings.[96] Of the 89% of school students with disability who attended a mainstream school, 71% attended only regular classes in the mainstream school.[97] Because of this, it is essential that educators and other school staff in mainstream settings are aware of and able to fulfil their obligations under the Disability Standards for Education, and that policy is put in place to ensure a move towards inclusive education.

ACT context

The ACT Education Directorate is guided by the Future of Education Strategy, a 10-year plan for education in the ACT. The ACT Government is also developing an Inclusive Education Strategy. The ACT Disability Strategy will align with the Inclusive Education Strategy.

What we are thinking about

As we shape the ACT Disability Strategy, are thinking about how:

- every part of the school system can be supported to maximise accessibility and inclusion
- we can enhance the capacity of the school workforce to confidently engage with students with disability
- we support a positive and inclusive culture in educational settings
- universal design can be employed in school infrastructure
- to ensure families and students are informed, supported, and empowered to make their own decisions about the school experience that will best suit them
- students and families can be fully supported through key transitions
- to ensure students with disability have positive school experiences that support them to feel safe and happy, reach their potential and be prepared for life after school.

POST-SCHOOL **LEARNING**

What we learned

What are the challenges?

We heard that students with disability are not always given enough information about their options after school. We heard that for many students, school is a big part of their lives, and this can leave a gap when school is over.

People told us that tertiary education can be too focused on gaining a degree or a qualification and that students who don't want the qualification may be left out of education opportunities.

> "Post-school learning should be driven by a person's passion, so why can't a person with disability do that?"

People told us they felt some tertiary institutions did not value inclusion. They told us about barriers they had encountered in course design and in physical environments and staff attitudes.

People told us about university campuses that are not physically accessible for them. We also heard that it is difficult in Canberra to find student accommodation that is accessible.

People told us that too often courses were not flexible, with entry requirements, attendance requirements and assessment requirements that create barriers to inclusive education.

> "It is not just the physical environment that is a barrier. It is also the timetable, assessments, schedule, etc which all feed into barriers that are not faced by my able-bodied peers. I can't meet the demands of such a hectic timetable even if it is all online."

We heard challenges people had faced trying to get reasonable adjustments. Students told us it is hard to know what supports are available or how to get them. They told us they sometimes felt like they were being accused of trying to 'rort the system' when asking for reasonable adjustments and they felt they were being treated with suspicion.

> "The whole process trying to get any help for disability is so hard."

We heard challenges people had faced with Registered Training Organisations, with students not being provided enough support to make their learning a success.

What are the ideas for change?

People suggested tertiary institutions and training organisations implement Disability Action and Inclusion Plans.

Transition support at the end of school was suggested, as well as bridging courses for students who need to build their skills before starting further education or training.

People would like to see individual support systems in tertiary education and training, such as education liaison officers as well as peer mentors.

People would like to see supports available to all students that need them, not only for the students that receive NDIS funding.

People would like learning organisations to offer more flexible options in course design, with information in a variety of formats and flexible ways to assess learning. They would like students to be able to create a tailored model of learning to suit their needs.

We heard that people would also like to see options for students that are learning for their own interest and not seeking to complete a qualification.

People would like clearer information for students, such as a one-stop hub for disability support information.

Reasonable adjustments should be easy to access and to reduce the amount of supporting documents students need to provide to get adjustments approved. They would like disability awareness training for staff, including training on invisible disability.

We also heard about the importance of working with tertiary institutions and training organisations to embed disability awareness and skills into many courses, to build disability awareness across sectors and shift community attitudes.

People also suggested free or subsidised course fees for students with disability.

What the evidence says

Article 24 of the United Nations Convention on the Rights of Persons with Disabilities states that people with disability have the right to ‘access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others’.[98]

The Disability Standards for Education apply to tertiary education providers, including vocational education and training providers and universities.[99]

People with disability over the age of 20 are approximately half as likely with people without disability to have a bachelor’s degree or higher tertiary qualification: 17% of people with disability have a bachelor’s qualification or higher, compared to 35% without disability.[100] This figure falls to 11% among people with severe or profound disability (as defined in the SDAC).[101] The Student Experience Survey (SES) is a national survey of higher education students in Australia. In the 2020 SES, undergraduate students who reported having disability were around 40% more likely to consider departing their course early than students without disability.[102] Postgraduate coursework students with disability were 50% more likely to consider departing their course early than students without disability.[103]

National Centre for Vocational Education Research’s (NCVER) National Student Outcomes Survey asks students if they identify as having a disability, impairment or long-term condition.[104] While students who identified reported being satisfied with the overall quality of their training at about the same rate as students who didn’t identify, employment outcomes were notably worse.[105]

Students who identified were:

- less likely (37%) to report improved employment status after training than those without disability (58%)
- less likely (45%) to be employed after training than those without disability (71%)
- less likely (75%) to report having achieved main reason for doing the training than those without disability (85%).[106]

People with disability are significantly underrepresented in vocational education and training, with rates of enrolment from people with disability far below the rest of the population.[107] The higher the level of the qualification, the greater the under-representation of people with disability — people with disability make up 14% of

Certificate 1 enrolments, but less than 4% of enrolments in qualifications at Diploma level or above.[108]

Ensuring people with disability have access to education and training to obtain secure employment is a goal of the current Australian Government.[109] The Federal Budget 2022 included a National Skills Agreement with $1.1 billion from the Australian Government and states and territories to provide 180,000 fee-free TAFE and vocational education places for priority groups which includes people with disability.[110]

An action arising from *Australia's Disability Strategy 2021–31* is the development of disability confidence training aimed at professionals. The Disability Best Practice Guide and Action Plan is underpinned by evidence and research, and developed in consultation with people with disability, and other experts.[111] This training will target occupations including education and other sectors to better respond to the needs of people with disability. [112]

Best practice

There are a number of initiatives nationally which aim to increase the participation and improve educational outcomes for students with disability in tertiary and vocational education. Flinders University, Adelaide delivers the Up the Hill project which enables students with intellectual disability to choose a topic of interest each semester and set and review their own individual semester goals, which may include personal goals such as making friends and using the library.

Students receive a certificate of recognition after completing 3 years of study. The average age of participating students is 32 years. Students are supported by peer mentors without intellectual disability as part of work experience placements.[113]

A study on Disability Support Officers (DSO) in TAFE colleges in Australia found they became strong advocates for students with dyslexia and learning disabilities and pushed beyond the boundaries of TAFE position statements to ensure students had the supports they needed. Students with dyslexia shared through interview they had excellent experiences at TAFE due to the support of the DSO.[114]

ACT context

There are a range of actions already underway. In 2022 the ACT Government commenced an Australian School-based Apprenticeship (ASbA) pilot program titled 'Head Start' for students from ACT specialist schools to access support and wraparound services tailored to individual needs.

The Education Directorate plans to redefine Vocational Education and Training (VET) Pathways to develop a single action plan for VET programs and supports and education pathways and embed the Head Start Program. This will include a review of student transitions and decision points, development of toolkits for schools, parents, students and carers and professional learning for teachers to enhance vocational pathways supports in schools.

The Education Directorate is supporting students with a disability to test their eligibility to access the NDIS, to ensure they receive School Leaver Employment Supports (SLES) through the NDIS.

The Education Directorate is planning a program to provide professional learning for school staff to ensure students with disability receive quality career education and vocational pathways education.

What we are thinking about

As we shape the ACT Disability Strategy, we are looking at:

- How the ACT Government can influence the availability of disability support in vocational and tertiary education settings.
- How to enable students to achieve their own learning goals and build their self-confidence and overall wellbeing.
- The link between post school learning and employment with a view to identify how these pathways can be strengthened.
- How people with disability can gain the skills and education they need to pursue work that is enjoyable and rewarding.
- How we support the inclusion of students with disability at universities and vocational colleges to build stronger relationships and improve community attitudes.

6 Health and wellbeing

ACT WELLBEING DOMAINS

Health

UNCRPD

Article 25 of the UNCRPD requires signatories to recognise '…that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'.[115]

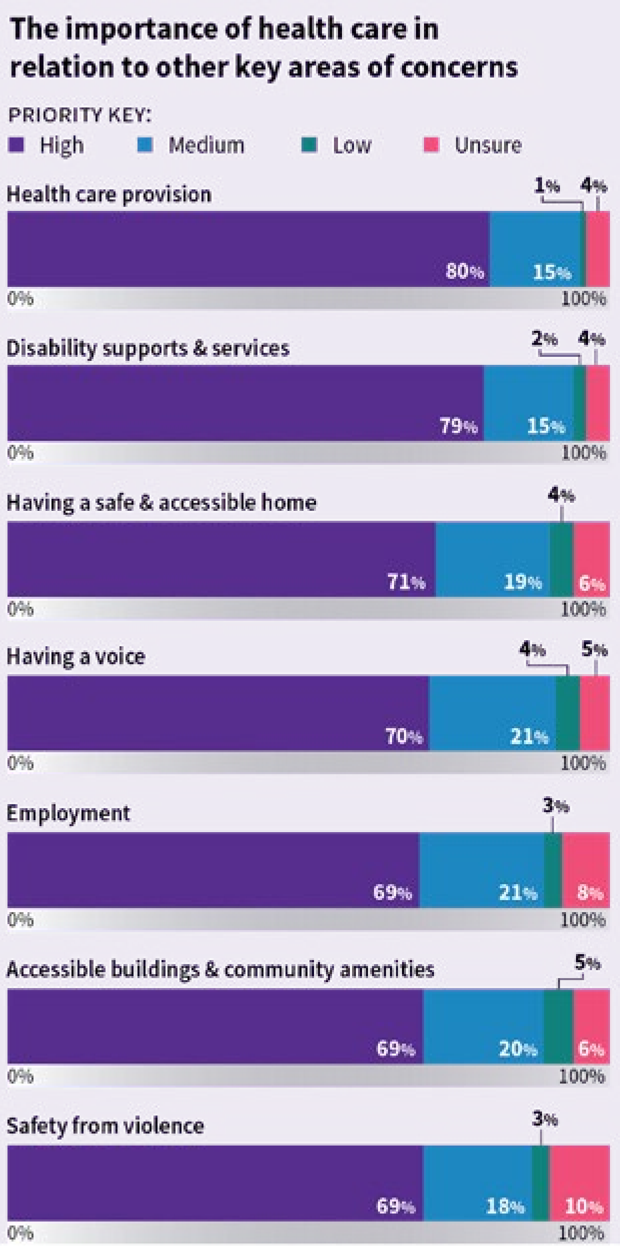
STORIES FROM THE COMMUNITY

> "Our son is an adult man with a disability. He is non-verbal, over 6 foot tall, and very physically active and agile. He has at least one carer, and sometimes 2 when in public, for all aspects of his personal care.
>
> He is unwilling to allow doctors and dentist to examine him. He also won't allow blood tests to be taken. He needs to have blood tests in order to check that his epilepsy medication is at a safe and appropriate dose. Every 3 or so years, his teeth are examined, and any necessary treatment is undertaken under general anaesthetic. Last year, he had dental treatment where he had a wisdom tooth extracted. It was decayed down to the gumline, and the adjacent tooth was also decayed. At the time, the opportunity was taken to do blood tests as requested by his GP. In January this year, his GP rang to say the blood tests showed white blood cell readings that suggested Leukaemia. He recommended another blood test be taken. Subsequently, a specialist at the hospital suggested that the readings could be because of the tooth being infected—but that early-stage leukaemia could not be ruled out. However, neither doctor was able to request hospitalisation for the blood test to be undertaken."

What we heard

Quantitative survey information

Across the survey, issues related to health care consistently ranked at or near the top of people's priority lists. When asked about challenges, 'access to health care' was third top issue, 63% of survey respondents rated 'finding and using health care services that are needed' as a big or very big issue.



When asked about top priorities for reform, health care provision was the highest ranked priority. When asked about the impact various reforms would have on the lives of people with disability, 61% felt 'increasing the confidence of health care professionals to engage with people with disability' would have a big impact on the lives of people with disability.

The wider consultation

What are the challenges?

We heard that it is hard to get appointments with specialists or allied health professionals.

> "My son was having frequent seizures and still it was months before he was able to get in to see a neurologist — where is the duty of care while we wait for medical help?"

We heard there is a shortage of specialists based in the ACT, especially specialist services for children with disability. We heard that wait-times in the public system are long, and people are resorting to travelling interstate to receive timely care. We heard this is an expensive and complicated solution that is out of reach for many people with disability in the ACT. People suggested that requirements for certain assessments from health care professionals as a prerequisite to accessing NDIS funding exacerbates the excess demand for health care appointments.

We heard the lack of health professionals includes lack of access to mental health professionals and that it is hard to get an appointment with a psychologist. The Deaf community told us there is no psychologist who uses Auslan in the ACT, and that psychologists available in the ACT lack understanding of Deafness or how mental health issues might manifest differently in Deaf people.

We heard that it is hard to get a diagnosis, and that a diagnosis is the only way to access many supports.

> "My daughter is on a wait list for an autism diagnosis, and she is 11, it is only free up to aged 13 but by the time she gets to the top of the wait list it may be too late to get it through that system."

> "The road to diagnosis and then maintaining levels of medical care is LONG and expensive and prevents many other outcomes from being achieved."

We heard that cost is a big issue in accessing health care. People told us that they were unable to find a suitable GP who offered bulk-billing. We heard many people had been unable to access specialist appointments, tests, and assessments through the public system. We heard about people who were under financial stress because of healthcare costs, and others who said they went without healthcare or assessments because they could not afford it.

People told us about challenges accessing preventative care. We heard it is difficult to get an appointment, especially in the public system, for people who require sedation for routine preventative care (including vaccinations, dental check-ups, pap smears, or blood tests). We learned that the barriers people with disability face in accessing healthcare in general are more complex when accessing preventative care. This includes barriers like inaccessibility of the built environment and systems, challenges related to transport, financial challenges, and provider attitudes and knowledge.

We heard many experiences of healthcare are not patient-centred. People told us that healthcare providers often did not believe people's own accounts of their experiences and health, or the accounts of family carers. Many people with disability told us they didn't feel respected in their interactions with health care providers, and that their health care providers don't take the time to know them and understand their health or their disability. People also found it difficult to build a relationship with their healthcare provider because they often did not see the same doctor twice, or felt their appointments were short and rushed.

People told us many health professionals lack disability awareness and disability-specific knowledge.

We heard that people believe that doctors and nurses in hospital settings often have no disability-specific training. People told us about negative experiences they or somebody they care about had in hospitals.

> “During a recent hospitalisation, the disabled adult in my life experienced challenges with health staff not providing disability appropriate care or having awareness of his disability… Small things get missed, like staff putting things out of his reach.”

We heard often health care providers don't know how to communicate with people with intellectual disability or people who don't communicate verbally.

> “Health care professionals need to speak to me in a way I understand. Speak clearly and ask me if I know what is going on.”

We heard health professionals often don't use communication technologies, like transcription apps, to make communication or recollection easier for patients. We heard that interactions with health care professionals did not include reasonable adjustments to support better communication or understanding of what to expect and what was happening to your own body.

We also heard from people with a whole range of disability experiences that healthcare professionals often don't communicate respectfully. We heard that healthcare professionals can presume people with disability don't have the capacity to understand and make decisions about their own health, that they speak to family carers or support workers instead of their patient, and don't take the time to hear their patient's views and concerns.

> “Doctors need to speak to me and not my mum.”

We heard about barriers culturally and linguistically diverse people face in accessing healthcare. People told us that health professionals often did not engage translators, or let patients know free translation services are available. For some families, this means that children act as translators and spokespeople for their parents. We also heard from culturally and linguistically diverse people that they often perceived bias or racism from health professionals based on the quality of their treatment.

The LGBTIQA+ community shared difficulties in finding safe, welcoming health care that is also disability-informed. We heard from trans and gender-diverse people who told us the medical care they received was rarely gender-affirming. They told us about health professionals using incorrect pronouns, using the name they had been assigned at birth rather than their correct name, and changing forms they had filled out to match the gender they were assigned at birth. People told us that some medical professionals brought sexuality or gender identity in as a factor in health issues when they felt it was not relevant.

> “The fact that I am queer is not a medical condition. Doctors often bring that into the story, but it is not appropriate.”

> “Specialists are even less willing [than GPs] to think holistically or to believe that my health condition is not because I am trans.”

People told us the health system is hard to navigate, and that systems are siloed rather than connected. We heard that primary care providers and diagnosing specialists often don’t make connections to other healthcare services or social supports people with disability might need.

We heard that the respective responsibilities of Medicare and the NDIA are unclear to both patients and providers. **We heard that without a strong advocate, it is difficult to get good healthcare and necessary supports.**

We heard there are accessibility problems in ACT health care facilities. We heard from the Deaf community about medical staff not knowing how to book an Auslan interpreter. People told us that the infrastructure that is meant to be accessible is sometimes not actually fully accessible. We heard that getting to Canberra Hospital is difficult because of limited public transport, lack of accessible bus stops and limited accessible parking.

We heard about mental health services that are not physically accessible or easy to access. People also told us that adolescent and crisis mental health facilities in Canberra are not physically accessible.

We heard from young people that it is hard to find free, disability-informed mental health care. They told us that free mental health care services or mental health support they could access at school often isn’t informed about neurodivergence.

We heard it is hard to find a GP offering home visits, making health care hard to access for people who can’t leave their home.

What are the ideas for change?

To address the shortage of specialist and allied health professionals and the difficulty of getting an appointment, people suggested the ACT Government work with the Australian Government and training universities to increase the number of graduates in Canberra. They talked about including disability awareness training or exposure to people with disability should be a part of all health professionals formal training.

People suggested cooperation with the Australian Government to make telehealth and eScripts more widespread and easier to access.

People wanted to see the capacity of Community Health Centres improved to meet the needs of people with disability. Participants told us the Community Health Centres offer a less intimidating and more accessible alternative to going to hospital. They wanted to see Community Health Centres given more resources and staff to be given special training so they can be the ‘first port of call’ for people with disability. An idea suggested multiple times was that the ACT Government consider opening a holistic disability health clinic, including GP appointments, dental check-ups, vaccinations, sexual health checks, blood tests, etc.

People wanted ACT Government to make sure buildings are designed with the input of people with disability, to avoid building facilities that aren’t truly accessible.

They wanted to see cooperation across ACT Government to make sure that healthcare facilities are accessible by public transport, and that access to healthcare facilities is considered in changes to routes or services. People wanted to be able to access extra subsidised taxi trips to attend medical appointments.

People also suggested implementing a fragrance-free policy in health care settings and developing alternatives to the emergency room for people with sensory sensitivity.

We heard suggestions about how to make health information more accessible and improve the capacity of health care professionals to communicate with patients. People told us health professionals needed training on how to communicate with people with disability. We heard that it would be helpful if health professionals incorporated transcription apps or other communication technology into consultations with patients who might find it useful.

The Deaf community suggested we increase the number of Auslan interpreters and look at ways to increase the confidence of health professionals to use Auslan interpreters. They also asked that the ACT Government make sure vital health information is available in Auslan.

People wanted to see patient advocacy services made available. We heard that for people who aren't able to advocate for themselves and don't have someone in their life who is available to advocate for them, it can be hard to navigate the health system or have their needs met.

People wanted to see improved outreach and services to culturally and linguistically diverse communities. They suggested that ACT Health and Canberra Health Services could partner with community organisations to distribute in-language information about health and disability.

What the evidence says

Health outcomes for people with disability

People with disability in Australia report poorer general health than people without disability — less than a quarter of adults with disability rate their health as good or very good, while the figure is close to two-thirds for adults without disability.[116] In 2022, an ACT Women's Health Matters survey of 91 women found only 15.5% rated their physical health as good or very good.[117]

We also see poorer mental health for people with disability. Nationally, 32% of adults with disability experience high or very high levels of psychological distress, compared to 8% of adults without disability. In the ACT Women's Health Matters survey, no respondents rated their mental health as excellent, while only 20% rated it as good and 38.9% rated their mental health as poor or very poor.[118]

Poorer health for people with disability results in higher use of health services. Nationally, people with disability have higher rates of use of GPs, medical specialists, and mental health professionals; and more hospital visits including the emergency room, day visits and overnight stays.[119]

Barriers to accessing healthcare for persons with disability

Long waiting times or unavailability of services

Long wait times for services, or the inability to access services locally, can be attributed to a health workforce shortage, which has been an issue nationally for several decades.[120] People with disability may be impacted more acutely because of their greater healthcare needs, reduced ability to travel, and reduced choice in providers due to provider attitudes and knowledge. Nationally, we know that one in 4 people ages 15–64 with a disability wait longer than they feel is acceptable to get an appointment with a GP.[121]

Cost

The cost of accessing health services can create financial stress for people with disability. Nationally, 7.6% of people with disability reported they delayed or did not attend a GP because of cost; and 4.6% did not see a medical specialist because of cost.[122] Given rates of bulk-billing among GPs and specialists in the ACT are among the lowest nationally,[123] the situation is likely worse in the territory. We know that people with disability are economically disadvantaged – the average income of a person with disability is $700 a week, compared to an average income of $1,343 for people without disability.[124] This means people with disability are less able to afford health care costs, including specialist appointments, medicines and transport.

Inaccessibility

The Australian Institute of Health and Welfare identifies inaccessibility of buildings as a major barrier for people with disability to access health services.[125]

Access to transport is an important factor in healthcare. People with disability face significant barriers to using transport in general. Among people with disability over the age of 15 living in the community, one in 7 are unable to use any form of public transport.[126] Around one in 4 need help with private transport.[127]

Inaccessibility of information can also be a barrier to accessing healthcare.[128] This includes information about health promotion and prevention, as well as information people need to participate in decisions about their healthcare.

Lack of disability knowledge among health professionals

Evidence for discrimination by health professionals against people with disability has been shown through studies involving both healthcare providers and people with disability.[129] Nationally, 59,000 people with disability self-reported to have experienced discrimination in a health care setting in 2018.[130]

Inability or unwillingness to provide accommodations, lack of disability knowledge, and discriminatory attitudes to people with disability are all factors that contribute to the neglect of people with disability in the health system. This is particularly the case for people with cognitive disability, with the Disability Royal Commission recently making the finding that 'people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system'.[131]

The Disability Royal Commission found there are no specific requirements or curriculum to teach health care students how to provide safe and quality health care to people with cognitive disability.[132] Research by Trollor et. al. found that Australian medical school curricula contained a median of 2.55 hours of compulsory intellectual disability content.[133]

Examples from other jurisdictions

Following is the evidence relating to initiatives or actions that may address some of the challenges discussed.

Workforce upskilling

A number of training programs for health professionals have been or are being developed across Australia, funded by Information, Linkages and Capacity Building (ILC) grants.[134] Three of the 28 funded programs will be available nationally, while the remainder are delivered in specific states. There are no programs funded specifically for health providers in the ACT.

A systematic review on disability training for health workers found programs that involved people with disabilities in delivery were most effective in improving knowledge, confidence, competency, and self-efficacy. However, they also noted that as few studies measure the long-term impact of training, it is difficult to compare the effectiveness of different training programs.[135]

Patient navigation

Various definitions of patient navigation have been developed to fit different contexts. Some definitions refer to services that help patients to navigate healthcare systems, access care, and manage their health conditions. One example is this widely used definition:

> “[a health navigator is] a person with or without a healthcare-related background that engages with patients on an individual basis to determine barriers to accessing care or following recommended guidelines. The patient navigator also provides information relevant to patients’ specific circumstances to facilitate self-management and access to care.”[136]

Other definitions are broader, and include navigating between healthcare services and other types of social service or supports:

> “The assistance offered to patients and carers in navigating through the complex health and social care systems to overcome barriers in accessing quality care and treatment, e.g. financial support, coordinating among providers and settings, arranging for translations etc.”[137]

Patient navigation has been shown to be effective to timely care for cancer patients,[138] and in reducing readmissions and days spent in hospital for chronically ill older adults.[139]

The role of Disability Health Liaison Officers created in the Victorian Health System presents a model of patient navigation specifically for people with disability, operating in the Australian health system context. Disability Liaison Officers ‘provide specialised disability information and support to people with disability, their supports, and staff to assist with assessment, management, and discharge planning’.[140] Disability Liaison Officers liaise within the health system and assist to connect with services outside of the health system.[141]

Comprehensive preventative health assessments

Comprehensive preventative health assessments for people with disability have been shown to be effective in helping identify new health needs, managing existing needs, as well as providing health promotion and preventative care.[142] Comprehensive preventative health assessments have been shown to be particularly helpful for improving healthcare for patients with intellectual disability.[143]

The Comprehensive Health Assessment Program (CHAP) is a tool that has been developed in Australia to facilitate comprehensive health assessments for people with intellectual disability. The CHAP consists of one questionnaire to be filled out prior to the appointment, followed by an appointment with a general practitioner to create an agreed health plan.[144] The CHAP tool has been specifically identified as an evidence-based tool that supports the greater uptake of general health assessment by the Australian Government Department of Health,[145] and increasing uptake of the CHAP took is identified as a desired outcome in the National Roadmap for Improving the Health of People with Intellectual Disability.[146] A number of licenses for the CHAP tool have been purchased by Office for Disability in the ACT and are available upon request.

Accessible health information

Providing information in more accessible language is advised to increase accessibility of health information for people with intellectual disability, people with lower literacy, or people whose primary language is not English.[147]

The University of Melbourne, Scope Australia, the University of Sydney, and Western Sydney University are collaborating in research to determine best practice for creating accessible written information.[148] This research attempts to address the lack of commonality across various guidelines on how to produce accessible written information, and to examine the evidence supporting different guidelines.[149] This research is co-designed and co-produced with people with disability.[150]

Medication cost reductions

Noting that the cost of medications is a responsibility of the Commonwealth Government, there have not been any national trials of reducing the cost of medication specifically for people with disability. However, the Commonwealth Closing the Gap Pharmaceutical Benefit Scheme Co-payment has shown that reducing medicine costs can have significant impact for a marginalised cohort. Under this Commonwealth initiative, Pharmaceutical Benefit Scheme medication is free for Aboriginal and Torres Strait Islander people with concession cards and subsidised for people without concession cards.[151] The scheme has led to increases in the use of medications, reductions in out of pocket spending, and a decline in hospitalisations for chronic conditions.[152]

Integrated and specialist care

For people with disability with multiple chronic health conditions or complex health needs including intellectual disability, models have been developed to provide extended and coordinated care. These models involve multi-disciplinary teams of health professionals, or cross sector teams made up of health and community care workers. Australian examples are the NSW Statewide Intellectual Disability Health Service[153] and the South Australian Disability Health Service.[154]

Integrated and specialist care models provide healthcare for people with needs that mainstream services are not able to meet.[155] The NSW Intellectual Disability Health Service takes a two-pronged approach, helping to manage complex or chronic health needs for people with intellectual disability, while also working to build the capacity of mainstream health professionals through training and advice.[156]

ACT context

The ACT Health Directorate is developing an ACT Disability Health Strategy in tandem with the ACT Disability Strategy, so we will take a whole of government approach to overcoming challenges identified by people with disability and their allies.

Canberra Health Services has finalised a Disability Action and Inclusion Plan, which will work to improve access to health services for people with disability in Canberra.

What we are **thinking about**

As we shape the ACT Disability Strategy, we are thinking about:

- How access to health services is impacted by factors such as transport, financial stability, and advocacy and support.
- How we can educate the next generation of health workers to deliver quality healthcare to people with disability.
- How we can address waiting times to access health supports and services.
- How we can improve the accessibility of health care facilities.
- How we can build the capacity of health professionals to:
  - support people with disability and carers to navigate the health system
  - provide information and advice to support people with disability to make decisions about their health
  - communicate respectfully and effectively with people with disability.
- How we can ensure our health communications are accessible.
- How we can develop expertise amongst our health care providers to provide holistic care for people with disability.

7 Having a home

STORIES FROM THE COMMUNITY

> “My son is in his thirties and has an intellectual disability and receives the Disability Support Pension. Like most other adults, he wants to live outside of home. He tried a number of shared living arrangements, but none worked out. The only places he could afford on the DSP were places he was sharing a bathroom with multiple people, and only had a small living space. There were lots of times he was in conflict with his housemates over keeping the bathroom and kitchen clean or sharing the living space. The places he lived had lots of other problems too—they were falling down, the landlord didn’t fix things that were broken, other housemates didn’t want to upgrade to faster internet. Eventually I felt like there was no option but to help him to pay for a more expensive rental property. He has his own bathroom, the home is spacious, and he has housemates with similar interests and habits. He is very happy there, and it’s a relief for me to see him happy. But I am on a pension myself, and it’s costing me a lot. I am a full-time carer to another family member, and money is an issue.”

ACT WELLBEING DOMAINS

Housing & home

UNCRPD

The UNCRPD states people with disability have the right to an adequate standard of living (Article 28), the right to live independently in the community, and the ‘opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement’ (Article 19).[157] Having access to safe and secure housing is also foundational to exercising and enjoying other human rights and freedoms associated with participating in social, economic, and cultural life.

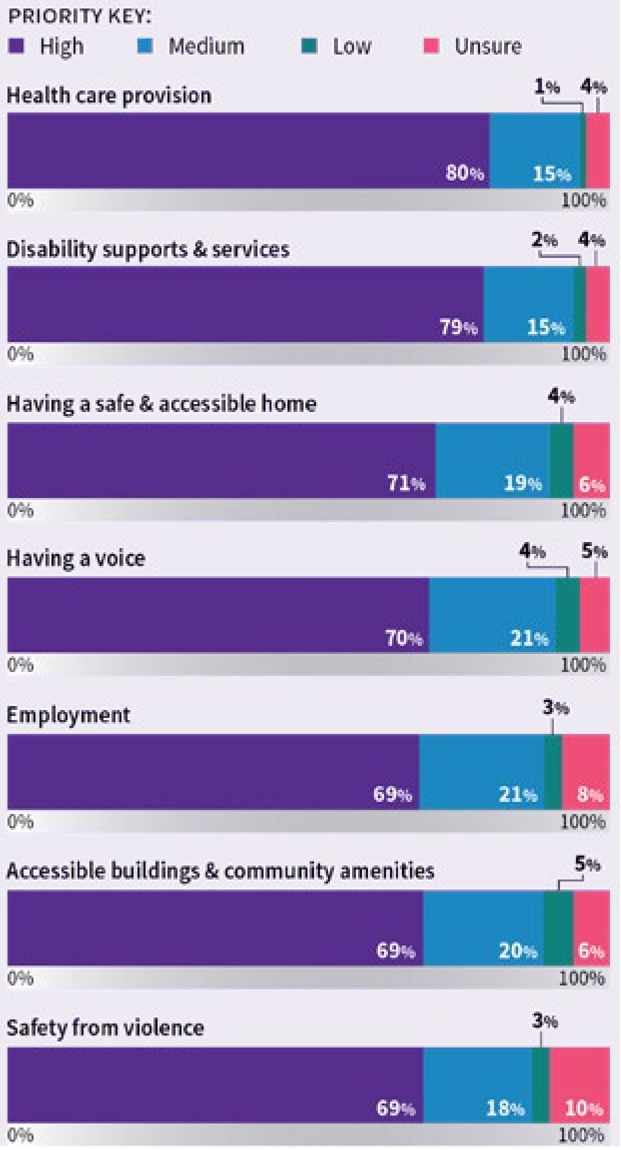
What we heard

Quantitative survey information

When asked how much of an issue various challenges were for people with disability, 46% of survey respondents rated ‘finding a place to live that is safe and accessible’ as a big or very big issue. When we look at the responses from family members of adults with disability, this number rises to 55%.

When asked to rank areas for action as a high, medium or low priority, 71% of survey respondents identified ‘Having a safe and accessible home’ as a high priority for reform and 19% as a medium priority. This made it the third highest rated priority.

The importance of having a safe and accessible home in relation to other key areas of concern



Survey respondents were asked to choose one area for action they felt would have the most impact on people with disability. ‘Having a safe and accessible home’ was the fourth most selected priority. This changed slightly for different groups, although it was in the top 4 for all groups.

Priorities by respondent group

	People with disability	Family or carer	Advocate or provider
1	Health care provision	Disability supports and services	Employment
2	Disability supports and services	Health care provision	Safe and accessible housing
3	Employment	Employment	Disability supports and services
4	Safe and accessible housing	Safe and accessible housing	Health care provision
5	Accessible buildings	Community attitudes	Community attitudes

The wider consultation

What does good life look like regarding having a home?

What are the challenges?

We heard about the of lack availability and affordability in the private rental market, especially for accessible homes. People told us that often houses that were advertised as accessible didn’t meet their accessibility needs or meet minimum accessibility standards.

We heard that people found it hard to have adaptions made to private rentals to make them more accessible.

We heard that even people who didn’t need accessibility features in their house told us they also struggled to find a suitable home in Canberra’s private rental market. The challenges they face include finding a home they can afford, competing with many other applicants for the same home, and finding a home close to shops and public transport.

We heard that affordability was an especially big issue for people receiving the Disability Support Pension.

We heard about people's experiences of not having choice or control over where they live or who they live with. We heard from people who were frustrated about not being able to find accommodation that suited their lifestyle and life stage while also granting them access to the supports they need.

People told us that shared accommodation is often the only option available. For some people, this is because the cost to rent a single-occupancy dwelling was too expensive. For other people, it is because they can only get access to the services and supports they need when they are sharing the services with other housemates.

Some people love shared living, and find it suits their personality and lifestyle. However, for others shared living is complex and stressful. Worrying about having a housemate to cover the rent, resolving conflicts, and feeling safe were all concerns raised by participants about shared living.

Family carers told us about the financial strain they are under providing housing outside of the family home for the person they care for. We heard from family carers who make a significant contribution to housing costs of the person they care for, so they can live somewhere that is not the family home or social housing.

People said that accessible homes are hard to find for purchase, and more expensive to build. Participants told us that not every block of land is appropriate to build an accessible home on, because of the need for more floor space and to be single storey. While Specialist Disability Accommodation (SDA) — NDIS-specific funding — can technically be used to buy or build a new home, participants told us this was difficult in practice.

People told us that it can be hard to find an accessible home in a location that also provides access to the community, amenities, and transport.

> “You can have the most accessible home in the world, and it can still feel like a prison if the surrounding neighbourhood and connection to transport is not accessible.”

Home ownership feels impossible to many people we heard from. Home ownership would provide a solution to many of the challenges people told us about related to accessibility, security, safety, choice, and control. However, consultation participants told us that home ownership was extremely difficult to achieve, given the financial disadvantage of people with disability.

We heard that it is hard to find homelessness services for people with disability. Participants told us about experiences where staff at homelessness services weren't disability aware. We heard that crisis accommodation is often not accessible, especially if you also have children or a pet.

We heard that social housing tenants with disability are living in homes that don't meet their accessibility needs. We also heard that there is a long wait for accessible social housing, both for potential tenants and tenants looking to transfer somewhere more accessible.

What are the ideas for change?

People told us there should be more social housing, including more accessible social housing. This would mean everyone who needed social housing could access it without having to wait a long time.

Participants suggested exploring new housing arrangements. Ideas included mixed-abilities rental or cooperative housing, where people of mixed experiences and abilities could share housework, care and have their support needs met.

We heard that people with disability want more pathways to affordable home ownership. People suggested The ACT Suburban Land Agency's affordable home purchase schemes could have specialist disability streams, or land purchase schemes could preference large, flat blocks for people who want to build accessible homes.

People want to see an increase in the number of affordable and accessible rental properties on the private market. They suggested offering incentives to landlords to rent to people with disability and improve the accessibility of their properties.

People wanted the ACT Government to ensure that **social housing tenants or applicants with disability were matched with accessible homes.**

People wanted to see policies that gave private renters more security. We heard that longer lease terms would help people feel more secure and make it worthwhile to invest in adding accessibility features.

People wanted to see more private and community Specialist Disability Accommodation built. People also wanted to see support for Specialist Disability Accommodation home ownership for people with disability.

People had ideas to make universal design more widespread. They suggested making it a compulsory part the curriculum of architecture and design courses. They thought universal design could be strengthened in building codes and planning legislation and that implementing these requirements should be enforced.

What the evidence says

Housing issues for people with disability

Accessibility in housing links to affordability and supply. People with disability are particularly disadvantaged when it comes to housing options and are more likely to experience housing stress compared to people without disability.[158] Access to suitable housing remains a major issue for people with disability,[159] with evidence indicating 'appropriate, affordable housing is out of reach for many people with disability — particularly for those who rent'.[160]

Housing inaccessibility and the absence of suitable housing is known to impact people with disability in many ways, resulting in homelessness; increased risk of experiencing violence or mistreatment; increased support needs; low rates of education and economic participation; poor health outcomes, and poor wellbeing and social inclusion outcomes.[161]

Poor housing outcomes for people with disability are largely due to access and affordability barriers. We also know that people with disability face many barriers that limit independence and often result in restricted choice about living arrangements. The barriers to housing access and affordability are compounded for people with disability because of other forms of disadvantage, such as lower incomes and poorer rates of employment.[162] For example, we know that 'households with a person who needs accessibility and support are typically poorer than other households and their search for affordable housing is exacerbated by inaccessibility'.[163]

People with disability often experience housing and living arrangements differently to people without disability. Many people with disability live in shared supported living arrangements, and a large proportion of people with disability aged over 25 years live with their parents.[164]

The shortage of accessible homes for people with disability, including post-construction home modifications, coupled with the barriers associated with building and/or securing an accessible home also prevent people with disability from finding a suitable home. People with physical disability experience even poorer outcomes as inaccessible designs restrict movement in their own home, and in other people's homes.

Nationally, the evidence tells us:

- Housing costs have contributed to growing inequality in Australia.[165]
- 96% of people with disability live in housing within the community rather than in institutionalised settings.[166]
- Close to two-thirds (64%) of people with disability own their own home.[167]
- People with disability are overrepresented in the rental market (32%), compared to people without disability (27%).
- Home ownership is falling, especially among the young and the poor, and as people with disability are more likely to face financial hardship this will disproportionately affect people with disability.[168]

There is not much data on the housing experiences of people with disability in the ACT, however we do know:

- 53% of households living in public housing include a person with disability.[169]
- people with disability make up 29% of households within ACT social housing.[170]
- More than 1,730 (12%) of income units receiving Commonwealth Rent Assistance received the Disability Support Pension as their primary payment type.[171]
- 142 specialist homelessness service clients in 2020–21 were NDIS participants. This represents 4.3% of ACT specialist homelessness services clients in 2020–21 (and excludes people with disability who are not NDIS participants or for whom NDIS status was missing and clients who only had support periods starting before 1 July 2019).[172]

ACT context

Within the ACT context there are many initiatives underway. The ACT Housing Strategy is delivering on actions to grow ACT public housing stock and the community housing sector, including reforms to strengthen the rights of renters.[173] Since 2018 over a thousand units, apartments and townhouses have been made available as part of the ACT Government's Affordable Home Purchase Scheme.

In 2021 most Australian states and territories (including the ACT) agreed to include minimum accessibility provisions for residential housing and apartments within the National Construction Code[174] based on the Silver Level Liveable Housing Design Guidelines. However, Silver Level standards will still not meet the needs of many people with disability.

As part of its Growing and Renewing Public Housing Program, Housing ACT is designing new public housing dwellings to meet AS4299's Class C Adaptable housing standard where possible. Where adaptable housing outcomes cannot be delivered, Housing ACT aims to deliver new properties to Liveable Housing Australia's Gold Standard.

The 2022 Federal Budget included housing supply initiatives with $10 billion invested in the Housing Australia Future Fund, to support the development of 20,000 new social housing dwellings and 10,000 new affordable housing dwellings over 5 years. A National Housing Accord brings together governments and industry to address supply challenges, with $350 million over 5 years from the Australian Government for 10,000 affordable homes with states and territories supporting an additional 10,000 new affordable homes.

What we are thinking about

We are thinking about:

- How to ensure everyone with disability can find a safe place to live that meets their access needs.
- How the ACT can utilise Commonwealth initiatives to increase supply and access to housing.
- How to influence local markets to support housing access and affordability.
- How to ensure people with disability have choice and control over how they live and who they live with.
- What alternative systems and models may be helpful in the ACT.
- What creates good security of tenure in housing and what systems allow for home ownership for people with low incomes.
- How we ensure that we hear from people with disability to ensure housing reforms and policies respond to their diverse needs.

8 Supports and services

ACT WELLBEING DOMAINS

Access & connectivity

Social connection

Safety

STORIES FROM THE COMMUNITY

Ishra* (*name changed for privacy) is the parent of two children and their older son Harry * has a disability and high support needs. The family does not socialise outside of the home as Harry's behaviour is hard to manage and they rarely go out in the community together. Ishra would like to find a community group where the family could be welcomed so they could make connections and get support from peers. They would also like options for after school care for Harry as well as respite care to recoup some energy. Ishra told us they have not slept uninterrupted since Harry was 3 years old and he is now entering his teenage years.

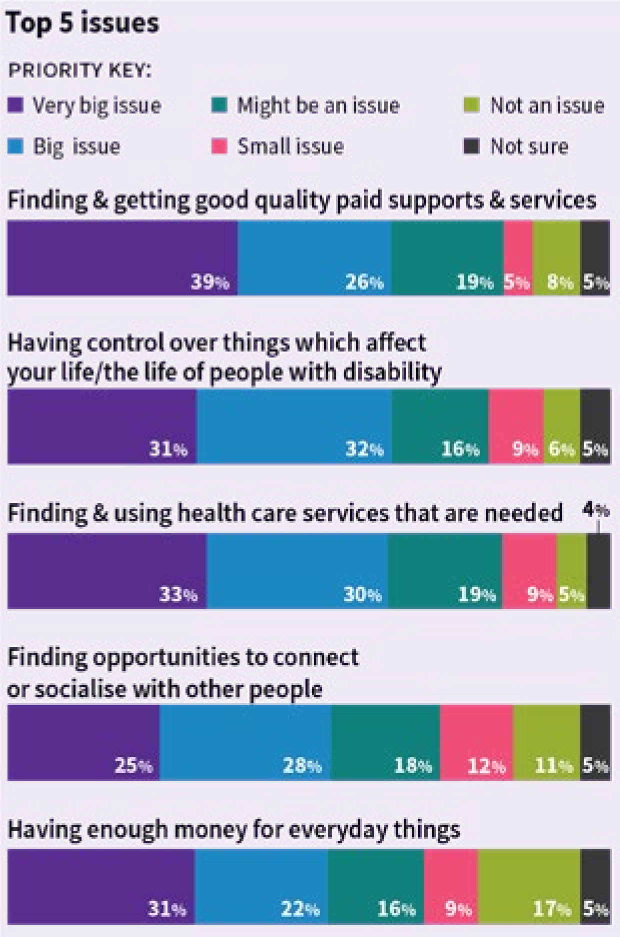
Harry has had many support workers as it has been impossible to find support workers to stay long term. Having the workers change so often makes Harry feel more and more anxious and there is no streamlined way of making sure each new support worker has the background information to enable them to provide high quality support.

Harry has had trouble accessing speech therapy in Canberra due to a lack of availability, so they have arranged online speech therapy from another country.

What we heard

Quantitative survey information

In the survey we asked people what their biggest challenges were. 'Finding and getting good quality paid supports and services' ranked first with 65% of respondents rating it as a big issue or a very big issue.



When asked to choose one top priority for reform, the most frequent answer was 'disability supports and services'.

When asked to rank possible reforms as high, medium or low priorities, 79% of respondents identified 'disability supports and services' as a high priority.

The wider consultation

What are the challenges?

We heard the system is hard to navigate. People told us they find it hard to know where to go or what was required to get information to start the journey, such as how to seek an assessment and diagnosis, or how to find and access supports and services.

Participants felt strongly that the NDIS was too bureaucratic and complicated. They did not know what information or supporting documents would help to make their application successful.

> "I am an analyst in the public sector doing a PhD and I can't fill in all the NDIS forms. How does someone who has not had the privilege of an education get anywhere with anything?"

Participants were exhausted by the administrative burden, and the need to communicate with multiple management layers and different bodies. They were also frustrated by how long they had to wait to find out the outcome of applications or reviews.

People told us one barrier was needing an appointment with specialists or allied health providers in order to access supports. We heard that often letters from specialists and allied health providers were needed to support applicants to access to services through the NDIS, and that not being able to get an appointment means not being able to access necessary supports and services.

People told us it is hard to find and keep support workers. We heard that the shortage of support workers had a major impact on the ability of people with disability to maintain employment. It also led people to continue to use support workers that made them feel uncomfortable or unsafe.

We heard people tell us they had to leave meetings and events early because they didn't want to keep their support worker or taxi driver waiting or make them cross, as they might not continue to support or drive them if they kept them waiting.

We heard that there is not enough oversight or regulation in service and support industries. People told us that there are not enough rules or checks to ensure that support workers are not abusing or exploiting clients. People also shared their deep concerns about the lack of regulation and oversight of service providers that are not registered NDIS providers.

We heard it is hard to find services and supports that are safe for LGBTIQA+ people, especially trans and gender-diverse people. Some people told us they felt the need to disclose their sexuality to potential support workers before hiring them, to avoid hiring a support worker who might subsequently treat them with prejudice. We heard experiences of support workers and service staff misgendering, dead-naming, and outing trans people.

We heard that for people not eligible for the NDIS, there are very few services and supports available. This includes people who acquired or were diagnosed with disability after the age of 65, people who have a condition that might be temporary, people who aren't eligible because of their visa status and people who aren't eligible for a variety of other reasons.

We heard that therapies and programs available through the NDIS are individualised and fragmented, rather than community-based and wraparound. People told us that while this model was good for having more choice, there are few opportunities for social connection and peer support.

Many people felt the for-profit nature of the NDIS service providers meant that profits come before people. They felt competition made providers unwilling to suggest the services of competitors, even if they might fit the person's needs better. Some people reported being pressured by service providers to take on additional supports they did not want or need.

Aboriginal and Torres Strait Islander people with disability told us there is a lack of culturally safe supports and services. We heard from many First Nations people that they have never had an Aboriginal or Torres Strait Islander support worker. We heard from many a fear of asking for help because people will judge you and say that you can't continue to parent or care for your family.

What are the ideas for change?

People suggested the ACT Government explore ways to increase the number of students studying allied health or disability sector courses, so there are more support workers and more services available.

People also wanted to see better education and training across the disability sector to build the skills and capacity of the workforce.

People wanted to see improved oversight of disability services and supports, and more checks and balances on who can become a support worker. People also told us that transparency is important — they wanted it to be easy to find out if services and supports had passed safety checks, or if support workers had been screened for safety. **People wanted the ACT Government to foster peer-to-peer support, so people with disability and family carers can connect and learn from people with similar experiences.** People suggested the ACT Government support or establish drop-in centres, forums, social and recreational activities, and a range of other initiatives to foster social connection and peer networks. People also wanted to have more options of community and group-based therapies.

People suggested the ACT Government find ways to support people to apply for support. Ideas included having libraries offer a service to help filling in forms, and employing disability navigators to assist people through application processes at government agencies. Some people also suggested that the community sector could provide this kind of service.

People liked the idea of having a central place or expert person to answer questions and provide information. This could take the form of a hub or drop-in centre, a liaison officer, or a social worker.

We heard from culturally and linguistically diverse communities that existing cultural organisations should be given resources to support the people with disability in their communities.

Similarly, **the LGBTIQA+ community spoke to us** about how providing LGBTIQA+ organisations with funding and resources to support people with disability could help people to safely access supports and services.

We also heard that system navigation problems should be solved by making systems simpler and more connected. People suggested this could be achieved by making sure information is available in an accessible format, making sure that service-users can ask for help from a person rather than having to navigate a website or fill out forms, and making sure service providers and health professionals are able to connect people with the next step in the process.

Consultation participants and community organisations asked for **support to strengthen their own voice and more funding for individual and systemic advocacy**.

What does the evidence say?

The evidence shows people with disability face many barriers to accessing and securing safe and inclusive services and supports across a wide range of systems and settings. This lack of access denies people from securing the services and supports they need and puts people with disability at risk of experiencing systemic neglect, and other forms of harm and mistreatment.[175]

The NDIS is one avenue for people with disability to access supports and services. We also heard from many people with disability who had challenges accessing mainstream supports and services delivered outside of the NDIS. Evidence[176] shows people need considerable skills and networks to successfully navigate the complexity of the NDIS processes and documentation, and that these skills and networks, 'are not equally distributed across the population, meaning that some groups are either entirely excluded from accessing the NDIS or are able to derive less benefit from the Scheme than others'.[177] This is especially the case for Aboriginal and Torres Strait Islander people with disability and people with disability from culturally and linguistically diverse (CALD) backgrounds, with both population groups less likely to gain access to the NDIS and NDIS services and supports.[178]

A 2019 independent review of the NDIS found 'there is a need to provide additional support to help people with disability navigate the NDIS, exercise informed choice and control, understand and implement their plans and have their voice heard in matters that affect them'.[179]

The 2022 National Disability Services State of the Disability Sector Report found that 83% of service providers reported problems recruiting disability support workers and 80% were unable to provide all services requested of them.[180] This reinforces the feedback from the community about the difficulty in finding and keeping support workers.

Research also demonstrates that people with disability subject to compounding forms of disadvantage are faced with additional barriers that also impact on access to and engagement of services and supports. For example, we know LGBTIQA+ people with disability are negatively impacted by discriminatory attitudes in health and disability sectors, and that staff often lack the knowledge, skills and confidence to deliver responsive and inclusive services.[181] Evidence also tells us that Aboriginal and Torres Strait Islander people with disability have low levels of engagement with disability supports and services largely because of issues associated with institutional racism, which includes disability service systems and programs of support not designed in a way to effectively understand and respond to diversity of experiences and need.[182]

What we are thinking about

As we shape the ACT Disability Strategy, we are thinking about:

- Ways people with disability and family carers can better access the services and supports they need to pursue their goals and live well.
- How ACT Government mainstream services can be more accessible and meet the needs of people with disability.
- How we can improve the safeguards around supports provided to people in the ACT.
- How we can foster opportunities for peer-to-peer support and connection.
- How we can support existing ACT Government programs and frontline staff to be disability confident and better meet the needs of people with disability.
- How we can work with community and business partners to provide safe and welcoming support to diverse communities.
- How we can support the individual voice of people with disability being heard in the provision of their supports and services.
- In the consultation we heard a lot about the NDIS. As the NDIS is a federal initiative, it is outside the scope of the ACT Disability Strategy. However, as a stakeholder in the NDIS, we will continue to advocate for the interests of people with disability in the ACT.

9 Employment

ACT WELLBEING DOMAINS

- Living standards
- Identity & belonging
- Economy
- Social connection

UNCRPD

The UNCRPD (Article 27) has committed Australia to protecting the right to work for people with disability (on an equal basis with others) and includes a requirement to ‘prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment’,[183] which covers conditions relating to recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions. Article 27 also states people with disability have the right to work in an environment that is open, inclusive and accessible. The *Disability Discrimination Act 1992* and the *Fair Work Act 2009* also prohibit employment related discrimination on the basis of disability.

STORIES FROM THE COMMUNITY

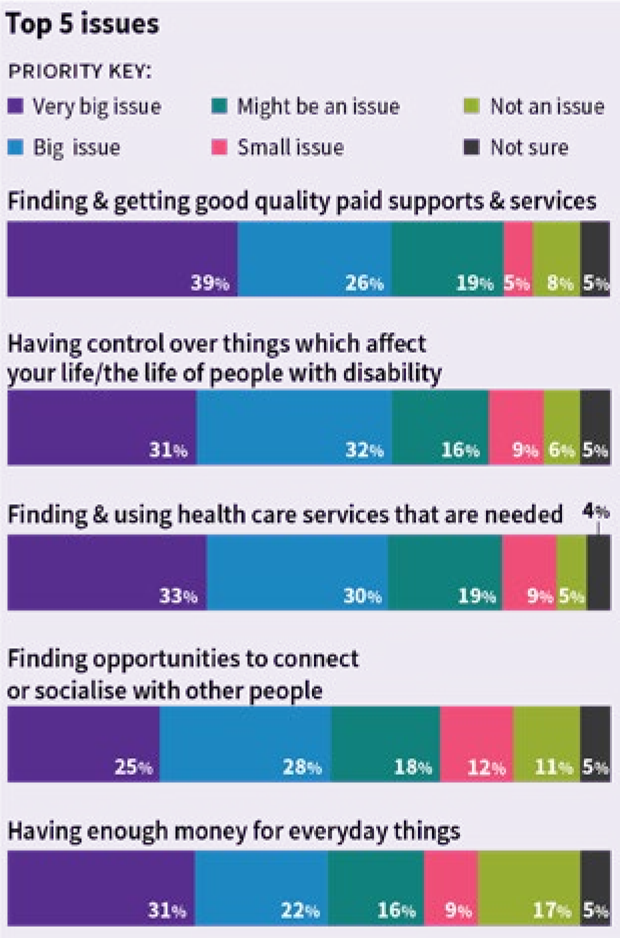
> “I was born with a physical disability. I have supportive parents who encouraged me to pursue an education and to follow my dreams. I completed school and went to university and got good results. I thought I was capable and able to succeed off my own resources, as I had done at school and at university. Once I finished university the job search began. I applied for job after job but without success. I did get interviews, but I would turn up for the interviews and that would be the last I heard from them. I honestly thought with my qualifications I could compete with anyone else. I was reluctant to resort to help from Disability Employment Services but finally I gave in. Once I had the support, I was employed immediately, and I have had a successful public service career since that time. What that tells me is that something needs to change in terms of the culture and attitudes of employers because for people with disability, it is simply not an even playing field.”

What we learned

Quantitative survey information

The survey included questions about issues that people with disability experience in the ACT and asked people to consider actions that would make a difference. We heard a lot that relates to employment in the responses.

First, we asked people about issues that affect them. The top 5 were:



‘Finding and getting good quality paid supports and services’ was the top issue. Disability Employment Services are included in supports. Supports and services can also be essential for some people with disability to ensure they are able to participate in the workforce.

‘Having control over things which affect your life’ was the second top issue. Employment provides financial security which allows more control over parts of life. Being able to find a job and feel empowered and satisfied in that job requires control over many things. The consultation found that people with disability feel sometimes decisions in the workforce are made for them, not with them.

The number 4 issue was ‘Finding opportunities to connect and socialise with other people’ and in the consultation people discussed how employment can provide social connection and belonging.

‘Having enough money for everyday things’ was the fifth top challenge, and one important benefit of employment can be the financial security it provides.

‘Finding work and getting and keeping a job’ was rated as a big or very big issue by 48% of people that completed the survey.

The survey asked people to pick one highest priority area for action. **‘Employment’ was selected as the third top priority for action.**

When asked specifically what would make a difference in the lives of people with disability ‘Increasing the confidence of employers to engage with people with disability’ was identified as the second top action people felt should be included in the ACT Disability Strategy — 69% of responders believing this would have a big impact.

Other employment actions were considered valuable — 54% of respondents felt ‘Mandatory Disability Action and Inclusion Plans for organisations’ would have a big impact and 27% felt it would have some impact. On the issue of ‘Employment targets for emplying people with disability’, 51% of people felt ‘Employment targets for employing people with disability’ would have a big impact and 27% felt it would have some impact.

What we heard

The topic of employment drew people’s attention in both the face-to-face workshops and in open text responses to the survey. There were strong feelings about the role employment and jobs play in people’s lives.

What are the challenges?

We heard that many workplaces do not make access and inclusion a priority.

> “I haven’t been able to attend a work Christmas party for the last 12 years as the venues are never accessible for me.”

> “If you disclose you have a disability you are immediately put in the ‘too hard basket’!”

Participants felt that many employers simply didn't know how to begin.

> “While most employers are open and even eager to create more inclusivity, many are unaware of where to start.”

Interviews with businesses arranged by the ACT Inclusion Council found that many employers are open, and keen, to be more inclusive, but often do not know where to start in terms of becoming an inclusive workplace or attracting applicants. The survey also found that employers hold misconceptions around the costs and provisions required to be an inclusive employer.

People shared experiences of recruitment processes that were not accessible.
People that are neurodivergent commented that job interviews often did not work well for them, as candidates were judged on social cues such as eye contact and rapid answers to questions. People from the Deaf community felt interviews discriminate against them. Many people said that job interviews should not be the only way to select a candidate and that the interview was often not closely related to the requirements of the job itself.

People told us about times they had not been offered reasonable adjustments in recruitment processes, even when they had informed the workplace of their disability.

> “Employers need to be more flexible in how they manage the job application process. We need to take employers by the hand and get them to think outside the box because there are all these potential employees out there that think a little bit differently and have unique skills to contribute but the recruitment processes don't support their chances.”

People with disability told us about bias and discrimination they had faced when seeking employment.

> “I have missed out on opportunities because of my disability. Others see the walking stick and have biases you can't do the job you are applying for.”

Many people felt there was not enough support for people with disability to find employment. Not all people with disability were eligible for support from Disability Employment Services.

People told us that students with disability did not have the same work experience opportunities as the other students. That without the opportunity to have work experience at school your chances of gaining a job when you leave school are diminished. People talked about wanting more assistance on this from their schools and their NDIS support providers.

> “The NDIS is siloed from education which is why a person with disability has to wait until they are 22 years old before they get a chance to have work experience, but work experience/first job should be age-appropriate. Other children get support to do work experience in years 9 and 10, and their first part-time job at 15 or 16 years of age.”

People told us they felt that school career counsellors were often not informed about opportunities for students with disability.

People shared barriers they had faced to promotion and career development once employed. They felt there was a virtual ‘ceiling’ placed on anyone who required reasonable adjustments.

> “The biggest challenge I face is career development. It is too distressing with anxiety to follow the standard process, so you can't have access to all the things that you want to have access to.”

We heard about the difficulties receiving and maintaining reasonable adjustments. Participants told us they were frustrated about having to tell their story over and over again to get and then keep the adjustments they needed.

> “It was quite a process to have to re-explain my disability experience; to disclose every time my manager changed and explain what assistance I need. Many staff don't understand what a reasonable adjustment looks like. Managers don't understand.”

They told us many people with disability did not know what adjustments were available or how to make a request. We heard that sometimes a supportive manager or boss may move on and is replaced by someone who is not told about the reasonable adjustments or is not willing to keep them in place. People told us that there was an expectation that they would soon stop needing the reasonable adjustments and were asked when it could finish.

We heard that flexibility is important, as reasonable adjustment needs can change over time. Some people with disability can go through times with reduced energy levels and often felt this was held against them in the workplace.

Many people shared that their requests for flexible working conditions had been refused.

Many people have found employers tend to make decisions on their behalf and assume incompetence or helplessness.

> “Often people do not approach you directly to ask what your needs are. I have experienced colleagues asking my manager what my reasonable adjustments are when I have been sitting right there. This is not okay — ask me, not others. I have a disability, but I am not stupid!”

Participants told us that too often people with disability are in employment not suitable to them and that people with disability don’t have the same employment choices due to attitudes and barriers.

> “Underemployment. Boredom. A lot of people with disability get stuck in the same job for way too long and they get bored.”

What are the ideas for change?

People felt the ACT Government was in a good position to lead by example as an inclusive employer. They suggested a support team to help new staff access reasonable adjustments, lead disability awareness training and support the creation of Disability Action and Inclusion Plans across government.

People suggested a range of job-specific disability awareness training and toolkits would be helpful, especially focusing on inclusive recruitment and management practices.

People wanted to see more flexible working arrangements and to see more actions to ensure reasonable adjustments are easily understood and available.

Some participants suggested staff with disability could be provided with ‘disability passports’ which they could take from one job to another to help with the transition and to maintain reasonable adjustments.

Many suggested targeted job creation, such as identified positions and quotas for hiring people with disability in larger organisations. They also suggested a recognition program to acknowledge managers and teams that are inclusive.

Participants suggested changes in hiring practices and a range of different recruitment methods rather than relying only on an interview process. People suggested the diversity statement on a job advertisement or position description should be up front and clear.

They suggested support and training for staff with disability to support career advancement and this could include peer support.

People also suggested there could be a program run by or funded by the ACT Government to support community and businesses employers to become more inclusive and accessible. This would support the confidence of employers toemploy people with disability.

More support for people to find the right job was suggested, with programs for school leavers, employment support for people not eligible for the NDIS, tailored job creation, and scholarships and traineeships for people with disability. People also suggested Disability Employment Service providers should hire people with disability to ensure they have the insight needed to provide quality services.

Interviews with businesses arranged by the ACT Inclusion Council identified many positives experienced by businesses that hire employees with disability. One suggestion was for a communications campaign that tells positive real stories about inclusive employment and to ‘bust the myths’ about cost and required support.

> “We’re doing it because it’s good for business. We’re doing it for our people. We’re doing it for our clients.”

> “The current staff become more loyal because the existing staff feel good about doing something purposeful.”

Businesses interviewed on behalf of the ACT Inclusion Council also suggested the ACT Government consider leveraging its procurement power in requiring business engaging with government to demonstrate proactive engagement of inclusive employment practices.

What the evidence says

Barriers to employment for people with disability in Australia

People with disability face numerous barriers to employment and are less likely to participate in the labour force compared to people without disability.[184] The labour force participation rates for people with disability has remained largely unchanged from 2003 (53%) to 2018 (53.4%), and the median income for people with disability is approximately half that of people without disability.[185]

The 2016 Willing to Work National Inquiry into Employment Discrimination against Older Australians and Australians with Disability found 'employment discrimination against people with disability is ongoing and systemic'.[186] The report confirmed that discrimination was underpinned by negative assumptions and attitudes held by employers and the community about the productivity and capability of people with disability, and that 'coordinated and effective action is required to address employment related discrimination and reduce the barriers to workplace participation'.[187]

Nationally, the evidence tells us:

- In 2018, 53.4% (just over half) of people with disability aged 15–64 ('working-age') had or were looking for a job, compared to 84.1% of working-age people without disability.
- The unemployment rate of working-age people with disability (10% or 113, 000) is twice that of those without disability (4.6% or 544,000).
- People with disability have lower incomes than people without disability. In 2018 working-age people with disability had a median gross income of $505 per week, which is less than half the $1,016 weekly median income of people without disability.
- Compared to people without disability, people with disability are less likely to be employed full-time. The rate of full-time employment of people with disability is half that of people without disability.[188]
- First Nations people with disability, women with disability, culturally and linguistically diverse people with disability, and LGBTIQA+ people with disability face additional barriers to finding and keeping a job.[189]
- Graduates with disability take 61.5% longer to gain full-time employment than other graduates.[190]
- 33.3% of people with disability who are employed are managers or professionals.[191]

Removing barriers to employment and retention of people with disability

The Willing to Work Inquiry found[192] that employers can address barriers by:

- Making leadership commitments to inclusive and diverse workplaces, including targets for employment of people with disability and widely promote inclusive policies and practices regarding the recruitment and retention of people with disability.
- Delivering non-discriminatory recruitment and retention practices which ensure cultures, processes, and practices do not discriminate against people with disability.
- Embracing and promoting hybrid work arrangements and a culture of flexible work, by ensuring job design, work location and hours are flexible for all.
- Helping to facilitate transitions and supporting employees who wish to transfer to other industries or roles by providing skills training and identifying transferable skills.
- Providing targeted education and training in the workplace about staff rights and responsibilities at work, including: reasonable adjustments, flexible leave options, internal grievance processes, and the nature and impact of discrimination.
- Building healthy workplaces by investing in health and wellbeing programs for staff and implementing healthy work practices to prevent chronic conditions and promote good health.

Employment of people with disability in the ACT Public Service

The *ACT State of the Service Report 2021–22* found that as at June 2022, 2.9% of ACT Public Service (ACTPS) employees identified as being people with disability, which is 787 employees.

Representation of people with disability in leadership is higher than the ACTPS average — 6.1% of executives and 4.2% of senior officers in the ACTPS identify as having disability.

The ACT Government has a current employment target of 5% people with disability by 2026.

Employees with disability in the ACTPS rated their job satisfaction at 68%, compared with 76% for the whole of the ACTPS.

Under 2021–22 enterprise agreements, ACTPS introduced disability leave provisions, granting leave for the purposes of activities associated with an employee's diagnosed permanent or ongoing physical or psychological disability.

Several ACT Government directorates have introduced initiatives to increase the employment and retention of staff with disability, such as staff networks and forums. Details about the specific activities of each directorate can be found in the *State of the Service 2021–22 Annual Report*.

ACT context

In the ACT there are several actions underway to support better employment outcomes for people with disability.

The Employ My Ability Associated Plan (Disability Employment Strategy) sits under Australia's Disability Strategy and is the national disability employment strategy for governments, employers and the broader community to improve employment outcomes for people with disability.[193] The ACT needs to report on actions relating to this plan.

In October 2022 two ACT-based organisations were awarded Information Linkages and Capacity Building grants from the Australian Government to improve employment outcomes for people with disability. The Canberra Business Chamber and ACT Disability Aged and Carer Advocacy Service. Both projects are expected to increase the confidence of employers to hire and support people with disability.

What we are thinking about

As we shape the ACT Disability Strategy we are looking at:

- Ways that people with disability can experience successful employment.
- How we can build the confidence of the workforce to value the contribution of people with disability.
- How to raise the status of the ACT Public Service as a best practice employer of people with disability.
- How to build more understanding about reasonable adjustments.
- How to achieve a range of flexible recruitment methods to improve access for people with disability.
- How to provide support and training for people with disability to achieve their career goals.
- How to build greater disability awareness and accessible work practices for all sectors including government, community, and business sectors.

10 Decision-making

UNCRPD

The right to make decisions is part of the UNCRPD. Article 3 (General Principles) include inherent dignity, as well as individual autonomy (including the freedom to make one's own choices), and Article 12 (Equal recognition before the law) accords persons with disabilities with legal capacity on an equal basis as others in all aspects of life.[194]

STORIES FROM THE COMMUNITY

> “ I live on my own and I make many decisions on my own. When I have big decisions to make there are different people I will ask for help to talk it through. My mother is my financial guardian because I have some investments from an inheritance to help pay for my medical bills and for my living costs. If I have a financial decision, I will talk it through with Mum and she always asks me for my opinion, which I think is important.
> Most everyday decisions I make on my own, such as what to have for dinner and what groceries I need to buy. For bigger decisions I often talk it through with my support worker or my NDIS coordinator. I bought a new fridge recently and my support worker helped me work out what size would fit in my kitchen and helped me to choose one that suits me.
> The most important thing for me is that even if someone is helping me to decide, they need to spend time to talk it through with me and to make sure they ask for my opinion rather than making the decision for me.”

About decision-making

All people have the fundamental right to make decisions about issues that impact their lives. People have better lives when they are presumed to have decision-making ability and supported to participate in decision-making. Many people with disability have reported that negative attitudes and other barriers within the community make it hard to have individual autonomy in decision-making.

It is important to acknowledge that decision-making falls on a continuum when a person has been identified to require support for decision-making. A **supported decision-maker** or supported decision-making network may support a person to make decisions by helping the person express their values, will and preference. The aim is to assist the person to build their decision-making ability and make informed choices and provide assistance in consultation with the person to identify their individual needs and preferences to any reasonable adjustment, cultural preferences, likes, dislikes, and views.

As a last resort, a **substitute decision-maker** may be appointed where a person is identified to have impaired decision-making ability. An example of a substitute decision-maker be:

- A private guardian formally appointed by ACT Civil and Administrative Tribunal (ACAT).
- A public guardian appointed by ACAT when there is no known private person willing or suitable to fulfill the functions of a substitute decision-maker.

The appointment of a private or public guardian can happen only as a last resort by ACAT, when someone has impaired decision-making ability and there is a need for a decision in relation to a specific matter, or if a guardian is not appointed the person's needs will not be met or the persons interests would be significantly adversely affected.

It is also critical to acknowledge that decision-making ability is fluid and may change over time as people broaden support networks and build capacity to make decisions independently. The focus of substitute decision-makers should be on the individual needs of the person they support and be reviewed regularly to ensure that substitute decision-making occurs only with the lightest touch possible for the shortest time possible.

What we heard

Quantitative survey information

In the survey, the second biggest issue affecting people with disability was 'having control over things which affect your life/the life of people with disability'. For 63% of survey respondents this was a big or very big issue.

Survey respondents were asked to consider priorities for action to be included in the ACT Disability Strategy. 'Support for people with disability to make their own decisions' was rated by 65% as a high priority and 22% as a medium priority.

The wider consultation

What does a good life look like regarding decision-making?

> “I have the right to participate in decisions about my own life!”

People want to be able to make decisions about their own lives, and have those decisions respected. This includes decisions about small things, like what to wear or what to have for breakfast. It also includes major life decisions, like where to live or who to hire as a support worker.

People want to be able to get help or advice to make decisions when they feel they need it. Consultation participants told us that there were circumstances in which support to make a decision was helpful.

> “My top priority is…“having support people help me understand what the implications of a decision might be, and respect my opinion of that decision. I often feel like I do not understand important aspects of my life like finance, legal matters, etc.”

People want to be able to ask for support in certain areas of life, when trying to make decisions in areas they feel they are not experts in.

Participants told us that it would be useful to have available people who were professional decision-making coaches or community volunteers with subject-matter expertise who could be consulted about making decisions in particular areas. We also heard that family carers, friends, and members of people's informal support networks play an important role in providing advice and support in making decisions.

People want to learn and develop the skills to make decisions for themselves.

Decision-making is a skill that most people have the opportunity to begin learning from early childhood. As people get older, they generally get to have a say in more decisions that impact us. Some people with disability aren't given the same opportunities.

We heard from young adults in the consultation who were frustrated at not being allowed to make the same types of decisions as their same-age peers.

> “Mum and Dad don't think I can make decisions that are right.”

People with disability, as well as family, support workers and advocates emphasised that people deserve the right to take risks, and the opportunity to learn from their choices. Rather than being prevented from making potentially “bad” choices, consultation participants were enthusiastic about equipping people with the skills to make their own decisions. People can develop these skills through life experience and by being allowed to make age-appropriate decisions from childhood. People can also develop these skills through workshops and classes, like the Down Syndrome Association's 'Decision-making for people with Down syndrome' workshop.

What are the challenges?

We heard that some people do not feel comfortable and empowered to make their own decisions, and **do not feel they have access to enough support or decision-making coaching from people they trust.**

> “Having support people help me understand what the implications of a decision might be, and respect my opinion of that decision. I often feel like I do not understand important aspects of my life like finance, legal matters, etc.”

Substitute decision-makers are often not informed about supported decision-making or disability rights. A substitute decision-maker is someone who is formally appointed on behalf of an individual by formal order of the ACAT, to make decisions for an individual.

We heard from ADACAS that knowledge about rights of people with disability to make their own decisions is not widespread, which can lead to substitute decision-makers acting against the interests of the person they are making a decision for or failing to respect their rights.

We hear that large systems drive people into applying for guardianship. We heard through the consultation that families felt they needed to apply for guardianship because large systems pushed them into taking decision-making responsibility on for their family member. We heard that the systems that people had the most trouble with was the health system, banking systems and the NDIS.

Family carers who played a significant role supporting their family member’s decision-making or acted as substitute decision-makers for their family member expressed concern about who would look out for their family member’s interests if they passed away.

> “A big fear is long-term financial abuse of my child who will inherit solid assets. My worry is that her finances will be eaten away by fees and people who manipulate her.”

What are the ideas for change?

> “What I would like to see in the new strategy is: for everyone to be able to make their own decisions; to get the help to make decisions when they need it; and be included in all decisions that affect them.”

Participants suggested that training on how to support someone to make decisions should be easily available and led by people with disability. This training could be available for formal carers, family carers, guardians, support workers, health professionals and family and friends.

> “Training for support workers, health professionals and other services on supported decision-making and how to respect the right of people with disability to make decisions.”

> “Supported decision-making is not taught but it needs to be.”

People with disability told us they want to be able to access support in making some decisions. This means that the people they ask for support need to have the right skills and knowledge. Carers and support workers who participated in the consultation told us they would be interested in attending supported decision-making workshops.

It was suggested there could be more NDIS funded decision-making coaches that would make up the mix of supports a person with disability can access.

Circles of support were suggested by participants, which involves a group of trusted people in a person’s life agreeing to take on a coaching role for decision-making on different parts of life, depending on what their interests are.

People suggested that decision-making education needs to start at school, for all students and particularly for students with disability to help build an understanding of rights, choice and control, how to make decisions and how to seek help making decisions in a safe and empowering way when help is needed.

Participants also suggested smaller caseloads for the Public Trustee and Guardian would ensure the support provided can be more personalised and responsive.

What the evidence says

Moving from substitute to supported decision-making

The Australian Department of Social Services commissions the University of New South Wales to create the resource, Good Practice in Supported decision-making for People with Disability[195] to promote supported decision-making. These guidelines outline steps for governments to take to transform to a model of supported decision-making, including legislation reform, policy reform and social reform. Legislative reform would recognise full legal personhood and legal capacity of all people regardless of disability. It would also ensure limited liability for a person supporting a person to make decisions provided they are acting in good faith and to make it clear that substitute decision-making processes are limited only to the matter defined in the order and decision and do not indicate the person lacks legal capacity. Policy suggestions include embedding supported decision-making across many settings such as justice, health, housing and education and to provide education, tools and resources on supported decision-making.

The Disability Royal Commission committee on decision-making[196] reported:

- Supported decision-making must be based on the will and preference of the person. It should not be based on what someone else thinks is in their best interests.
- The way a person communicates should not be a barrier to getting support in decision-making.
- The person can choose the support, say no to support or change the support for different decisions.
- Decision-making rights and getting support should not rest on ‘mental capacity’ assessments.

Supported decision-making pilot programs in Australia

A supported decision-making project was conducted by the Office of the Public Advocate in South Australia from December 2010 until 2012. The project aimed to enable people with a cognitive disability to make individual decisions about a variety of life choices. This involved establishing an agreement between a person with disability and a supported decision-making supporter. This small study consisted of 26 people with an intellectual disability or acquired brain injury that may have been otherwise subject to a Guardianship Order. Evidence from this study suggested participants felt increased confidence in decision-making and had broadened existing support networks, and individuals reported to have more support available. While the findings of this program were positive, due to the small nature of the study it was undetermined if this type of pilot program would have the infrastructure to support alternatives to a guardianship model. [197]

Currently the Office of the Public Advocate in South Australia is undertaking a project called Living My Life. The project is funded through a grant on behalf of the NDIA. The aim is to explore how people can be in charge of their own decision-making while also reviewing how to record the wishes of people who have a guardian, which can be used to inform future decisions.[198]

ACT context

In the ACT there are actions underway to shift to supported decision-making. In September 2022 the ACT Government introduced a bill seeking to amend the *Guardianship and Management of Property Act 1991*. This bill would result in 2 changes to the law. Firstly, the ACAT would be required to consider whether a person could access supports to make, communicate and participate in decisions. If the person could access these supports, this would be a factor for ACAT to not appoint a guardian or manager. Secondly, where guardians or managers are appointed, they would be required to facilitate a supported decision-making approach as far as practicable.

This is a first step to the ACT adopting a supported decision-making model. Further reform is required to shift culture and practices, which will in turn support further legislation reform to transition from a model of substitute decision-making to supported decision-making.

The ACT Government has funded ADACAS to work with young people with disability and their families to learn about supported decision-making, practice making decisions with support and build a supported decision-making plan.

What we are thinking about

As we shape the ACT Disability Strategy, we are looking at:

- How the ACT can promote supported decision-making through legislative reform, policy and programs.
- How we can build a culture of decision-making coaching as a role that is accepted by many people that are important to a person with disability.
- How we can support institutions and service providers to reduce their reliance on substitute decision-making and transition to a supported decision-making model of service delivery.
- How education can build decision-making skills.
- Ways to increase awareness of the individual needs of people with disability and work across service-systems, government, and the community sector to grow the knowledge of decision-making pathways.

Image credit: Felix, age 12

11 Safety

ACT WELLBEING DOMAINS

Safety

UNCRPD

Article 16 of the UNCRPD states that ‘State Parties shall take all appropriate…measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects’.

Article 15 protects the freedoms of people with disability from ‘torture or cruel, inhuman or degrading treatment or punishment’.

STORIES FROM THE COMMUNITY

> “I am vision impaired and use a cane. I have been overcharged by taxi drivers twice which makes it hard for me to trust and makes it challenging to get around town as I cannot drive. I need to rely on taxis a lot and I wish taxi drivers were better trained on how to work with people with disability. I know a friend of mine who has an assistance dog and he has been refused taxis and Ubers when they see the dog, which is just so unfair.
>
> Sometimes when I am out and about, I feel scared. I know of a lady who was mugged, and she walked with a cane. I feel when I am out in the community, I look vulnerable and an easy target. I am afraid of being followed and singled out because I look like I won’t be able to defend myself. My friend was followed, and someone tried to snatch her bag.
>
> At night-time street lighting is very low so it is not safe for me to be out at night. If I do need to call the police, I can do so but I want to feel sure they will understand how to help me best given my vision impairment.”

What we heard

Quantitative survey information

Challenges from the survey

In the survey, 42% of people felt that 'Feeling safe in the community' was a big or very big issue and 22% responded that 'Feeling safe at home' was a big or very big issue.

Priorities for reform in the survey

'Safety from violence' was rated as a high priority for reform by 69% of respondents and 18% as a medium priority. 'Feeling safe in the community' was rated as high priority by 58% of respondents and a medium priority by 24%.

The wider consultation

What are the challenges?

Being safe from violence was identified as a high priority issue by people in our consultation, with challenges to safety in the home, in the community and in accessing services and supports, including disability support services as well as services to respond to experiences of violence or mistreatment.

We heard people with disability can feel unsafe at home. People told us they need more choice about where they live and who they live with, and who enters the home (and when).

> "We were broken into while we were at home. It is very frightening to feel so vulnerable in your own home."

The safety of women with disability at home was raised. We heard women with disability are at increased risk of violence and mistreatment in the home and have reduced opportunities to respond to violence. We were told that women with disability have been denied supports when escaping violence or when seeking help from emergency or crisis services due to the lack of accessible, suitable, and safe options.

> "Women with disability struggle to be believed and trusted as credible by police and other institutions."

We heard that people with disability can feel unsafe when out in the community. Lack of inclusion was cited as one cause, including lack of consideration for diverse needs of people with disability.

> "A world where people aren't frightened of using public transport because the next bus might not be accessible."

We heard women with disability face barriers accessing services when responding to violence or harm. We were told many domestic and family safety services are not accessible and not designed to respond to the diverse violence and harm experiences of women with disability

> "People with disability leaving a violent relationship might have children with disability, meaning that multiple people with disability are looking for accommodation that doesn't exist."

People feel staff at domestic violence accommodation and support services often lack training on how to support people with disability.

> "Family safety and family violence services are not designed to act for people with disability."

We heard that disability services and supports are not equipped to adequately prevent or response to gendered violence and harm.

People with disability can feel unsafe at home due to the behaviour of carers, informal supports and disability services. We heard people with disability may be afraid of harm, including retribution for speaking up or taking action against people that had a formal or informal role in their life and who were threatening their safety or choice and control.

> "There have been a few instances recently where disability support workers have brutally assaulted their clients. Disability services need to be much more vigilant about who they choose to hire and how they supervise their employees."

The shortage of support workers means that some people may stay with a service even if they do not feel completely safe or comfortable. People also told us it is hard to find information about vetting and safety checks of potential support workers.

Some people with disability are at risk of intersectional disadvantage, compounding their sense of being unsafe. Aboriginal and Torres Strait Islander people with disability told us they want to access services that are free from judgement, stigmatisation, and discrimination.

> “I feel like I’m going to get bowled over’ [whilst walking out and about].”

People told us about feeling unsafe when out and about, including on public transport, in shops and businesses, at school or work, in and around urban centres or hubs (e.g. Civic) and when interacting with everyday programs, services or supports. This is discussed in detail in the Accessible Communities chapter.

People with disability can feel unsafe in the community due to the increased risk of being a victim of crime or experiencing discrimination, bullying and harassment.

> “If you are vision impaired and using a cane, you are identified as a person with disability which makes you visible and vulnerable.”

People told us about challenges in the built environment that can lead to physical injury for people with disability. These are discussed further in the *Accessible Communities* chapter of this report.

People told us about issues with disability awareness among emergency services workers and feeling that emergency services are less accessible and that some people with disability can experience communication difficulties when trying to get support from emergency services. As an example, we heard how members of the Deaf community may not feel safe out in the community at night due to communication barriers preventing contact with emergency services.

> “People with disability fall through the cracks.”

We heard some people with disability may not have access to adequate, disability-informed sex education. This may result in people not being informed about body autonomy, sexuality, sexual health, and relationships and can place people with disability (in particular — but not only — women) at increased risk of experiencing sexual violence, abuse and mistreatment.

> “Being able to have safe and disability aware sexual health is a challenge for the disabled community!!”

People feel the disconnection between systems and lack of integrated supports can result in the needs of women with disability being overlooked, or can leave women with disability without supports, or without options to respond to experiences of violence or harm.

We heard that people with disability can be more vulnerable to scams and financial exploitation. Parents and guardians of children with intellectual disability are concerned about their children falling victim to scams or being financially exploited by someone they know, especially after the parent’s death. People with vision impairment reported being overcharged by taxi drivers.

What are the ideas for change?

We heard people with disability have good strategies to help them feel safe, with many respondents raising the importance of social connectedness and having strong and trusted relationships with family, friends, neighbours, support workers and wider social networks to call upon if needed.

People would like to see better collaboration between services in domestic violence situations, such as between crisis services and disability services. People suggested an increase in violence prevention services for people who use violence, both for people with disability and people without disability.

People suggested more disability-specific training for staff at domestic violence services as well as the use of universal design in physical crisis facilities and services. An audit of existing crisis accommodation was suggested. Participants also suggested that disability sector workers be trained to identify warning signs of trauma, violence, exploitation, and neglect.

The community would also like to see increased oversight of disability support workers to reduce the risk of mistreatment of people with disability by support workers.

It was suggested that people with disability are given greater access to sex and relationship education and that sex educators are disability aware and trained.

There were several suggestions on how to improve interactions between emergency responders and people with disability. Disability awareness training was one frequent suggestion as well as more disability liaison officers in police stations. The Deaf community proposed a review of services for people with hearing impairment to contact emergency services and to communicate with police.

As with all focus areas, people suggested that all changes to services and physical settings should be co-designed with people with disability to make sure they are fit for purpose.

What does the evidence say?

Evidence tells us that having a disability increases a person's risk of experiencing all types of violence, abuse, neglect and exploitation, compared to people without disability.[199] We also know that people with disability are between 2 and 10 times more likely to experience violence compared to people without disability.[200] Lack of choice, control and autonomy, coupled with exclusion from social, economic and cultural life, places people with disability at increased risk of violence and harm.[201]

There are gaps in ACT and national data in relation to people with disability, safety, and incidences or experiences of violence and harm. Although data in the ACT is incomplete, we do know 65% of adults with disability (aged 18–64) nationally have experienced physical or sexual violence, partner violence, partner emotional abuse or stalking in their lifetime, compared with 45% of adults without disability.[202]

Evidence also tells us people with disability, as a cohort, are more likely to experience physical violence than other types of violence. Diverse groups of people with disability are also at increased risk of experiencing violence, abuse or neglect. For example, we know people with intellectual disability experience abuse and neglect at high rates and that the recognition and response by people who support people with intellectual disability is often poor.[203] We also know that the service system does not adequately prevent and respond to violence against people with disability. For example, women with disability seeking support are often 'caught in a cycle of successive referral, without ever receiving appropriate or timely interventions that ensure their pathway to safety'.[204]

National figures also tell us:[205]

- women with disability experience higher rates of partner violence and sexual violence compared to women without disability, with more than one-third of women aged 18–64 having experienced violence by a current or previous partner, compared with one in 5 women that age without disability

- younger adults with disability experience violence at much higher rates than other adults with disability. One in 4 people with disability aged 18–29 are estimated to experience violence compared to around one in 10 people with disability aged 45–64 years. Risk of violence is higher for younger women with disability (aged 18–29), who are twice as likely to experience sexual violence compared to young women without disability in that age group
- children with disability are 3 to 4 times more likely to be victims of violence than children without disability.

We also lack data on issues related to the experiences of people with disability who are at risk of multilayered discrimination and oppression. This includes people with disability with other identifies or diversity characteristics associated with disability type, age, gender, class, First Nations, LGBTIQA+ and CALD related statuses. The available evidence does strongly suggest people with disability subject to multiple oppressions are at increased risk of experiencing violence, abuse, neglect and exploitation.[206]

We know that people with disability in institutionalised, closed, and segregated settings are at increased risk of experiencing violence, including diverse forms of harm, such as restrictive practices.[207]

Additionally, people with disability are at significantly greater risk of experiencing restrictive practices in their homes, at work, in detention facilities, and in the health system and mental health settings. For instance, research tells us that restrictive practices are routinely used in group homes,[208] and that the use of restrictive practices across NSW is likely increasing.[209]

To ensure services are accessible, frontline services should engage women with disability as partners during key planning stages of service development to ensure the services are designed to and respond to the diverse access and participation needs of women with disability.[210]

Research tells us that we need to broaden our understanding of access and accessibility: 'access for women with disabilities is about much more than simply removing physical barriers to service buildings. Good practice principles for accessibility suggest that services must be approachable, acceptable, affordable, available, and appropriate'.[211]

Evidence also tells us that specific forms of disability awareness training for first responders, such as police, can bring about improved interactions and outcomes for people with disability. For example, scenario-based training is effective for enhancing police capacity to appropriately respond to people with psychological disability. Further benefits are derived from directly involving people with disability who have experienced police contact in the development and delivery of such training programs.[212]

What we are thinking about

As we shape the ACT Disability Strategy, we are looking at:

- How to ensure all people with disability can reach out for help when they need it.
- How the systems can work better together to ensure disability services and crisis services work together.
- How to improve the accessibility of responder services to domestic and family violence, and sexual assault.
- How to increase the availability of accessible crisis accommodation.
- How to increase disability knowledge and awareness for frontline responding agencies.
- How to improve interactions between police and emergency responders and people with disability.
- How, as an NDIS contributor, we can provide safeguards to improve quality and accountability of supports and services to prevent mistreatment and abuse.
- How to increase disability support worker awareness of the warning signs of trauma, violence, and neglect and appropriate actions to take.
- How to improve access to body awareness and sexual health education, along with rights-based education for students with disability.
- How to improve services and support for people who use violence.
- How to ensure changes to programs and facilities are co-designed with people with disability.

12 Justice

ACT WELLBEING DOMAINS

Government & institutions

Safety

UNCRPD

Article 13 of the UNCRPD recognises the right of 'effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages'. This means that people with disability in Australia should be protected by the law, be able to use the law and be able to participate in all stages of legal processes and procedures on an equal basis with others in the community.[213]

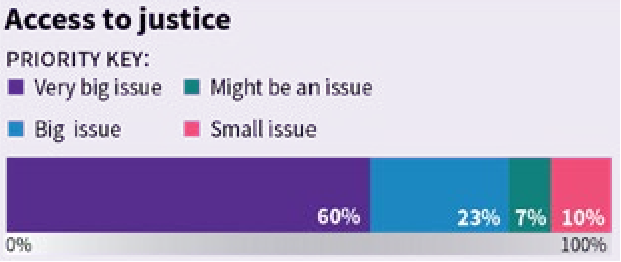
STORIES FROM THE COMMUNITY

> “I am a woman with intellectual disability. I was assaulted by someone I know. I didn't report this to police because I didn't know how to do that. I told someone about it and got help to report this to the police. Police got someone who is an intermediary to help me explain what happened. This was good but police said there wasn't enough evidence to charge the person. I had support from a disability liaison officer to get a personal protection order so the person who hurt me isn't allowed to contact me. I had to wait a long time and found it hard to understand all the steps that had to be done so the person who hurt me wouldn't be allowed to come near me anymore. I nearly didn't go through with it because it was so hard.”

What we learned

Quantitative survey information

The survey asked people about issues that impact people with disability in the ACT. Of the respondents, 83% rated ‘Access to justice’ as a big or very big issue.



People were asked to considered actions that could make a difference in the lives of people with disability.

‘Increasing the confidence of justice professionals to engage with people with disability’ was rated by 52% as potentially having a big impact. Disability awareness within sectors came up across many focus areas for the consultation and is a cross-theme issue.

‘Mandatory Disability Action and Inclusion Plans for organisations’ was rated by 54% as having the potential to make a big impact and by 27% as having some impact. We know Disability Action and Inclusion Plans have been an important element of the *ACT Disability Justice Strategy 2019–2029*, as they improve disability awareness in many services and organisations within the justice system.

What we heard

What are the challenges?

We heard disability is often not identified and fear of stigma means some people don’t want to disclose their disability. We heard people in the justice system often do not have access to the right screening or assessments to help them get the services and reasonable adjustments they need.

> “People with disability don’t want to disclose their disability because of stigma and bullying. They may not even be aware that they have disability.”

> “There isn’t enough screening for people in the justice system. Screening is needed for invisible disabilities like ADHD, FASD, autism and acquired brain injury. It is more difficult to screen for these conditions unless staff are properly trained.”

We heard about a lack of early intervention and support for people with disability in the ACT, especially people with complex needs. We heard how this lack of support can mean people end up in the justice system.

> “It’s hard to divert young people from the criminal justice system once they are in it. Many young people don’t get diagnosed until they are in Bimberi.”

> “A person we support during crisis cycles in and out of prison. He never has support or housing when he gets out of prison. It’s no surprise he ends up frequently in crisis.”

People told us police are often the only response when a person with disability is in crisis and that this can sometimes make a crisis more complicated.

> “When my child had a behavioural episode we rang the mental health crisis line and they told me we had to call the police but that is in no way an appropriate response.”

> “My child had a psychotic reaction … the police had no experience with autism. My child locked themselves in a room and refused to talk to the police, so they just left.”

We also heard people with disability who are victims of crime still face barriers to reporting crime and engaging with the justice system.

> “It’s a challenge for people with disability to report because it depends on their situation. Sometimes their reports are dismissed.”

> “It’s difficult to get justice as a victim, especially as a woman with disability who has been assaulted.”

What are the ideas for change?

People in the consultation wanted early intervention and holistic support for people with disability to stop people from entering the justice system and to reduce contact with the justice system. Some participants said it is important to make existing diversion pathways, like the drug and alcohol sentencing list, more accessible to people with disability.

People told us that they wanted holistic case management for people with complex needs.

People felt that better access to free screening and assessments, especially for children and young people, would reduce the number of people with disability in the justice system.

We heard that we need more accessible ways for people with disability to report crime. Participants also mentioned the importance of affordable or free legal assistance for people with disability.

Victims of crime with disability need to be better supported to feel safe and respected throughout the process.

We heard a good justice system ensures reasonable adjustments are made for victims, witnesses, accused people and offenders so everyone in the justice system knows what to expect and what is expected of them. **Participants felt having better training for staff to understand disability would improve the use of reasonable adjustments.** They suggested more screening and assessments for invisible disability, such as cognitive impairment and neuro-developmental disability for people in the justice system.

People spoke highly of the work disability liaison officers in the justice system have been doing to improve the experience for many people with disability. They recommended more disability liaison officers in the justice system including in First Nations organisations who support people with disability in the justice system.

What the evidence says

The Law and Justice Foundation did a national survey in 2012 to assess the legal needs of Australians. The report indicated people with disability were the most socially excluded of all disadvantaged groups due to systemic barriers and the experience of cumulative disadvantage.[214] The Law Council of Australia and the Australian Human Rights Commission have both examined issues of access to justice for people with disability.[215,216] They identified barriers to people with disability enjoying equal access to justice including:

- Lack of support and reasonable adjustments to access protection, report or defend criminal matters or participate in justice processes
- Negative attitudes and assumptions about people with disability which can mean they are viewed as unreliable or not capable of giving evidence, making legal decisions, or participating in legal proceedings
- Lack of community supports and programs to prevent violence and disadvantage and address health and social risk factors which leads to contact with the justice system.

Nationally, the evidence tells us:

- People with disability are 2.2 times more likely to have legal problems.[217]
- People with disability are 1.4 times more likely to be the victim of property crime.[218]
- People with disability are 2–10 times more likely to be subject to violence.[219]
- Police action rates are lower for victims of crime with disability, especially in relation to violent incidents.[220]
- One in 3 adult prisoners reported a chronic health condition that affected participation in day-to-day activities, education, or employment,[3] 40% of adult prisoners have experience of a mental health condition[3] and up to 35% of adult prisoners have intellectual disability.[221]
- A study of young people in detention showed approximately 50% experience intellectual disability or borderline intellectual disability, 50% had severe difficulties in language skills, over 80% experience psychological disorders and approximately 58% meet criterial for attention/behavioural disorder.[222]

- Aboriginal and Torres Strait Islander people are 1.7 times more likely to be living with a disability.[223]
- First Nations people with disability are almost twice as likely to experience discrimination as non-Indigenous people with disability,[224] more likely to experience violence,[225] and more likely to have contact with the criminal and civil justice system.[226, 227]
- Chances of future offending increase the younger a child is first in contact with the justice system.[228]

ACT context

ACT Disability Justice Strategy 2019–2029

In 2019, the ACT Government consulted with people with disability and the community about disability justice issues in the ACT. We heard then that people with disability in the ACT experience many barriers to equal access to justice. More information about what we heard then can be found at *Towards Disability Justice in the ACT: Summary of Research and Consultations 2019*. What we learned led to the ACT Government's *Disability Justice Strategy 2019–2029* and *First Action Plan 2019–2023*.

Since then, a lot has been done to make our justice system more accessible and responsive for people with disability. However, there is still work to do. What we heard in the ACT Disability Strategy consultation will help identify which actions need to continue from the First Action Plan and what new actions to include in the Second Action Plan of the *Disability Justice Strategy 2019–2029*.

The consultation and research to inform the *ACT Disability Justice Strategy 2019–2029* identified 5 themes for the life of the strategy.

1. **Information and communication:** accessible information and supports for people with disability to better understand how to navigate justice issues so people with disability know their rights, can express their views and information is shared effectively and appropriately through the system.
2. **Education and guidance:** improving the capacity of the justice system to have the knowledge and expertise to ensure people with disability access appropriate supports and reasonable adjustments.
3. **Identification, screening and assessment:** having more identification, screening and assessment points for people in the justice system will help people get the right support at the right time.
4. **Better service delivery:** improving services for people with disability will help address the risks associated with contact with the justice system.
5. **Data, research and review:** improving knowledge and data and disability and justice across the ACT will help shape future actions so they are effective.

The *Disability Justice Strategy First Action Plan 2019–2023* (First Action Plan) outlines commitments aligned with the themes above. Many of the great ideas provided by community members through consultations for the development of the Disability Justice Strategy contributed to the actions in the First Action Plan.

There has been progress during the first 3 years of the First Action Plan in all 5 areas. You can read more about the progress in the *Third Annual Progress Report for the Disability Justice Strategy 2019–2029*. Some good things that are happening are:

- Justice system staff attended training to learn about creating accessible information.
- Documents were translated into Easy English.
- Social scripts, person centred narratives with simple language and images to help a person know what to expect from legal services supports were created.
- Best practice guides have been developed to support ACT Policing and CYPS on how to better support people with disability.
- ACT Courts and Tribunal launched online training for staff to improve disability awareness.
- DLOs employed across the justice system have been supporting staff in their organisations to better understand and respond to people with disability.

While there has been progress, there is still more work to do, and this has been evident from the feedback provided by participants during the ACT Disability Strategy consultations. Participants told us there has been noticeable improvement for people with disability in the justice system.

Participants highlighted the work of the DLOs and the community of practice has led to better outcomes for people with disability. Participants also told us people with disability continue to face barriers in accessing justice in many areas of the justice system.

The ACT Government is developing the Second Action Plan which will outline actions to address remaining gaps for people with disability. Actions are focused on early and holistic support to stay out of the justice system or be diverted from the justice system. The Second Action Plan is due to be released in mid- to late-2023.

What we are thinking about

We will consider how we can:

- Divert people with disability from the justice system.
- Provide earlier intervention and support so people are less likely to come into contact with the justice system.
- Improve pathways for reporting crime for people with disability.
- Continue to improve identification, screening and assessment of disability in the justice system to inform reasonable adjustments and supports.
- Continue to develop education and training for justice sector workers.
- Consider holistic support for people with disability when they come into contact with the justice system and when they leave custody.

13 Emergency and disaster management

ACT WELLBEING DOMAINS

Access & connectivity

Safety

STORIES FROM THE COMMUNITY

> “I think the challenges and social isolation caused by COVID has had an impact on people living with disability. It has impacted our ability to get out and about and our mental health. The increased cost of food and living is also an issue.
>
> We need a conversation about emergencies and disasters—because people with disability are usually the first impacted and the last assisted.”

What we **learned**

People told us that good emergency and disaster management means ensuring the whole community is prepared and that the whole community is made aware of what could happen and what the consequences could be. People should be given the support and resources they need to plan and prepare.

We heard that information about emergencies and disasters needs to be available to everyone. This means vital information is accessible in a range of formats to fit different communication and comprehension styles. Vital information also needs to be available in Auslan, as well as community languages.

People talked about how infrastructure that is designed to be used in emergencies and disasters, like emergency alert and evacuation systems, needs to be designed with people with disability in mind.

We heard how effective responses to emergencies and disasters rely on police and first responders being disability-aware and confident.

What are **the challenges?**

We heard that often emergency alert systems and procedures aren't designed with people with disability in mind. We heard examples of workplace buildings that signalled evacuation with alarms that couldn't be detected by Deaf employees. Participants shared examples such as being left at their desk when an evacuation drill took place.

People told us that vital information is often not available in an accessible format, or in Auslan.

We heard that police and emergency responders often lack disability awareness and don't always know how to engage with people with disability.

Overwhelmingly, we heard about the COVID-19 pandemic. We heard that some elements of the initial response to the COVID-19 pandemic were positive for people who were at increased risk of developing severe illness from COVID-19.

In the early stages of the pandemic, processes and systems were put in place by both government and the private sector that allowed people to minimise their risk while continuing to work, study, and access essential services.

We heard that helpful activities included the expanded home delivery and delivery-to-boot services allowed people to safely buy groceries. Increased availability of telehealth allowed people to keep accessing healthcare. Greater flexibility to work from home across many sectors was valued also.

Deaf people spoke positively about the use of Auslan interpreters during COVID-19 press conferences.

We heard from people with disability as well as family carers about positive experiences they had at the Access and Sensory Vaccination Clinic, which helped people to be more confident.

People who had faced barriers to getting out of the house before the pandemic told us that the sudden shift to a contactless world vastly expanded the options of services, products and experiences available to them.

We heard about the ways people with disability felt they had been overlooked in COVID-19 responses.

Some people told us that people with chronic conditions couldn't access their regular medical care.

People had to deal with sudden cancellations of regular therapies or groups and weren't supported to find alternatives. Many people with disability and family carers felt socially isolated and burnt out because of reduced supports.

> “While leisure centres were closed, it made rehab difficult, and opportunities for seeing people for conversation have been few and far between — most group activities shut down.”

We heard about difficulties people had trying to book an interpreter to be present for COVID-19 vaccination or testing appointments.

Parents and young people told us that students with disability weren't given enough support in the transition to remote schooling.

Some people told us they were frustrated at return to 'business as usual', when the dangers are still very real in the lives of people who are at high risk of developing severe illness from COVID-19. They felt that the onus has now been placed on people with disability to protect themselves from COVID-19.

We heard that early on in the pandemic, people felt there was a sense of community and shared responsibility for protecting the most vulnerable. As the pandemic entered its second year, people felt that attitudes towards protecting the most vulnerable had changed.

We heard that people with disability felt they had been overlooked when decisions were made about removing mask mandates in public places.

What are the **ideas for change?**

Co-design of emergency and disaster response with people with disability is the first crucial step.

People told us that emergency responses need to have the voices, rights and agency of people with disability at the centre. This includes consulting with people with disability and considering the impacts of policies and plans on people with disability. In the context of COVID-19, it means making sure the rights and freedoms of people with disability are considered in conversations about rights and freedoms.

People told us that when we evaluate how government has responded to emergencies and disasters, people with disability need to be at the centre of the conversation.

People suggested the ACT Government make sure health, emergency response, and disability services have lines of communication in place. People wanted to make sure that when emergencies and disasters happen, all 3 sectors can share information as well as concerns.

People asked for emergency and disaster alert and evacuation infrastructure that works for people with disability. For example, using more visual and dynamic signage, so that Deaf people can be notified of important information, or in case of emergency.

People asked for more disability awareness training for police and first responders. They also suggested that we have more disability liaison officers in policing.

People told us that in cases where people with disability need to take extra steps to stay safe, they need to be supported by government to do so. In the case of COVID-19, this means giving people free access to the personal protective equipment and medication they need; protecting their right to work and study from home; and making sure people with disability have contactless ways to access essential services and participate in the community.

We heard that government needs to consider the long-term impacts of emergencies and disasters on people with disability, not just the short-term impacts. In the case of COVID-19, this means planning and budgeting for long COVID and considering ways to support people who cannot return to normal life in the community because COVID-19 is still in transmission.

People suggested we do more to make the community aware of the impacts of emergencies and disasters on people with disability. People shared their ideas for awareness campaigns about how continuing to wear a mask and social distancing where possible would have a major impact for people at high risk of serious COVID-19.

We were reminded to think about the diversity of the disability community, and how policies and changes that benefit some people might make life harder for others. We heard about the impacts of isolation, lost services and supports, inability to access medical care, and barriers to communication that emerged during the COVID-19 pandemic. The community reminded us that there are many voices and views, and that government needs to consult and consider widely.

What the **evidence says**

The right to protection and safety in emergencies and disasters

The Sendai Framework for Disaster Risk Reduction is an international agreement between UN Member States, with the goal of the substantial reduction of disaster risk and losses.[229] The Sendai Framework explicitly identifies the need for governments to engage with people with disability in the design and implementation of emergency and disaster policies and plans,[230] and to empower people with disability to publicly lead 'universally accessible response, recovery, rehabilitation and reconstruction approaches'.[231] The Sendai Framework was adopted by Australia in 2015.[232]

The National Disaster Risk Reduction Framework and the Australian Disaster Preparedness Framework are Australia's national frameworks for emergency planning and response. Despite being the chief means of applying the Sendai Framework to Australia, the National Disaster Risk Reduction Framework makes no specific reference to engaging with or responding to people with disability.

Under *Australia's Disability Strategy 2021–2031*, governments have established TAPs to achieve goals in key areas. The Emergency and Disaster Management TAP sets out actions for the federal and state governments to improve outcomes for people with disability in national emergencies.[233]

Experience of people with disability in emergencies and disasters

People with disability are disproportionally impacted by disasters, as they are at greater risk of death, injury, and loss of property.[234] People with disability are also likely to have greater support and healthcare needs, adding complexity to staying safe during a disaster.

Inaccessible information and advice contribute to the increased risk to people with disability during emergencies and disasters. The Disability Royal Commission heard that 'information and advice provided by governments during emergencies overlooks the specific needs of the disability community and is often inaccessible to many people with disability'.[235] Research conducted in NSW found that Deaf people are excluded from disaster preparedness and vulnerable to disaster due to communication barriers — there is limited access to disaster information in Auslan, emergency messages are usually communicated via audio form or in complex written language, and it is difficult to communicate with emergency personnel.[236]

Inaccessible emergency and disaster infrastructure also frequently contributes to the death, injury, and isolation of people with disability. During the 2019–20 bushfires, some people with disability had difficulty accessing evacuation shelters due to the lack of ramps, railings and accessible toilets.[237]

As well as requiring the same support as people without disability through emergency response and recovery processes, people with disability may also have pre-existing support needs with self-care, mobility or communication. The continued provision of these supports may be complicated by the fact they come from diverse sources, including family, friends, and disability and health service providers.[238] Maintaining necessary supports through an emergency event requires comprehensive forward planning by people with disability and any other people involved in providing supports or care. However, people with disability are frequently excluded from conversations about emergency and disaster planning.[239]

Best practice

Disability Inclusive Disaster Risk Reduction is a practice that actively includes and engages with people with disability and their representative organisations in preparing for disasters.

The Queensland Department of Communities, Disability Services and Seniors partnered with the Centre for Disability Research and Policy at The University of Sydney, the Queenslanders with Disability Network and the Community Services Industry Alliance to produce a Disability Inclusive Disaster Risk Reduction Framework and Toolkit.[240] The framework and toolkit are designed as a roadmap for people with disability, community and disability support services, and local disaster management to co-design disaster risk reduction.

The Person-Centred Emergency Preparedness (P-CEP) Toolkit has been developed by the Centre for Disability, Research and Policy to enable disaster preparedness for people with disability. The tool, which was co-designed and tested by people with disability, enables people to tailor their emergency preparedness planning to their individual support needs. The P-CEP is function-focused, not deficit-focused. It emphasises the role of local community assets and cross-sector collaboration.

The P-CEP tool is a workbook or conversation guide that people with disability can go through by themselves, or as a conversation with family, friends, or support providers. In early 2020, the ACT Community Services Directorate commissioned an adaption of the P-CEP tool for COVID-19 and tailored for the ACT. The original P-CEP tool is non-specific about hazards — by adapting it for COVID-19, the resource asked more direct questions and provided clearer, situation-specific guidance.

The Ideal Accessible Communications Roadmap has been developed by the ACCAN, in partnership with people with disability and other experts. The Roadmap establishes a set of shared goals to illustrate what is needed to ensure all people with disability in Australia have full and equal access to communications technologies and services.[241] The Roadmap supports organisations and individuals to create an accessible communications sector, including telecommunications, communications technologies, online services, and broadcasting. The roadmap outlines specific goals relating to accessible communications for emergency services, accessible emergency announcements, and accessible community meetings in emergency situations.

What we are thinking about

As we shape the ACT Disability Strategy, we are thinking about:

- How we can have clear communication protocols when disaster or emergencies occur.
- What the best ways are to prepare people, so they know what to do when unforeseen events occur.
- How to ensure infrastructure utilised in emergencies is accessibility.
- How we include people with disability in the development of response plans and recovery plans.
- How we share information and data across government partners in emergencies to ensure people who have high support needs are considered in responses and plans.
- How we hear the voice of people with disability and their supporters in the work we do around responding to emergencies and recovery.

Thank you and next steps

The Disability Strategy Project team would like to thank all the people who participated in the consultation and gave their time, experiences and ideas outlined in this listening report.

This work would not have been possible without the efforts of people with disability seeking better outcomes, the Disability Reference Group and our allies and partners across government and community.

The *Disability Strategy 2023–2033* and the first 4-year Action Plan will be considered by government and presented to the ACT Legislative Assembly in mid-2023 for endorsement and action.

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