



Right to opportunity

Consultation report to help shape the next national disability strategy

December 2019

A [summary](#) of this report is also available.

Acknowledgements

Department of Social Services and the authors of the report, The Social Deck, extend our thanks to all those who participated in the consultations, in particular to people with disability and their families and carers from all over Australia who took the time to share their stories. We acknowledge people with disability may have overcome barriers to attend or participate in consultation activities, and we sincerely thank you for your efforts to take part in the consultation process.

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We acknowledge the traditional custodians of country throughout Australia and recognise their continuing connection to land, waters and culture.

The voices of people like **Judy from Devonport** feature throughout this report. We sincerely thank all of the people who attended events, to give their feedback and those who kindly shared their stories to help inform the next national disability strategy for 2020 and beyond.

 [Play video](#)



Disclaimer

This author of this report is The Social Deck Pty LTD.

The analysis presented in this report reflects data from the public survey and what people said in survey comments, community workshops across the country, specific engagements with Aboriginal and Torres Strait Islander peoples, an online forum and in-depth discussions. Tens of thousands of unique inputs and comments were made during the course of the consultations and these are collected, de-identified and maintained as a rich data source for disability policy development.

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Any views and recommendations of third parties contained in this report do not necessarily reflect the views of the Commonwealth, or indicate a commitment to a particular course of action.

All direct quotes in this report are excerpts from the survey and what people said during the consultation process. It is, however, important to note that neither the Department of Social Services (DSS) nor The Social Deck was able to verify the accuracy of the comments. Nor should the analysis be read as representative of all Australians with disabilities, because participants and respondents were self-selected.

This report will not be the only source of data to inform the development of the National Disability Strategy. As the consultations took place during Federal Government Caretaker period, there was not a discussion paper or public submission process. The Commonwealth and state and territory governments will undertake further consultation early in 2020 to continue to inform the next national disability strategy.

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[The appendices are available to download.](#)

Introduction

The *National Disability Strategy 2010-2020* has been a guiding document for national disability policy and legislation for almost 10 years. It was released following consultation with people with disability, their families and carers, the disability sector and the wider community. The strategy was informed by the [2009 Shut Out report](#).

The current National Disability Strategy aims *'to guide government activity across mainstream and disability-specific areas of public policy, drive improved performance of mainstream services in delivering outcomes for people with disability, and provide leadership towards greater inclusion of people with disability.'*

One in five Australians have a disability. The current strategy is about creating a more inclusive society that enables Australians with disability to fulfil their potential as equal citizens.

It is also the main way Australia implements the United Nations [Convention on the Rights of Persons with Disabilities \(CRPD\)](#). The CRPD is a human-rights based approach to disability and sets out legal obligations to make sure people with disability have the same rights as everyone else.

Disability policy has undergone significant and ground-breaking reform since the release of the first National Disability Strategy. Most significantly was the introduction of the National Disability Insurance Scheme (NDIS), which began full rollout from July 2016, following trials throughout the country. The NDIS will be implemented across all states and territories by July 2020. The NDIS supports a better life for hundreds of thousands of Australians with a significant and permanent disability and their families and carers.

However, the NDIS is only one part of a broader system supporting people with disability. For the 4.37 million people in Australia who live with disability, more than 85 per cent will not be eligible to become NDIS participants. It is critical to the thousands of people who contributed to the consultations that the next strategy complements the NDIS, but also includes a strong focus on areas and actions outside of the NDIS, to make sure access, inclusion and wellbeing for all people living with disability improves.

Developing the next national disability strategy for 2020 and beyond

At the end of 2020, the current strategy will come to an end.

Governments across Australia are working together to design a new strategy for national disability policy for 2020 and beyond.

The COAG Disability Reform Council has agreed to develop a new national strategy to guide disability policy, programs and legislation over the next 10 years.

Developing the next strategy means establishing a revitalised set of principles, as well as new guidance that meets expectations of people with disability and the broader community. Most importantly, that it upholds Australia's commitment under the CRPD.

The next strategy will continue to guide disability policy, legislation and funding across Australia, at all levels of government.

About the consultation process

Consultations ran from April to July 2019.

They were designed to explore the things that are important to people, to explore what's improved or gotten worse since the first strategy was developed in 2010, and to allow people to share their own individual stories, experiences and opinions about the issues affecting them.

Parameters of this report

This report follows an analysis of what was said during the period of consultation from April to July 2019.

It summarises what many people who took part in consultations said and presents a number of statistically representative insights about the issues people with disability in Australia are facing. It also suggests some specific ideas and areas people said should be included in the next national disability strategy.

Direct quotes from people who attended consultation workshops and who made comments in the survey have been included throughout the report. More than 10,145 free-text comments were made in the survey, predominantly by people with disability, and thousands of individual comments and inputs were also collected in the workshops, online forum and meetings with stakeholders.

This report is not intended to present policy recommendations or provide evidence on specific issues. It is based only on what individuals have said and shared, from their own experiences. It does not represent views of submissions from organisations or seek to qualify or verify the issues raised. It should be considered alongside existing data and reports about issues affecting people with disability in Australia, which provide further evidence about the issues raised in the consultation.

Two key limitations of the consultation process which affect this report were:

- Representation of people with disability was comparably lower in face-to-face workshop events, in contrast to the survey where around 40 per cent of respondents self-identified as being a person with disability. As a result, we have recommended more targeted face-to-face engagements of people with disability in a future round of consultation to ensure the voices of people with disability, from different backgrounds and situations, are heard.
- Consultations took place during the Federal Government Caretaker period. They were exploratory to gain data on people's views and experiences but did not ask for comment on specific ideas or policies and did not include a public submission process or a discussion paper to inform the consultations.

This report, along with numerous other reports and data sources, will assist the Australian Government and state, territory and local governments, to work together on developing the new strategy. It is intended further consultation with people with disability, their families and carers, and the sector, will take place before a new strategy is finalised by the end of 2020.

Links with other recent reports

Two independent reports in 2018—a review by University of NSW Social Policy Research Centre on implementation of the National Disability Strategy 2010—2020 and a review by the Productivity Commission into the National Disability Agreement—were used to inform the topics and questioning of the public consultations. They also built on findings from the 2017 Senate Inquiry into delivery of outcomes under the National Disability Strategy.

In addition, the Australian Government has developed its second and third periodic reports to the UN Committee on the Rights of Persons with Disabilities (CRPD) (September 2019). Australian Disabled People's Organisations (DPOs), Disability Representative Organisations (DROs) and Disability Advocacy Organisations have also collaborated to develop the Civil Society Shadow Report on the Convention on the Rights of Persons with Disabilities, which presents the perspective of people with disability in relation to Australia's compliance with its obligations under this Convention.

The National Disability Strategy is the main way Australia upholds and implements its obligations under the United Nations Convention on the Rights of Persons with Disabilities. The Australian Government and Civil Society reports to the UN cover many of the same areas to the themes and issues included in this consultation report.

In undertaking the next steps to design the national disability strategy for 2020 and beyond, Governments will consider the full range of consultation inputs, including the reports referred to above as well as other research, data, independent reviews and reports available.

[A Summary can be downloaded as a separate report](#)
[An Easy Read of the summary is also available](#)

Participation and methodology

Public consultation to inform the development of a future strategy for disability policy was undertaken from April to July 2019.

Who was engaged to inform this report?

This report is based on an analysis of thousands of individuals' inputs and comments from people with disability, their families and carers, and other stakeholders such as disability advocates, service providers and academics. People were consulted in a number of different ways.

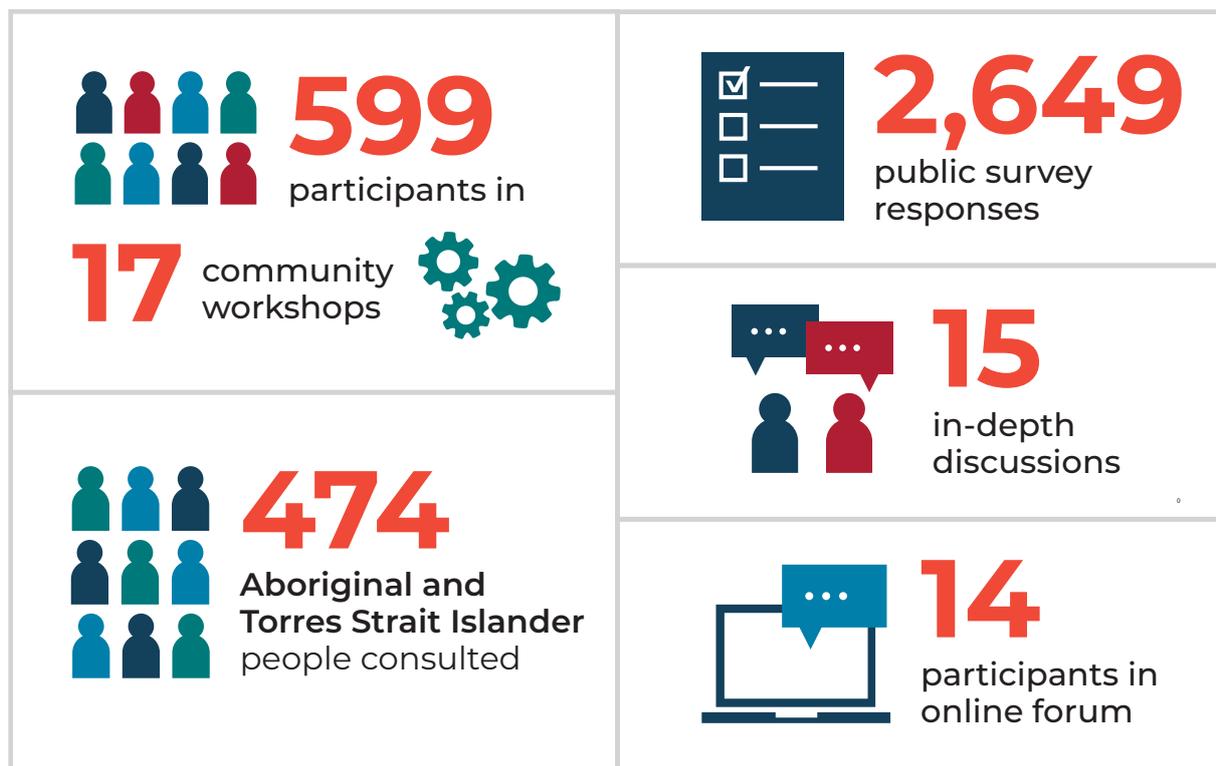


Figure 1. Participation numbers across different consultation activity.

Face-to-face community workshops

From 29 April to 14 June 2019, The Social Deck conducted 17 community workshops over various metro and regional locations across Australia, in Brisbane, Perth, Townsville, Sydney, Newcastle, Canberra, Hobart, Devonport, Geelong, Melbourne (2 workshops), Adelaide, Berri, Alice Springs, Darwin, Campbelltown, and Bunbury.

An experienced facilitator with lived experience of disability co-facilitated each workshop.

A total of 599 people with disability, their families and carers, advocates and service providers attended the 17 workshops. Around one-quarter of participants (n = 153) identified as having a disability or being a parent or guardian of a child with disability (refer [Appendix B – Table 1](#)).

The purpose of the 3.5-hour workshops was to seek input from people to help inform a national disability strategy for 2020 and beyond. A high-level agenda is at [Appendix C](#).

A variety of methods for engagement were used during the community workshops, which provided opportunities for people to provide input in different ways:

- Participants were asked to consider questions at tables and provide group input on butcher's paper.
- A workbook was provided to allow people to provide their own individual input at tables, if they wanted to.
- An online engagement tool was used to allow participants to provide individual inputs on their own devices.
- A series of Easy English cards and iPads were also used at topic stations to ensure people could provide their views on specific questions and topic areas.
- Facilitators assisted participants who were unable to physically write or move to topic stations.

Consultation with Aboriginal and Torres Strait Islander communities

A total of 474 Aboriginal or Torres Strait Islander people were engaged (formally and informally) to inform the next national disability strategy through a number of specific engagements:

- The First Peoples Disability Network (FPDN) consulted 78 Aboriginal and Torres Strait Islander people through a total of nine community consultations.
- Tasmanian Aboriginal Centre undertook targeted consultations with 20 Aboriginal people with disability across Tasmania.
- Consultations were held with 96 Anangu (Aboriginal people) from the NPY Women's Council member communities in NT, WA, and SA.
- In Queensland, ADA Australia as auspice of the Aboriginal and Torres Strait Islander Disability Network of Queensland (ATSIDNQ), undertook consultations with 280 Aboriginal and Torres Strait Islander people with disability in various locations across Queensland.

Targeted discussions and stakeholder meetings

In March 2019, the Department of Social Services and The Social Deck held two forums with key stakeholders from Disability Representative Organisations and the National Disability and Carers Advisory Council. The purpose of these forums was to gain advice and specific ideas about the next strategy, and to inform the consultation process.

From 29 April to 14 June 2019, 15 in-depth discussions were also conducted with a targeted cross section of key stakeholder groups and individuals. This included advocacy organisations and service providers (refer [Appendix B](#) Table 1).

Public survey respondents

From 3 May to 17 June 2019, the Australian community could complete an online survey via Survey Monkey. The survey was also available as an Auslan video and as a downloadable, interactive Easy Read PDF.

Overall, **2,649 respondents** completed at least some of the survey questions.

People with lived experience of disability (people with disability, families and carers) made up the majority of the responses (Figure 2). Of the respondents who completed the standard version of the survey, approximately:

- 40 per cent (n=1,051) had a disability
- 43 per cent (n=1,149) were parents, guardians or other family members of a person with disability.
- 13 per cent were carers of a person with disability. 34 per cent of carers also reported having a disability.

Reason for interest in the National Disability Strategy (n=2,649)

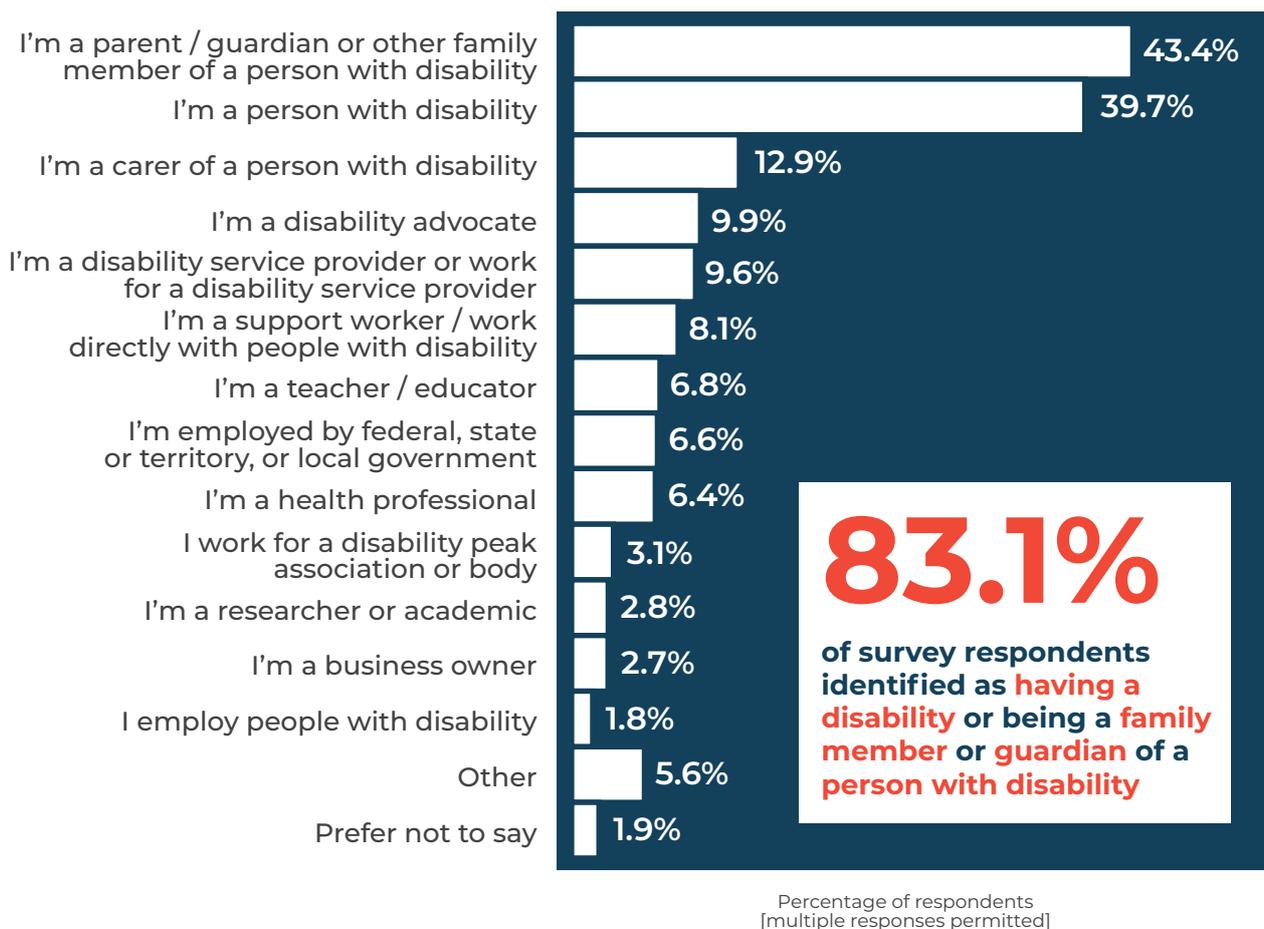


Figure 2. Reason for interest in the National Disability Strategy – respondents who completed the standard survey. (Q: Please tell us which of the following statements best describes you. Please select all that apply.)

The majority of survey respondents were women (77 per cent, n=1,452).

Sixty per cent of survey respondents were from a major city.

Twelve per cent of respondents (n=228) were from a culturally or linguistically diverse (CALD) background and 53 respondents identified as Aboriginal or Torres Strait Islander.

A more detailed breakdown of respondent demographics is at [Appendix B](#).

Open online forum

An online forum gave all Australians, no matter where they live, the opportunity to participate in shaping the next national disability strategy. The forum was open from 17 to 21 June 2019, and was hosted on the Department's Engage.DSS online platform. The Social Deck moderated the forum during business hours by posting a series of questions.

Over the course of the five-day open forum, 14 people participated. A total of 59 comments were made across the four topic areas.

Analysing results

The methodology for data collection, analysis and reporting followed a data driven, thematic analysis approach. The approach allows us to obtain an in-depth understanding of key themes and subthemes along with the issues and suggestions that were most commonly raised, and the differences between locations where consultations took place. While common themes and issues are outlined in this report, there are also a number of specific issues that were raised by particular cohorts or groups, and these are demonstrated in quotes and stories.

In addition to thematic analysis, we undertook quantitative analysis of survey responses and have used de-identified quotes to illustrate key findings.

Qualitative themes and issues are summarised from:

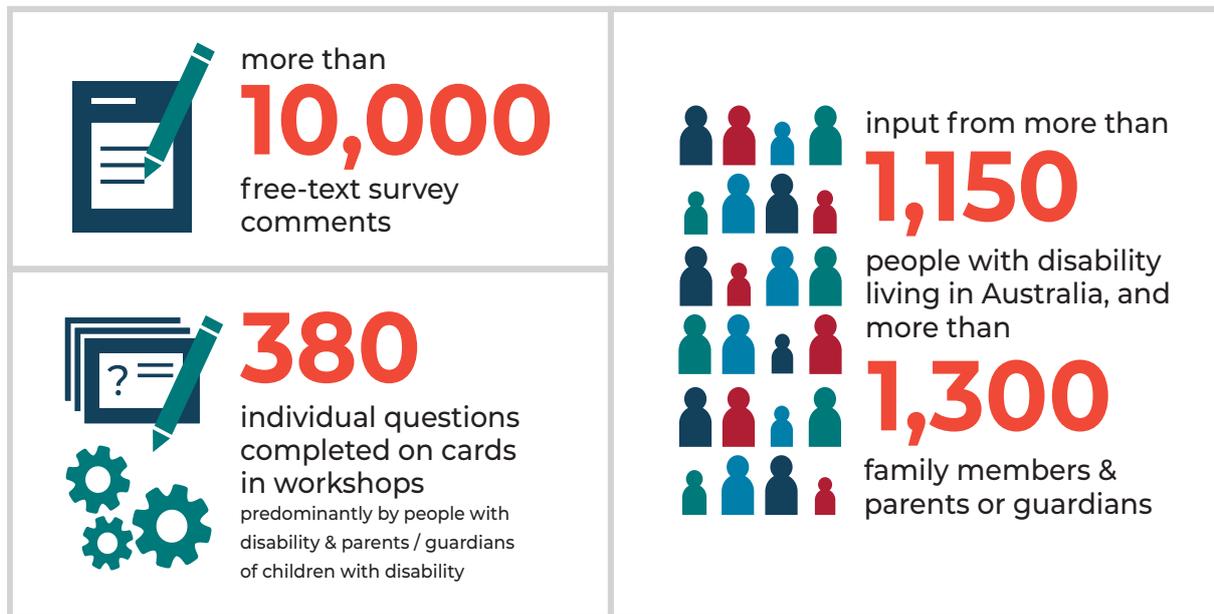


Figure 3. A snapshot of the amount of qualitative data inputs received from people with disability informing this report.

Scope of the consultations

It was not in scope to compare findings of what people said in the consultations to other research and evidence. In particular, when it comes to reporting on what people said is improving, or not, the analysis of this report is based only on data collected through the consultation activities outlined. It is not presented or analysed in relation to other data or evidence on whether outcomes for people with disability are improving, or not.

A range of data was collected during the consultations and has been used as the basis of preparing this report. The introduction section of this report outlines some of the key reviews and reports that will also be important inputs towards the development of the new strategy.

Consultation questions and topic areas

The purpose of the consultations was to hear from people about what is important for the next national disability strategy. This included talking to people about the things that will make their life better, and what a national strategy for disability might look like and could achieve beyond 2020.

In community workshops and the online forum, we asked people to provide their views and ideas against four key topics. These were:

Human rights and being equal

- Self-determination, and choice and control
- Rights protection, safety and justice
- Legislation
- Public awareness
- Advocacy

Inclusion in all community life

- Inclusive and accessible communities
- Accessible buildings, facilities, transport and services
- Accessible information
- Accessible recreation and tourism
- Community support and community attitudes
- Recognition and support for specific groups and demographics

Independence and wellbeing

- Financial security
- Employment and careers
- Lifelong learning and skills
- Personal support services
- Health and wellbeing

Emerging areas

- Technology
- Interaction with the NDIS
- An ageing population
- Social enterprise and cooperatives
- Entrepreneurship and microenterprise - opportunities for people to start their own business

Topics were selected with an understanding that the six outcome areas of the current Strategy are interrelated when it comes to how they affect the lives of individuals. As a result, except for where things have improved, questions were not categorised by specific outcome areas. The intentional overlaps between topic areas were designed to encourage people to think about issues, and why they're important to them, from different perspectives. Questions used in discussions are at [Appendix C](#).

Part A: Findings

A summary of what people said during consultations

In this section:

1. [What's happened in the past 10 years](#)
2. [The treatment of people with disability](#)
3. [Issues affecting the lives of people with disability](#)
4. [Issues affecting different groups and demographics](#)

'We need to be more inclusive of the community, find jobs for people with disabilities, open opportunities for people with disabilities, and give them the space to live meaningful lives within our communities.'

Hear from Karen in Melbourne.

 **Play video**

Chapter 1: What's happened in the past 10 years

In this chapter:

- [A comparison of what is better and what got worse](#)
- [What people said has improved](#)
- [What people said has not improved.](#)

Before designing a new national disability strategy for 2020 and beyond, it is important to reflect on what people say is happening now. This includes changes in the disability sector and services, and what is contributing to and affecting the lives of the 4.37 million people with disability in Australia.

This chapter focuses on people's views on what has improved, and what has not.

Throughout consultations, people consistently recognised improvements across the six outcomes areas of the current National Disability Strategy.

However, analysis also shows there remains significant barriers to people with disability being able to live independently, to be employed and financially secure, and to have the access to services and opportunities they need and have the right to. This included access to mainstream services such as health, education, housing and transport, and opportunities to fully participate in community life.

Based on thematic coding (including of the 2,152 respondents to the question about what has improved over the past five years), Figure 4 shows a basic rating of improvement against the six outcome areas of the current National Disability Strategy.

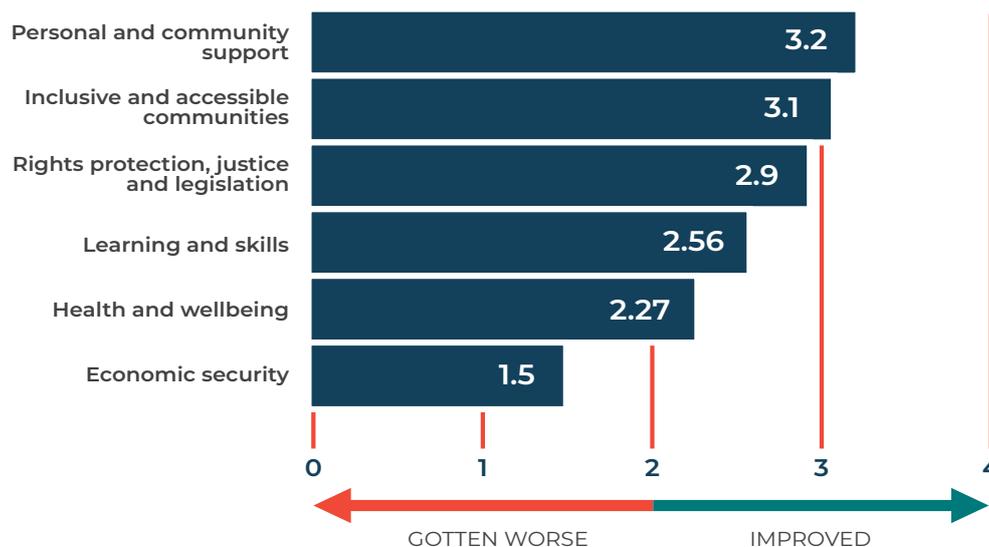


Figure 4. A summary of improvement rating based on combined results of Mentimeter, survey and thematic coding of community workshop, online forum and survey results.

Many people noted it is difficult to know if things are improving, as they have not seen data or reporting through the national strategy showing what progress has been made.

A comparison of what is better and what got worse

To help determine what is improving and what is not, the survey asked people to reflect on specific areas they thought had improved or worsened for people with disability over the past five years.

Survey respondents rated the degree to which a range of different influences on the health, wellbeing, and inclusion of people with disability were better or worse (refer Figure 5).

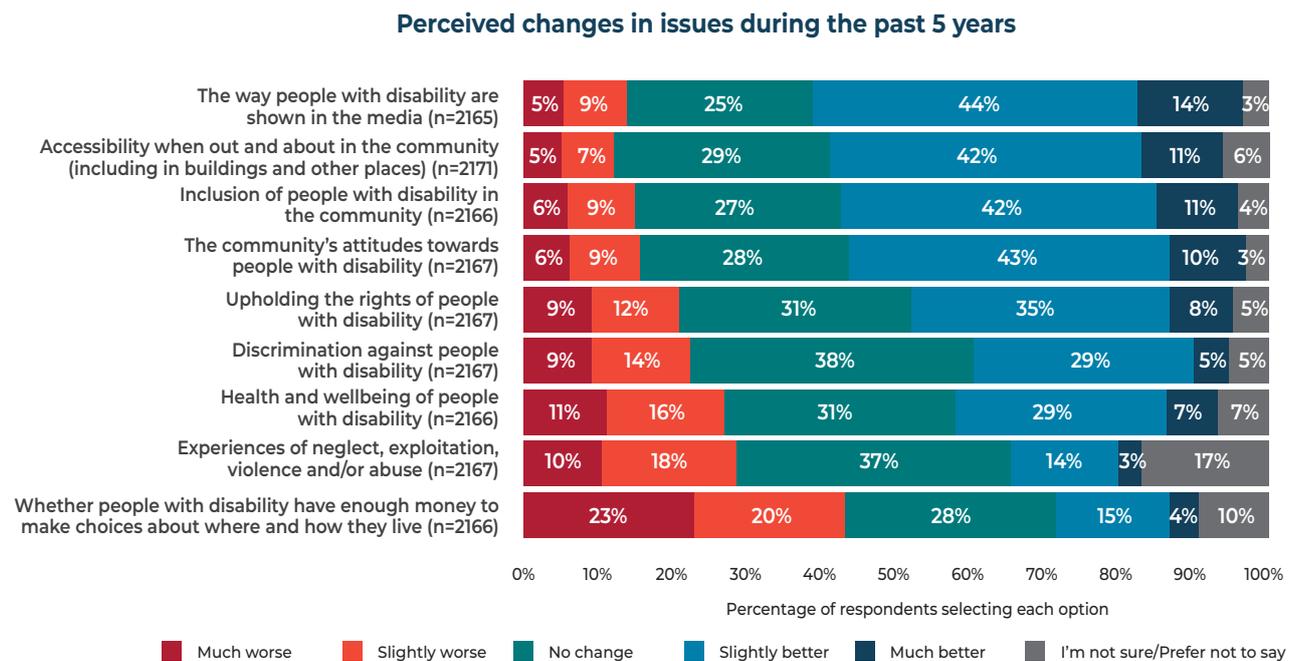


Figure 5. Perceived changes in issues during past five years – respondents who completed the standard survey (Q. We want to know how people with disability are treated in Australia. How much have the following issues got better or worse over the past 5 years?)

Across each of the issues listed, a large proportion of respondents said there had been no change.

The greatest perceived improvement was the way in which people with disability are shown in the media, followed by accessibility when out and about, inclusion of people with disability in the community, and community attitudes.

The area respondents rated as having improved the least over the past five years was having enough money to make choices about where and how they live—71 per cent said this had not changed or had gotten slightly or much worse.

Of significant concern is that the three areas which relate to rights protection, safety and discrimination of people with disability all ranked in the bottom half of the ratings (got worse), compared to other areas.

- Only one-third of respondents said discrimination of people with disability had gotten better.
- Just over one-quarter reported that experiences of neglect, exploitation, violence and/or abuse had gotten worse over the past five years.

For the small sample of respondents who completed the Easy Read survey, health care and financial security were the two issues that had improved the least during the past five years. The rights of people with disability being respected, the way people with disability are shown in the media and being included in the community were identified most often by Easy Read survey respondents as areas that have improved.

What people said has improved

Across the consultation activity, people were asked to share their own views on what has improved, or not, for them, or people they know or care for. Common areas people said had improved over the past five to 10 years were:

- access to individualised services and support, as a result of the NDIS
- community attitudes and awareness, driven by more visibility of people with disability
- inclusion and access in communities, including to public buildings, facilities, parks and events.

Increased access to individualised services and support

The area of significant improvement mentioned most often was increased access to quality, individualised support, services and treatment for people with disability.

Many people shared experiences about the positive changes in their lives since the introduction of the NDIS. People acknowledged the unprecedented reform effort to make the NDIS happen. However, we heard there are negative effects of the intense focus on the NDIS. Many people cannot access the NDIS, and some have not had positive experiences in the process and feel there are no longer other alternatives for support. However, people mentioned the NDIS gave them access to individualised support and services that may have been previously unavailable.

Community attitudes

Improvements in community attitudes and awareness of disability were seen as a positive sign of progress over the past 10 years. Many people said it helps that people with disability are now more visible in the media. People noted that seeing people with disability in the media more frequently has helped to reduce stigma and led to greater acceptance of people with disability in the broader community.



‘People with disability are being seen much more in the media, advertising, etc. and in mainstream shows. ‘Being seen’ in positive roles and mainstream settings does wonders for the self-esteem of other people with disability, and is representative of the society we live in.’



'Awareness within the wider community and social media has had an impact on disability becoming more socially accepted and 'normal' which has also given people with disability more of a voice to be seen and heard.'

Some people commented that there is a growing appreciation of what people with disability can offer and are capable of.

However, improved awareness was not reported across all types of disability. Intellectual, psychosocial, sensory and hidden disabilities are seen as continuing to be substantially misunderstood in the community and in workplaces.

Inclusion and access in communities

Many people with disability reported that access in their communities and to places, events and facilities is improving. While people consistently noted there is a long way to go, efforts made by governments to implement access and inclusion plans, and to make public transport, government buildings and sports and arts centres more accessible, was noticed.

Other areas of improvement

Other areas of improvement people noted during community workshops included:

- a move away from institutions and progress towards assisting people with disability to live independent lives in line with Australia's obligations under the UNCRPD
- access to information online and to technologies, including assistive technologies
- improvements to safety and justice
- progress towards more employment and education opportunities for people with disability, due to more inclusive attitudes and practices in workplaces and educational institutions.

There were mentions of the recent establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. People felt the government had taken action to ensure improvements in the area of safety and protection for people with disability.

Changes not specific to disability, such as new technologies and better access to information online, have also contributed to improvements in people's lives. However, there were also a range of areas people said could have improved as a result of new technologies but have not seen significant improvement in the past five to 10 years, such as employment rates.

What people said has not improved

Many areas of improvement reported during consultations, were also areas people consistently said had not improved. Key areas of overlap between what had and what had not improved included:

- issues related to the NDIS – this was raised most commonly in the survey in which majority of respondents were people with disability, their family members and parents / guardians
- inclusion and accessibility in community – this was raised most commonly at community workshops
- community attitudes, understanding and awareness of disability – this was raised consistently in both the survey responses and community workshops.

Other specific areas people commonly noted had not improved over the past five to 10 years were:

- government policy and investment
- access to health, hospitals and medicines
- enforcement of rights and discrimination legislation.

Issues were also highlighted with governments working together. People said a lack of coordination and issues with the integration of disability within mainstream policy and agreements negatively affected the lives of people with disability.



'Investment in disability policy needs to explore and connect to education, health, housing and employment.'

In regards to community awareness, results of the survey ([Appendix B](#)) showed there were still significant issues in the perceptions of, and attitudes towards, people with disability. Without a baseline it is difficult to know if this has changed over the past five to 10 years. However, the large majority of respondents (83 per cent) agreed 'people without disability are unsure how to act toward people with disability', demonstrating a lack of improvement in awareness and understanding of disability as a result of the first National Disability Strategy.

Chapter 2: The treatment of people with disability

In this chapter:

- [The rights of people with disability](#)
- [Discrimination](#)
- [Safety](#)
- [Advocacy](#)
- [Community attitudes and inclusion](#)
- [Leadership roles](#)
- [The language used](#)

Most people think the way people in the community treat people with disability is directly affected by their awareness and understanding of disability.

During consultations, people with disability shared negative experiences about the way they were treated by others in the community. People generally attributed poor treatment to:

- poor perceptions in the community
- a lack of understanding of disabilities
- a lack of access to advocacy, or the ability to self-advocate based on an understanding of their rights.

People said that people without disability were likely to feel more comfortable, and be encouraged to interact with people with disability, if they had a better understanding about their day-to-day challenges and capabilities.

In the public survey, 83 per cent of respondents agreed that 'people without disability are unsure how to act toward people with disability' and 63 per cent agreed 'people without disability ignore people with disability'. More than half (58 per cent) of respondents did not agree that 'people without disability are comfortable asking people with disability what supports they need'. Just under half (43 per cent) did not agree that 'people without disability think people with disability are approachable'.

The introduction of the NDIS and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability were identified as helping to shine a light on the issues people with disability face and increased public discourse about disability.

Many people identified a number of areas where the treatment of people with disability had improved:

- Increased awareness of disability and the rights of people with disability in the community and by services. Some people attributed this to requirements to have disability inclusion plans.
- Seeing people with disability in the media.
- Awareness of abuse, neglect and exploitation of people with disability, particularly since the announcement of the Royal Commission.
- Slightly more involvement of people with disability in politics, advocacy organisations, media and other high-profile settings or roles.

The rights of people with disability

A lack of understanding of the rights of people with disability by people and services across the community leads to the discrimination, exclusion and marginalisation of people with disability.

Many people said there needs to be a stronger focus on the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in Australia. People said Australia could do much more to incorporate the CRPD into policy and legislation, promoting and protecting the rights of people with disability.



'There are UNCRPD Legislation that is supposed to safeguard against those with disabilities, including by federal and state government. But I don't think it's taken seriously enough to help those with a disabilities.'

Workshop participants suggested an Australian (or federal) Human Rights Act to strengthen rights for all. They acknowledged some states were taking more significant action on this, and particularly mentioned the introduction of a Human Rights Bill in Queensland.

However, a national approach was identified as important to avoid inconsistencies and to recognise that rights and discrimination are not confined within borders, particularly as people spend more time online. A suggestion of new legislation and codes of practice was made to prevent discrimination and uphold the rights of people with disability.

Forty-three per cent of total survey respondents (and 36 per cent of respondents with disability) identified that upholding the rights of people with disability has improved over the past five years (See Figure 2 in [Appendix B](#)). However, in survey comments and at workshops many people noted improvements don't extend to upholding the rights of diverse and often more excluded groups. This included specific references to:

- Aboriginal and Torres Strait Islander people
- People with intellectual disability
- Parents with intellectual disability relating to their rights to have and care for their children
- People who are incarcerated
- People from CALD backgrounds, in particular new migrants and women.

NPY Women's Council noted that Anangu did not have the level of Western education and understanding about mainstream human rights. The NPY Women's Council consultations noted,

'the key message from the consultations is that a lot more work needs to be done to build the capacity of people to understand their human rights. This work needs to be ongoing. More resources need to be put into developing a workforce ideally of Aboriginal people who could do this work.'

People said there was little information available to inform people with disability about their own rights. In the survey, 60 per cent of respondents said it was very or somewhat difficult to find information about the rights of people with disability ([Appendix B](#)).

People from CALD backgrounds may also not be aware of their rights as a person with disability, and additional work is needed to ensure rights legislation is better communicated to people from CALD backgrounds, including to be delivered in multiple languages.

Workshop participants said people with intellectual disability were less likely to understand their rights, and this is often because information about rights is not provided in suitable and accessible formats. Survey respondents who identified as from a CALD background (228 respondents), reported more often than other respondents that it was difficult to find information about rights.



'CALD have lack of understanding of the rights of PwD, lack of knowledge on disability in general due to different cultural understanding.'

'[People] don't know what to do when they're discriminated against.'

Hear from Tammy in Devonport.

 **Play video**



'Ensure people with intellectual disability have accessible information and opportunities to learn more about their human rights and how to protect them.'

Specific measures and advocacy were identified as being needed for marginalised groups who were more likely to be discriminated against. Specific mentions of this included people who were LGBTIQ+, from CALD and Aboriginal and Torres Strait Islander backgrounds, and homeless people.

Discrimination

Workshop participants reported that discrimination of people with disability continues to exist in Australian communities. People with disability and their carers shared examples of discrimination:

- The poor treatment of children with disability in mainstream schools, specifically related to segregation of students, and suspension and expulsion of students as a result of behavioural issues, when they were not well understood in the school.
- Poor discrimination legislation or enforcement related to inclusive education with no consistent, national standards about the treatment of children with disability in schools.
- Discriminatory practices against parents with intellectual disability regarding the care of their children, and about their rights to be parents, including practices of forced sterilisation of women.
- Being refused transport or taxis as a result of having a disability, or requiring assistance, such as a guide dog.
- Discrimination for different types of disability; relating to cases of discrimination where disabilities were hidden or less understood by the community and services.

Discrimination was a major problem raised in consultations with Aboriginal and Torres Strait Islander people, as well as the lack of knowledge of the Disability Discrimination Act (DDA). FPDN said, '...regrettably some First Peoples with disabilities experience significant discrimination when it comes to access to their own Aboriginal services.' People thought this is sometimes as result of services not being aware of their obligations under the DDA and CRPD.

FPDN recommended that one of the most meaningful activities the NDS could immediately support is education of Aboriginal and Torres Strait Islander people with disabilities about their rights under the DDA and CRPD.



'it would be safe to say that not one of the 78 participants made any reference to the DDA nor the United Nations Convention on the Rights of Persons with Disabilities.' - FPDN

LGBTIQ+ were also identified as facing additional levels of discrimination by people within and outside of the disability community.

There were numerous mentions throughout the consultation of discrimination against people whose disability is hidden, generally relating to mental health and psychosocial disability.

People raised issues about a lack of understanding, and the enforcement of, disability rights through the DDA. Some people said the DDA was not well understood in the community, or by justice and some legal services.

There were concerns about differences and discrepancies in the way the Commonwealth Government and state and territory legislators interpret the DDA and thought protection under the DDA was weakened by inconsistent interpretation and implementation across states and territories. A number of people said they thought there were too many exemptions given under the DDA, making compliance inconsistent.

A few people reported that it was costly and difficult to make complaints under the DDA, and when complaints were made, action was not taken or supported through the legal system.



“It’s quite a significant process to make a complaint... Even the resolution of some of those complaints can be arduous and take up a lot of time and energy. Processes around complaints; legislation and the protections of human disability rights, and how complaints are made, are a barrier for people.”



“We need more effective human rights and discrimination complaint mechanisms to much reliance on single individuals to make complaints when the benefits are often systemic.”

A suggestion was for the focus of the next national disability strategy to be on making the DDA a more common, understood and proactive piece of legislation in the community, rather than it being only compliance-based.

Safety

Conversations on the way people with disability are treated in the community highlighted concerns about their safety, particularly for those who feel more vulnerable, such as women. The establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was welcomed.

Safety in the home was a critical area people raised and suggested it is included in the next strategy. People noted that as more and more people with disability are able to access individualised supports, it’s likely this may lead to more services and supports being delivered in a person’s home. Therefore, there may be a need for increased protection, quality and safeguards.

Stronger links between protections of people with disability and domestic violence prevention were also suggested. This particularly related to the need to better reflect the protection of women with disability in other policies and agreements, such as *National Plan to Reduce Violence Against Women and their Children*.

Advocacy

Funding disability advocacy organisations rated highly as a priority for survey respondents regarding government action and investment ([Appendix B](#)). This was supported by participants in community workshops. Support for advocacy was mentioned across consultation topics and questions as important for improving the lives of people with disability. Although advocacy was identified as a fundamental principle of the current National Disability Strategy, investment in and support for advocacy had not improved over the last 10 years.



'Disability advocacy must be addressed separately in the strategy. The recognition of advocacy is currently in the NDIS Act (s4) but there is [sic] no actions to improve access to advocacy and promote the role of advocacy within the sector and particularly within the NDIS, partner organisations and disability service providers.'

A lack of support for advocacy was said to have affected the way people with disability were treated in the community and by government. Many relied on advocacy to ensure their rights were upheld and to seek help in addressing issues of discrimination and poor treatment.

People encouraged more work to promote and support self-advocacy in order to ensure people's rights are upheld.



'Investments to build in safeguards and strengthen rights being upheld through self-advocacy and building social capacity.'

Concerns about a lack of funding for advocacy and reduced advocacy for people with disability came through public survey comments. This was often linked to changes in state or territory policies or legislation.

Workshop participants thought support for advocacy had reduced over the past five to 10 years and there was a critical gap in advocacy in regional areas. For example, Townsville attendees noted there were very few advocacy organisations available to support people with disability, and that these organisations were required to cover a very large geographic area. This limits access for many people, in particular people like those who live in rural communities and Aboriginal and Torres Strait Islander people.

Workshop participants said there should be more funding for advocacy. A stronger national approach and investment in advocacy would ensure the rights of individuals—no matter where they live—are protected.



'[We need] Access to advocacy that is well funded and proportionate to disability funding, that meets the costs of delivering advocacy support. Currently there is a stand-alone system for advocacy in each state.'

Advocacy was raised as critical for supporting Aboriginal and Torres Strait Islander people. The NPY Women's Council reported a greater level of advocacy support is needed for access to health, education, employment, housing and transport. Aboriginal and Torres Strait Islander people with disabilities and their families also expressed a preference to receive individual advocacy support from Indigenous-owned and operated organisations.

Community attitudes and inclusion

Survey respondents mentioned awareness of disability and acceptance of people with disability had increased, to varying degrees, within the community during the past five years. Some respondents owed this growing awareness to increased media attention (such as in the news, dramas, and sports), which gives people with disability a greater visible presence.



'Coverage of disability and the issues disabled people face has increased in the media, so general public awareness has increased.'

However, many people throughout the consultation reported that poor attitudes and perceptions, and a lack of understanding of disability, remain significant issues. In community workshops, 'social acceptance, attitudes and disability literacy' was most commonly mentioned as an issue creating barriers for people with disability.

Concerns about negative community attitudes towards disability were more prominent among survey respondents aged under 25.

People particularly identified that more community understanding is required of different types of disability, and in particular disabilities which are intellectual or cognitive impairments or are hidden.

'We've got to stop putting people with disability in a box... I want to change the attitude to how they see different people with different levels of their disabilities.'

Hear from Tanya in Tully.

[▶ Play video](#)

A number of people suggested improving community awareness and attitudes towards people with disability would help to improve inclusion in all of community life. To improve awareness and attitudes, people suggested:

- programs and campaigns to shift social attitudes and stereotypes around disability

- incorporating education about disability into the school curriculum
- educational campaigns for business about the benefits of being inclusive to customers, and
- visibility of people with disability in mainstream media.



'Better media on different disabilities - a bit like the huge reach that 'You Can't Say That' has got in getting the community talking. But at the next more specific and detailed level.'



'Education about disabilities from an early age - including in kindergarten, preschool and school curriculum. This could include general classroom education on sign language.'

Specific educational programs could be put in place for educating businesses and health professionals about working with people with disability.

'Australian people need more and more and more training about disability. About the diversity of people with disabilities.'

Hear from Tammy in Devonport.

[▶ Play video](#)

Disability literacy of professionals was a concern, particularly in relation to people who have invisible disabilities and people from Aboriginal and Torres Strait Islander and CALD backgrounds. People said disability literacy could be delivered through dedicated education and training programs across the breadth of community services and particularly, but not exclusively, to:

- NDIS and Centrelink staff
- the police and justice sector
- areas of education and health.



'The health sector needs improvement as nursing staff are not trained to support people with disability, and doctors don't treat people with disability properly.'

The essence of inclusion

Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) lands

Anangu said that people with disabilities are a part of their community. Anangu do not tend to classify people with disabilities or frail aged in these categories. In essence they are not defined by their disability. They are part of the community and of their families. This is clearly demonstrated as people are included in all cultural, social and recreational activities. Anangu do not exclude people because of their disability. The main reason people may miss out on participating is due to limited access to resources e.g. transport, fuel, equipment and support staff.

Source: NPY Women's Council consultations

How a lack of community understanding creates barriers

The most common barriers identified throughout consultations were generally connected or related to a lack of disability literacy or understanding of disability in the community.

These considerations are demonstrated below:



Leadership roles

The consultation period highlighted the importance of including people with disability in leadership and decision-making roles.

Participation and inclusion in the form of advocacy amongst and for people with disability is improving. Having people with disability involved in politics, and in leading advocacy organisations, was said to have helped provide a voice to affect change.



'The advocacy and mobilisation of stabled advocates through peak advocacy organisations and online through social media. This has enabled people to band together, join forces, share information and engage actively in politics that concern us. I'd argue that whilst there are a lot of negative stories of injustice, hurt, pain... there is also a degree of optimism and a call for better visions for a future where disabled people truly do have opportunities.'

However, it was highlighted that such positions should not just be within disability services but across all sectors and particularly within government.



'Develop stronger legislation to enforce better inclusion practices across Australia. This could include requiring States/Territories to develop their own legislation, or strengthen their current legislation.'

The very limited numbers of people with disability in senior government and chief executive roles, and on Boards in Australia, meant a lack of progress for participants, particularly in community perceptions and attitudes towards the capabilities of people with disability.

They believed a lack of inclusion of people with disability in leadership had negatively affected people with disability, as decisions were made about people with disability without the input of those who have lived experience of it.



'The absence of people who have lived experience of disability in high offices, government and policy decision making roles is the largest barrier to people with disability...'

Language

People with disability and other participants at workshops talked about the type of language used in the community to describe people with disability. There were differences in the way people with disability felt towards particular terms and language used to describe disability.

People who participated in the FPDN workshops said in Indigenous languages there is no comparable word for disability, people felt this is evidence that disability has always been seen as an accepted part of the human experience. Using inclusive and non-discriminatory language was an important issue for Aboriginal and Torres Strait Islander people with disability. They wanted government and the community to be

aware of and avoid language that causes stigma or contributed to poor treatment of people with disability.

In community workshops, people put messages on a billboard they wanted 'the world to see and hear'.

My message to the world

- **Tap into our abilities**
- **We have to wake up the silent majority**
- **Don't pity me**
- **Every Australian counts. Count on me**
- **Different but equal**
- **Include me, work with me, let me teach you**
- **Disability pride is a real thing!**
- **Speak to me**
- **Nothing about us, without us**
- **Don't stare, just say hi**
- **What you want is what I want**
- **See the person, not the disability**
- **Humanity is exciting—we are all unique**
- **Please smile at me**
- **I am just like you**
- **I can do things you can't**
- **I made a difference**
- **I am not your inspiration**
- **Just because I cannot speak, doesn't mean I have nothing to say**
- **I am a real person, just like you**
- **I am a person not a problem**
- **See me as a person not as a disability**
- **Don't ask me how you can help me, ask me how I can help you**
- **I live in your world every day, try to understand mine**
- **Isn't it about time you got to know me?**
- **I can communicate, I do communicate, so why don't you communicate with me?**
- **Look at my face - hear my voice**
- **We are the same**
- **We aspire to be meaningfully engaged as equal citizens of our society**
- **Allow us to be self-determining about our own needs**
- **People with disabilities are people**
- **Come and join - have fun with us**
- **We all have differing abilities!**
- **Don't assume, ask!**
- **My rights, your rights, our rights**

Chapter 3: Issues affecting the lives of people with disability

In this chapter:

- [The extent of the issues](#)
- [The issues affecting people](#)
 1. [Employment and financial security](#)
 2. [Availability and cost of assistive technology](#)
 3. [NDIS and access to disability supports and services](#)
 4. [Affordable and appropriate housing](#)
 5. [Inclusive education](#)
 6. [Health and wellbeing](#)
 7. [Participating in the community](#)
 8. [Accessing the community, places and facilities](#)
 9. [Accessing information](#)
 10. [Emerging technologies](#)
 11. [Recognition and support for carers](#)

A significant amount of feedback was provided in consultations about the issues and barriers that were affecting the lives of people with disability, as well as ideas for how these issues could be improved.

Through all forms of consultation activity, people were asked to discuss or rate the issues and barriers that were affecting their lives, or the lives of people with disability they knew or cared for.

A variety of specific issues and barriers were identified. The most common were:

- employment and career opportunities for people with disability
- having enough money for daily expenses, including affording aids, equipment and assistive technology
- having access to quality supports and services, including through NDIS
- accessing information about policies, programs or supports, and information about the rights of people with disability
- accessing the community.

The extent of the issues

As shown in Figure 6, the majority of survey respondents reported that finding and keeping a job, and work and career opportunities, were major or significant issues for people with disability.

Almost 40 per cent of survey respondents with disability reported being employed or self-employed.

After employment, the next biggest issues were access to affordable aids, equipment and assistive technology, and accessing quality supports and services. Respondents who completed the Easy Read survey also reported that finding and getting good quality supports and services is a major issue.

Community attitudes and access to sport, recreation and leisure activity were overall rated as less of an issue. They were mentioned as being a major or severe issue less than 50 per cent of the time by respondents. These were also issues confirmed through the community workshops.

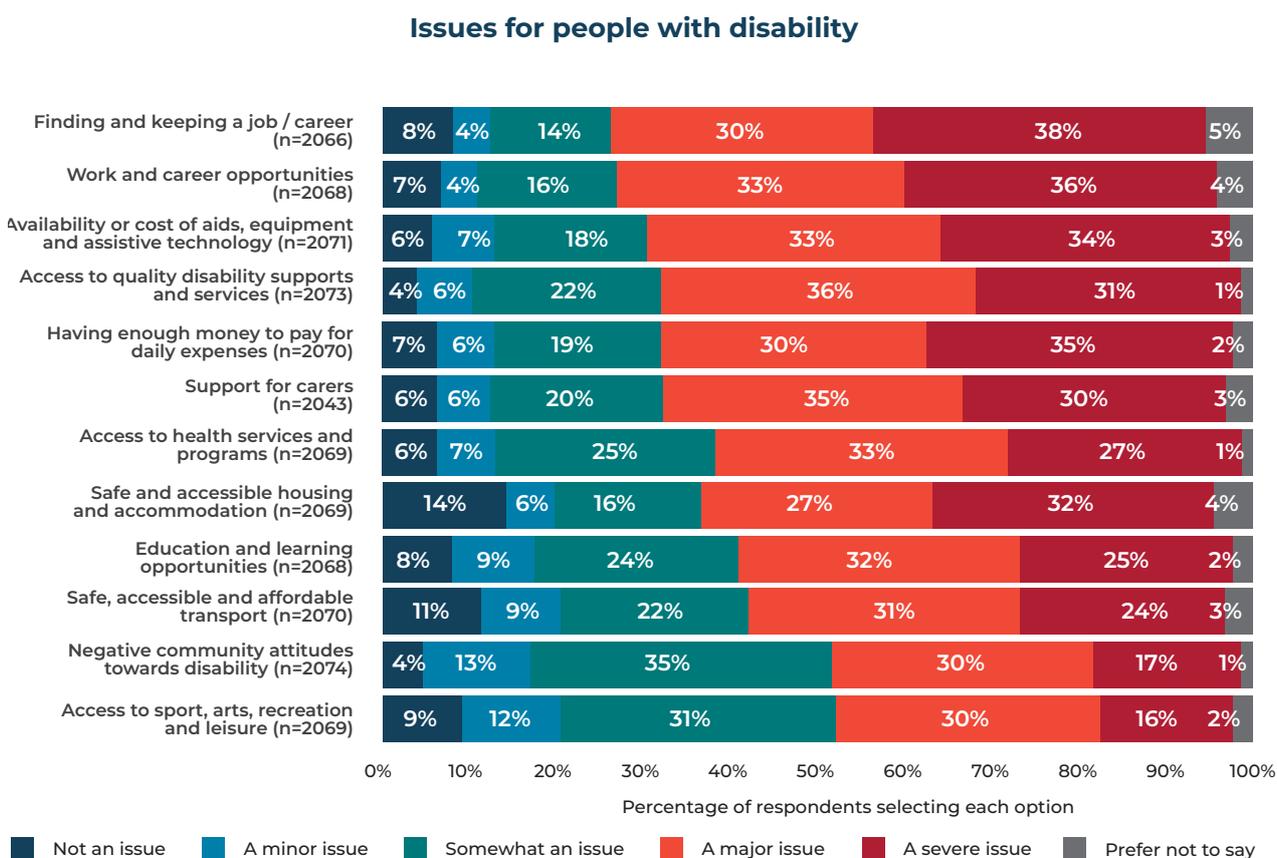


Figure 6. Current issues for people with disability - respondents who completed the standard survey. (Q. How much are each of the following areas an issue for you, or someone you know who has a disability?)

The issues affecting people

1. Employment and financial security

Survey results ([Appendix A](#)) showed finding and keeping a job and work and career opportunities were the biggest issues for people with disability. In workshops, people said having employment with fair wages was critical to being able to achieve independence and to live a full and healthy life.

Employment was also highlighted as an area where national policy and strategies could have significant effects as services are nationally run and employers are not confined to borders.

In this area, people wanted:

- employment targets to achieve real action in increasing employment rates of people with disability
- more personalised employment assistance to be offered to people with disability, noting the significant gaps in employment compared to the rest of the population



'Employment Assistance should be available at any time you need it not just when leaving school or losing your job.'

- more to be done to support workplaces to be inclusive and accessible so that people with disability have opportunities in all types of employment
- improvements in the workplace environment and education of people in the workplace about disability
- increasing employment rates of people with disability in the public service to be a critical action for national policy.



'Funding of identified positions in government-funded sectors (such as government departments and universities) for people with disability in the same way that identified positions are made available to people with ATSI heritage. And not just entry-level pools but positions at all levels.'

People identified that employment opportunity should not just be related to getting a job. People with disability should be supported to start and grow their own businesses. They identified specific actions to assist the development of business opportunities and social enterprise for people with disability, such as:

- changes in government procurement policies to support government departments and services to engage social enterprises
- campaigns to increase awareness of disability-led and -focused social enterprises, and the value in using their services.

People suggested the Government should be phasing out supported employment models for people with disability into the future, so people have access to meaningful employment that delivers healthier life outcomes. Some people noted this would require more investment for psychological supports and other assistance for people at work in mainstream, open employment.

Regarding financial security, many people said fair and equitable access to the Disability Support Pension (DSP) was critical. The DSP needs to keep up with cost of living into the future, and particularly account for the higher cost of living for people with disability.

For those who were not able to access the NDIS, there were limited supports to assist with the high cost of living. Some people said their ability to access the wider community was disrupted because of a lack of money, for transport, for instance. There were examples given in remote communities where people felt the costs of fresh food was beyond what many people with disability could afford.

2. Availability and cost of assistive technology and aids

Access to aids and assistive technology was seen as a major issue and crucial for improving access in the community, and the inclusion of people with disability in community activities.

In the survey, more than 30 per cent of respondents were very or somewhat dissatisfied with access to the equipment, aids or assistive devices needed to access information online and use technology (Figure 7).

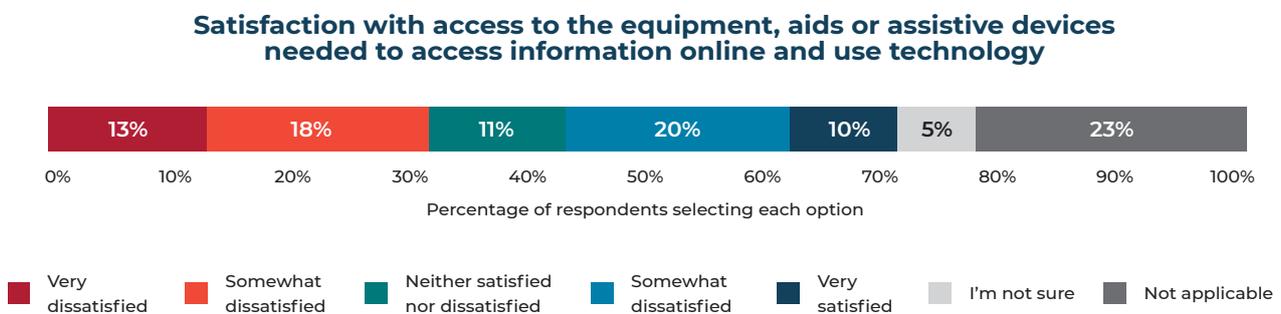


Figure 7. Satisfaction with access to the equipment, aids or assistive devices needed to access information online and use technology - respondents who completed the standard survey. (n=1,905) (Q. How satisfied are you with the access you, or someone you know with disability, have to the equipment, aids or assistive devices needed to access information online and use technology?)

The potential for technology to improve accessibility was raised across consultation activity, however many people noted the importance of ensuring these technologies are accessible to all.

That included suggestions for increased government support to address the cost of accessing aids and technologies.



'Give us free access to the Internet (NBN is more expensive!) and subsidised equipment to keep up with technology changes to help alleviate extreme isolation and allow access to vital info/research and contact with others in similar situations.'

In this area, people said a future strategy should enable:

- information on new technologies to be made more readily available to people. One workshop participant suggested a website or hub be made available with the latest advice in assistive technology, and this be shared with all parts of the sector.
- access to new technologies, aids and equipment for all, with extra support for those who are least likely to be able to afford it.

3. NDIS and access to disability supports and services

The NDIS was one of the most common examples provided about what had improved for people with disability over the past few years. People said the next strategy would need to build on and now complement the NDIS.

While the majority saw the NDIS as a positive action and investment, many people raised specific issues about accessing the NDIS, and about the supports they received. Some stakeholders said they thought coordination across government and resourcing for disability programs and supports, which should have been driven by the national strategy, were affected by the introduction of the NDIS.

The need to strengthen the NDIS workforce and better training for NDIS staff and other disability workers was mentioned regularly throughout the consultation. This included the need to have people with lived experience in NDIA positions. People noted workforce strategies should include appointments of local people to lead engagement on the NDIS in remote areas. This will help to address the significant gaps and issues in people accessing NDIS supports in those locations.

Survey respondents commented that a future strategy should enable:

- more quality providers to ensure access to quality supports and services
- strategies to attract and retain a range of suitable, qualified providers
- more monitoring of providers, including registration and accreditation, to ensure providers' services meet the individual needs of people with disability.



'A National Workforce Strategy which features a strong promotional campaign and appropriate funding for the right training and qualifications to attract and retain new workers to the sector.'

Some people mentioned the need to have more collaboration between service providers in the NDIS. They suggested government would need to invest in initiatives to promote collaboration over competition, despite the fact that a principle of the NDIS is to have more competition in disability services.

There was acknowledgement that what is funded under the NDIS will need to change and evolve over time as new technologies and assistance become available. As a result, it was noted that plans and funded supports need to remain flexible.

Suggestions to demonstrate government effort in non-NDIS supports said this will be critical to re-balance the focus of national disability policy and people's understanding of the barriers the majority of people with disability still face. People regularly commented that *"the NDIS is not for everyone and will not address barriers for majority of people with disability."*

4. Affordable and appropriate housing

Thirty-two per cent of survey respondents said access to affordable and accessible housing and accommodation was a severe issue. Another 27 per cent said it was a major issue.

Comments highlighted housing for people with disability was not enough of a priority. Many people said housing affordability is likely to get worse into the future.

In this area, people said a future strategy should enable:

- more to be done to strengthen building codes, standards and requirements to ensure housing is accessible into the future
- tailored strategies and supports for people with disability to be included in national housing agreements between Commonwealth and state and territory governments.



'...the accessibility to affordable and appropriate housing has not improved and that's going to be a huge need into the future. I mean, it always has been a huge need but with housing prices going up, particularly in the areas that were traditionally cheaper housing, they're going up to the point where people on benefits just cannot afford them so that's financial access but also obviously they're not necessarily accessible in terms of the physical environment either.'

'People with disability, they want to be able to buy a house or be able to get into a house. I think all houses should be built universal design to the liveable housing guidelines.'

Hear from David in Hobart.

 [Play video](#)

5. Inclusive education and lifelong learning

Access to education and schooling was raised by workshop participants more times than any other area when it came to having independence and wellbeing. In the survey, education and learning opportunities did not comparably rate as highly as an issue for people as some of the other areas, though 57 per cent of respondents still reported this as a severe or major issue for people with disability (See Figure 2 in [Appendix B](#)).

In this area, people said:

- better access to education and lifelong learning would lead to jobs and career opportunities for people with disability
- it is critical that the next national disability strategy has a strong focus on education for people as a pathway towards living a full, financially secure and independent life.
- there should be a stronger focus in the next strategy on transitioning from schooling to higher education, training and employment
- career pathways for students with disability could start earlier in their schooling, with training and employment pathways able to be tailored to the interests, skills and attributes students demonstrate
- existing programs are limited to only some locations, mainly in cities, and should have more investment to be rolled out across Australia, including in more regional areas.

People said a focus on inclusive schooling is critical for children and young people. All schools, including mainstream public and private/independent schools need to have resources set aside to ensure adequate accessibility and support for students with disability, and training for teachers and educators.

Parents raised concerns about the impacts of excluding children from schools early in life, due to their disability or behavioural issues related to their disability, and that this sets them up to fail later.



'Need to provide the right level of supports in schools so students are not suspended or expelled due to disability related behaviour.'

Some people suggested school programs need to be co-designed with parents and students. Schools and other education settings should be used to help improve awareness and understanding of disability in the community.



'More discussions or focus on young people within high school to become more knowledgeable about their/other disabilities and how this can impact them in employment.'

A number of people reported that opportunities for lifelong learning are not as accessible or available to people with disability. People suggested more information and support is needed to help people with disability to find out about learning, education and training opportunities and the next strategy could include more actions to support governments in working together to improve these opportunities.

6. Health and wellbeing

In the survey, more than half (58 per cent) of respondents said the health and wellbeing of people with disability has not changed or has got worse over the past five years. This was the third “worst” issue of the nine issues provided and substantially more people with disability reported it as being worse compared to people without disability (See Figure 2 in [Appendix A](#)).

In community workshops, many people raised issues with access to mainstream health services and hospitals, primarily related to physical access and having support workers available to assist through health and hospital experiences.

There were also concerns about poor treatment by medical professionals in hospitals and health services.

In this area, people said:

- more training for health professionals is required so that they better understand disability, including invisible disabilities
- access to health supports had worsened for people since the introduction of the NDIS due to a ‘passing of the buck’ between what is covered by health services and by the NDIS

- improvement might happen through better recognising disability in hospital and health agreements between Commonwealth and state and territory governments.

Mental health needs to be a key focus in the next national disability strategy. People recognised that:

- mental health and psychosocial disability are becoming better understood and the intersection of mental health and disability should be specifically recognised in all policies and programs
- some groups of people with disability are often more likely to experience mental health issues.



'The assessment and evaluation of government's actions to address the gaps for people with disability should have an explicit focus on mental health and wellbeing. Health and wellbeing indicators can provide an important indication of the success or otherwise of policy and service provision. [Name removed] recommends that mental health and wellbeing is central to the measurement and evaluation of the NDS implementation and outcomes.'

7. Participating in the community

During community workshops, people shared experiences of instances where they were welcomed and felt included to participate in community activities. Events and other activities had been made more accessible to people with disability over the past 10 years.

However, while people shared experiences of improvement in access and participation, they consistently identified participation in community, employment and leadership as issues for people with disability.

The differences in people's frequency in participating in community activities was mixed:

- Just over half of survey respondents reported they participated in activities such as recreation, entertainment, social activities, and watching sport at least once a week, or almost every week.
- Just over 40 per cent said that they rarely or never participated in these activities (Figure 8).

Frequency of participation in activities in the community (n=2081)

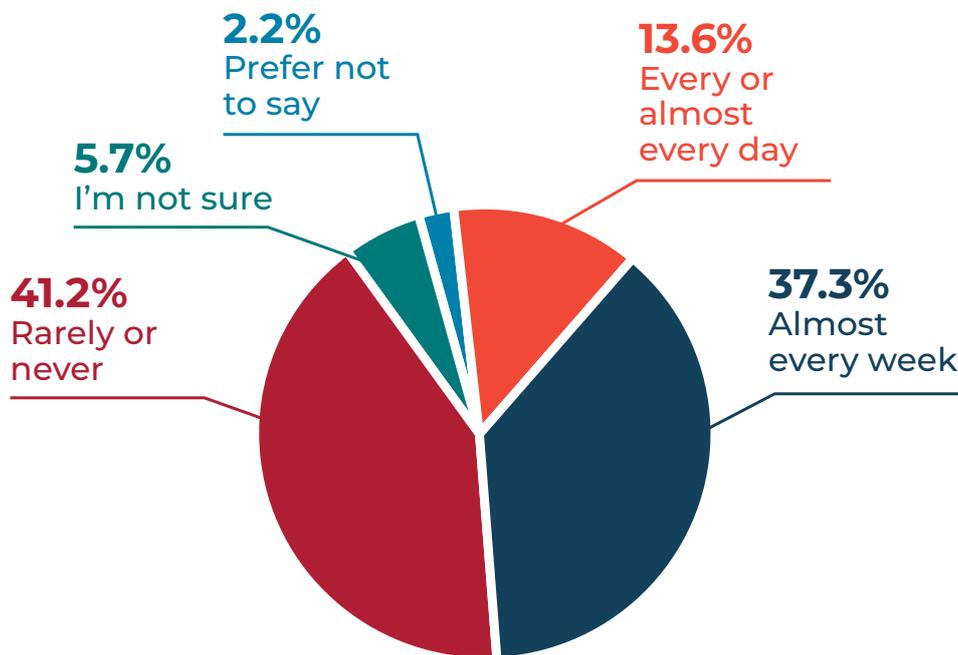


Figure 8. Frequency of participation in activities in the community - respondents who completed the standard survey. (Q. During the past month, approximately how often did you, or someone you know with a disability, take part in activities in the community? This includes activities such as playing or watching sport, recreation, entertainment, and social activities. This doesn't include working or studying.)

Frequency of participation in activities varied slightly by state and territory (See figure 4 in [Appendix A](#)). Participation in activities was most frequent among respondents from New South Wales, and least frequent among respondents from Queensland and South Australia.

In the survey, people also identified barriers that prevent them from participating in community activities. The most common was not being able to afford the activity (See figure 5 in [Appendix A](#)).

“ When people remain unemployed, they do not have enough money for daily living expenses, the ability to live independently or to participate in community. This perpetuates a cycle where people with disability remain invisible.’

Some people said there was a lack of effort to ensure events in the community are accessible, and this was perceived as a signal that people with disability were not welcome at events. Some parents described not being able to take their child(ren) to community activities, due to a lack of understanding about invisible disabilities among people in the broader community.



'Parents with children or young people with challenging behaviours find it hard when choosing a suitable environment for example, children with sensory issues, availability of disability facilities e.g. toilets, parking, change rooms, safety issues etc.'

In the online forum, participants said they were prevented from accessing the community and participating in events or doing daily tasks due to:

- sensory issues
- a lack of awareness in community of chronic fatigue and similar conditions
- and impacts of exposure to chemicals.



'The need for a fragrance-free environment is almost without exception overlooked when it comes to discussion and practice around accessibility and inclusion. As an individual with chemical sensitivity I'm excluded from participating in education, including my children's education, community events and workshops of all kinds, volunteering in my community, employment outside of my home, even accessing government services such as Centrelink – or important health services, such as getting a Pap test in a fragrance-free environment.'

8. Accessing the community, places and facilities

In the survey, more than half of respondents reported that accessibility when out and about in the community is getting slightly or much better (53 per cent) (See Figure 2 in [Appendix A](#)).

But in comments many people still noted key issues with accessing buildings, places and other facilities in the community, including issues relating to:

- physical access
- community attitudes and perceptions
- a lack of awareness of how services, places and events can ensure safe access for people with sensory issues.

Universal design was raised as the core principle for accessibility of buildings, places and activities in the community. People said universal design could:

- be applied everywhere to improve access and use, to the greatest extent possible, by all people regardless of their age, ability or other factors
- be implemented through changes to standards and building codes
- be co-designed with people with lived experience of disability
- include government funding and incentives to the private sector
- ensure new buildings and environments are accessible through working with local governments, planners and developers
- be applied to the design of all services, activities, sports and recreation in the community.

A large number of respondents suggested changes to the built environment, including design and building legislation, that would improve the lives of people with disability. Some of the suggestions were:

- accessible parking close to main venues
- improved footpaths and building access
- accessible toilets in public spaces, including facilities to cater for people with complex needs (e.g., hoists, change facilities)
- low sensory spaces (i.e., low noise and light, fragrance-free)
- accessible railway stations and tram stops
- access to nature (e.g., bushland, beaches).

Improving access to transport was also one of the most common areas raised in survey comments and workshops. People said more accessible and affordable transport is needed to assist people to access employment, health services, community activity, and sport and recreation activity.

People suggested funding is needed for 'whole of journey' transport, not just for one-off transport options which may not be suitable, accessible or available to people when they need it.

There were suggestions of benefits to businesses when improving accessibility for their customers and employees. Providing funding to local communities, or incentives to business owners, to improve accessibility would have a positive effect on all of the community.

Tourism and recreation plans by state governments were pointed out as not having strong links with disability inclusion or ensuring accessibility. The benefits of accessible tourism could be better promoted.



'Educate the tourism industry on the advantages for catering for people with disabilities.'

People said improvements had been made in regard to access to sports, recreation and arts in the community, and this was generally driven by individual organisations and clubs, or local Councils.

They suggested:

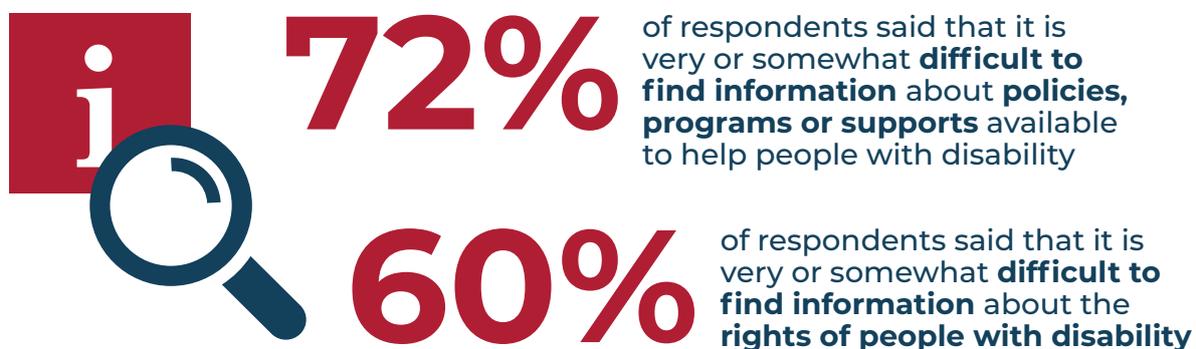
- more investment to support clubs and organisations at local levels to make their facilities more accessible and cultures more inclusive
- investing in clubs and organisations is particularly important for young people with disability who should not be prevented from participating in activities with their friends and peers
- the arts has an important role in increasing confidence and self-esteem
- focus on more inclusion in the arts to assist people with disability who are vulnerable to mental health illness or feelings of isolation and exclusion.

In consultations, the NPY Women’s Council noted the role of art as therapy and as a meaningful activity to people’s quality of life. They stated, ‘people who were able to undertake some art practice were happy as were their family members. The art practice takes place at their homes, in art centres or at aged care centres.’

9. Accessing information

Accessing information was raised as a key issue or barrier for people with disability across the consultation activity. Generally, people said when information was not easily available to people it prevented them from getting the support they needed. They were prevented from participating in their community and from accessing services.

In the survey,



Accessing information was also the fifth most common barrier raised in community workshops. Many people said the complexity of information about disability legislation, policy and programs made it very difficult for people to find and understand how to get the most out of services and supports.

Survey responses showed young people under the age of 25 find it significantly easier to find and access information.

In all of the specific Aboriginal and Torres Strait Islander consultations, participants raised concerns about the lack of information about services and supports provided in communities that are culturally appropriate and in their language, affecting peoples’ ability to find and access what they needed. People also said the reliance on digital information creates significant barriers for those living in remote communities, where internet is limited.

 *‘...a more effective means by which vital information becomes broadly understood and retained by key stakeholders in Communities must become part of the next strategy.’ - ATSIDNQ consultation report.*

While people acknowledged governments are using Easy Read formats to share some information, there was concern this is still not consistently done across education, health and other mainstream policies and services.

A number of people also raised concerns about the over-reliance on Easy Read products, cautioning that many people will still not be able to engage in this format. Personal, face-to-face and video remain important mechanisms for sharing information with people with disability.



'Rights protection, justice and legislation is worse because people are still unable to access legal documents in Easy Read, such as to change deeds, contracts, etc.'

A key criticism about ensuring people with disability have access to information was that requirements for information to be accessible is left up to interpretation within the DDA, rather than mandated.

Many people in community workshops who were hearing or vision impaired raised important issues about availability and funding for the supports needed to access information:

- While accessibility solutions exist, they are not always adequately funded or invested in to ensure they are available to everyone who needs them, when they need them.
- The number of trained Auslan interpreters was low and there is a lack of future investment in Auslan.
- Auslan could become a more mainstream language, with schools and universities encouraged to include it as part of their teaching.
- There was a lack of audio description in television and online, which some participants felt should be legislated.

Some community workshop participants shared experiences about the risks in not being able to access information during emergency management situations, or to be able to vote or fill out the ABS census: important occasions where all Australians have the right to be counted.



'I turned up to vote but the venue wasn't accessible and I couldn't find help.'

Accessible information for emergency management

Canberra

When public information on a fire scare wasn't accessible for people with a hearing disability in a rural area near Canberra, they created their own avenues of getting the message out.

'We knew someone who lived out there and we had to make sure they got that information,' said a Canberra participant.

The participant has a degenerative hearing impairment and is a part of an online community of other people with hearing disability.

'Because it was at a lower level, not a full-scale bushfire scare on the TV, the standard practice is listen to the ABC radio. That's the only way to get that news. Our community was quite worried. And mobile phone reception was down.'

The community connected over social media to spread the message in the hope of reaching the person in danger.

He also related the issue of accessible information to other opportunities to participate in public life.

'What people need to do about the flu season coming up, for example.'

'When accessibility is not considered from the start, the onus is back on the community to advocate and ask for it.'

10. Emerging technologies

Technology was identified as having the potential to change the lives of people with disability. Workshop participants said the assistive technologies that had emerged over the past 10 years had already significantly improved access for people with disability.

'Technology has come a long way and also has a long way to go... There needs to be a lot more awareness for people with disability in what is actually available.'

Hear from Robert in Melbourne.

 Play video

The most common ideas for new technologies that people said would improve the lives of people with disability in the future primarily included assistive technology and were:

- smart devices, including in the home
- speech to text
- voice activated technologies
- robotics
- autonomous vehicles and wheelchairs.

Workshop participants said they wanted to see:

- continued investment by government in the area of technology
- virtual reality as a critical emerging area that can improve the lives of people with disability
- further investment by governments in how virtual and augmented reality technologies can be used to improve access to information.

Emerging artificial intelligence, including robotics, was considered an area which will significantly improve the lives of people with disability in the coming years. This included Artificial Intelligence which assists in the home, with cleaning, cooking and other supports.

However, an over-reliance on technology and online systems created some problems for people, particularly where access was not equally available. An over-reliance on technology can also create barriers.

A specific example was the transition to touch screen technology in banking, which some participants described as having significant negative effects for some people with disability.



'Technology is great, but we can't lose the face to face information provision and support as a lot of tech is not accessible to people with intellectual disability.'

Online communities are improving the lives of people with disability. Many people with disability reported using social media to get and share advice and have used social media to access supportive networks and communities.

The use of online channels to engage people with disability in policy designs and decisions which affect them was identified as being important in the future. Remote, online access to work, meetings and events could also improve people's participation in employment and leadership roles.



'Improved access to information via web-based options and social media. You can become part of virtual support groups rather than having to travel long distances or just going without.'

11. Recognition and support for carers

Across consultation activity, people talked about the need to ensure the role of informal and unpaid carers is recognised and respected.



'Carers are fully enabled to advocate on behalf of people with disability - specific consideration needs to be given to parents trying to support needs of their children.'

Survey respondents mentioned there needs to be more support for unpaid carers of people with disability, especially for those who are single parents and/or have a disability themselves. When asked to prioritise government action, almost all survey respondents (90 per cent) believed that greater support for families and carers should be a high or essential government priority (See Figure 9 in [Appendix A](#)).

Sixty-five per cent of respondents to the survey rated 'support for carers' as a severe or major issue.

In community workshops, people said more carers are needed and that this would only be made possible by recognising the important role carers play in the community.



'...there is not enough carers, so the education needs to show there is incentive, people who want to get into caring should be encouraged.'

The effect on young carers as the population ages was raised by a number of people in community workshops. Similarly, the effect of carers who are ageing was also raised as an issue for consideration.



'No legislated carer rights to have care/support for PWD so carers can work and plan for their old age.'

ATSIDNQ raised that in the absence of formal carer supports for many Aboriginal and Torres Strait Islander people who live with a disability, informal family carers traditionally provide the necessary supports.

They suggested that the recognition of the roles that family carers play must be part of any new national disability strategy. The strategy should ensure carers are aware of their right to access things the system makes provision for, including:

- carer pension
- carer allowance
- remuneration of out of pocket expenses
- carer companion card
- other forms of carer support.

Workshop participants raised the Productivity Commission's recommendations to include a focus on carers in the next national disability strategy. Some people said this was important, however some noted that support for and recognition of carers needs to have its own strategy or focus and should be embedded across mainstream services and agreements.

Some people said stronger legislation on carer rights could ensure better supports for people with disability.



'[A strategy about] a person with disability should also think of the carer and unpack it from the person with the disability's needs: look at where they're aligned and where they're separate. Do not cluster the word 'family' and 'carer' at the end of the sentence like an add-on but really, sincerely think of each section of the strategy as it relates to carers as well as people with disability and to align it with the Recognition Act for Carers.'

Chapter 4: Issues affecting different groups and demographics

In this chapter:

- [People living in regional, rural and remote areas](#)
- [Aboriginal and Torres Strait Islander peoples](#)
- [People from CALD backgrounds](#)
- [Age groups](#)
- [Gender and sexuality](#)
- [People from lower socio-economic backgrounds](#)

This section describes what is affecting specific groups.

Across consultation activity, better recognition of people with disability from diverse groups was considered critical for the next national disability strategy.

A person's age, gender identity, sexual orientation and cultural background was said to influence their views and experiences, including how they are treated by others. Some population groups may experience several levels of interconnected barriers and additional discrimination.



'It is acknowledged that the current NDS recognises that not all people with disability are alike and that the diversity of experiences of people with disability underpins the outcome areas of the NDS. This related primarily to people with disability from diverse backgrounds. It will be imperative that the next NDS also recognises the importance of ensuring that the specific needs of people with different kinds of disabilities are acknowledged and addressed and that a 'one size fits all' approach will not achieve this.'

There were differing and sometimes conflicting views about how different groups should be recognised in the strategy.

Some people said specific sections recognising women and children, or recognising specific groups or genders, could lead to excluding others. Their preference was for a strategy to be equal for all.

Some pointed out that recognition of specific groups should not attempt to place people within one group. Survey respondents emphasised that all people with disability should be treated equally, irrespective of the group(s) to which they belong.

A widely held view was that specific actions be put in place to address barriers caused by intersectionality. This could come through programs and funding for organisations to engage with specific groups, and be flexible enough to cater for each individual's unique circumstances and needs. Partnerships with organisations and communities were identified as critical in this area.

The public survey prompted respondents to suggest actions for improving the lives of people with disability from specific groups, such as:

- age groups
- genders
- LGBTIQ+ status
- Aboriginal and/or Torres Strait Islander peoples
- CALD groups
- people from remote or rural locations
- lower socio-economic groups.

In total, 1,493 respondents provided at least one suggestion for supporting people with disability from specific groups. Detailed coding of the responses revealed some of the suggestions included in this section:

- Improving awareness of different types of disability.
- Educating NDIS staff, service providers and health professionals about different needs and groups.
- Faster access to supports, more assistance to access support and making sure supports are affordable for disadvantaged groups.
- Offering more mental health supports to vulnerable groups.
- Support for children, including early intervention, and for older people who are not eligible for the NDIS.

People living in regional, rural and remote areas

When comparing results of what is an issue for people with disability using a geographic split, two distinct issues were more significant for those living outside of major cities:

1. Safe, accessible and affordable transport (59 per cent of people outside of major cities said it was a major or severe issue, compared to 54 per cent in major cities).
2. Access to sport, arts, recreation and leisure (52 per cent of people outside of major cities said it was a major or severe issue, compared to 44 per cent in major cities).

The shortage of services and supports in regional, rural and remote areas was a concern across consultation activity. Ensuring availability of supports and healthcare in rural and remote areas was the most common response to survey prompts about ideas to improve the lives of people with disability from specific groups.

While NDIS had improved individualised supports, many people said access to these supports was limited in some areas. Different strategies and funding models for NDIS supports were suggested in areas where there are significant gaps in services.



'Funding tied to approved service providers is useless in regional areas. It would be much better if I could hire the kids next door to do my garden and lawn than having to pay someone to do one hour travel to do one hour work from an approved service organisation.'

A large number of people acknowledged the challenges of living with disability were greatly amplified for people living in remote and rural locations.

Concerns included the lack of specialist services and healthcare in rural and remote locations, as well as the lack of transport options/funding to travel to specialist appointments in urban centres.

The disadvantages were profound for Aboriginal and Torres Strait Islander people living in rural and remote areas. There was an emphasis on more support for Aboriginal and Torres Strait Islander people with disability, developed in consultation with specific communities to ensure culturally appropriate support.



'Aboriginal and Torres Strait Islander people need access to services in remote areas - we are chronically under servicing these communities as we don't fund services sufficiently to be present, build relationships, understand people with disabilities needs in these communities and then provide the supports for them to have a good and meaningful life. We tell them to leave country if they want help - it's wrong.'



'I think there should be an NDIS bus that travels to remote and rural locations, OT, Physio, Speech - people should also be appropriately funded for travel. In my opinion OT, Speech and Physio in regional and rural areas are not existent and if they are they are at capacity, it is a huge barrier for anyone with a disability atm.'

Finding out what services were available in regional areas was also an ongoing challenge. In addition to making sure more services are available in regional areas, people suggested there should be a way for people to find their closest services on the NDIS register by searching a postcode.

There were issues with services in small remote communities not being linked or connected. Participants in Aboriginal and Torres Strait Islander consultations have had children or people they care for undergo multiple assessments for different types of support, which cost time and money.

ATSIDNQ suggested looking at new collaborative models to better join up services in rural and remote communities. This included upskilling clinic staff on disability access issues so they become a change agent in remote communities.

Alternatively, it could be a partnership model. Dedicated disability trained staff would share costs with health organisations, building sustainable, collaborative practice models. Inter-disciplinary expertise, including allied health, would carry across health and disability.

Transport was also raised as a key issue for people living in regional and remote areas. According to ATSIDNQ, the total absence of affordable transport meant people could not make it to specialist appointments. This in turn contributes to the poor management of chronic diseases in Indigenous communities. For people with disability who required accessible modes of transport, the problem was further compounded.

Some people suggested more education in regional and rural areas about disability, and celebrating local disability champions, could assist to overcome issues of isolation and discrimination.

Aboriginal and Torres Strait Islander people

A series of consultations were facilitated across the country with Aboriginal and Torres Strait Islander people with disability.

First Peoples Disability Network's (FPDN) consultation workshops highlighted the importance of the next National Disability Strategy sitting within a broader social justice framework. It must respond to and recognise the intersectional nature of discrimination experienced by Aboriginal and Torres Strait Islander people with disability.

They reported that broad systemic issues were consistently identified as requiring urgent attention to make the National Disability Strategy effective for Aboriginal and Torres Strait Islander people with disability. This section is structured in line with the systematic barriers and issues identified in FPDN's consultations. The section also incorporates key findings from the consultations conducted by NPY Women's Council, Tasmanian Aboriginal Centre and ATSIDNQ.

Discrimination and rights

Many Australians with disability experience very serious discrimination. According to FPDN, issues of discrimination could be particularly acute for Aboriginal and Torres Strait Islander people with disabilities. Many people in Aboriginal communities are unaware of laws in place to protect their rights.

FPDN reports that recognising and responding to intersectional discrimination was the most pressing challenge for the National Disability Strategy as it relates to Aboriginal and Torres Strait Islander people with disabilities. At each of the Aboriginal-specific workshops, there were examples given of intersectional discrimination (though not explained in these terms). Examples of intersectional discrimination included discrimination based upon race and disability or race and disability and gender.



Racism, ableism and intersectional discrimination for people at the intersection of two marginalised populations.

It was also noted that intersectional discrimination can affect people differently at different stages of their life and through different systems. This is demonstrated by the diagram below.

LIFE-STAGE ASPECT	Peri-Natal	Early childhood	Schooling years	Young people	Justice	Health	Ageing
Aboriginal and Torres Strait Islander	Low awareness of disability Environmental factors, increased likelihood of low birth-weight	Low awareness of disability Exposure to trauma Increased likelihood of OOH – off country, unsta-ble home setting	Low awareness of disability "Bad black kid syndrome" – punitive schooling over supported disability	Less likely to secure employment Increased likelihood of police contact	Denial of rights – over incarceration	Subconscious bias – institutional racism	Reduced life expectancy Disability happens earlier in life and with more co-morbidities.
Disability	Low birth weight and environmental factors in developmental disability	Disability assessments aren't carried out to the extent that they need to be	Undiagnosed and unsupported disability	Less likely to secure employment Communication impairments, reduced capacity to negotiate conflict	Denial of rights – indefinite detention and fitness to plea for people with cognitive and psychiatric disability	Subconscious bias – diagnostic overshadowing	Inadequate public infrastructure especially in remote communities.

Avery S. (2016) 'The life trajectory for an Aboriginal and Aboriginal or Torres Strait Persons with disability'. In: Aboriginal and Torres Strait Islander Perspectives on the Recurrent and Indefinite Detention of People with Cognitive and Psychiatric Impairment. First Peoples Disability Network.

FPDN suggests that the national rollout of a program to educate and inform First Peoples about their human rights is needed.

Poverty and lack of access to money

The vast majority of Aboriginal and Torres Strait Islander people with disability live in poverty. Whilst there is no substantive data on the prevalence on poverty there are some indicators that are consistent across the country. These include the fact that only a small percentage of Aboriginal and Torres Strait Islander people with disabilities are in employment. There are high rates of homelessness and overcrowding in houses, and very poor educational outcomes.

Poverty causes a lack of access to the money people need for their daily expenses. It also means Aboriginal and Torres Strait Islander people with disability are likely missing out on support, aids and technologies, as many do not have the resources or means to find and organise access.

People wanted to see funding models which reflect actual costs in regional and remote areas better considered. ATSIDNQ reported, 'some Torres Strait Islanders have been forced to make difficult decisions and relocate from their island of origin due to the unsustainable costs associated with accessing on-going treatment.'

FPDN suggests, a 'Whole of Community Response to disability programs' is needed. They also suggest undertaking qualitative and quantitative research into the poverty experienced by First Peoples with disabilities to better understand and respond to how this can be changed over the next 10 years.

Lack of community infrastructure

A lack of community infrastructure was a critical issue in regional and remote Australia. It meant major support initiatives such as the NDIS were often ineffective.

The NPY Women's Council report explained that Anangu experience very high levels of trauma, psychological distress, high rates of suicide and self-harm and are overrepresented in gaols and mental health hospital admissions.

They also discussed the limited access to appropriate disability supports in communities:

- Less access to, or no use of, primary mental health services.
- Limited understanding and discussion on the underlying causes of disabilities among community members.
- No training in special needs for local people to build up their knowledge and understanding.
- Limited resources for the community schools in the fields of special needs of children with disability.
- Limited youth sport and recreational opportunities in remote communities.

The lack of sport and recreation has long been recognised as contributing to volatile substance misuse and other drug use by young people in communities.

Many Anangu raised the need for more facilities on the lands to cater for people with disabilities. They talked about how existing buildings such as aged care facilities and family centres could have extra facilities built on to meet the people's needs. These places could be used for respite stays, for social contact, meals and mentoring support.

System issues in crisis

Systemic issues are adversely affecting Aboriginal and Torres Strait Islander people with disabilities, including:

- overburdened and under-resourced:
 - » education system
 - » police and justice system
 - » mental health sector
 - » disability services
- a transient workforce (school teachers on short rotations, fly-in-fly-out workforce)
- the need for an Indigenous workforce with a professional background in disability
- a lack of community-owned (not government) service responses
- very low accessible housing stock
- Aboriginal people not being in positions of power (such as local government) in their communities
- access to fresh, healthy produce.

Food security was a major issue. In one remote community it costs \$9 for a lettuce. This leads to poor nutrition which places a further burden on the health system.

The rollout of the NDIS had not reached and benefitted Aboriginal and Torres Strait Islander people and their families as well as it had for other people with disability.

ATSIDNQ suggested Systems Navigators in their report on consultations in Queensland. Navigators would assist those who lack the ability to engage and navigate the system themselves. Navigators would be part of the community, speak the language(s) understood by stakeholders and remain available not only to inform but actively assist, troubleshoot and advocate for those who lack the capacity to navigate the system unsupported.

Medical model of disability

A rise in the medical model of disability was a concern in Aboriginal and Torres Strait Islander consultations. This was largely attributed to the NDIS.

Some people reported missing out entirely on the NDIS because they were unable to either:

- access a diagnosis, because it was not possible to get one in the community in which they live
- access the funds required to get a diagnosis was beyond their means.



'The National Disability Insurance Scheme, for example, is requiring a higher degree of medical diagnosis than ever before for people with disability.' - FPDN.

Disability is also not a label generally used in communities.



“In traditional language there was/is no comparable word for disability, this is evidence that disability was/is an accepted part of the human experience. The notion that someone is a lesser person or that they should have to take the undignified approach of having to talk themselves down to get support is incongruous with an Aboriginal approach to disability.” - FPDN.

Community and culturally appropriate led responses

First Peoples communities are the thought leaders on disability inclusion.

Approaches and services delivered to Aboriginal people are likely to be less effective if they are not designed and led by Aboriginal people. FPDN found that Aboriginal-led responses to disability were virtually non-existent around the country other than some isolated cases. They noted an Aboriginal-led approach to disability is essential and would require investment from government. The approach may take a generation or more and must be led by Aboriginal and Torres Strait Islander people with disabilities themselves.

Similarly, in Queensland, people identified a lack of culturally appropriate and community-led responses as preventing people with disability from accessing what they need.



‘If every Aboriginal and Torres Strait Islander person with a disability in Australia is to gain access to support in ways that are fair and equitable, it will require a commitment to strategies that are culturally appropriate and culturally-safe. Building capacity from within a Community rather than rolling something out over the top of a Community is called for. The timeframes from community capacity building may look very different from one Community to another. Without more of this, too many of ‘our mob’ will continue to go without because the critical information doesn’t ever reach them.’ - ATSIDNQ consultation report.

ATSIDNQ suggested developing culturally safe and sustainable models of delivery through involving agencies and individuals who operate them, who are already in communities. This would support the ground-up development model of a service.

NPY Women’s Council agreed in their report, ‘it is important that services for people with disability are run by local Aboriginal-controlled organisations not by outsiders. They provide a really important safety net for people with disabilities and their families. It shows the need to learn from and build on existing initiatives.’

Trauma informed responses

FPDN notes the importance of the next strategy taking a trauma-informed approach for Aboriginal and Torres Strait Islander people with disabilities, as is now the policy in the area of child welfare.

A trauma-informed National Disability Strategy would ensure a humane and compassionate approach to addressing the needs of all Australians with disability. There was a growing feeling that disability was being increasingly commodified and that the NDIS, for example, took a punitive approach to accessing it.

Accessing services and asking for help was often a deeply traumatic experience for people with disability, and their families and carers. This was exacerbated by a system that lacks real understanding of the lived experience of people with disability, their families and their carers.

In the NPY Women's Council consultations, some people raised concerns about the way the NDIA and NDIS funded services are treating people in their communities. NPY Women's Council said many people raised concerns about the way the NDIS conducts their consultations in the communities. 'People said they mostly don't know when they are coming to visit, that they don't bring information in a format they understand, that they have quick visits and that they either don't have an interpreter or they are utilising someone who is not from the NPY region.'



'We worry when NDIS talks to people with disabilities, they don't understand. It's like they're tricking people.'

FPDN suggests, in partnership with Australians with disabilities, government develops a set of principles for government and non-government services to adhere to that relate to recognising and understanding the trauma experienced by many Australians living with disability.

Access to information in culturally appropriate and accessible ways

In Queensland, one of the most immediate barriers to inclusion and access for Aboriginal and Torres Strait Islander people was the absence of information available to them in their primary spoken language.

This has affected people being able to access the supports they needed. For example, Queensland Aboriginal and Torres Strait Islander participants knew little about the NDIS and the function of the NDIA. Even people with disability who had registered for the NDIS consistently spoke about the complexity, both in terms of the language used and navigating systems.

According to ATSIDNQ, the barrier that language posed to stakeholders in understanding the disability system and what it might offer them was a fundamental barrier. Language must be included in a disability strategy 2020 and beyond.

Families and carers

ATSIDNQ noted that the cultural norm around family taking care of their own was a strength. A person's disability was said to be almost invisible within the family because of the way the family supports the individual in an organic way. The way disability is conceptualised in the Aboriginal and Torres Strait Islander context, and the natural wrap-around family support system, reduce the effect of the disability for the individual.

People from CALD backgrounds

It was widely noted that people with disability from CALD backgrounds face additional barriers. Commonly identified barriers for people from CALD backgrounds included:

- language barriers that prevent people from accessing information
- for some groups, cultural considerations that affected understanding and acceptance of disability
- being able to access supports and services, including through the NDIS.

For example, some respondents were particularly concerned that people from minority groups would be excluded from funding and support due to the difficulty and costs associated with seeking funding through NDIS plans.



'The news about the uptake of NDIS for people with CALD backgrounds said that 49 per cent of Australians now were born either overseas or one parent born overseas and the uptake of NDIS is only seven per cent. I would like to be a voice for people who are not using English as a first language. It's a very complex issue.'

More proactive assistance for these groups was suggested to help with accessing funding and support. The challenges of managing NDIS plans was also a possible barrier for people from minority groups.



'CALD and older carers have no idea how to ask for what they need as the planning process is very complex and dependent on the ability of the Nominee to advocate for what is necessary. NDIS workshop and information sessions are woefully inadequate.'

Some respondents also recommended more accessible information about what funding, services and support is available, particularly for:

- minority CALD groups
- lower socio-economic groups
- people with newly acquired disabilities.

There were concerns that the voices of people from CALD backgrounds were not heard, because they could not access consultations in language or in appropriate settings. Some participants said more should be done to ensure engagements and information are more accessible to these minority groups.

For CALD people with disability, there may be a perceived stigma attached to disability and this might prevent people from seeking support.

This was seen to specifically affect new arrivals and humanitarian entrants. An example from the Canberra workshop was that humanitarian refugees can have a combination of migration, not understanding disability and disability services, and having complex needs.



'Often the case is that—particularly for refugees fleeing—they are dealing with PTSD, dislocation, which is compounded and they are not being adequately addressed because of siloing of disability and the migration sector.'

Some survey respondents emphasised the need for quality mental health services, particularly for people in this group.

Age groups

Children

Children and young people are not being given the level of opportunity they should be to be part of the community and to live independently in the future, according to workshop participants.

Parents spoke about the barriers their children faced, particularly in accessing mainstream schooling or in the way they are treated in the community. Many parents shared significant issues about a lack of understanding in the community on different types of disability, and how this affects their child's behaviour.

Children and access in community

In survey responses, some parents described not being able to take their child(ren) to community activities, due to the broader community's lack of understanding about invisible disabilities. Some were not able to physically access some areas of the community with their children.



'As a parent of a child with ASD (Autism) and ADHD and two other children with ADHD, I often feel judged by community members (members of the public) for my children's (often unpredictable and uncontrollable) behaviours. Some particularly bad memories come to mind - one involved a member of the public ranting about my "modern parenting" on public transport in response to one of my children's behaviour; another time a member of the public requested I take my child elsewhere (out of the shopping centre), referring to my child as "not a child, but a monster!" in response to her behaviour.'

It was however noted by many participants that access to children's events, playgrounds and playgroups had significantly improved over the past five to 10 years for children with disability.

Children and schooling

Access for children to mainstream schooling and an understanding within the education system were the issues most commonly raised in relation to children.



'I think it is wonderful when you see more children with disability attending their local schools. All children should be exposed to peers with physical and intellectual challenges, this will ensure our society becomes understanding, and inclusive.'

Inclusion in mainstream schooling and access to education was identified by many people as having improved. When asked about improvements over the past five years, people noted things are getting better in mainstream schools.



'Inclusion in mainstream schools has improved for many students with parents, teachers and students working together in many cases.'

Workshop participants said children with hidden disabilities were disadvantaged and discriminated against. One person noted the systematic rejection of students in schools, particularly students with autism, intellectual disability or mental illness.

Public survey respondents wanted schools to be better funded and resourced to ensure that they are inclusive of children with disability. This should include more social programs and a focus on different approaches to making schools more welcoming for children with disability.

Also raised was the issue of equipping school teachers with knowledge and skills for teaching children with hidden disabilities.



'Teachers and schools must undertake evidence based professional development on ADHD. It is the most common mental disorder in children and very under treated in Australia yet there is still so much stigma, misinformation and discrimination.'

Education and awareness about disabilities among school teachers was said to be insufficient. This was particularly the case for children with ADHD, some of whom had been disciplined or suspended from school as a result of the behaviours associated with their condition.



'Improve public school resources for accommodation for children with invisible disabilities like ADHD and Autism Level 1 and make more social programs available in public libraries for kids to learn social skills.'

There was also concern for a lack of accessibility for children in some school and community settings. While people acknowledged schools had made significant improvements, participants said more could be done to make it easier for students who are deaf, blind or have other physical disability to be fully included.

Parents also identified issues in accessing early childhood and early intervention services for children with disability. They wanted their children to have access to the same opportunities as other children right through their early years. It was noted this requires more investment and targeted programs focused on younger children.



'Definitely young children, I have noticed early childhood intervention is disjointed and very delayed. Support in early childhood settings is very inadequate and I have personally experienced a high amount of stress ensuring my son has his additional needs met. I am very concerned about what will happen once he has to go to school, at this point I am not comfortable to send him to a mainstream setting and I have very little trust that his needs will be met.'

Children and the NDIS

As outlined in [Chapter 1](#), people identified that the NDIS has led to significant improvements in the way children access individualised support and treatments.

However, some parents also identified issues relating to processes under the NDIS that were affecting access to support for their child. This included reports of the significant burden of the NDIS planning process, making it difficult for parents to ensure their children received the right support.



'With the rollout of the NDIS, parents have to take on more individual responsibility for overseeing their children's goals, plans, and plan management. These parents need more support in order to take on this responsibility effectively - without this, their children are missing out on much-needed equipment and other supports. They need increased support at every stage of the NDIS planning process - pre-planning, creating goals and structuring supports to achieve these goals, and management of the plan. This is especially true of those who are also from lower socio-economic or culturally/linguistically diverse backgrounds.'

Parents also identified that there was not enough support, including through NDIS plans, for respite. While funds may be available, the services often were not there in some communities.



'Getting respite for parents and carers of children with disabilities and behavioural needs is really hard as not much is available.'

Parents of children with neurological disabilities, primarily those with ADHD, indicated that more services and supports were required for a child to reach their full potential. In particular, they noted the challenges associated with raising a child with ADHD. They thought that like autism, ADHD should be formally recognised as a disability and be eligible for financial support.

Aboriginal children

Consultations held by NPY Women's Council with Aboriginal people raised concerns about the high number of NPY children and young people with disability in state sanctioned care.

These children typically lived with non-Aboriginal foster families. A number of them were placed through state child protection systems. It was raised that, rather than viewing the issue as one of lack of services in the communities that prevents them living on the lands, the authorities approach it from a welfare perspective. Participants said it was difficult for families to get their children back.

Families subsequently dealt with staff who were not based on the lands and who were not always sympathetic or understanding of the families' wishes. In some cases, families did not know details about where their children were living, who was looking after them and had not seen them in recent times. In some instances, families had not seen them for a few years.

Families gave a clear message that there needed to be proper support so they can visit their children or that children are brought back to community for regular visits. Many spoke about their worries that extended family members missed out on seeing their relatives and getting to know them. They were worried their children were losing their language and connection to culture and country the longer they stay away.

Stories were also shared in the FPDN consultations about the additional risks and impacts for Aboriginal children and family when children are denied access to services. One person shared their story with FPDN.

A single parent of two children with disability

A single parent of two children with disability told his story of being constantly asked to jump through hoops to get support for his children. He felt exasperated that he and his children were being placed into the 'too hard basket' because he was either being denied access to services, or services were slow to respond to his family needs. He felt deep frustration that he constantly had to 'retell his story' which he felt was undignified for him and his children to have to go through. One of his children is at grave risk of incarceration and is a very vulnerable person who is at risk of abuse and exploitation. The parent stated powerfully that the 'hardest thing to do is ask for help' meaning help from the 'system'.

Parents and families

Further to supporting and recognising the needs of children, participants raised the need for more support for, and recognition of, the families of people with disability.

Parents and carers of children with disability shared concerns for their own health and wellbeing. One suggested a person-centred approach in disability could better consider the needs of the child as well as the whole family, who support the child in being able to live life to their full potential.



'I need help as a carer for a child with a disability. My body is breaking down because of the extra work that's required. My mental health is a roller coaster because I don't get the sleep I need and I need to not only care for my child during the day, I need to live my life AND... on top of that, I have to put some serious work into future planning for my child, because one day I won't be here and I don't trust the systems that are currently in place to actually look after him properly. I sometimes think I won't be allowed to die, because there is no one and no system and no help around that even comes close to adequately caring for my child.'

A Geelong parent discussed the need for more help in addressing issues of abuse. They thought many police were uneducated about disability and did not know how to manage reports of abuse on children with disability.

Parents' capability to raise children with disability was brought up in a number of the community workshops. In the in-depth discussion with Positive Powerful Parents group, through the Self Advocacy Resource Unit (SARU) Victoria, two parents shared experiences of a lack of support and respect for them in raising their children. They explained significant issues in the community and the police and justice system's understanding of intellectual disability, and their capacity as parents. While some programs were in place to offer support, legal and other barriers created significant stress, which affects them, their children and family.

Young adults

Compared to other survey respondents young people are less concerned about whether people with disability have enough money to make choices about where and how they live. However, those aged under 25 were significantly more concerned about negative attitudes toward people with disability when compared to other respondents.

Hearing the voice of young people

Newcastle

It's important to hear young people who can advocate on, for and to other young people on disability issues. As the group raised in the Newcastle community workshop 'attitudinal change begins at a young age.'

One young man from Newcastle said young people with disability have a lot to contribute, but they are often overlooked when it comes to having input on the decisions that affect them.

Some cohorts can also be caught between age brackets where they are no longer a child, but not yet an adult. They are caught in-between the population segments.

Housing

The most significant issue raised for young adults was housing and accommodation.

People said forcing young people who have significant disability and no other option for care into nursing homes remains an issue. However, some workshop participants said significant progress had been made towards moving young people from nursing homes into other accommodations.

Young people and parents noted there is poor housing availability and affordability for young people with disability who may not be able to access a fulltime job.



'Independent living options are tailor(ed) towards high-care or older people. Young adults between 18 – 30 who require modified living and minor support have no option but to rent privately and access paid domestic support or stay at home with parents. If they struggle to get a job, can't get the pension because they're still at home and they don't require round the clock medical supervision then they get overlooked.'

There was a strong focus on supporting young people in group homes and some examples were shared where young people had joined together in group living to achieve independence.



'We discussed the possibility of getting accommodation for young adults. There are some great pilot programs in other countries where there are small residential sites with young adults living together instead of having to live in some aged care facility.'

Involvement of young people

On a number of occasions, workshop participants raised the importance of involving young people in the future of disability policy. Young people with disability should have the opportunity and be encouraged to engage in more consultations and design processes. It was noted by a number of the younger workshop participants that their friends and peers often do not find current mechanisms used by governments to engage on these issues appealing, suitable or easy to access.

A strategy that's relevant to young people

Harrison Kirkwood, National Disability and Carers Advisory Council

In sharing experiences of young people, Harrison Kirkwood said:

'Young people with disability are a distinct population who are developing their independence.

We want a support network that allows us the freedom to try different things; different employment settings, new activities and to push boundaries.

We're at a stage where we need help to get life established. With support early on it's easier later to do what we want to be able to live independently.

The strategy needs to be aware of the things that are relevant to young people, Things like having a desire to travel, to move out of home, to start a career etc – knowing that all our life transitions are ahead and that these will need to be taken account of. Young people should be recognised and embraced to try things out as other young people are able to do.'

Older people

Compared to other survey respondents, more people over age of 65 reported health and wellbeing for people with disability is improving. Older people were also proportionately more likely to participate in activities in the community almost every week (63 per cent of respondents over age 65).

However, many people said that older people—those over the age of 65—were being adversely affected by their exclusion from the NDIS and a lack of integration between disability policy and aged care. Many people were concerned about the lack of disability-specific support for older people who were unable to access the NDIS. This included concerns about the lack of support and funding for people over the age of 65 who are deaf to be able to access Auslan interpreters and assistive technology, and to have equity in access to information as society moves to a more digital age.



'Access to appropriate assistive technology for over 65's. There is reasonable access for under 65's through NDIS, but this is either not available to over 65's or is significantly capped.'

In workshops some people said the lack of supports for people over 65 years of age had gotten worse since the NDIS due to a stretched disability support system. People noted reduced disability-specific support in aged care facilities. Similar to hospitals and other health settings, people wanted more effort made to ensure adequate and appropriate care for disability in aged care. This included recognising that additional assistance and resourcing was required to help older Australians to access activities and other services in the community.



'There is very limited disability-specific support in aged care facilities, which means people are at a high risk of missing out on not only social and community access, but also everyday needs and care. If disability was a special interest group in aged care, there would be a clear pathway, process and identified supports for people 65 and over with disability.'

Workshop participants shared feelings of discrimination toward older Australians who live with disability. Compared to other survey respondents, a larger proportion of those over 65 reported that people without disability are unsure how to act toward people with disability.

Gender and sexuality

Women make up 77 per cent of the survey respondents and outnumbered males in many of the community workshops. Therefore, the overall results and issues raised in this report could be interpreted as more representative of the views of women.

Access to money and employment were the two biggest issues raised in the survey - this shows a common barrier for women with disability is gaining access to employment and careers.

People also raised a number of specific issues relating to gender. These included:

- identified higher risks of abuse and homelessness among women with disability
- discrimination for gender diverse people who are seen as not “fitting in a box” within societal norms
- additional barriers and costs associated with diagnosis, and sometimes supports, for some people who are gender diverse, including requirements to “prove” their status
- data collection requires improvement to better understand the additional barriers and issues faced, including for women and gender diverse people
- non-therapeutic sterilization of women with disabilities.

There were a number of mentions of the importance of ensuring disability is reflected within existing women’s, and women’s safety, policies and agreements across all levels of government. For example, people mentioned stronger links are needed with the National Women’s Health Strategy. They also identified the National Plan to Reduce Violence Against Women and Their Children as an area where disability should be strongly included, recognising that women who live with disability are disproportionately affected by violence and abuse.

In survey comments, people said law reform is needed around sexual and reproductive violence against women with disabilities. This most commonly related to making non-therapeutic sterilisation of women with disabilities unlawful.

Some people said the recognition of gender considerations and differences in programs and strategies was getting better.



'I think what has changed is a greater understanding of needing to put disability into both mainstream and targeted group areas. Especially issues for women have turned from being an add-on at the end to being integrated into projects.'

Some people suggested gender and gender equality be reflected as a specific issue in the next national disability strategy. However, others also raised concerns that references to gender may exclude people from specific policies and actions.

Sexual orientation and gender identity

Eight per cent (n=151) of survey respondents identified as LGBTIQ+. While the extent of issues and specific barriers raised by LGBTIQ+ respondents were mostly consistent with other survey respondents, when comparing and analysing results, some specific issues that appeared particularly important to those who identified as LGBTIQ+ were:

- access to money and career or job opportunities
- access to healthcare and health services
- feeling safe.

The slightly higher rate of concern about access to employment and money among the LGBTIQ+ survey respondents could possibly be caused by increased prevalence of discrimination in workplaces or services, which was an issue reported in survey and workshop comments.

A number of comments were made in the survey and workshops about a lack of understanding among health professionals and disability services in regards to LGBTIQ+ community. This appears to be a particular issue in regional and rural areas.



'Speaking as a young adult of the LGBT+ community living in a rural area, it is very hard to have mental/psychiatric disabilities taken seriously and not written off as lazyness or teenage angst. Medical practitioners aren't very educated in any of these areas where I'm from.'

A number of workshop participants raised the cross impacts for people who identify as LGBTIQ+ with disability. They reported additional barriers to being included and feeling a sense of belonging. People reported that being LGBTIQ+ and having a disability could increase experiences of discrimination, and people were not always accepted in one or the other group.



'Equality doesn't mean equal to everyone, and within the communities people are not always safe within their own communities as well. So, someone who is transgender and autistic might not be safe in either space. There might not be a social space for them or there mightn't be understanding for them...'

Some comments suggested there needs to be a better understanding of people with disability who identify as LGBTIQ+ to inform design of programs and better understand the effects of policy decisions on this group.

People said new policies and actions should be co-designed with people who are LGBTIQ+, as well as other specific groups, to make sure policies protect and support people. This includes by addressing additional barriers people may face as a result of intersectionality, and ensuring there are not unintended, adverse effects as a result of policy decisions.

People from lower socio-economic backgrounds

Survey respondents identified lower socio-economic groups as being particularly disadvantaged in accessing financial, social and medical support. People in these groups needed a holistic approach to assist with claims, funding applications, and accessing services and treatment.



'People from low socio-economic backgrounds are having much more trouble accessing DSP due to excessive evidence requirements requiring updated specialists reports written specifically to address DSP criteria.'

Respondents wanted more support in schools in lower socio-economic areas, and free access to activities people would not be able to otherwise attend.



'Education and support for people from low socioeconomic backgrounds to explore possibilities, including available social and community supports. Many of these people come from a generational poverty background and are often not aware of activities and services that can help them engage more broadly with others and the community.'

Some workshop participants noted that people from lower socio-economic backgrounds were not given opportunities to be as involved in informing policies and in the co-design of policies and programs.

Targeted engagement with people from lower socio-economic backgrounds would assist to better design policies and initiatives that engage people with disability who are living in poverty or are homeless or disadvantaged.

Part B:

Implementation & measurement

In this section:

5. [Relevance of a National Disability Strategy](#)
6. [Action plans and aligning with mainstream agreements](#)
7. [Measurement and indicators](#)
8. [Accountability and reporting](#)

Chapter 5: Relevance of a National Disability Strategy

In this chapter:

- [The relationship between the NDS and NDA](#)
- [The relationship between the NDS and NDIS](#)

Workshop participants said having a National Disability Strategy that guides policy, programs and legislation for disability is critical. People engaged in workshops said the document remained relevant and was important for guiding national policy for disability. Some people said having a nationally consistent approach to disability was critical as people were not confined within their states or territories, and the NDIS has made the majority of disability services, supports and safeguarding national.

However, people's awareness of the National Disability Strategy is not high. Almost half of survey respondents had not heard of the National Disability Strategy prior to taking the survey.

Across the consultation activity, a number of people said more effort should be made to raise the profile of the National Disability Strategy, and that this should occur across all areas of the community, not just in the disability sector.



'As a parent to an adult with a disability, I've never even heard of the National Disability Strategy except someone shared a link to the survey on Facebook. That should tell you that you are failing totally to engage with the people who should be your stakeholders.'

The relationship between the NDS and NDA

People mentioned the relationship between the National Disability Strategy and National Disability Agreement (NDA). However, many people did not have a clear understanding of how they work together. There was general awareness of the recent Productivity Commission review into the NDA with participants in workshops noting that recommendations from the Productivity Commission and the consultation report for the next National Disability Strategy should be looked at and considered together.

People said better aligning the NDA and strategy would assist to make both more relevant for people. Many people were supportive of the Productivity Commission's recommendation to align the NDA and national disability strategy to have a single set of outcomes and performance reporting framework.



'The NDS needs to be in "lockstep" with the [National Disability] agreement.'

The relationship between the NDS and NDIS

There was confusion about what the National Disability Strategy is, and if and how it differed to the NDIS. Many survey respondents assumed the National Disability Strategy was another term to describe the NDIS.

There were some concerns the NDIS has taken the focus and importance off the National Disability Strategy. Some participants thought the strategy was not as relevant to people as the NDIS, as it did not bind governments to specific actions.



'With all the excitement and anticipation surrounding the NDIS, the National Disability Strategy has been forgotten about. We see this in the withdrawal of state and territory governments from transport and equipment subsidy and advocacy funding programs. This has led to some reduction in services for the many thousands of people with disability who are ineligible to be NDIS participants..'

Chapter 6: Action plans and aligning with mainstream agreements

In this chapter:

- [Requirements for disability inclusion and action plans](#)
- [Local government involvement and action](#)
- [Disability policy in mainstream agreements](#)
- [Commitment in the community](#)

The [UNSW Social Policy Research Centre's independent review of the implementation of the National Disability Strategy](#) provides detailed recommendations for improving implementation of the strategy. Public consultations raised similar themes and ideas to those raised in stakeholder consultations during the independent review.

Requirements for disability inclusion and action plans

Workshop participants recommended state and territory and local governments have disability inclusion and action plans. This applied also to all mainstream services in government. Requiring mainstream services and public facilities to have disability inclusion and action plans would create immediate and tangible improvements in accessing the community.



'A strategy is only effective if you have a clear plan to deliver on its objectives. There are some good initiatives and ideas, but also a lot of motherhood statements that do not translate into results or effective change.'

Governments, at all levels, need to be resourced to implement action plans and actions under the National Disability Strategy. Many participants said resources should enable the involvement of people with disability to co-design plans and actions so that they have the most impact at state, regional and community levels.



'More than anything the renewed National Disability Strategy needs to be resourced through funding. A National Disability Strategy without funded programs attached and with no resourced monitoring or implementation body will not have meaningful impact. It must also work to set out clearly the roles of the Commonwealth and those of the States and Territories in implementing the goals and aims of the NDS. A lack of clarity leads to no implementation.'

Local government involvement and action

People raised the importance of the National Disability Strategy in local community policy and programs. The role of local government was raised on many occasions. In particular, people wanted to see local government play a stronger role in the implementation of the National Disability Strategy.

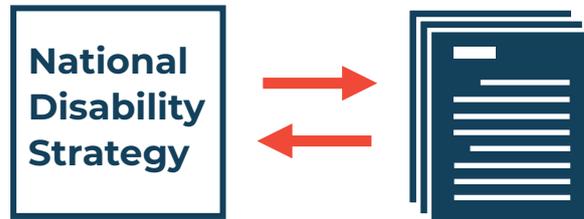


'Don't overlook the role that Local Government can play in building local community capacity. Reflect the roles of Local Governments as well as State & Territory Governments in the Strategy. Victoria has had a fantastic State funded program across Local Government areas titled Building Inclusive Communities. The roles were funded at State level, but delivered in local communities through a community development approach. The infrastructure of this state-wide initiative that has been in place for well over a decade will now come to an end with the introduction of the NDIS. This is a lost opportunity - not only for Victoria, but for other States/Territories to replicate in an appropriate way for them.'

Workshop participants commonly referenced improvements by local government to ensure their communities were more welcoming and inclusive of people with disability. Many local councils now have disability advisory or reference committees to help councils ensure planning and infrastructure is more accessible, and community development prioritises inclusivity of people with disability. There were calls for the role of local government to be more strongly reflected in the next strategy.

Disability policy in mainstream agreements

A common area of discussion and concern was the siloing within disability policy-making. Disability must be a part of all mainstream agreements and considered in legislation, particularly with buildings and infrastructure, transport, housing and education.



Participants raised concerns that the current National Disability Strategy sat as a separate document, without sufficient linkages into other agreements and strategies.



'...we talked about a desperate need for connectivity between national strategy. There is to be an awareness of the strategy for the protection of children, the violence plan, the women's health strategy, because otherwise we continue with this program to silo disability rather than integrating it.'

Evidence of the disconnect between the National Disability Strategy and mainstream agreements is shown by the fact that the majority of areas people said have improved relates to action taken in disability policy, such as the introduction of the NDIS, or legislation to promote disability inclusion. However, mainstream areas such as employment, education, housing and transport are more commonly identified as not having improved. People thought improvements in these areas were likely to be more effectively progressed through mainstream agreements.



'...there's still a lot to be done in terms of that mainstream access and, those intersections between disability and mainstream.'

Commitment in the community

To achieve positive change for people with disability, participants said the strategy needed to ensure commitment from all levels of government, and by business and the wider community.

Incentives and accreditation were recommended to encourage this commitment. For example, one idea raised was to have accreditation for local Councils and businesses to show and reward those who have taken significant action towards inclusion and accessibility. Another suggestion was to have a disability accessibility rating in place, similar to a star rating for energy efficiency.

Chapter 7: Measurements and indicators

In this chapter:

- [Measuring success](#)
- [Data collection](#)
- [Access to data](#)

The National Disability Strategy will only have an impact if there are clear outcomes included in the strategy, and changes are measured over time.

Measuring success

Workshop participants described what success would look like in five to 10 years' time. Some of the common areas noted included:

- Improvements in global rankings, such as among Organisation for Economic Co-operation and Development countries.
- A human rights approach and specific human rights legislation to better implement and align with the CRPD.
- More employment opportunity for people with disability.
- More inclusive communities that can be accessed by all – with accessible housing, transport, and community spaces.
- Policies and actions designed in full by and with people with disability.
- Positive changes for individuals, driven by system reforms, and improved outcomes for all people with disability.

Participants said success needed to be defined in order to set the desired outcomes for the strategy over the next 10 years. Some noted that success should mean positive changes for individuals, driven by system reforms. Measurements for success should focus on improving outcomes for people with disability, requiring a person-centred approach to defining success and changes.

At workshops, there was significant discussion about how the next National Disability Strategy could be measured, and the specific indicators or measures that should be used to show progress.

Many people said they would prefer to see targets set by government, rather than relying on the use of quotas.

Shopping list for change

In the Canberra community workshop, one group shared their 'shopping list' for change.

- Building codes adhered to.
- People can choose where and how they want to live.
- People have jobs and are not the most underemployed people in the community.
- We have value and count.
- We can quantify the experience of disability.
- We can identify people with disability in systems and there are report cards about inclusion for all governments.
- The report is read live to the public and talked about on an annual basis in Parliament.
- Clear targets are set.
- There is training and awareness for disability.
- People self-identify as they feel safe to do so.

People identified specific types of measurements or indicators they would like included in the next national disability strategy. Common suggestions were:

- percentage of people with disability in employment
- students with disability accessing mainstream education and improved outcomes in school education and attainment
- reduced waiting lists for disability and health supports
- numbers of people with disability in leadership positions, in Parliament and on Boards
- access to advocacy
- representation of people with disability in the justice system and incarceration rates
- reduced complaints, and incidences of abuse and neglect
- improvements in economic wellbeing/status
- growth in number of social enterprises/businesses run by people with disability
- fewer young people in nursing homes
- wage parity
- numbers of disability inclusion and action plans.



'Any measure should be against the general population. An obvious one should be employment rates. Health and well-being, improvement in life expectancy.'

Metrics to show improvement for individuals were identified as being complex, as they would need to consider all aspects of someone's quality of life, and there were many influences affecting a person with disability's life.

There were also suggestions to measure trends and gather qualitative data as a more useful indicator of positive change over time. Tracking trends could include:

- visibility of people with disability—in the community, in media and in senior leadership positions
- community attitudes
- people with disability's satisfaction with government supports and services
- community sentiment and comments about people with disability, including in media and social media
- happiness: surveys which show happiness indicators or trends in wellbeing, and happiness over time or at specific times of year
- sex and dating: understanding relationship trends that affect people's lifetime wellbeing.



'Basically, sex and relationships are not talked about, let alone measured correctly. We think there should be a better strategy for measuring that.'

Qualitative measures were preferred by some workshop participants. They cautioned relying only on indicators which were likely to need to be at a system level and would not necessarily determine change for the person. Some suggested longitudinal studies and data would be more appropriate to measure change over the long term, for example, over a 10-year strategy.



'Changes in people's lives is often not determined by numbers but by their experience.'

Qualitative measures are required to understand if employment is meaningful and if the experiences of students in education settings are positive. Measures should be about the number of people who gain access, and about their experience and satisfaction with services.

There were also suggestions for data to be used to show the contributions of people with disability in Australian communities. For example:

- contribution of people with disability to Gross Domestic Product (GDP)
- contribution of people with disability to sport and the arts
- more up to date statistics and research into benefits of employing people with disability.

People acknowledged the need to establish a baseline to ensure changes could be measured over the next 10 years. Some existing data, such as the Census, NDIS data and the National Disability Strategy survey, could be used as a baseline.

Data collection

There was support across consultations to improve data collection to help governments and organisations design better policies and programs for people with disability.

Many said more data needed to be collected. There should be a holistic strategy set by the Australian Government for data collection. People thought all government services should be required to collect data, especially:

- mainstream health
- employment
- housing
- education
- transport.

A suggestion was made to implement a national pilot to test data collection methods. The strategy for data collection would then be developed and implemented consistently across states and territories.

A national survey was also suggested to track progress against the next national disability strategy. Some said this should be annual, others suggested every two years.

There was significant focus on the use and effectiveness of the Census to better understand disability in Australian communities. Many people said the Census had not done enough to ensure people with disability are accurately counted. Others said the Census should be used and built upon to further collect specific data about people with disability.

For some people, additional questions about disability should be added to the Census. This would give a better understanding of disability data nationally and at the regional level. Possible question topics were:

- type of disability
- access to the community
- changes in quality of life since last Census.

There were strong recommendations for the need to ensure better data is collected to show intersectionality of people with disability. Current data collection does not provide enough of an understanding of things that can cause additional impacts or barriers in the lives of a person with disability, such as:

- type/s of disability
- gender
- cultural background
- Aboriginal and/or Torres Strait Islander status
- languages spoken
- sexual orientation
- literacy level

- socio-economic status
- housing or living situation
- geographic location.

Comments were also made about the need to ensure data is collected to ensure data is not only collected on those people with disability who are more likely, or find it easier, to be counted. This included a number of suggestions for collecting data on hidden disabilities.

A common suggestion in workshops was to include I have a disability on forms for mainstream services similar to the way it is now included for whether people are of Aboriginal or Torres Strait Islander background or speak a language other than English at home.

There were other consistent areas mentioned for data collection with detailed suggestions:

- **Employment:** while employment data can be sought from multiple places, data could also be collected from employers about the numbers of applications from people with disability.
- **Education:** schools should be required to report specifically on educational outcomes for children with disability. This should include mainstream schooling. Schools should be required to collect data on the number of enrolment refusals of students with disability. Schools could also help to collect information about what is changing for students over time, including more qualitative data about their experiences and aspirations.
- **Health:** more data could be collected when people with disability access mainstream health services, such as hospitals, dentists, physiotherapy and allied health, and psychology. This could assist in understanding the needs of people with disability when it comes to accessing health, and to better integrate health and disability supports.
- **Housing and homelessness:** governments should have a good understanding of housing used by people with disability, as well as the number of people with disability who are homeless or at risk of being homeless.
- **Prisons and justice:** better data should be collected about people in prisons, including qualitative data about behaviours and insights that might assist in developing preventative strategies and in informing improvements and requirements in the justice system. More data should be collected about the number of people with disability who access the justice system, through the court system and police, including people with disability in indefinite detention situations.
- **Access to technology:** There needs to be a better understanding of how much assistive technology is currently used by people with disability, as well as the barriers to accessing it. Data could be collected on the quantity of assistive technology purchased in a given year and tracked over time to assess whether people are gaining more access to technologies.

Some people wanted more money to be spent on research that will monitor new and emerging areas that might affect the lives of people with disability in the future.

Access to data

People suggested that access to data should be addressed in the next national disability strategy. Specifically, they said there was not enough sharing of data between agencies and researchers. In particular, some people suggested sharing of data about access to disability employment services and NDIS between governments and with researchers would assist in understanding trends and designing policies based on evidence.

There were limited concerns raised about asking people to identify as having a disability during data collection, or concerns about how data will be used.

Chapter 8: Accountability and reporting

In this chapter:

- [Reporting](#)
- [Independent oversight](#)



'We can't wait every 10 years for improvements, it needs to be dealt with annually. What is working feeds back through and it is a living document capable of constant improvement.'

To raise the profile of the next strategy, participants said governments should be held more accountable to the areas of action in the National Disability Strategy and report annually to Parliament.

In the public survey, 70 per cent of respondents said it is a high or essential priority for government to 'develop measurable goals and concrete targets and report against them'

When discussing accountability, people identified a lack of government action and accountability as a significant weakness in the current National Disability Strategy implementation. Some people said this had not improved over the life of the 10-year strategy.



'We are ten years on from the previous strategy and nothing has changed. Because there are no consequences for people to change their behaviour, no incentives for councils to make better environments, no funding for them to do so, no incentives for business and a general lack of awareness that any of this is even a problem or that the solutions are just too hard or too expensive.'

Many people said governments had not been held accountable to implementation and reporting on progress against the strategy. Some wanted more transparency and flexibility in implementing the next strategy, so when things do or do not happen, the public and stakeholders know why.

Reporting

Workshop participants discussed how and when governments should report on progress under the National Disability Strategy. Annual reports were favoured to ensure government remains accountable to progressing actions, and for measuring change.

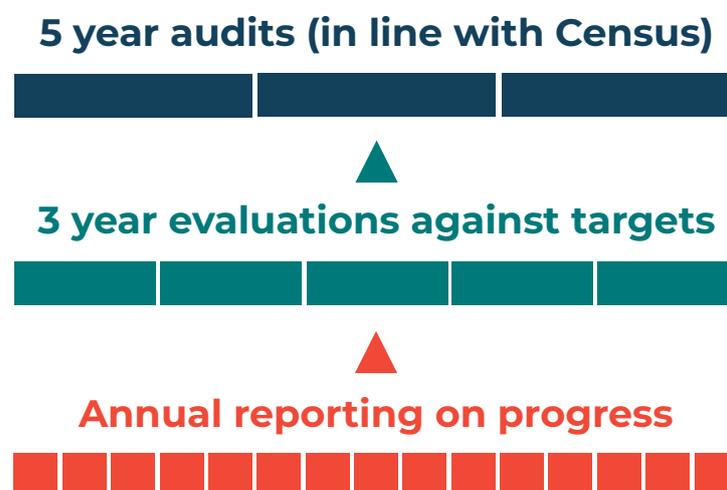
Performance reporting must be more stringent in the next strategy and be a requirement for all levels of government. There were also suggestions that reporting be aligned with reporting on the NDA.

 *'[Name removed] supports the Productivity Commission's recommendation that performance reporting under the new NDA and NDS be merged, utilising a single national performance reporting framework and resulting in a single performance report.'*

Some people want more force on government agencies to maintain commitments and to report on progress of actions more regularly. Some suggested requiring the Commonwealth, and state and territory governments to report publicly on a regular basis against a consistent reporting framework. People suggested this would help to show areas or jurisdictions where progress was not being made and make governments more accountable.

'Requiring government to submit an annual report on disability' made up about a quarter (25 per cent) of the responses people provided when discussing accountability and reporting in workshops.

In regard to frequency of reporting, many people suggested a staggered approach, and that reporting could align with existing data collection, such as the Census. Some people suggested 5-year complete audits, in line with Census, three-year evaluations against targets, and annual reporting on progress. The 3-year timeframe for evaluation was seen as important to allow enough time for real change to be assessed, and to avoid over-consultation of people with disability.



Some stakeholders recognised the importance of reporting requirements in government, but also suggested the reporting framework within the next National Disability Strategy help guide their reporting, making it more systematic and the data more useful.



'Accountability lies with Government and all of us. As a Disability Service provider, we will be looking to the Strategy to assist in how we report on our activities - how they contribute to the overall strategic goals in the Strategy. Perhaps Government and Parliament could adopt a similar approach, across all relevant Government Departments.'

Independent oversight

A number of people throughout consultation activity suggested an independent body, or part of government separate to current disability portfolios, should be established to monitor and report on progress of the next national disability strategy. For example, some people suggested a Commonwealth Statutory Advisory Council similar to what exists in Victorian Government. Others suggested an independent Disability Commission.

It was also suggested an implementation group could be established to ensure areas of action in the next strategy are implemented across all levels of government. While people noted existing Disability Reform Council arrangements, they said this structure provided oversight but did not ensure accountability to the implementation of actions and improvements in the community.

Part C:

Next steps

**for designing the next
national disability strategy
2020 and beyond**

Designing the next strategy with people with disability

The consultations explored many issues and ideas with people with disability, their families and carers, and other stakeholders. However, as noted in the introduction to this report, these consultations were exploratory and there is still more to be done to design the next strategy, particularly to focus on specific sections, issues and impacts for different groups. People with disability should be directly engaged in designing the new strategy.

Combining these consultations, the independent reviews and other reports, there is already a wealth of data on individuals' and key stakeholders' views about the next strategy and how it could be improved. Therefore, the next phase of engagement should focus on informing and designing specific policy options, ideas and components of the next strategy, based on this broad consultation data. The following are recommendations for designing the next national disability strategy.

Written submission process

Many organisations requested the opportunity to provide written public submissions, after consulting with their own members and people they work with and support. It is recommended the Government provides the opportunity for a public submission process to help inform specific policy options for the next national disability strategy, and to seek further information on ideas and issues.

Co-designing the strategy

People mentioned regularly and in detail the need to co-design the next strategy with people with disability, from the beginning. To help achieve co-design, it is recommended the next phase of engagement include:

- **Targeted co-design workshops** between policy makers and people with disability to develop specific sections of the next strategy. It's proposed these are done with small groups and over multiple days/sessions.
- **Targeted focus groups** to further understand and validate issues from the broader consultations, particularly with different demographics, diverse groups and types of disability.
- **Expert roundtables** bringing together academics and leaders in the sector with people with disability to discuss how the next strategy might respond to critical issues.
- **Government and business roundtable** to discuss how business and employment can be better reflected in the next strategy, with specific measurements to achieve outcomes.
- **Testing language with people with disability** to ensure the next strategy fully supports and promotes inclusion.
- **Government and governance workshops** to finalise arrangements for how the strategy will be implemented, measured and reported on prior to finalising the next strategy.

Employ people with lived experience to design the strategy

The Government should employ people with disability in key positions of influence to design the strategy. People said this would help to make sure the strategy is genuinely co-designed and is implemented in a way that meets the needs of people with lived experience of disability.



'It should be a high priority to make as many people employed in association with the National Disability Strategy are actually people with disabilities. Nothing about us without us. We know better than anyone without a disability ever can.'



'You need to employ people to do this and work very hard at not taking a top down approach. As they say "nothing about us, without us".'

Considerations for the next strategy

Based on feedback in the consultations, the following recommendations are made for developing the next national disability strategy:

- **Undertake additional, targeted engagement** on specific options and ideas for inclusion in the next strategy.
- Provide the **opportunity for people to make a submission** on specific ideas and options for the next strategy.
- Determine how Australia will respond to and maintain its **commitments under the UNCRPD**, through actions, measurement and reporting under the next national disability strategy.
- Focus on the **rights to have access to opportunity** in regard to independence and wellbeing. This could be a key topic area to explore in the next round of consultations and in designing the new strategy.
- **Link NDIS to broader policies** for inclusion, rights protection, safety, and access to services and supports for all, and demonstrate more clearly how the NDIS, over time, will contribute to improving the lives of all people with disability (such as increasing the market of disability services available).
- Demonstrate governments' responsibilities and efforts **to support people with disability outside of the NDIS**, to help drive improvements to mainstream services and support systems used by people with disability in areas like health, transport and education.
- **Reflect emerging areas**, including advancements in assistive technology, with specific strategies for how government will support these to ensure they can be accessed by all.
- Consider a dedicated section and strategies to **improve community attitudes, awareness and understanding** (with a focus on [disability literacy](#)).
- Include practical guidance for all governments and the community to help overcome barriers to participation and access, including involvement of **local government** who can achieve improvements at the regional and local community levels.
- Add **more recognition, focus and supports for different groups** in the next strategy, including Aboriginal and Torres Strait Islander people, people from CALD backgrounds, people with intellectual disability and people living in rural and remote areas.
- Recognise that all minority and diverse groups can face additional barriers and intersectional discrimination and that an effective response to intersectional discrimination can only be achieved by a whole of government response
- Have a strong focus on **specific measurements and commitments to how governments will report** on progress being made to improve outcomes for people with disability, against an evidence-based measurement framework.

Appendices

[The appendices are available to download.](#) They include:

- Appendix A: Supporting survey data and graphs
- Appendix B: Consultation participants – breakdown of demographics
- Appendix C: Community workshop agenda.