## Right to opportunity

Consultation report to help shape the next national disability strategy

## SUMMARY REPORT

December 2019

This is a summary of the <u>detailed Consultation</u>

Report to help shape the next national disability

strategy for 2020 and beyond.

An <u>Easy Read</u> and <u>AUSLAN</u> version is also available.

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## 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 <u>2009 Shut Out report</u>.

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.'

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 with disability improves.

Developing the next strategy means establishing a revitalised set of principles, as well as new guidance that meets the expectations of people with disability and the broader community. Most importantly, that it upholds Australia's commitment under the United Nations <u>Convention on the Rights of Persons with Disabilities (CRPD)</u>.

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

## Who was engaged to inform this report?

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

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.

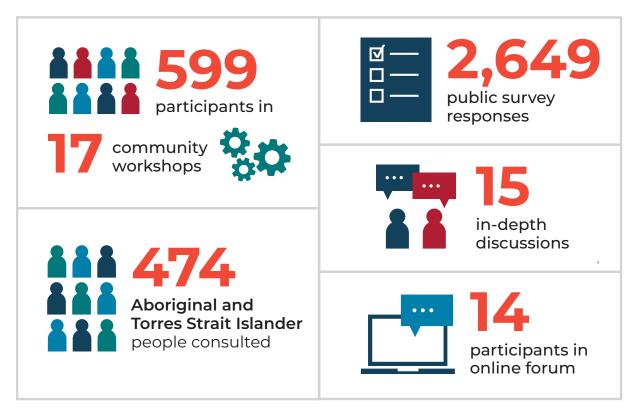


Figure 1. Participation numbers across different consultation activity.

## **Key statistics from survey**

\*The following figures are results of the public survey completed by 2,649 respondents.

- Majority of respondents (53%) reported that each of the following areas have improved during the past five years:
  - » accessibility in communities
  - » inclusion
  - » community attitudes
- More than 80% of respondents said 'people without disability are unsure how to act toward people with disability'.
- 31% of respondents who have disability reported discrimination has got worse during the past five years, compared with 29% who said it has got slightly or much better.
- 34% of respondents who have disability reported that experiences of neglect, exploitation, violence and/or abuse had got worse over the past five years.
- Finding and keeping a job, and work and career opportunities are rated most often as the most severe issues for people with disability. This is closely followed by having enough money to pay for daily expenses.
- About half of people with disability do not regularly participate in community activities and events.
- 72% of respondents said it is very or somewhat difficult to find information about disability supports and services. Slightly less (60%) said it is very or somewhat difficult to find information about the rights of people with disability.
- Less than one third of respondents report being satisfied with the access they, or someone they know with disability, has to the equipment, aids or assistive devices needed to access information online and use technology.

# What is important for the next national disability strategy?

People said the six outcome areas of the current National Disability Strategy were comprehensive. However, the next strategy will need to respond to new and emerging areas that are affecting the lives of people with disability.

## Nothing about us, without us

A common and important message we heard during consultations was: nothing about us, without us. This message was strongly represented across all consultation topics and methods.

It was clear people with disability need to be involved in all aspects of designing, implementing and monitoring the strategy, and the programs and actions that affect them. A number of workshop participants said the involvement of people with disability in the design of policies, actions, places and infrastructure had not improved significantly over the past 10 years, and that in the future, 'all decisions that are made that affect people with disability must involve people with disability.'

People said the strategy, and all actions and initiatives that sit within it, need to be co-designed with people with disability. This includes with specific and diverse groups of people with disability who are most affected. It also includes ensuring people with disability are employed in positions in government and the disability sector who design and implement the policy.

## Improved implementation and reporting

Many people said governments need to be held more accountable to the next national disability strategy. They suggested a stronger commitment to action, and better measurement of progress and change, with regular mandated reporting.

Some people suggested a dedicated, accountable and possibly independent authority to track and report on progress made across governments. A lot of people want to see annual reporting to Parliament/s and said this would help to raise the profile of the National Disability Strategy.

People also noted that indicators and outcome measurements need to be set from the beginning of the next strategy so that progress towards achieving positive change for people with disability can be better monitored and evaluated.

The way in which the strategy interacts with mainstream agreements, the NDIS and the National Disability Agreement needs to be a significant focus of the next strategy. As we heard in consultations, one of the most common frustrations and areas for improvement is ensuring disability is included in mainstream agreements, and in all community services. This is important to ensure the rights of people with disability to access the same opportunities in the community as everyone else are upheld.

## Key areas of focus

Throughout the consultation activity, people identified areas of concern and issues, which should be addressed in the next national disability strategy to help improve the lives of people with disability in Australia. Feedback is summarised in four key areas:

- Upholding the rights of people with disability
- Inclusion in community life
- Independence and wellbeing
- Responding to the NDIS and other emerging areas.

## Upholding the rights of people with disability

43% of total survey respondents (and 36% of respondents with disability) identified that upholding the rights of people with disability has improved over the past five years. Another 31% said there had been no change during the past five years.

People consistently said a focus of the next strategy should be on upholding the rights of all people with disability in Australia. This includes making sure people with disability have access to the same things in the community as everyone else. Outcomes for people with disability will get worse if they continue to be excluded from employment, services or activities, or are not treated with the same respect as others in the community.

Upholding the rights of people with disability is the responsibility of all Australians. People with disability wanted to see more done to improve awareness and understanding of disability in the community, and of the *Disability Discrimination Act* (DDA). They also said the DDA needs to be more consistently and strongly enforced.

People said more support for advocacy is important in ensuring inclusion of people with disability and that the rights of people with disability are upheld.

It was recognised that people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) backgrounds, and some people with intellectual disability, should be given additional support and information to understand their rights. People said there was currently limited information about people's rights available in language and delivered in accessible and culturally appropriate ways.

People said a federal Human Rights Act is required, and/or there needs to be stronger actions in the next strategy, to ensure Australia is meeting its obligations under the United Nations Convention on the Rights of Persons with Disabilities.

## Inclusion in all community life

53% of survey respondents said accessibility when out and about in the community has improved during the past five years.

41% of survey respondents reported they rarely or never participate in activities in the community, such as recreation, entertainment, social activities and watching sport.

Related to rights, is the responsibility of everyone in the community to ensure people with disability have the same access as everyone else.

We heard from people that access and inclusion was improving, but people with disability still faced many barriers to participating in the community and to accessing what they need and want. The common barriers raised related to social acceptance and attitudes in the community, access to adequate supports including through the NDIS, and access to opportunity in employment.

One of the biggest issues for people was not having enough money to be able to participate in the community. Forty-eight per cent of survey respondents said being able to afford the activity was preventing them from taking part in activities in their local community.

Access to information was improving with the availability of online systems and new assistive technologies. However, there were concerns in the community that some groups, such as people from lower socioeconomic backgrounds or those living in rural and remote areas, will miss out on these emerging technologies. Some people identified the need to increase awareness of the importance of accessible information for people with intellectual disability or cognitive impairment.

Feedback about the treatment of people with disability showed there were ongoing issues with discrimination and exclusion of people with disability in the community. Most commonly, people raised issues about exclusion from education settings, transport and employment. Many parents shared experiences about a lack of inclusive education practices in mainstream schooling.

People also shared experiences of poor treatment, discrimination and abuse. People noted abuse and discrimination can be worse for specific types of disabilities, groups and demographics including women, people with intellectual disability, Aboriginal and Torres Strait Islander people, people from CALD backgrounds, and people who identify as LGBTIQ+.

People with disability and their families or carers said improving the community's understanding of disability would significantly contribute to the way people are treated, valued and included in community life.

## Independence and wellbeing

23% of survey respondents said having enough money to make choices about where and how they live has got much worse during the past five years. Respondents also rated finding and keeping a job and career opportunities as the biggest issues for people with disability.

Only 36% of survey respondents thought health and wellbeing of people with disability had improved during the past five years.

People suggested independence and wellbeing will be driven by upholding people's rights to access mainstream services, and through improving their access to opportunity – particularly in employment, education and housing.

People said it would be important for a new strategy to drive improvements to mainstream services and support systems used by people with disability outside of the NDIS. This includes in areas like health, transport, housing and education.

While the NDIS is helping to improve independence and choice and control for many people who have access to it, people noted it won't deliver opportunity for all people with disability. There was concern in the community that current employment and education gaps for most of the 4.37 million people who live with disability will not be reduced unless there is more action in the next strategy about inclusive employment and education, including throughout every stage of a person's life.

People with disability reported they are still being excluded from employment opportunities, not based on their abilities or skills, but on perceptions of employers and a lack of access in workplaces. This is preventing them from being able to live independent lives with enough money and resources for everyday things.

People said more significant action is needed to improve workplace environments, attitudes and culture. However, some people also shared positive examples of how government programs and campaigns were supporting their employment. Many people identified the next strategy should focus on achieving more open, inclusive employment for people with disability.

The health and wellbeing of people with disability was strongly linked to having the right to opportunity (in employment and education), and to having the money to pay for accessible and appropriate housing, health and medical needs, aids and other equipment. A lack of money for these types of daily expenses was one of the biggest issues for people with disability.

People said health outcomes would only improve when people with disability had more opportunities for paid work, to live safely in appropriate and affordable homes, and to participate in community sports, arts and leisure activity.

Many people noted that support for mental health, including early intervention and supports, needs to be more strongly reflected in the next national disability strategy. People noted mental health as an area that has changed over the past 10 years, particularly in relation to diagnosis, care and awareness.

Important to supporting the independence and wellbeing of people with disability is ensuring the role of informal and unpaid carers is recognised and respected. More people reported that support for families and carers was an essential priority compared to any other area when asked to prioritise government action. This included respondents with disability.

## Responding to NDIS and other emerging areas

80% of survey respondents said that activities that build on and complement the NDIS should be a high or essential priority for government action.

67% of survey respondents said availability or cost of aids, equipment and assistive technologies was a major or severe issue.

We heard during consultations many positive stories about improvements in people's lives as a result of the NDIS. However, of the estimated 4.37 million people living with disability in Australia, only 10 to 15 per cent will be eligible for, or are likely to access, the NDIS at full scheme.

People were concerned that focusing only on the NDIS could leave out millions of Australians with disability, including people over the age of 65, refugees and new migrants, people in rural and remote locations and those whose disabilities are less understood. Some people said the significant focus on the NDIS over the past five years, while critically important, had shifted responsibility for provision of services and supports away from government and put the onus on individuals and families.

Many people said they wanted to see government focus on fixing the issues with the NDIS planning process, to avoid negative impacts on individuals. This included improving access to supports, and to address service gaps. People raised concerns that the intent of the NDIS to strengthen the market of disability services had been slow and gaps in supports for people - including those eligible and ineligible for NDIS - are now emerging and getting worse.

#### Technology

When it came to identifying things that would help or affect people with disability in the future, assistive technology and inclusive IT were listed more times than any other area. Some people identified that technology is both an enabler and a barrier for people with disability and suggested care should be taken about what governments focus on and invest in when it comes to technology.

Over the next 10 years, there will be significantly more advances in technologies, such as robotics and virtual reality, which will assist people with disability in accessing information, participating in community and to live independently. These will be driven by global and market forces, however people said governments in Australia should be supporting innovation and technology advances. In addition, people said we need to ensure everyone in the community can access these technologies if they need them.

One way some people suggested technology and new and emerging products could be better supported is through assisting people with disability to be involved in establishing start-up businesses and social enterprise.

#### Ageing population

People were also concerned about the lack of supports for people over 65 who have disability. This included affects on the wellbeing of those who care for family members as they grow older, including younger Australian carers. People also noted affects on carers and family members who are ageing themselves, and suggested unpaid carers may need more targeted support as the population ages.

#### Climate

Climate change was also mentioned by people during consultations, with some noting that any changes and variations in climate will have a greater affect on some groups of people, including people with disability, than the rest of the population.

## Issues affecting different groups and demographics

Consultations identified that barriers and issues greatly affect the lives of people with disability who are from minority and intersectional groups.

People noted some population groups experience several levels of interconnected barriers and additional discrimination. It is critical to recognise and better understand these issues, and to include recognition of different groups in the next strategy. The following groups were identified as needing specific recognition and supports.

#### People who live in regional and remote areas

The shortage of services and supports in regional and remote areas was a major concern. People in these areas commonly identified access to safe and affordable transport and to facilities in the community as bigger issues than people who live in major cities. People who are eligible to access the NDIS raised issues about a significant lack of supports and services available in the community to use their plan.

People identified that community attitudes and awareness could sometimes be worse in regional and remote areas, where the visibility of disability was not as common. Access to advocacy was also noted as a particular issue in regional, rural and remote areas, with some people reporting services can cover hundreds of kilometres.

#### Aboriginal and Torres Strait Islander people

In Aboriginal language there is no comparable word for disability. This is evidence that disability has always been accepted by Aboriginal and Torres Strait Islander people as part of the human experience. In consultations, people said experiences of discrimination for Aboriginal and Torres Strait Islander people with disability included intersectional discrimination based upon both racism and ableism. The discrimination can occur when Aboriginal and Torres Strait Islander people start interacting with systems and people who are external to the community in which they live.

One of the most significant challenges for Aboriginal and Torres Strait Islander people with disability is being able to access basic supports, or income, to support day-to-day living. In some regional and remote communities people said the costs of living can be higher than in other locations and this can have an effect on the health and wellbeing of people with disability.

Many Aboriginal people would not self-identify as carers, they simply see supporting their family members with disability as part of their role and responsibility within the family. One of the great strengths of Aboriginal communities is the role that extended families play in supporting a family member with disability. However, the lack of appropriate disability-related resources in communities to help this to happen remains a significant challenge.

#### People from CALD backgrounds

A common issue raised for people from CALD backgrounds with disability was a lack of access to information about disability supports available and about their rights in the community. People said additional work is needed to ensure rights legislation is better communicated to people from CALD backgrounds, and this needs to be delivered in multiple languages and provided in safe and accessible ways.

Concerns were raised that people with disability from CALD communities may experience additional levels of discrimination. A stigma of disability can exist in communities where disability is less understood or accepted. Some people said this might prevent people from identifying and seeking support for their disability. People noted that new arrivals and humanitarian entrants can be particularly at risk.

#### Children and young people

A common issue raised about children with disability was a lack of action to ensure schools are inclusive, as well as a poor understanding of some children's disabilities, including autism and ADHD. For young people with disability, a common issue was appropriate housing and ensuring they are empowered and given opportunities early on to be able to achieve what they want in life.

#### People aged over 65

The most common issue raised relating to people with disability over the age of 65 was that they cannot access the NDIS, and as a result felt that access to supports was reducing. People also reported that over 65s could experience additional discrimination and less access to opportunity in employment.

#### Women

The safety of women with disability, who were considered by some to be more vulnerable in the community, was a common issue raised. Access to employment and having financial security were also major issues raised by (and about) women with disability.

#### People who identify as LGBTIQ+

The understanding of intersectional issues for people with disability who identify as LGBTIQ+ was a concern for the community. There were some reports that people could be excluded from both communities and face additional barriers in gaining employment and accessing healthcare.

#### People from lower socio-economic backgrounds

Consultations recognised that people with disability were particularly disadvantaged when they did not have the access to money for daily expenses and for assistive technology, to participate in social activities or to access medical supports.

## What would success look like?

Community workshop participants described what success would look like in five to 10 years' time. Common statements 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 opportunities 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.

## Messages of positive change

Participants in workshops shared messages about what they would like the community to know and hear about disability. Below is a collection of some of the messages shared.

- We all have human rights
- Inclusive life is a right
- Know more about your human rights
- Jobs for everyone, apply here
- Change the script
- My town cares
- Every Australian counts. Count on me
- Disabilities are everyone's responsibility
- Inclusion is for everybody
- Diversity is everyone's business
- Universal design is for everyone
- Acknowledge disability
- Employment for all through community connections

- Inclusion makes life better for everyone
- Better together we are stronger that way
- Embrace the differences!
- Make each day count! Acceptance is key!
- Disability can happen to anyone at anytime
- See the ability
- reThink disAbility
- Dis the 'dis' in disability
- Diversity the society we want celebrates strengths and ability
- Don't walk in front, don't walk behind, walk together
- 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 CRPD, 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.

This is a summary of the Right to opportunity: shaping the next national disability strategy consultation report.

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