SVA Social Ventures Australia

SVA Perspectives: Disability

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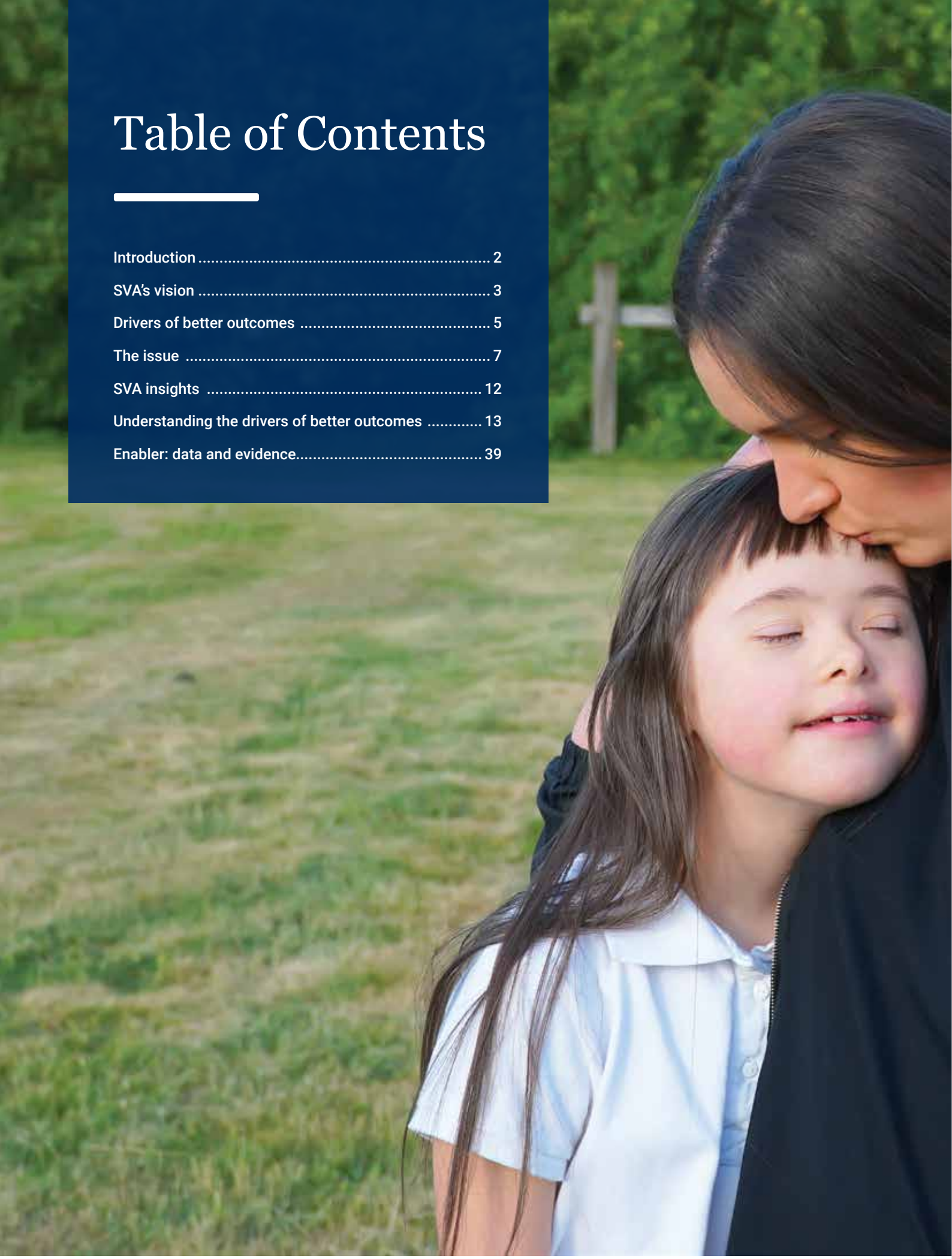


Introduction

Social Ventures Australia (SVA) is working towards an Australia where all people and communities thrive.

While there have been positive efforts and investment from governments and the social sector over recent decades, one in four people in Australia experience disadvantage.

People with disability are significantly more likely to experience exclusion and disadvantage than other groups in our community.

SVA is committed to understanding the structural causes behind persistent disadvantage, then finding and supporting the innovative approaches that can create systemic change. Since 2002, we have taken an evidence-based approach to supporting community service organisations, philanthropists, governments and businesses to make decisions that lead to improved outcomes for people experiencing vulnerability and exclusion. Through our work, we have developed a practical understanding of what it takes to tackle disadvantage.

In 2016 SVA released a series of Perspective Papers in the areas of education, employment, housing and the drivers of better outcomes for First Australian people and communities.

We have now expanded this set of insights to include papers on two new focus areas: disability and mental health. In addition, we have expanded on our education Perspective Paper to look at three specific cohorts at particular risk of experiencing entrenched disadvantage: children in out-of-home care, Aboriginal and Torres Strait Islander children, and children and young people disengaged from formal schooling.

We hope that these papers spark debate, innovation and collaboration among practitioners, community members, funders and policy makers – towards an Australia where everyone is able to thrive.

Suzie Riddell
CEO
Social Ventures Australia

SVA's vision

SVA has a vision for Australia where all people and communities thrive.

We believe that all Australians with disability should have the right to be full and equal participants in our community, free from discrimination, ableism and violence. People with disability should have opportunities to exercise their voice and have choice and control on the things that will impact upon their lives.

Understanding the experiences of people with disability in Australia begins with understanding that the concept of disability is socially constructed, meaning that it has been created and accepted by people in our society as a way of describing the experience of disability.

Historically disability in Australia has been informed by a medical model of disability. A medical model is centred on impairments as the problem and is focused on changes to the life of a person with disability (such as therapy, specialist services and in some cases even segregation) with no societal change required.

A social model of disability centres societal and attitudinal barriers as the problem. In this model, disability results from the interaction between people living with impairments and an environment filled with barriers, and the focus is placed on changes to society.[1] This includes a breakdown of societal and attitudinal barriers, including discrimination, that is required for people with disability to thrive in our communities.

The social model of disability is a central component of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), that Australia became a signatory to in 2007. The UNCRPD sets an international benchmark for realising the human rights and fundamental freedoms of people with disability.

A national consultation process on the experience of people with disabilities and their families in Australia in 2009 concluded that:

> *"The people who participated are, just like all other Australian citizens, individuals with their own needs, abilities, ambitions and priorities. They are united only by the experience of living with disability. Yet a consistent message from their contributions is the desire to have the same opportunities as everyone else for a fulfilling and productive life. Many said they face a constant struggle to obtain what the rest of the community would consider to be an ordinary life. They do not want special treatment—they just want the barriers removed so they can get on with living."*[2]

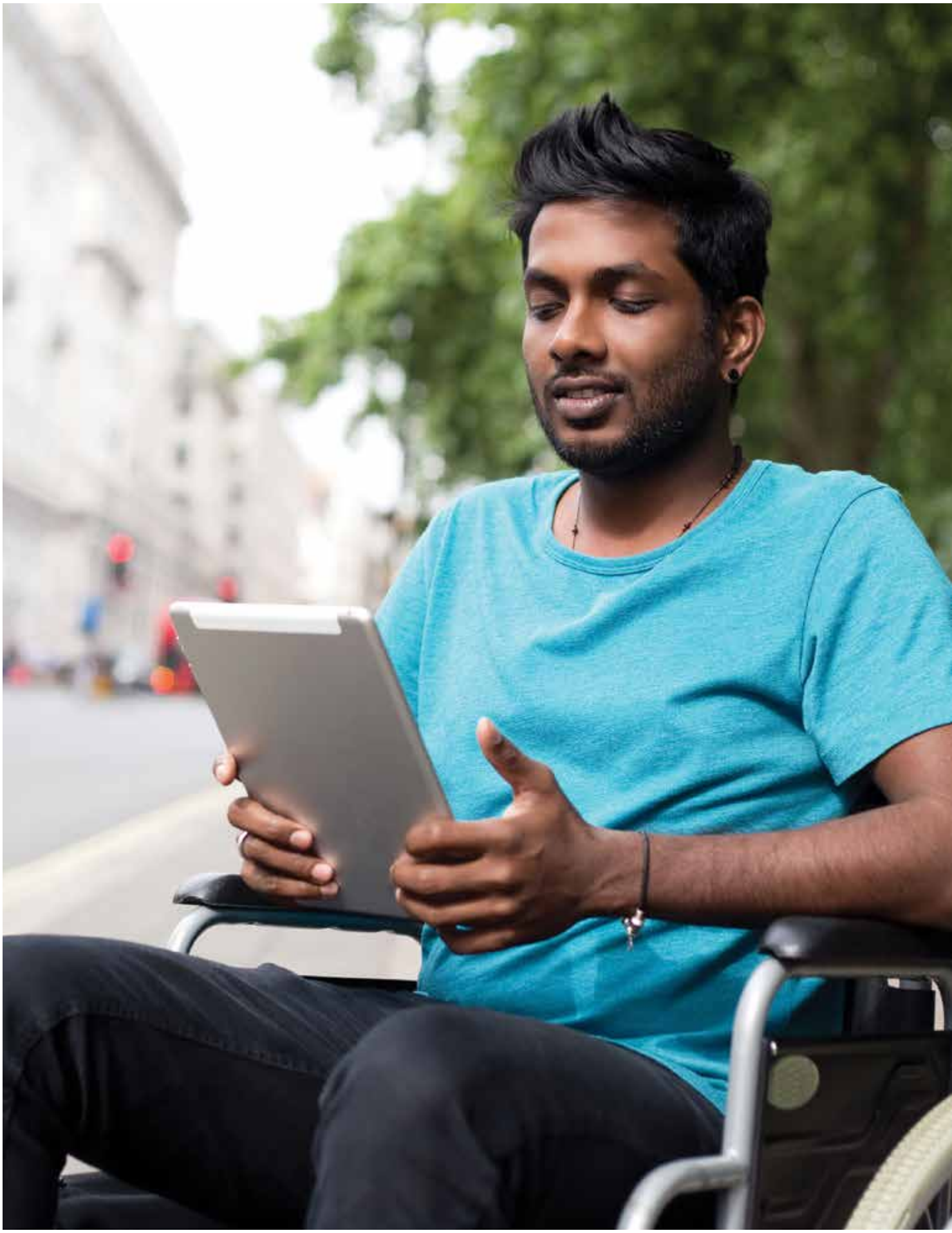
There is both a social and economic imperative in ensuring the lives and rights of people with disability are transformed. People with disability in Australia represent about 20% of the overall population and this is a significant portion of the population that is at risk of exclusion. Reports estimate that by reducing unemployment rates for people with disability by just one-third would provide a $43 billion increase to Australia's GDP over a decade.[3] There should be no reason for people with disability to be excluded if the physical, social, attitudinal, environmental and cultural barriers to participation in our society are removed.

Different types of disability, including physical disability, sensory disability, intellectual disability and psychosocial disability, need to be recognised and accounted for when designing policy and services. This will ensure that all policy is inclusive, and services are accessible and appropriate for all people with disability. In addition, intersecting experiences of discrimination must be accounted for – in particular, the experiences of women and girls with disability, LGBTI people with disability, older people with disability, Aboriginal and Torres Strait Islander people with disability, and people with disability from culturally and linguistically diverse (CALD) backgrounds.[4]

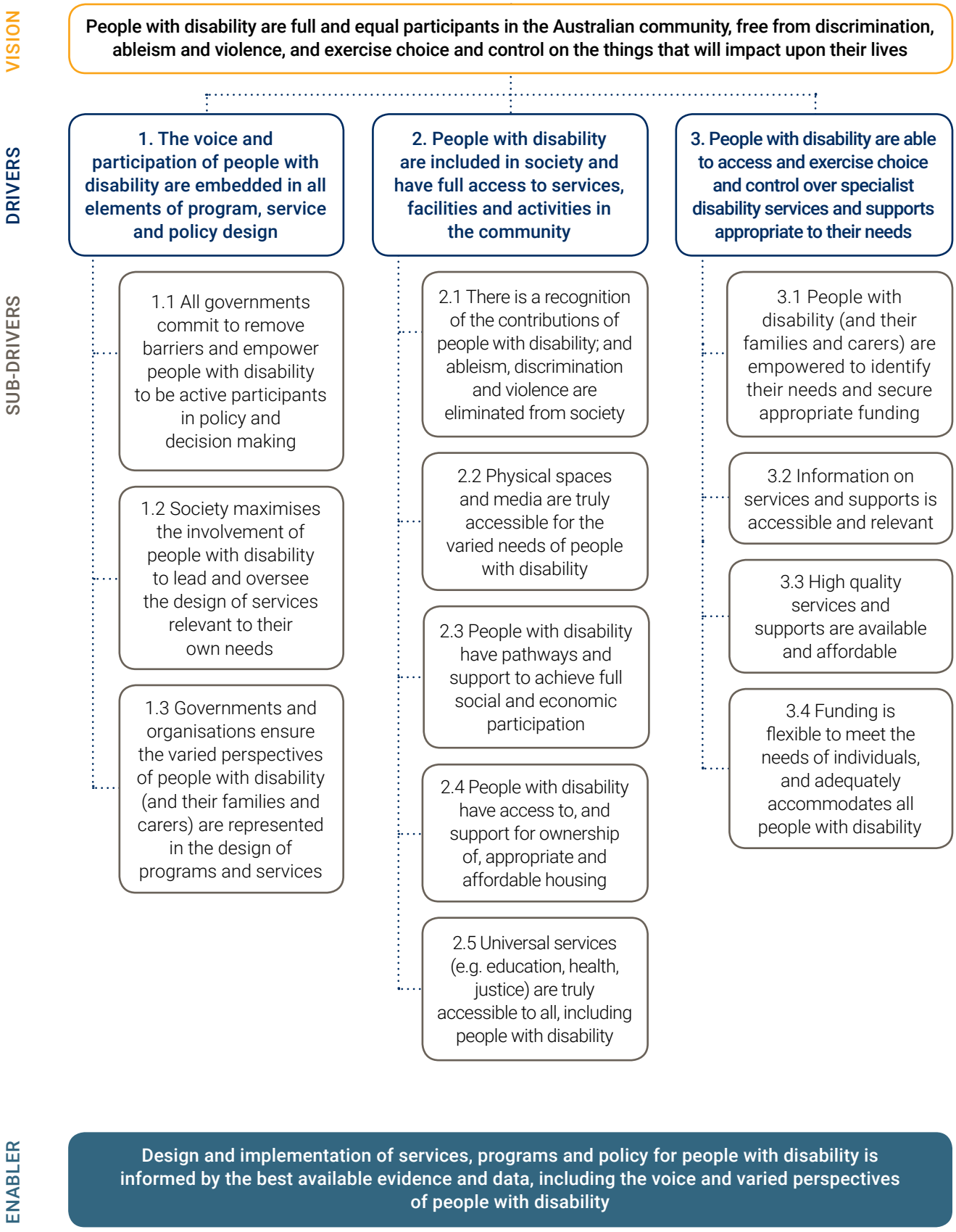
In Australia, disability policy is underpinned by a commitment to implement the rights outlined in the UNCRPD, and the National Disability Strategy (NDS) is the national framework agreed to by all governments in 2010 to achieve this goal. The NDS sets out a broad and ambitious agenda for reform, the most well-known of which is the National Disability Insurance Scheme (NDIS). We recognise that any changes to these policies must start with the empowerment, voice and participation of people with disability, and their families and carers, in all elements of program, service and policy design and delivery.

We have developed an evidence-informed perspective on what we believe is required to ensure all people with disability are full and equal participants in the Australian community.

1. People with Disability Australia, "Social Model Of Disability," 2018, https://pwd.org.au/
2. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia" (Canberra, 2009).
3. Deloitte Access Economics, "The Economic Benefits of Increasing Employment for People with Disability" (Sydney, 2011).
4. AHRC, "A Future Without Violence: Quality, Safeguarding and Oversight to Prevent and Address Violence against People with Disability in Institutional Settings" (Sydney, 2018).



Drivers of better outcomes

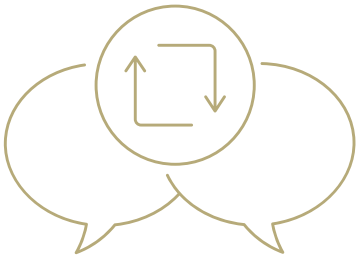


Scope of this paper

This paper aims to take a systems lens to disability in Australia, and in doing so our perspective recognises the enormous complexity and differences between people with disability in Australia.

This paper has also taken a cohort approach by looking at the current situation for people with disability as opposed to looking at the disability sector. This recognises that many of the drivers of better outcomes for people with disability sit within the services and structures in our community and are not the sole responsibility of the specialist disability sector but the responsibility of the whole of society.

While acknowledgement and illustrations are provided where possible, it is not within the scope of this paper to capture all the nuance and complexity related to the different types of disability, the role of culture in defining an individual and a community's experience of disability and the full spectrum of interactions between related systems and sectors that intersect with disability.



A note on language

This document follows People With Disability Australia's (PWDAs) recommendation in using 'person-first' language (e.g. person with disability, rather than disabled person), but we recognise that this preference is not universal amongst people with disability.

When referring to Aboriginal and Torres Strait Islander people, the full term has been used in most instances.

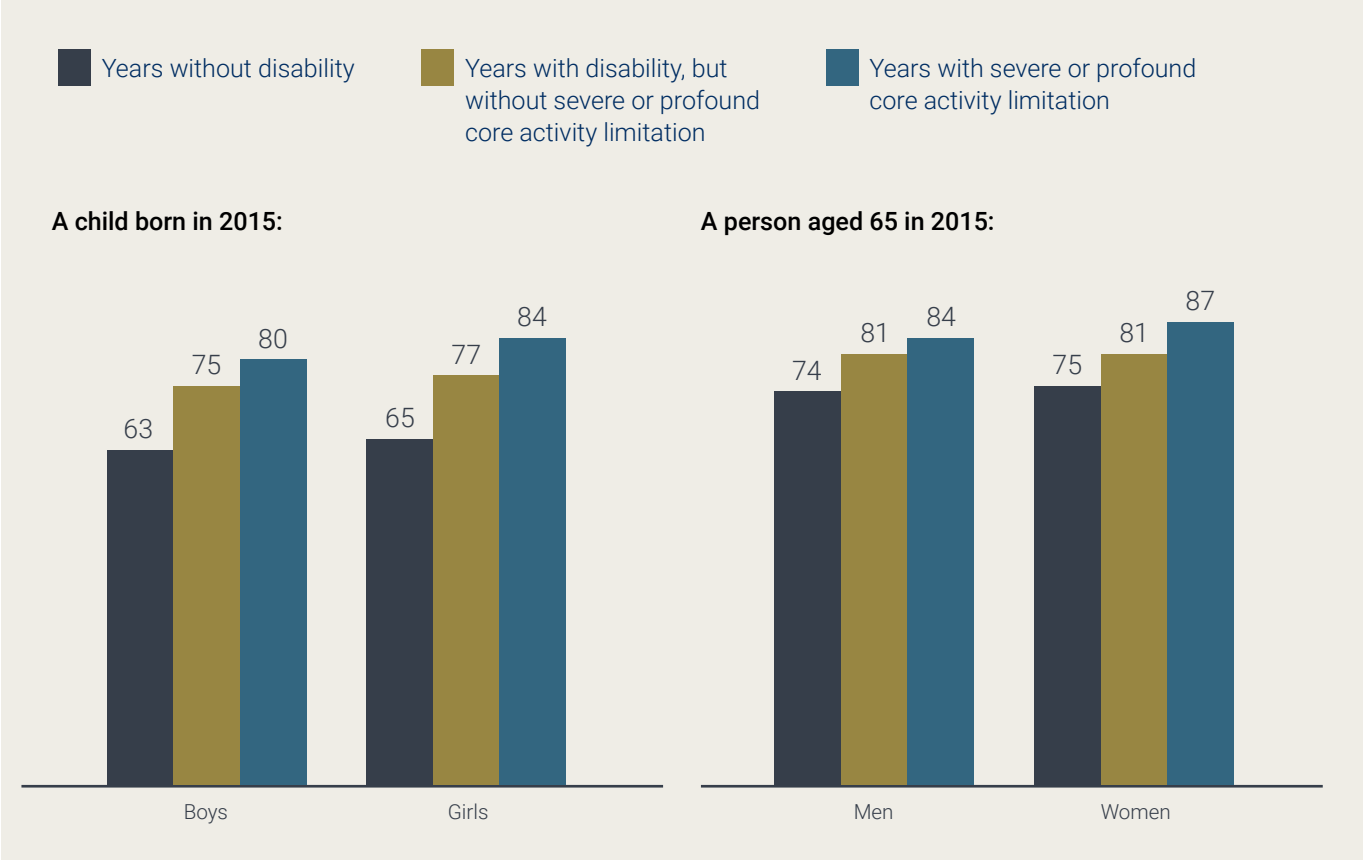
The issue

How many people are impacted by disability in Australia?

Almost twenty per cent of Australians (~4.3 million people) experience disability and this figure has remained relatively stable since 2001.[5] Data from the Australian Bureau of Statistics in 2015 shows that a majority (78.5%) of people with disability reported a physical condition as their main long-term health condition whilst the other 21.5% reported mental and behavioural disorders.[6]

At birth, Australians can expect to live, on average, over one-fifth of their lives with some level of disability. And by age 65, Australians can expect to live, on average, over half of their remaining years with some level of disability (Figure 1).[7]

Figure 1: Life and health expectancy in years



5. R Reeve et al., "Australia's Social Pulse" (Sydney, 2016).
6. ABS, "Disability, Ageing and Carers: Summary of Findings, 2015, Cat. No. 4430" (Canberra, 2016).
7. AIHW, "Life Expectancy and Disability in Australia 1988 to 2003, Cat. No. DIS 47" (Canberra, 2006).

What are the different kinds of disability?

Different types of disability, including physical, intellectual, sensory and psychosocial disabilities, require different solutions and this should be front of mind when designing both policy and services as well as ways for people with disability to participate in these processes.

People with intellectual disability may have difficulty learning and applying knowledge and in decision-making. They could struggle to identify and choose options at key life transition points (from home to school, from school to adult life), and require support during times of change to ensure they can exercise their own choices. For children experiencing development delay, specific early intervention and therapeutic support is often required.[8]

The needs of people with psychosocial disability can change in nature over their lifetime and key challenges include the management of social and emotional aspects which affect their ability to fully participate in life. There is a strong focus on recovery for people with psychosocial disability and this is dependent on the availability, quality, intensity, and appropriateness of care they receive.[9]

For people with physical disabilities the main challenges are in mobility, transport and self-care. Because of these challenges, they often require capital supports including home modifications and assistive technologies. However, a key barrier is the accessibility of public spaces and infrastructure and a lack of consideration for their needs. For people with sensory disability, the main challenge is communicating and receiving information in an accessible format and having the appropriate adjustments made to ensure accessibility.[10]

What are the impacts of disability on individuals and communities?

The way in which disability is perceived and constructed by society can have significant negative impacts on individuals as well as their family members, friends and carers, and the wider community. It can contribute to experiences of isolation, discrimination and stigma as well as health issues. For many people with disability, there are connected and overlapping experiences of poverty, social exclusion, unemployment and homelessness as well as limited opportunities to advocate for their own needs.

People with disability tend to experience social exclusion and poorer outcomes across several social, economic, and wellbeing domains when compared to other members of society, including education, employment, housing and health and wellbeing. Some groups face multiple forms of social exclusion and discrimination such as Aboriginal and Torres Strait Islander peoples, people from CALD backgrounds, people who live in rural and remote areas and newly arrived refugees.

Exclusion and discrimination:

- The Social Exclusion Monitor found that 55% of Australians who have a long-term health condition or disability experience some level of exclusion. Almost 16% experience deep social exclusion.[12]
- 8.6% of Australians with disability aged 15 years and over and living in households (281,100 people) reported they had experienced discrimination or unfair treatment because of their disability in the last 12 months.[13]
- Higher proportions of young people with disability (aged 15 to 24 years) reported the experience of discrimination (20.5%) compared to those aged over 65 years (2.1%).[14]

8. ABS, "Disability, Ageing and Carers: Summary of Findings, 2015, Cat. No. 4430."
9. ABS.
10. ABS.
12. The Brotherhood of St Laurence, "Social Exclusion Monitor: Health," 2018, https://www.bsl.org.au/research/social-exclusion-monitor/who-experiences-social-exclusion/health/.
13. AIHW, "Disability in Australia: Changes over Time in Inclusion and Participation Factsheets: Community Living, Cat. No. DIS 67" (Canberra, 2017).
14. AIHW.

Violence:

- 70% of women with disability having reported being victims of violent sexual encounters at some time in their lives.[15]
- 90% of women with an intellectual disability have been subjected to sexual abuse, with more than two-thirds (68%) having been sexually abused before they turn 18 years of age.[16]

Education:

- Only 41% of people with disability have completed year 12, compared with 62.8% of people with no disability (see Figure 1).[17]
- Just 17% of people with disability have a bachelor's degree, compared to 30.1% of people without disability (see Figure 2).[18]

Figure 1:
Rates of year 12 completion, by disability status

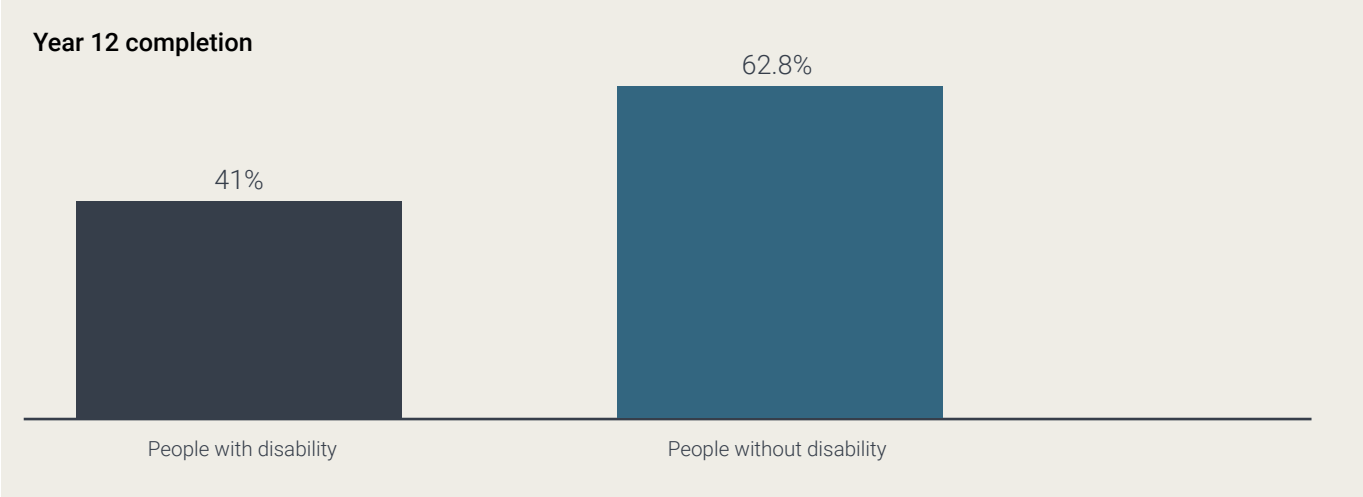
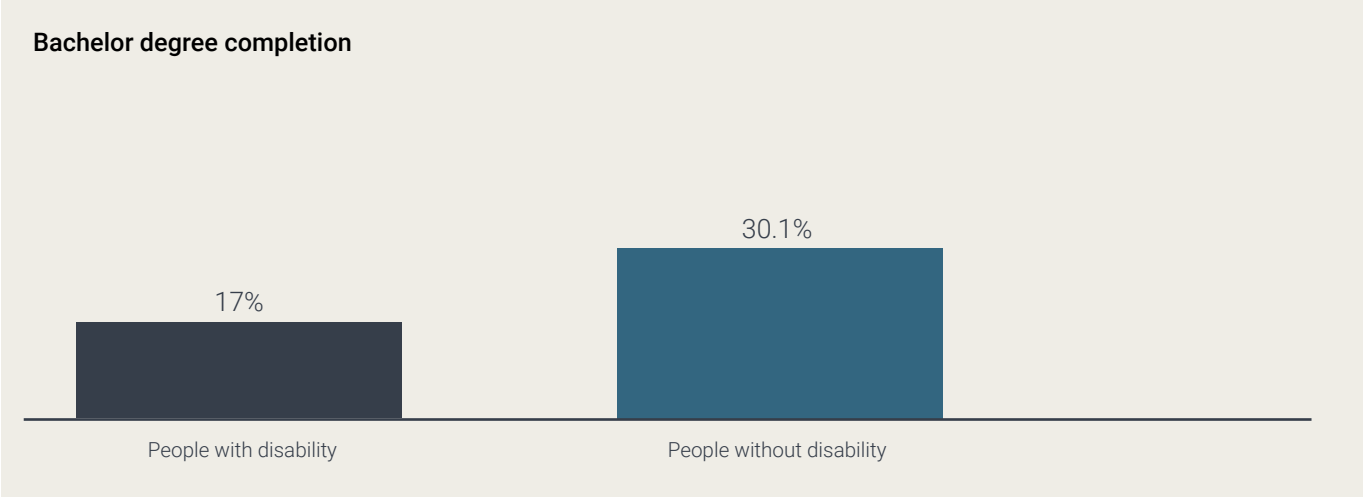


Figure 2:
Bachelor degree completion rates, by disability status



15. C Frohmader and T Sands, "Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings" (Sydney, 2015).
16. Frohmader and Sands.
17. People aged 15 -64, living in households (i.e. not in care institutions). ABS, "Disability, Ageing and Carers: Summary of Findings, 2015, Cat. No. 4430."
18. People aged 15 -64, living in households (i.e. not in care institutions). ABS.

Employment:

- The labour force participation rate of working age Australians identified as having a disability is 53.4%, much lower than the rate of other Australians (83.2%) (see Figure 3) and lower than the average participation rate of people with disabilities across the OECD.[19]
- Median gross income for people with disability is $465 per week, compared to $950 per week for people without disability (see Figure 4).[20]

Figure 3:
Labour force participation rates, by disability status

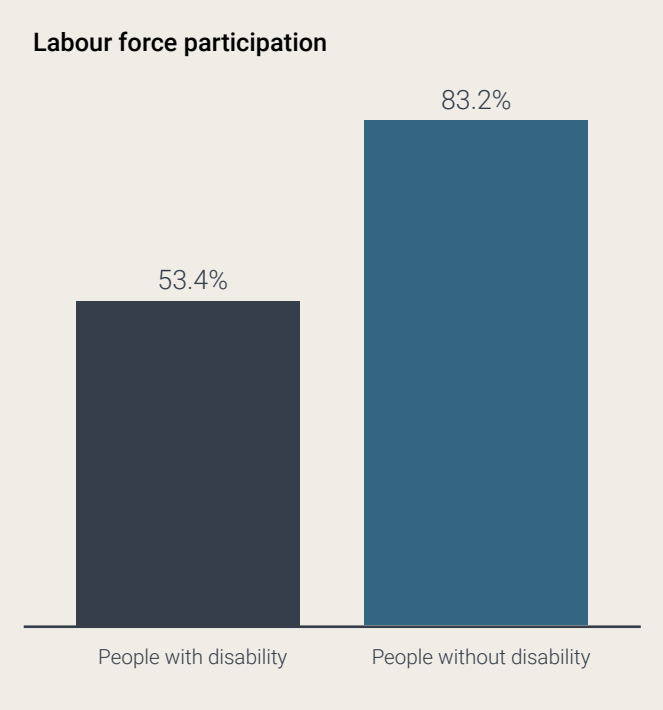
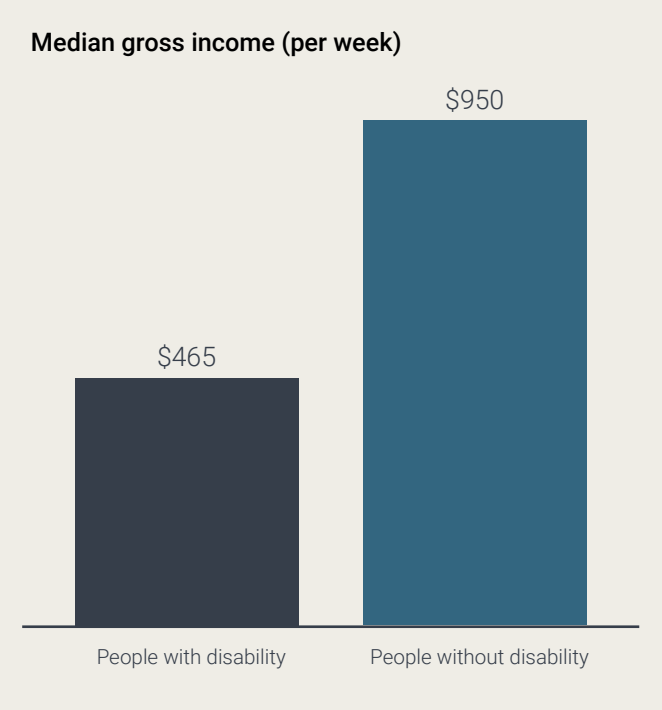


Figure 4:
Median gross income ($/week), by disability status



Health:

- People with disability are 3 times more likely than those without disability to delay seeking health treatment or advice.[21]
- 20% of people with disability aged under 65 avoided seeing their GP due to cost, with this figure increasing to 25% when accessing a specialist.[22]
- 45% of Aboriginal and Torres Strait Islander people have a disability or long-term health condition.[23]

Many of the poor outcomes experienced by people with disability are driven not by the nature and severity of a person's impairment, but by the failure of society to make our communities, buildings, services and public spaces inclusive and accessible to people with disability. In the past, people with disability have had their basic human rights infringed upon and have experienced high levels of discrimination. Marginalisation and the lack of choice and control over their lives have also resulted in a less tolerant and inclusive society where people with disability were hidden, forgotten and purposely shut out of life.

19. People aged 15 -64, living in households (i.e. not in care institutions). ABS.
20. People aged 15 -64, living in households (i.e. not in care institutions). ABS.
21. AIHW, "Access to Health Services by Australians with Disability, Cat. No. DIS 70" (Canberra, 2017).
22. AIHW.
23. First Peoples Disability Network Australia, "Policy Platform Federal Election 2019."

What do responses to disability in Australia currently look like?

The development of the National Disability Strategy 2010-2020 was the first time in Australia's history that all governments committed to a unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes.[24] This included the introduction of the National Disability Insurance Scheme (NDIS) which was a landmark policy event for Australia.

The premise of the NDIS was to replace a system that was unfair, underfunded, fragmented and inefficient with an insurance scheme that would provide cover for all Australians in the event of significant disability and fund long-term high-quality care and support (but not income replacement).[25]

Whilst this has been a welcome change and a great aspiration, there have been many teething issues and structural problems. Within this market, people with disability are expected to operate as consumers – making choices about which services they wish to use and having control over how they are delivered. In the relatively early life of the NDIS, more work is needed to ensure the disability and mainstream services markets are capable of delivering options in sufficient numbers, variety and location to provide people with disability the opportunity to fully exercise choice and control over their services and supports.

There is also evidence that the ability to exercise choice is greater amongst men and those with higher incomes, and that the most vulnerable were those with intellectual disability or complex needs, substance abuse, mental health or forensic issues, socially isolated older carers and those from CALD backgrounds.[26] (See section 3 for more detail on current disability services in Australia.)

The NDIS is only intended to provide services to a relatively small portion, around ten percent, of the people with disability in Australia.

Most people with disability access – or want to access – the same things that people without disability do: a suitable job, a good education, housing that suits their needs, transport around their community. These things are also addressed in the wider NDS which is set to be refreshed in 2020. There is more work to be done to ensure that services, facilities and communities are available and accessible to people with disability, and that people with disability are empowered and supported to advocate for what they want and need. (See section 2 for more detail on universal services.)

24. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments" (Canberra, 2011).
25. Productivity Commission, "Disability Care and Support, Report No. 54" (Canberra, 2011).
26. Eleanor Malbon, Gemma Carey, and Ariella Meltzer, "Personalisation Schemes in Social Care: Are They Growing Social and Health Inequalities?," BMC Public Health 19, no. 1 (June 24, 2019): 805, https://doi.org/10.1186/s12889-019-7168-4.

SVA insights

Through partnerships with a diverse range of organisations and governments throughout Australia, we have developed a set of insights on mechanisms for enabling systems change in Australia's disability sector. This is not intended to be an exhaustive list. It represents our perspective based on our experience on some of the essential systemic changes required to improve outcomes.

- The **rights, voice and participation of people with disability should be paramount in discussions and decisions** which affect them. Where possible, people with disability should lead and oversee the design of policies and services that affect them. However, this does not negate the need for other approaches, such as systemic advocacy, to ensure that the varied perspectives and needs of people with disability who do not want to or cannot participate are captured and given a voice as well.
- The government must play a more active role in stewarding **the development of a quality disability services market** that adequately supports all people with disability, including:
  - Ensuring a thorough understanding of the varied needs and desires of people with disability, including those experiencing intersectional disadvantage. This needs to include training for all staff and organisations.
  - Ensuring accessible and relevant information about services is available to all people with disability, and that individuals are empowered to make meaningful informed choices.
  - Employing, monitoring and adjusting appropriate pricing and investment approaches to ensure an adequate supply of quality services for all people with disability, with particular attention paid to potential thin markets and providers of last resort.
  - Continuously monitoring and ensuring a rapid response to addressing implementation difficulties that impede on providers' ability to focus on quality versus transformation, and additionally considering providing structural adjustment funding to ensure that a robust market develops.
  - Embedding a strong focus on quality standards including choice and control into the regulation of services.
  - Using data to continually improve the commissioning and regulation of services, such as by making demand data available for service providers to respond to.
- Service delivery organisations must focus on getting better not just bigger. This includes **redesigning their organisation and services to situate consumers at the centre** and **implementing client feedback loops** to systematically and frequently collect and act on client feedback. Our research found that only 1 in 18 of Australia's largest and most innovative disability services providers collected and used feedback in line with best practice, while 3 had no formal process for collecting and acting feedback at all. This is a missed opportunity for insight and for impact.
- Social policy and program frameworks must enable and incentivise **integration, collaboration and cooperation between the disability sector and other universal services** (such as housing, employment, education, health and justice) to reduce the risk of people missing out on service or receiving services with conflicting or contradictory approaches.
  - For example, due to fragmentation across governments and portfolios there is insufficient consideration of how housing support (e.g. through social and affordable housing) could improve outcomes and reduce the need for and cost of NDIS support.
  - Similarly, there needs to be a holistic approach to meaningful education and employment pathways, with a spectrum of options required to suit the needs, abilities and desires of people with disability.
- Service delivery organisations should collaborate with government and the private sector to explore and invest in **innovation, technologies, infrastructure, and services that can reduce the reliance of people with disability on attendant care** and increase their independence where possible.
- Recognising that services for majority of people with disability are not within the remit of the NDIS, and that all people with and without disability interact with non-specialist social policies and programs, all government, private and not-for-profit organisations need to **embed universal design approaches and genuine accessibility** into their policies, programs and services.

Understanding the drivers of better outcomes

1. The voice and participation of people with disability is embedded in all elements of program, service and policy design

- 1.1. All governments commit to remove barriers and empower people with disability to be active participants in policy and decision making
- 1.2. Society maximises the involvement of people with disability to lead and oversee the design of services relevant to their own needs
- 1.3. Governments and organisations ensure the varied perspectives of people with disability (and their families and carers) are represented in the design of programs and services

The voice and participation of people with disability in all things that will impact upon their lives is at the heart of any transformation in the experiences of people with disability in Australia.

Voice and participation means both inclusion in decision making, as well as equal opportunity to exercise choice and control over things that impact on someone's life.

Empowering voice and participation will ensure that policy is inclusive, and programs and services are designed appropriately and do not further perpetuate experiences of discrimination, marginalisation, violence, segregation and isolation. It is vital that people with disability, including those who have intersecting experiences of discrimination such as Aboriginal and Torres Strait Islanders, people from CALD backgrounds, LGBTI, people living in regional and remote areas, people living with mental ill-health, and people involved with the criminal justice system, are included in all decisions that affect them, at all levels of policy and in all areas of public life. This means not just as clients or participants but as citizens.

The experiences of people with disability in Australia have historically been characterised by discrimination, isolation, segregation and a loss of personal power and autonomy. Many people with disability continue to experience discriminatory and disempowering practices, as well as ongoing experiences of violence and abuse – the gravity of which has been recognised through the announcement of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in 2019.

As a signatory to the UNCRPD, Australia has committed to actively involve people with disability in the development and implementation of policy, law and decision-making processes that affect them.[27] Meaningful participation is essential to ensure that policies, programs and services are configured and implemented in ways which meet the needs of people with disability. Despite Australia's commitment, there is still further work to be done to ensure all people with disability are empowered to be involved in these processes.

There are few formal advisory bodies at the federal, state and territory levels, to enable people with disability, their families and representative organisations to provide advice to Ministers.[28] We commend those that exist. For example, the National Disability and Carer Advisory Council (NDCAC) provides advice on a range of matters including the implementation of the National Disability Strategy.[29] People with disability are also key participants in the shadow reporting to the United Nations on Australia's performance under the UNCRPD, which happens every four years.[30]

However, it remains difficult to assess the degree to which the advice of people with disability has been factored into decision-making. With the formation of the NDIS, an Independent Advisory Council (IAC) was established to provide advice to the Board of the National Disability Insurance Agency. The federal legislation underpinning this states that people with a disability must form a majority on the IAC and the NDIA Board must have regard to the advice provided and respond appropriately. This is one of the only processes mandated by law for an organisation to report how it responds to advice received from people with a disability. Unfortunately, despite the legislation, the COAG Disability Reform Council's Communiqués for 2018 do not include any reference to this advice - limiting a transparent assessment of the impact the IAC has had on policy and decision making in this space.[31]

27. United Nations, "Convention on the Rights of Persons with Disabilities" (2007).
28. NSW Government Department of Family and Community Services, "Disability Council Overview," 2019, https://www.facs.nsw.gov.au/inclusion/advisory-councils/disability/overview; Queensland Government Department of Communities Disabiltiy Services and Seniors, "Disability Advisory Councils," 2019, https://www.communities.qld.gov.au/industry-partners/stakeholder-engagement/disability-advisory-councils/contact-us; Victorian Government Department of Health & Human Services, "Victorian Disability Advisory Council: About VDAC," 2019, http://www.statedisabilityplan.vic.gov.au/vdac.
29. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."
30. Luke Michael, "Australia Set to Face UN Scrutiny over Disability Rights," Pro Bono Australia, May 17, 2019.
31. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."

Beyond the limited formal mechanisms, there remains significant work required to build the awareness and capacity of organisations to meaningfully engage people with disability in policy and decision-making processes.

Many organisations display a general lack of understanding of disability and how they can modify their decision-making environments to promote the inclusion and participation of people with disability.[32] They often do not consider the different types of disability and varied perspectives and needs (e.g. accessible information or venues) when working with or consulting people with disability. Governments have an important responsibility to provide training to build the capacity of its staff to effectively engage people with disability.

It has also been anecdotally reported that some people with disability have low expectations of policy makers and their ability to respond appropriately to them. There are many examples where people with disability who participate in advisory groups have reported being spoken down to or not being called upon.[34] Other barriers to meaningful involvement in policy and decision-making processes include a lack of payment for time and travel costs; inaccessible venues and information; and an expectation that others, such as family or advocates, could participate instead of people with disability themselves.[35]

If the right steps are taken to reduce the barriers mentioned above, then people with disability can add real value – as shown in the good practice example below.

NSW Council for Intellectual Disability

The NSW Council for Intellectual Disability (CID) is a user-led organisation providing people with intellectual disability opportunities to build their skills and engage in decision-making processes. Training offered focuses on developing leadership skills and encourages people in the art of speaking up.[36] People with intellectual disability play key governance roles in the organisation and more than half of all Board positions must be held by people with intellectual disability.[37]

CID undertakes systemic advocacy through channels such as public campaigning and policy, in addition to offering disability awareness training, translation of materials into Easy English and consulting services.[38] As part of their advocacy work, CID has run a number of policy roundtables bringing together people with intellectual disability, academics and government decision-makers to highlight good practice and seek positive change. While roundtables are not necessarily a new concept, these events are very much driven by people with intellectual disability, as the Chair, participants and as majority members of panels and focus groups.

CID is acknowledged for building the capacity of people with intellectual disability to play a leadership role in decision-making environments through increased 'experience and confidence to act as advisers and educators to government, service providers and academics.'[39] CID also actively facilitates inclusion by supporting people in ways that work for them. This includes making support people available to Board members and offering preparation support to people engaging in education and training sessions.[40]

A CID Board member, who has an intellectual disability, recently spoke at the United Nations Conference of State Parties, demonstrating that with the right support, people with disability can make highly effective contributions to decision-making environments at all levels.[41]

32. Catherine Grant, "Participating in Arts- and Cultural-Sector Governance in Australia: Experiences and Views of People with Disability," Arts and Health 6, no. 1 (January 2, 2014): 75–89, https://doi.org/10.1080/17533015.2013.826259.
34. Patsie Frawley and Christine Bigby, "Inclusion in Political and Public Life: The Experiences of People with Intellectual Disability on Government Disability Advisory Bodies in Australia," Journal of Intellectual and Developmental Disability 36, no. 1 (March 14, 2011): 27–38, https://doi.org/10.3109/13668250.2010.549465.
35. Sam Battams and Anne Johnson, "The Influence of Service Users and NGOs on Housing for People with Psychiatric Disability," Health Sociology Review 18, no. 3 (October 17, 2009): 321–34, https://doi.org/10.5172/hesr.2009.18.3.321; Sally Robinson, Karen R. Fisher, and Robert Strike, "Participatory and Inclusive Approaches to Disability Program Evaluation," Australian Social Work 67, no. 4 (October 2, 2014): 495–508, https://doi.org/10.1080/0312407X.2014.902979; Frawley and Bigby, "Inclusion in Political and Public Life: The Experiences of People with Intellectual Disability on Government Disability Advisory Bodies in Australia"; Grant, "Participating in Arts- and Cultural-Sector Governance in Australia: Experiences and Views of People with Disability."
36. Council for Intellectual Disability, "NSWCID: What We Do," accessed June 5, 2019, http://www.nswcid.org.au/what-we-do/what-we-do.html.
37. Christine Bigby and David Henderson, "Raising the Voices of People with Intellectual Disabilities and Changing Systems: The Contribution of the NSW Council on Intellectual Disability to Social Change" (Melbourne, 2018).
38. Council for Intellectual Disability, "NSWCID: What We Do."
39. Bigby and Henderson, "Raising the Voices of People with Intellectual Disabilities and Changing Systems: The Contribution of the NSW Council on Intellectual Disability to Social Change."
40. Bigby and Henderson.
41. Bigby and Henderson.

Greater recognition of the different types of disability and diverse perspectives of people with disability is also required, and opportunities should be created to capture their experiences and opinions.

To enhance the participation of people with disability in policy or decision-making, organisations should consider using accessible venues, providing accessible briefings or Easy English materials, setting meetings at the right pace and tone, and providing training on expectations within advisory settings so that people are clear on how to engage with the content discussed and how to contribute meaningfully.[42] Otherwise, the lack of adjustment, perceived or otherwise can lead people to feel that their involvement is tokenistic and they may drop out of the process altogether.[43]

Among the different types of disability, there remains a continued under-representation of people with intellectual disability on bodies providing advice to governments - calling into question whether government policies and services adequately reflect what people with intellectual disability want and need.[44]

While the participation of people with disability in decision-making should be encouraged where possible, it is also important to recognise that some people cannot or may not want to participate themselves.

For those people who cannot or do not want to speak up, the role of systemic and individual advocacy can be vital to ensuring the varied perspectives of people with disability are included.

Unfortunately, from June 2020 State Governments will no longer fund independent disability services, including funding for disability advocacy. Without certainty of funding for systemic and individual advocacy, people with disability, who may face barriers in advocating for themselves and navigating complex systems, may be at risk of being left with no one to support them and, where necessary, advocate on their behalf.

This is unacceptable as the evidence clearly shows that systemic advocacy bodies have a role to play to ensure all people with disability have the opportunity and support to participate in policy and service design processes should they wish to. The funding for advocacy either needs to be rectified, or other mechanisms that could ensure representation for people with disability should be explored.

The voice and participation of people with disability is necessary in both the design and delivery of services specific to the needs of people with disability, but also all universal services, to ensure that the social barriers and attitudes that reinforce discrimination are being addressed.

42. Frawley and Bigby, "Inclusion in Political and Public Life: The Experiences of People with Intellectual Disability on Government Disability Advisory Bodies in Australia."
43. Robinson, Fisher, and Strike, "Participatory and Inclusive Approaches to Disability Program Evaluation"; Grant, "Participating in Arts- and Cultural-Sector Governance in Australia: Experiences and Views of People with Disability."
44. Frawley and Bigby, "Inclusion in Political and Public Life: The Experiences of People with Intellectual Disability on Government Disability Advisory Bodies in Australia."

2. People with disability are included in society and have full access to services, facilities and activities in the community

- 2.1 There is a recognition of the contributions of people with disability; and ableism, discrimination and violence are eliminated from society
- 2.2 Physical spaces and media are truly accessible for the varied needs of people with disability
- 2.3 People with disability have pathways and support to achieve full social and economic participation
- 2.4 People with disability have access to, and support for ownership of, appropriate and affordable housing
- 2.5 Universal services (e.g. education, health, justice) are truly accessible to all, including people with disability

Ableism, discrimination and violence

Awareness of disability in our community is slowly changing. While it has increased since the creation of the NDIS, there is a long way to go to eradicate the experiences of discrimination and exclusion that people with disability have traditionally been exposed to. We still have work to do to ensure that all people with disability have the same fundamental rights as other Australians.

As described by the Australian Cross Disability Alliance (ACDA):

> *"Despite Australia's international human rights obligations, and the strong global movement to recognise people with disability as subjects of human rights law on an equal basis, in the Australian context, people with disability remain subject to the effects of ableism - the practices and dominant attitudes in society that denigrate, devalue, oppress and limit the potential and rights of people with disability. Ableist practices, which continue to pervade many of our state institutions, see people with disability experience and be exposed to, profound and intersecting discriminations that often have aggravating and compounding effects."*[45]

Many people with disability participate actively in all aspects of life, but discrimination and ableism are still prevalent. The introduction of the Disability Discrimination Act 1992 (Cth) was a critical step to recognising and protecting the rights of people with disability, but discrimination continues to occur with one in 12 people with disability reporting an experience of discrimination or unfair treatment in 2015.[46]

Australia's universal services, such as education, health and justice, need to transform dramatically if they are to be truly integrated and inclusive. (See section 2 on access to universal services.)

As the chair of the National People with Disabilities and Carer Council, Rhonda Galbally, has observed:

> *"For many years people with disabilities found themselves shut in, hidden away in large institutions. Now many people with disabilities find themselves shut out, shut out of buildings, homes, schools, businesses, sports and community groups. They find themselves shut out of our way of life."*[47]

An essential component to creating a more inclusive society is public awareness of the fundamental human rights of people with disability, and acknowledgement of the contributions that people with disability make in our communities. This starts by recognising the contributions that people with disability have already made in our workplaces, public spaces, media and communities as well as creating more opportunities, such as inclusive education and employment pathways, for people with disability to continue to do so. For this to be achieved, people with disability also require better social protection including income support and access to affordable housing, to enable full social and economic participation in life.[48]

Sadly, there remains a high incidence of violence against people with disability. It is often gendered in nature with more than 70% of women with disability having reported being victims of violent sexual encounters at some time in their lives.[49] Women with an intellectual disability are even more vulnerable, with a staggering 90% having been subjected to sexual abuse, with more than two-thirds (68%) having been sexually abused before they turn 18 years of age.[50]

45. Frohmader and Sands, "Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings."
46. AHRC, "Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability," 2016.
47. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."
48. Zoe Aitken et al., "Do Material, Psychosocial and Behavioural Factors Mediate the Relationship between Disability Acquisition and Mental Health? A Sequential Causal Mediation Analysis," International Journal of Epidemiology 47, no. 3 (June 2018): 829–40, https://doi.org/10.1093/ije/dyx277.
49. Frohmader and Sands, "Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings."
50. Frohmader and Sands.

A 2015 Senate Inquiry into the violence experienced by people with disability in institutional and residential settings highlighted that:

> *"…a root cause of violence, abuse and neglect of people with disability begins with the de-valuing of people with disability. This de-valuing permeates the attitudes of individual disability workers, service delivery organisations and most disturbingly, government systems designed to protect the rights of individuals. This de-valuing takes many forms. People with disability are often communicated about, not communicated to and are frequently denied the right to make the most basic of decisions about their lives. They miss out on fundamental learning experiences at school and throughout life, often though a patronising prism of 'protection.' Their choices about day to day living are taken away: sometimes in more benign ways by people trying to 'help', sometimes by service providers in the guise of efficiency, but all too often by people exerting malicious control. In many cases people with disability have their legal capacity taken away, the very status in law that defines the rights of individuals. From this legal disregard of them as a person in their own right can flow serious and far-reaching repercussions. They lose the right to make decisions about their life, where they live, who they live with, what they eat, who they can see, and even decisions about their own bodies."*[51]

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is a significant step towards bringing public awareness to the experiences of people with disability and directly addressing the social norms and barriers that underpin violence, discrimination and abuse.

Accessibility

> *"We want to contribute to Australian society, but we usually find that we can't access the workplace, can't access public venues, can't have a holiday because there is no suitable accommodation."*[52]

Physical spaces

The physical environment is an obvious barrier for many people with physical disability participating in community life. The AIHW reports that more than 1 in 4 found it difficult to access buildings, facilities and public transport in the community in the previous 12 months.[53] Access difficulties were commonly related to the design of buildings and their approach and surrounds such as stairs, internal doors, corridor widths, ramps, handrails and lighting.[54]

Under Australian law, there are national accessible design standards which newly built or upgraded public spaces and buildings must conform to. But facilities designed to be accessible often fail people with disability due to mismanagement. For example, accessible checkout lanes in supermarkets are often closed and accessible toilets are kept locked or used for storage.[55] There is certainly a need for these standards to be applied as they were intended to ensure equitable access to public spaces for people with disability. Change is also needed in many existing public spaces and buildings which are not legally required to be upgraded but pose significant barriers to access. For example, when Senator Jordon Steele-John joined the Australian Parliament in 2018, he was unable to enter the floor of the Senate and had to use a special desk placed away from other Senators, as the chamber is not accessible for wheelchair users.[56]

The first step in removing barriers is to incorporate universal design into our community resources such as the design and build of parks, houses, shopping centres and sporting arenas.[57] This is the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability.[58] As the Centre for Universal Design Excellence explains: 'universal design is a fundamental condition of good design. If an environment is accessible, usable, convenient and a pleasure to use, everyone benefits.'[59]

51. Senate Community Affairs References Committee, "Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings, Including the Gender and Age Related Dimensions, and the Particular Situation of Aboriginal and Torres Strait Islander People with Disability" (Canberra, 2015).
52. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."
53. AIHW, "Access to Health Services by Australians with Disability, Cat. No. DIS 70."
54. AIHW.
55. Ilan Wiesel et al., "We Can't Just Leave It to the NDIS to Create Cities That Work to Include People with Disability," The Conversation, May 7, 2018.
56. Brett Worthington, "Jordon Steele-John Has the Loneliest Seat in the Senate, and It's Locking Him out of the Parliamentary Process," ABC News, April 2, 2018.
57. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."
58. Centre for Excellence in Universal Design, "What Is Universal Design?," Universal Design, 2014, http://universaldesign.ie/What-is-Universal-Design/.
59. Centre for Excellence in Universal Design.

Australia has taken some important steps towards introducing this concept and thus reducing barriers, including the adoption of minimum accessibility standards for public transport and buildings. However, there is certainly more work to be done to make sure that to the greatest extent possible, all of our public spaces can be used by everyone.[60]

Transport

The ability to move around the community is a fundamental right for people with disability and is essential to their participation in education, employment and social events. In order to move freely around the community, people with disability need access to public as well as private transport through modified motor vehicles and accessible parking.[61]

Unfortunately, public transport is often designed without people with disability in mind, with access issues such as steps and lack of seating for those with difficulty standing. Additionally, people with disability are often still unable to make use of footpaths, cycle paths and local roads as many of these have not been designed to be fully accessible. A continuous accessible path of travel for people with disability needs to connect public transport nodes with local services and accessible housing.[62] Information on transport options must be available in accessible formats, and public transport services must be sufficiently frequent and reliable that they are a realistic option for people to use to access their destination.

Australia has improved its accessibility standards for public transport but now needs to move beyond compliance. The Australian Government released The Whole Journey: A guide for thinking beyond compliance to create accessible public transport journeys in 2017 which provides guidance on how transport planners and providers, architects, engineers, builders, certifiers and all levels of government can work together with people with disability to achieve this goal. It includes facilitating best practices based on innovation and continuous improvement, human-centred design, understanding, consultation and collaboration.[63]

Media and information

People with disability require information to be provided in accessible and appropriate formats that meet their individual needs. This refers to how digital, web and broadcast content can be used, read or viewed by people with disability, particularly those who are blind, vision impaired, deaf, hearing impaired, or who have a cognitive condition or mobility disability.[64]

Creating access to media and online information, enabled through technology, empowers people with disability to be more independent, to gain knowledge, make their own informed choices, and be active members of our society.[65] This in turn promotes social inclusion and greater well-being as people with disability feel connected and informed.

Unfortunately, many organisations make mistakes in this area. For instance, blind and vision impaired participants received vital correspondence on the NDIS in the form of regular letters, or as PDFs that do not accommodate a screen reader.[66] This oversight made it extremely difficult for people to get the information they needed to manage their lives. Thankfully, the NDIA has since introduced an automated system so people can receive correspondence in their preferred format, be that large font, audio, e-text or braille.[67]

This demonstrates that the provision of effective access to websites, online information, digital communications, streaming services and broadcast television, as well as access in the classroom, cinema and the arts is fundamental to the inclusion of people with disability and should be mandatory across all formats.[68]

60. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."
61. COAG.
62. COAG.
63. Australian Government Department of Infrastructure Regional Development and Cities, "Transport for People with Disability," 2018, https://infrastructure.gov.au/transport/disabilities/.
64. Media Access Australia - inclusion through technology, 2019, https://mediaaccess.org.au.
65. Media Access Australia - inclusion through technology, 2019, https://mediaaccess.org.au.
66. The Guardian, "NDIS sent letters to vision-impaired and blind people in format they could not read", 2019, https://www.theguardian.com/australia-news/2019/jun/29/ndis-sent-letters-to-vision-impaired-and-blind-people-in-format-they-could-not-read.
67. The Guardian, "NDIS sent letters to vision-impaired and blind people in format they could not read", 2019, https://www.theguardian.com/australia-news/2019/jun/29/ndis-sent-letters-to-vision-impaired-and-blind-people-in-format-they-could-not-read.
68. Media Access Australia - inclusion through technology, 2019, https://mediaaccess.org.au.

Social and economic participation

Social inclusion

There is a wealth of research available on the importance and impact of social networks and interpersonal relationships for people with disability on their overall wellbeing and feelings of social inclusion, however social exclusion often starts from a very young age. Children with disability face barriers to social inclusion and participation in many of life's activities. Alarmingly, children with disabilities are three times more likely to be maltreated compared to other children and that risk is highest for children with behavioural disorders and intellectual disability.[69]

Supporting people with disability to achieve relational wellbeing requires moving beyond the narrow definition of relationships as primarily sources of 'informal support' and shifting to recognise the other valuable and varied roles they play. One NDIS study suggests that policy needs to adapt to recognise and support positive and fulfilling relationships between people with disability and their family, friends and significant others in their lives, not only for individual benefits, but also for the success of the scheme overall.[70]

There has been a long-term shift towards supporting people with disability to live at home or in the community, rather than in institutional care.[71] In 2015, the majority of people with disability were living in a household, but despite this shift, around a third of people with disability still do not leave home and socialise as often as they would like.[72] The Australian Institute of Health and Welfare (AIHW) also reports that around 2 in 5 people had avoided community situations in the previous 12 months because of their disability.[73]

Employment

The labour force participation rate of working age Australians with disability is well below that of other Australians. In 2015 labour force participation rates were 53.4% for people with disability and 83.2% for those with no reported disability.[74] The unemployment rate for people with disability was also higher at 10% compared to 5.3%.[75] These rates have barely shifted since 1998 and the gap in employment rates is significantly wider in Australia compared to other OECD countries.[76] While not all people with disability are in a position to engage in paid work, the differential with other countries suggests that there is room for improvement in labour force engagement which in turn will improve social participation for people with disability.

69. Telethon Kids Institute, "Children with Disabilities 3 Times More Likely to Be Maltreated but Risk Varies by Disability Type," 2017.
70. Ariella Meltzer and Laura Davy, "Supporting NDIS Participants' Interpersonal Relationships," The Mandarin, March 21, 2019.
71. AIHW, "Disability in Australia: Changes over Time in Inclusion and Participation Factsheets: Community Living, Cat. No. DIS 67."
72. AIHW.
73. AIHW.
74. ABS, "Disability, Ageing and Carers: Summary of Findings, 2015, Cat. No. 4430."
75. ABS.
76. OECD, "Sickness, Disability, and Work - Breaking the Barriers (A Synthesis of Findings Across OECD Countries)" (Paris, France, 2009), https://doi.org/10.1787/9789264088856-en.

Case Study: High Growth Jobs Talented Candidates

High Growth Jobs Talented Candidates (HGJTC) is an innovative program that matches people with disability with employers looking for candidates to fill roles in high growth industries. It was designed to increase employers' capability to employ people with disability, while at the same time helping to better prepare candidates with disability for the jobs of the future. The project focused on the needs of employers and candidates, ensuring an effective job match.

HGJTC uses a demand-led brokerage model that starts with the employer to build their confidence to employ people with a disability. It works backwards to prepare and match job seekers to identified jobs. HGJTC has four main components: engage and understand employer needs; equip employers; engage and equip service providers; and deliver and review. The program was delivered by the Australian Network on Disability (AND) in partnership with Social Ventures Australia (SVA) and funded by the NSW Department of Family and Community Services (FACS). It worked with eight businesses employing around 57,000 staff nationally. In addition, Disability Employment Service (DES) providers and a disability specialist organisation supported the program by sourcing suitable job seekers.

Over a two-year period, the program achieved outcomes for both employers and job seekers. For employers, the program reduced fear and uncertainty and built capacity to recruit and retain people with disability. Substantial activity was undertaken to improve employer confidence and capacity to hire and support people with disability. For the employers involved, six of the eight developed or adjusted internal policies and procedures as a result of the program.

For job seekers with disability, the program supported 39 placements with very high retention rates. Of the 39 job seekers placed, 31 remained employed at the time of the evaluation 79%. 25 out of 27 eligible employees had successfully reached 12 weeks of employment or more 92%. This is substantially higher than typical DES results, which see just 31% of people still employed at 12 weeks.

The HGJTC initiative shows that engaging employers and encouraging them to make systemic changes including to their processes and culture, requires a significant commitment of time and a specific skill set from the external organisation supporting them. This is particularly so for employers in high growth industries that are undergoing rapid change across their whole business.

For job seekers with disability, where the demand-led brokerage model has been followed, interview and selection processes have been more successful than where there have been gaps in the process. These include gaps in disability confidence training with employers (due to unavailability of staff or changes in personnel) and explicit conversations around the need to look beyond employment gaps have not occurred.

Importantly, the experience for candidates participating in the HGJTC project has been overwhelmingly positive and includes increased confidence and motivation for all candidates whether they have been successful in securing a job or not. These learnings give credence to the unique need for, and value of, a demand-led brokerage model to improve the participation rate of people with disability in the labour force.

Alternate models of employment

For some people with disability, open employment or employment in mainstream jobs may not be their desired goal. About 20,000 people with moderate to severe disabilities are employed by Australian Disability Enterprises (ADEs). ADEs can act as a link, helping to source training and work experience with the aim of securing a job or continuing in supported employment.

ADEs often support people with intellectual disability to engage in tasks such as packaging, assembly, production, recycling, screen printing, plant nursery, garden maintenance and landscaping, cleaning services, laundry services and food services.[77] At their best, ADEs can offer work opportunities to people who might otherwise be entirely excluded, and some facilitate transitions to open employment. However, many ADEs have been criticised, because they may have segregated workplaces and pay low wages. These features of ADE employment can reinforce marginalisation and low expectations of people with disabilities.[78]

Social enterprises are another strategy for providing employment for people who have been locked out of the general workplace or need a transitional pathway into work elsewhere. Research suggests that for people with intellectual disability, employment in a social enterprise is more desirable than either employment in the open market or in an ADE.[79]

However, the level of business/market development and opportunities for employment in social enterprises are currently limited. Further work is needed to develop and scale social enterprises to enable them to be an employment option for more people, thus expanding employment choice for people with intellectual disability.[80] Several Australian governments are currently actively seeking to expand social enterprise development, including through 'social procurement', where government preferentially sources goods and services from organisations producing social benefit.

The systematic and historical exclusion of people with disability from the workplace means that a number of strategies must be pursued. More needs to be done to ensure that employers understand their obligations and are equipped to provide inclusive workplaces. At the same time a vibrant and well-supported social enterprise sector will expand the opportunities for some people with disability to find a workplace that meets their needs. The counterproductive effects of income support structures that entrench poverty and reduce access to housing, health and other supports must be recognised and addressed. There also needs to be a broader strategy around disability employment to reflect the varied needs of people with disability and build pathways for employment where appropriate.

77. Australian Government Department of Social Services, "Australian Disability Enterprises," 2019, https://www.dss.gov.au/disability-and-carers-programmes-services-for-people-with-disability/australian-disability-enterprises.
78. Roger J. Stancliffe, "Inclusion of Adults with Disability in Australia: Outcomes, Legislation and Issues," International Journal of Inclusive Education 18, no. 10 (October 3, 2014): 1053–63, https://doi.org/10.1080/13603116.2012.693395.
79. Ariella Meltzer, Rosemary Kayess, and Shona Bates, "Perspectives of People with Intellectual Disability about Open, Sheltered and Social Enterprise Employment," Social Enterprise Journal 14, no. 2 (May 8, 2018): 225–44, https://doi.org/10.1108/SEJ-06-2017-0034.
80. Meltzer, Kayess, and Bates.

Case study: SVA Venture Vanguard Laundry Services

Vanguard Laundry Services is a social enterprise creating employment opportunities for people previously excluded from the workforce, predominately due to mental illness. It is also an example of social procurement, as St Vincent's Health committed to a long-term contract to support the laundry. The laundry has an in-house Career Development Centre to support disadvantaged jobseekers into sustainable career opportunities. In the first 9 months of FY19, Vanguard successfully transitioned 27 people to new jobs beyond Vanguard.

James had applied for numerous jobs, but nobody would hire him. At one point he spent an entire year trying to get hired. When he finally did get a job, it didn't work out because of the workplace's perceptions around mental illness.

Today James has steady employment with Vanguard. It has improved his sense of self and working in an environment where he feels safe has made life just that little bit easier. He's particularly pleased to be following in the footsteps of his father, who also used to work in a laundry.

'I'm proud of Dad for doing what he did, I'm very proud to be able to work in a laundry too. Working in the laundry suits me down to a tee!' he says. Steady employment has made a real, positive impact on James life. He was able to save enough money to make a special trip to Sydney to see his daughter for the first time. While he was nervous, it turned out to be a great weekend and his daughter said it was everything she wanted.

Employment discrimination

The Disability Discrimination Act 1992 (Commonwealth) requires all employers to make reasonable adjustments so people with disability can engage in work aligned with their skills.[81] However discrimination remains a substantial barrier to employment. A high proportion of both people with disabilities who are unemployed and those who are employed report that employers are a major source of disability discrimination.[82]

The Australian Network on Disability's 2017 survey of employers' disability confidence found that many placed little importance on the inclusion of people with disabilities in their workplace and 36% believed that 'our type of work doesn't suit people with disability'.[83] AND has developed the Access and Inclusion Index which provide workplaces with the tools to measure their delivery of practices that foster accessibility and inclusion.[84] The online tool helps workplaces by investigating their progress in 10 areas including workplace adjustments, recruitment and selection and career development.[85] Workplaces that have been rated highly have fostered inclusion by ensuring that mentoring and training is delivered in an accessible manner, annual awards for exceptional inclusion practices are held and the formation of a diverse team who provide career support and development to staff members with disability.[86]

The Commonwealth Government's job access website provides information for employers about how to engage people with disability in their workforce and about financial assistance and incentives. Despite these initiatives there is clearly much more that needs to be done with employers to ensure that people with disabilities have equal access to employment opportunities.

"B is a 45-year-old woman. Several years ago, she was diagnosed with Type 2 diabetes, and this has now led to the loss of most of her vision. She lost her job last year after her employer refused to provide workplace adjustments or give her time off to learn how to use assistive technology. She is now finding it harder and harder to cope and is stressed and anxious most of the time because she can't get accurate and consistent information about the social security benefits she is eligible to receive as an unemployed person. Most of the printed information is inaccessible to her, and she can't fill in the forms independently."[87]

Income support

For people with disability who cannot work, income support is vital. Lack of access to employment is a major factor in the poverty experienced by many people with disability as well as other forms of exclusion. The poverty risk for people with disability in Australia is double that of those without, and higher than in many other OECD countries.[88]

The Disability Support Pension (DSP) provides financial support to people with disability who are unable to work because of their disability. In 2016–17 there were about 760,000 people receiving the DSP. Increasingly restrictive eligibility rules have led to a decline in the number of people getting access to this payment. It has been reported that 73,000 DSP claims were rejected in 2017-18, a rejection rate

81. AHRC, "Disability Discrimination Act Guide: Earning a Living," 2012, https://www.humanrights.gov.au/our-work/disability-rights/dda-guide-earning-living.
82. Stancliffe, "Inclusion of Adults with Disability in Australia: Outcomes, Legislation and Issues."
83. Australian Network on Disability, "Access and Inclusion Index Benchmark Report 2017-18" (Sydney, 2018).
84. Australian Network on Disability, "Access and Inclusion Index," 2019, https://www.and.org.au/pages/access-inclusion-index.html.
85. Australian Network on Disability.
86. Australian Network on Disability.
87. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."
88. OECD, "Sickness, Disability, and Work - Breaking the Barriers (A Synthesis of Findings Across OECD Countries)."

of 70%.[89] The Commonwealth Ombudsman has highlighted evidence that many remote Indigenous applicants who should be eligible have been denied access to Disability Support Pension because of poor assessments.[90]

New work requirements for younger DSP recipients and the introduction of eligibility reviews have also contributed to reduced DSP numbers.[91] Reduced access to DSP for people with disability has exacerbated the risk of poverty and therefore made it more difficult for many to secure appropriate housing, health services and other support.

> *"Disability support recipients live lives of fear and desperation. Sooner or later every disability support recipient I know has confessed to the concern they feel over the 'what if' factor—what if government stops paying social security/ disability support?"*[92]

An increasing number of people with disabilities who cannot find work rely on Newstart or Youth Allowance. These payments are well below the poverty line and have much steeper withdrawal rates for those who have a part-time income. They are also subject to more stringent job search and activity obligations.

Appropriate and affordable housing

Like many other Australians, people with disability face challenges accessing secure and affordable housing. However, people with disability are more likely than the rest of the population to be living with their parents after the age of 25, to be in 'shared supported accommodation' facilities, or living in institutional settings. People with disability are over-represented in housing assistance programs and the homeless population and are more likely to experience housing stress.[93]

In 2015, the Disability Housing Futures Working Group estimated that after full NDIS rollout, there would still be between 35,000 to 55,000 NDIS participants whose housing needs were not being met, and that there would still be many more people with disability who were not eligible for the NDIS experiencing housing stress.[94]

While a small proportion of people with disability with very high support needs can access Specialist Disability Accommodation (SDA) under the NDIS (see Section 3 for more on this), the majority rely on the general housing market. This may involve home ownership (by themselves or in a family home), private rental, or social and affordable housing. Given high housing costs in many parts of Australia, and the economic exclusion that many people with disability face, home ownership or renting in the market are out of reach for many people with disability. For some people with disability, the only feasible option is social and affordable housing, of which Australia has a significant shortage. One model estimates that there is a current shortfall of over 650,000 social and affordable homes, and that without policy change this will grow to 1 million homes by 2036.[95]

In addition to affordability issues, if a person has accessibility requirements, such as no-step entrances or proximity to accessible transport and services, their options are even more limited. There is a lack of appropriate housing stock and of information about accessibility.[96] People with severe or profound disability face even greater challenges; there is evidence that they are increasingly contacting specialist homelessness services for support to deal with the risks of homelessness.[97] People with disability facing a lack of housing options may also be vulnerable to violence in their homes:

> *"A woman with a physical disability was forced to move into a group home with two men with autism when her family was no longer able to support her. The woman feared for her safety as she had no way of defending herself when she was hit by one of the men…"*[98]

There are some approaches emerging that show promise in enabling people with disability to find and secure their own housing. Shared ownership models, in which people with disability share the equity in a property with an organisation that puts up a share of the capital, are attracting increasing interest.[99] Some people with disability have accumulated some savings as a result of living at home or in institutions for long periods of time with low or no costs. While these savings may not be enough for an outright purchase, the shared equity model is a viable option for some.[100]

89. Luke Michael, "Disability Groups Weary as DSP Appeals Skyrocket," Pro Bono Australia, February 22, 2019.
90. Commonwealth Ombudsman, "Department of Human Services: Accessibility of Disability Support Pension for Remote Indigenous Australians, Report No. 05/16" (Canberra, 2016).
91. Australian National Audit Office, "Qualifying for the Disability Support Pension, ANAO Report No. 18 2015-16" (Canberra, 2016).
92. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."
93. Ilan Wiesel et al., "Moving to My Home: Housing Aspirations, Transitions and Outcomes of People with Disability, AHURI Final Report No.246" (Melbourne, 2015).
94. Disability Housing Futures Working Group, "People with Disability Living in Inadequate Housing: Prevalence, Trends, and Health and Workforce Participation Outcomes" (Brisbane, 2016).
95. Laurence Troy, Ryan Van Den Nouwelant, and Bill Randolph, "Estimating Need and Costs of Social and Affordable Housing Delivery" (Sydney, 2019).
96. Courtney J. Wright, Heidi Muenchberger, and Jennifer A. Whitty, "The Choice Agenda in the Australian Supported Housing Context: A Timely Reflection," Disability and Society 30, no. 6 (July 3, 2015): 834–48, https://doi.org/10.1080/09687599.2015.1038336.
97. AIHW, "Specialist Homelessness Services Annual Report 2017–18" (Canberra, 2019).
98. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."
99. Ilan Wiesel et al., "Shared Home Ownership by People with Disability, AHURI Final Report No. 277" (Melbourne, April 7, 2017), https://doi.org/10.18408/ahuri-7104001.
100. Wiesel et al.

Case Study: Project Independence

SVA has worked with Project Independence, a not-for-profit community housing provider, to provide people with an intellectual disability a new pathway to home ownership. Project Independence's latest development will create homes for 10 residents, with accommodation for a live-in Resident Coordinator to support residents. This arrangement offers residents flexibility, a long-term housing option, and a stepping stone to independent living. It also gives them the ability to acquire equity in the property.

Each resident will complete a one year 'try before you buy' rental period during which they live in the unit to assess if Project Independence is the right accommodation option for them before purchasing. Residents can then build up equity in the property through their regular payments out of their Disability Support Pension. The first two developments in Canberra have been operational for over 12 months and SVA's investment, which is likely to take the form of a construction loan, will partly finance the development of the third ACT development. Other finance includes $1.5 million in philanthropic grants and in-kind donations from partners including the Snow Foundation and Icon.

Project Independence Chair, Glenn Keys says 'The Project Independence model is unique in Australia, in that it provides a home ownership option for people with an intellectual disability. We start by understanding the needs and goals of each resident, to build both the independent living skills and financial independence of our residents, which leads towards true home ownership. We partnered with SVA as they understand the need for flexible financing and the complexities of scaling innovative social programs. This relationship is critical for being able to roll out Project Independence, at scale, across Australia.'

Other promising models combine social housing provision and support services. SVA is working with Flourish Australia on the Resolve Social Benefit Bond (SBB), Australia's first social impact investment aimed at improving mental health outcomes. The Resolve Program is an innovative, peer-led and delivered community support program that brings together short-term accommodation, individual outreach and a warm line of support to people, with the aim to avoid hospitals unless that course of action is absolutely necessary. Essential to the success of the Resolve Program is a peer workforce. Flourish are a national leader in the employment of mental health peer workers, which is supported by academic and practice evidence demonstrating that people with mental health issues are far more likely to trust, relate to and respond to someone who has their own experience of a mental health issue – a peer worker – than staff without mental health histories. The Resolve SBB is an innovative approach to building the evidence base in support of early intervention approaches, as well as demonstrating the cost savings to government through a reduction in participants' utilisation of health and other services, in particular by reducing the number of days spent in hospital.

As another example, the NSW Housing and Accommodation Support Initiative (HASI) has been effective at supporting people to live independently in the community. HASI applies a client-centred approach to provide support that includes the provision of social housing concurrently with case-managed clinical mental health services and support workers who work within and outside of the person's home to build skills and assist them to overcome challenges.[101] Many of the people assisted through the HASI scheme had dual diagnoses that included physical and intellectual disabilities. The initiative aimed to provide support to access and maintain tenancies, recover, stay connected with and participate in their communities; and experience improvements in the quality of their life.[102] The HASI evaluation showed positive health and tenancy outcomes for participants including improved mental health, increased social and community connectedness, reduction of time spent in hospital and reduced costs for NSW Health and Housing Government funders.[103]

Ensuring that people with disability have affordable access to appropriate housing requires an adequate and appropriate supply of housing stock across the housing continuum, appropriate support services to help people maintain tenancies and improve their quality of life, and effective transitional pathways to provide opportunities for people to move along the continuum. To achieve this, governments must ensure that the appropriate combination of funding, regulation, and service provision are in place. It is beyond the scope of this paper to consider the full range of challenges and opportunities for Australian social and affordable housing market; more on this can be found in SVA's Housing Perspective Paper.[104]

It should be noted that there is significant scope for the state and Commonwealth governments to work together to streamline funding and support related to housing for people with disability, not least because the provision of appropriate and affordable housing has been shown to reduce the need and cost for additional support services. As noted above, many people with disability rely on social and community housing, much of which is not fit-for-purpose. There is an opportunity for state governments, which generally control the policy settings for social and community housing, to collaborate with the NDIS on an investment approach that sees an investment in accessible, appropriate social and community housing stock that reduces the need for NDIS supports.

Universal services

A major goal of the NDS is to improve participation of people with disability in mainstream services. However, to achieve this aim, the majority of these services which include education, health, housing, and justice need to actively transform themselves to become more inclusive and accessible.[105]

Education

People with disability continue to have lower levels of educational attainment, both in secondary and tertiary education settings, compared to other Australians, limiting employment prospects for many and contributing to the continued exclusion of people with disability from our society.[106] People with disability were also more likely to have completed a qualification at Certificate level (28.4%) compared with those without any disability (22.5%).[107]

Children with disability have traditionally had terrible experiences with the education system and according to the AIHW only 81% of children and young people with disability attended school in 2015.[108] This has slightly increased since 2003 but more needs to be done to ensure Australia creates an inclusive and accessible educational culture. There is a need to improve the capability and

101. Kristy Muir et al., "Challenging the Exclusion of People with Mental Illness: The Mental Health Housing and Accommodation Support Initiative (HASI)," Australian Journal of Social Issues 43, no. 2 (December 1, 2008): 271–90, https://doi.org/10.1002/j.1839-4655.2008.tb00102.x.
102. Muir et al.
103. Muir et al.
104. Social Ventures Australia, "SVA Perspectives: Housing" (Sydney, 2016).
105. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."
106. AIHW, "Disability in Australia: Changes over Time in Inclusion and Participation in Education, Cat. No. DIS 69," 2017.
107. AIHW.
108. AIHW.

systems of all education providers to deliver inclusive high-quality educational programs for people of all abilities.[109] There is also a need to ensure that NDIS-supported services work seamlessly with educational services, so that children are not denied access due to disputes about which agency is responsible for supporting them.

There is new research gaining traction in early learning settings, that with the right guidance and support, educators can effectively include and teach children on the autism spectrum in mainstream childcare, alongside their non-autistic peers.[110] This demonstrates the need for mainstream education programs to be designed for people of all abilities from early childhood to tertiary and vocational settings.

Health

People with disability experience much poorer health outcomes than people without disability and this is often due to a health system that does not meet their needs. People with disability tend to experience lack of accessibility of health services, lengthy waiting times, prohibitive costs and discrimination by health professionals.[111] Because they typically experience a higher incidence of co-morbidities, they often require the coordination of their care between multiple health professionals as well as care from family and friends. Reports indicate that a lack of training or experience in disability, may lead health professionals to assume that the symptoms are part of the disability, not a separate health condition that requires treatment, in turn creating higher rates of morbidity and mortality.[112] Where a person lives, and the severity of their disability also makes a difference to their service access and the treatment they receive.

> *"They need clear signage, awareness and education for people in the hospital system for deaf people, especially when you are sick and unable to convey your needs."*[113]

Adherence to the medical model for the design of disability services has unfortunately created dependence rather than personal autonomy for people with disability and a health system that is not equipped to properly cater to their needs.[114] People with disability should also receive the same preventative health care as others, but this does not always happen for reasons including physical barriers, lack of knowledge by health providers, stereotyping or communication difficulties.[115]

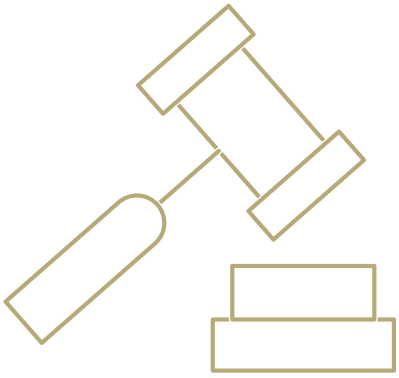
Australia's health system therefore needs to be responsive to the needs of people with disability and there is a great deal more to be done in the provision of appropriate and affordable health services for people with disability. There is a need for the incorporation of universal design and a greater coordination and integration of disability and health services into a person-centred model, so that people with disability don't 'slip between the cracks.'

Justice

There is an over-representation of people with an intellectual disability both as victims and offenders in the criminal justice system as well as significant rates of acquired brain injury amongst both male and female prisoners.[116]

People with disability who have complex needs face even greater obstacles within the justice system and require assistance to navigate the system. There is also a need for greater attention to be paid to people with disability who are transitioning out of custody into the community, to ensure continuity of support. Many states and territories have committed to court diversion programs for people with disability to respond to both their disability and offending needs.[117]

People with disability need access to justice on an equal basis which may require aids and equipment in order to facilitate their effective participation in all legal proceedings. Disability awareness training for the judiciary, legal professionals and court staff would help to ensure the effective participation and protection of rights for people with disability.[118]



109. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."
110. Giacomo Vivanti et al., "Outcomes of Children Receiving Group-Early Start Denver Model in an Inclusive versus Autism-Specific Setting: A Pilot Randomized Controlled Trial," Autism 23, no. 5 (July 8, 2019): 1165–75, https://doi.org/10.1177/1362361318801341.
111. AIHW, "Access to Health Services by Australians with Disability, Cat. No. DIS 70."
112. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."
113. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."
114. Institute of Medicine, Disability in America: Toward a National Agenda for Prevention (Washington, D.C.: The National Academies Press, 1991), https://doi.org/10.17226/1579.
115. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."
116. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia"; Women With Disabilities Australia, "Submission to the National Human Rights Consultation" (Rosny Park, Tasmania, 2009).
117. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."
118. COAG.

3. People with disability access and exercise choice and control over specialist disability services and supports appropriate to their needs

- 3.1 People with disability (and their families and carers) are empowered to identify their needs and secure appropriate funding
- 3.2 Information on services and supports is accessible and relevant
- 3.3 High quality services and supports are available and affordable
- 3.4 Funding is flexible to meet the needs of individuals, and adequately accommodates all people with disability

The National Disability Strategy (NDS)

In an ideal world, specialist disability services would not be required as society would be inclusive and accessible to everyone.

Currently, specialist disability services and supports remain a critical enabler for many people with disability to be full and equal participants in society.

The NDS is the overarching document that outlines Australia's plan to change and transform the experiences of people with disability in Australia while also demonstrating the benefits for all Australians of more inclusive communities.[119] The NDS incorporates the principles of the CPRD into six key policy areas:

- Inclusive and accessible communities
- Rights protection, justice and legislation
- Economic security
- Personal and community support
- Learning and skills
- Health and wellbeing.[120]

A review of the NDS published in 2019 that consulted with key sector advocates and experts concluded that the implementation of the NDS had been "uneven, and a consistent, systematic approach to implementation across Australia had been absent". Continued attention is required to ensure the full set of priorities in the NDS are implemented – particularly for the large number of people who will not qualify for the NDIS.

Clearly more needs to be done to ensure greater collaboration and communication between governments, advocacy bodies, services and individuals including greater political will and leadership to ensure the strategy is implemented in a way that achieves its aims.[121]

Services specific to the needs of people with disability

Many people with disability access specialist services and support to assist them with activities of daily living, economic and social participation in the community, and other aspects of their lives. These services may be delivered in a person's home, a specialist group facility, or in the community. The availability, quality, intensity, range, specificity and appropriateness of services and supports is a critical determinant on the empowerment of people with a disability to be full and equal participants in our community.

For many people with disability in Australia, specialist services and supports have historically been characterised by a loss of personal autonomy and power, especially for those living in institutional and residential settings. As described by the Australian Cross Disability Alliance (ACDA), "one of the most pervasive human rights violations experienced by people with disability in Australia is their segregation, isolation and confinement from the community in institutional and residential settings".[122] While there have been improvements over time, the previous disability support system was still largely "underfunded, unfair, fragmented, and inefficient, and gave people with a disability little choice and no certainty of access to appropriate supports."[123]

The introduction of the National Disability Insurance Scheme (NDIS) in 2013 represented a seismic shift in social service delivery in Australia. Arising from a grassroots movement, the new scheme aims to reclaim choice and control for people with disability from a service system that was predominantly determined by professionals.[124] Including choice and control, the objectives of the NDIS are the provision of reasonable and necessary supports, encouragement of inclusion of people with disability in the community, and maximising independence.

The NDIS aims to achieve outcomes for three groups of people:

- All Australians – Providing insurance against the costs of support for any Australian in the event that they or their family member acquire a significant disability
- All people with disability – Providing information, linkages, and referrals to services in the community
- Eligible people with disability – Providing access to funded individualised supports to people with significant care and support needs, as a supplement to the roles played by family and community to engage support people with disability.[125]

119. COAG.
120. COAG.
121. L Davy et al., "Review of Implementation of the National Disability Strategy 2010-2020 Final Report (SPRC Report 4/19)" (Sydney, 2019), https://doi.org/10.26190/5c7494b61edc4.
122. Frohmader and Sands, "Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings."
123. Productivity Commission, "Disability Care and Support, Report No. 54."
124. Deborah Warr et al., "Choice, Control and the NDIS : Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme" (Melbourne, 2017).
125. Productivity Commission, "Disability Care and Support, Report No. 54."

At full roll-out, 460,000 Australians with disability or around 10 per cent of people with disability are expected to gain access to individualised supports.[126] While implementation is not yet complete in all states and territories, it is already the primary funder of services to people with disability in Australia. But the design and implementation of the NDIS faces significant challenges to adequately:

> *"meet the needs of very diverse service users with very diverse needs and circumstances, which entails working around a broad range of disabilities, personal situations, life course contexts, locational contexts and extant service systems. These factors ensure that there will be many challenges in meeting people's expectations and delivering effective and efficient services."*[127]

The introduction of the NDIS has had profound consequences both for people with disability in accessing appropriate and adequate supports; and for service delivery organisations to transition to new operating models that enable quality and appropriate services to be delivered to all consumers within the confines of the new market environment.

Identifying needs and securing funding for people with disability

The NDIS was designed with the principles of choice and control for participants at the centre. In broad terms, people with disability have moved from accessing block-funded disability services that offered little choice or control due to funding constraints and budgets held by service providers, to being the "holder" of individualised funding to access reasonable and necessary supports that are approved by the National Disability Insurance Agency (NDIA).

Within this market, people with disability are expected to operate as consumers – making choices about which services they wish to use and having control over how they are delivered. However, choice and control is not always meaningfully available to people with disability for a variety of reasons including complexity of systems, inadequate support to exercise it,[128] a lack of familiarity with the required concepts, inexperience of making choices and/or undeveloped communication tools to engage in planning and decision-making. While the new consumer-directed market has created greater satisfaction among those who are able to exercise choice and control, successfully accessing appropriate funding and supports under the NDIS has not eventuated for all participants.[129]

The consumer-directed design largely favours people with strong cognitive abilities, typically people with physical disability or people with families or carers who can be strong advocates for them. People with severe intellectual disability or psychosocial disability, who may struggle to make informed decisions, are at risk of being excluded from the scheme. There is already emerging evidence that those least able to navigate the system are more likely to receive less funding.[130]

An evaluation of the NDIS trial sites found that people with intellectual disability and psychosocial disability were the least satisfied that their supports were reasonable and necessary.[131] The Productivity Commission identified in 2017 that

> *"The NDIS planning process is complex and confusing, and often lacks clarity and transparency. It is difficult to access information about assessment tools that are used by the NDIA and how support allocation is determined. There is also limited information to help scheme participants and their families, carers and advocates navigate the planning system. Scheme participants are often not aware of their rights and options, such as their entitlement to request a face-to-face meeting or have an advocate present during the planning meeting. There needs to be greater transparency and clarity around the NDIA's planning processes. There also needs to be clear and up-to-date information about what participants should expect during the planning conversation, when it will occur, and how the information gathered during the conversation will be used."*[132]

Additionally, a project trying to build the planning skills of people with intellectual disability who use assisted communication devices found that some of the devices themselves did not include the words, 'plan, choice or goal'.[133]

Local Area Coordinators (LACs) are currently the official conduit for linking people who would like to access the NDIS with information and support. LACs can assist people to: understand and access the NDIS; create and implement plans; and review plans if changes need to be made. However, there remains a gap for many people with disability around understanding how to access the NDIS

126. National Disability Insurance Agency, "What Is the NDIS?," 2019, https://www.ndis.gov.au/understanding/what-ndis.
127. Warr et al., "Choice, Control and the NDIS : Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme."
128. Warr et al.
129. Kostas Mavromaras et al., "NDIS Evaluation Consolidated Report" (Adelaide, 2018).
130. Malbon, Carey, and Meltzer, "Personalisation Schemes in Social Care: Are They Growing Social and Health Inequalities?"
131. Mavromaras et al., "NDIS Evaluation Consolidated Report."
132. Productivity Commission, "National Disability Insurance Scheme (NDIS) Costs, Study Report" (Canberra, 2017).
133. Jaquie Mills and Laura Jones, "Increasing Access to Information, Choice and Control for NDIS Planning: A Project in Co-Design," Intellectual Disability Australia 39, no. 3 (2018): 16–19.

and to advocate for reasonable and necessary supports. There is a significant variation in the skills and capabilities of individual LACs, particularly around their understanding of the nuances of different types of disability, which affects the quality of support they provide to those seeking to access the NDIS. Some service delivery organisations have stepped in to provide this support to existing clients on an unfunded basis, however this presents some challenges to their financial sustainability.

Additionally, NDIS planners who are responsible for approving NDIS plans have also been observed to have a variable understanding of the different types of disability and therefore what constitutes 'reasonable and necessary supports.' All these challenges can present significant barriers to people with disability securing adequate support for their needs, and particularly affects people with lower cognitive abilities or those who do not have strong advocates.

Eligibility

Discussions continue about who should be eligible for the NDIS and who is actually able to access it.[134] While the NDIS provides greater access to disability services for some, those found ineligible have experienced a contraction of access to services or a rise in the cost of services that had previously been at no cost to them.[135]

This is particularly stark for people experiencing psychosocial disability.[136] The NDIS is designed for people with a significant, long-term and permanent disability, which is at odds with the recovery model generally used by the psychosocial support sector.[137]

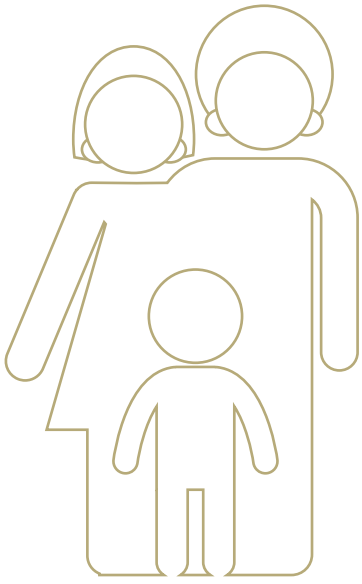
Encouragingly, the recently released Progress Report: General issues around the implementation and performance of the NDIS by the Joint Standing Committee on the NDIS have recommended that the NDIA work with the mental health sector to refine the psychosocial disability stream before it is rolled out nationally to ensure it is fit-for-purpose.[138]

It is important to note though that even if the psychosocial disability stream is modified to be fit-for-purpose, by its very design, the scheme, which is premised on an insurance model, must intentionally exclude certain groups of people with disability to ensure the overall financial sustainability of the scheme. A challenge that has already presented itself in the implementation of the scheme so far is ensuring adequate coverage and supports for those who may not be eligible for the NDIS. This requires greater collaboration between NDIA and the federal and state governments to ensure those who are ineligible for the NDIS do not fall through the cracks.

Early intervention for children

It is well established both internationally and in Australia through the First 1000 Days movement that the most effective time to intervene to improve a person's likely life outcomes is in early childhood: "Experiences in early childhood have a lasting impact on an individual's future; what happens during the first 1000 days – the period from conception to the end of a child's second year – has the greatest potential to affect health and wellbeing throughout the life course… Many challenges in adult life, including major public health concerns such as obesity, heart disease, and mental health problems, once regarded solely as products of adult behaviour and lifestyles, are now known to be linked to processes and experiences that take place during the first 1000 days."[139]

As mentioned previously, children with disability face increased rates of social exclusion and barriers to participation in many of life's activities. As childhood is a critical time for development, the NDIS has implemented the Early Childhood Early Intervention (ECEI) approach which is available to all children aged 0-6 years with a developmental delay or disability.[140] This recognises that timely access to best-practice early childhood interventions is vital for children with disability to ensure that they achieve the best possible outcomes throughout their life. The ECEI approach aims to ensure that parents or primary caregivers are able to provide these young children with experiences and opportunities that help them gain and use the functional skills they need to participate meaningfully in their environment.[141]



134. Karen R Fisher, "Understanding the NDIS: Many Eligible People with Disabilities Are Likely to Miss Out," The Conversation, 2016.
135. Kostas Mavromaras et al., "NDIS Evaluation Consolidated Report - Appendix to Final Report" (Adelaide, 2018).
136. Jennifer Smith-Merry et al., "Mind the Gap: The National Disability Insurance Scheme and Psychosocial Disability. Final Report: Stakeholder Identified Gaps and Solutions" (Sydney, 2018).
137. Smith-Merry et al.
138. Joint Standing Committee on the National Disability Insurance Scheme, "Progress Report 2019: General Issues around the Implementation and Performance of the NDIS" (Canberra, 2019).
139. Centre for Community Child Health, "The First Thousand Days – Our Greatest Opportunity, Policy Brief No. 28" (Melbourne, 2018), https://doi.org/10.25374/MCRI.5991184.
140. Early Links Inclusion Support Service, "NDIS Early Childhood Early Intervention Approach," 2019, https://www.earlylinks.org.au/ndis-early-childhood-early-intervention-approach/. Early Links Inclusion Support Service.
141. National Disability Insurance Agency, "Help for Children under 7," 2019, https://www.ndis.gov.au/understanding/how-ndis-works/help-children-under-7.

Accessing information about services and supports

Given the barriers people with disability face to exercise choice and control in relation to disability services, there is significant debate over what it means for a disability service system to be driven by consumer choice.[142] Flexible systems, that take account of a person's specific disability, culture, communication and literacy levels, are important in delivering disability services that are effective and capable of achieving positive outcomes for all people who are eligible for them.

Information needs to be accessible and relevant as well as people with disability being empowered to use it. This will only come about through capacity building and/or engagement strategies so that people with disability are supported to access information and therefore have meaningful choice within the scheme.

Officially, NDIS participants can seek assistance from LACs and, if eligible, from Support Coordinators to understand what services and supports are available in their area. However, the degree to which participants are made aware of different services and supports available is highly dependent on the specific knowledge and capabilities of individual LACs or Support Coordinators. There is also significant variation in outcomes for people based on their capacity to interpret the complex arrangements and self-advocate for their needs.[143] New organisations are emerging to try to address this issue, typically in the form of online directories with user reviews.

However, challenges will continue to remain for certain cohorts, for instance people with sensory or intellectual disability, people from culturally and linguistically diverse backgrounds, or people who identify as Aboriginal or Torres Strait Islander. For example, enhancing access to disability services for people who were born overseas and/or speak a language other than English at home may require efforts such as translated information, targeted channels to alert people that these services are available in Australia and how to access them, and targeted campaigns to de-stigmatise the experience of disability.

An evaluation of the NDIS trial sites found that satisfaction of service supports was lower for people with intellectual disability, psychosocial disability and those unable to advocate for themselves, in terms of access to choice and control; and people with intellectual disability and psychosocial disability were the least satisfied that their supports were reasonable and necessary.[144]

A deep dive on disability in the Aboriginal and Torres Strait Islander context

Disability in Aboriginal and Torres Strait Islander communities is both more prevalent and more complex compared to other Australians. The high rates of disability are partly attributed to the impact of colonisation, intergenerational trauma and ongoing social, cultural and political marginalisation as well as a major lack of public infrastructure in remote Aboriginal communities. The complexity is due to a high number of co-occurring disabilities and the fact that these multiple disabilities are compressed within a life expectancy that is much lower than other Australians.[145]

An evaluation of the NDIS found the number of Aboriginal and Torres Strait Islander people with disability participating in the scheme was an underrepresentation of the actual high levels of disability. While awareness of the NDIS has improved, Aboriginal and Torres Strait Islander people have been identified as particularly struggling with the complexity of NDIS processes and documentation and their understanding of the NDIS remained low throughout the course of the evaluation.[146]

Other barriers for Aboriginal and Torres Strait Islander peoples accessing and applying for the NDIS include social and geographical isolation in urban, rural and remote communities; fear of government services and asking for support (particularly where children are involved due to past experiences of child removal); and that there is no dedicated Aboriginal and Torres Strait Islander support unit within the NDIA.[147]

142. Warr et al., "Choice, Control and the NDIS : Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme."
143. Mavromaras et al., "NDIS Evaluation Consolidated Report."
144. Mavromaras et al.
145. Scott Avery, Culture Is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability (Sydney: First Peoples Disability Network Australia, 2018).
146. Mavromaras et al., "NDIS Evaluation Consolidated Report - Appendix to Final Report."
147. Smith-Merry et al., "Mind the Gap: The National Disability Insurance Scheme and Psychosocial Disability. Final Report: Stakeholder Identified Gaps and Solutions."

The research conducted by the First People's Disability Network's Culture is Inclusion project found that Aboriginal people with disability 'experience a unique form of intersectional discrimination and social inequality.' That is, they are subject to discrimination that is both related to their disability as well as their race.[148] Consequently, there are specific challenges for Aboriginal and Torres Strait Islander people in accessing both disability and universal services, over and above those faced by non-Indigenous people with disability, and many services are not culturally safe or appropriate.

The diagram below shows how the experience of intersectional discrimination for Aboriginal and Torres Strait Islander people accumulates over the life course.[149]

Life-Stage Aspect

Peri-Natal	Early childhood	Schooling years	Young people	Justice	Health	Ageing
Low awareness of disability, Environmental factors, increased likelihood of low birth-weight	Low awareness of disability, Exposure to trauma, Increased likelihood of OOHC – off country, unstable 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 comorbidities.
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 over shadowing	Inadequate public infrastructure especially in remote communities.

Aboriginal and Torres Strait Islander Disability

148. Avery, Culture Is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability.
149. Avery.

The right to self-determination and empowerment of Aboriginal and Torres Strait Islander people is fundamental to improving the outcomes for Aboriginal people with disability. Self-determination must be driven by Aboriginal people. While state and federal governments have a role in setting a coordinated national policy framework, they must be prepared to cede some decision-making authority and management responsibility, allowing Aboriginal and Torres Strait Islander communities to assume greater control of their futures, especially given the higher rates of disability in these communities.[150]

First People's Disability Network Australia has developed ten priorities to address disability inequity for Aboriginal and Torres Strait Islander people in the NDIS and National Disability Strategy.[151] The ten priorities are:

1. Invest to create an Aboriginal Community Controlled Disability Service Sector for the provision of disability supports by Aboriginal people with disability for their communities;
2. Address the barriers facing Aboriginal people in accessing the NDIS;
3. Prioritise timely interventions to ensure supports and services are provided, and available over the long-term, and at the right time in people's lives;
4. Recognise and value existing knowledge, skills and expertise within Aboriginal and Torres Strait Islander communities. We are leaders in the inclusion of people with disability;
5. Resource a community-directed research strategy which specifically focuses on Aboriginal and Torres Strait Islander disability;
6. Endorse and support peer-to peer leadership to ensure that Aboriginal people with disability lead the engagement with community themselves;
7. Develop and implement an access to justice strategy for Aboriginal people with disability, particularly those with cognitive impairment, sensory and intellectual disability;
8. Develop and implement programs for inclusive education and employment for Aboriginal people with disability in line with national strategies for their full social participation;
9. Create links between the National Disability Strategy and Closing the Gap Framework for coordinated policy and programs at the Commonwealth, State and local levels in partnership with Aboriginal people with disability and their organisations; and
10. Develop an Aboriginal and Torres Strait Islander Disability Performance Framework for the independent monitoring of the social and economic outcomes of Aboriginal and Torres Strait Islander people with disability.[152]

An accessible, affordable and high-quality disability service and support system

The proliferation of high-quality disability services and supports in sufficient numbers, variety, and location is critical to ensure people with disability have the opportunity to exercise choice and control. The introduction of the NDIS has already seen tremendous growth in the number of providers operating in the market for disability services and supports, however significant challenges remain to ensure an equitable distribution of supply and a high quality of all services and supports.

Thin markets, or areas where there is an inadequate supply of services to meet participant needs, have started to emerge. These markets present a serious challenge to participants exercising choice and control, as without a sufficient supply of options, choice and control becomes a 'theoretical concept.'[153]

Thin markets have been observed for people living in rural and remote areas, people from culturally and linguistically diverse backgrounds, and Aboriginal and Torres Strait Islander people, people requiring specialised supports, and people with complex needs required services such as early childhood intervention, behavioural intervention, and specialist disability accommodation.[154]

For example, at the time of the NDIS trial, people living in remote Aboriginal communities in the Barkly Region of the Northern Territory experienced an unviable disability services market that included ongoing shortages of disability workers - limiting choice and control to a 'theoretical concept'.[155] Additionally, where people in rural areas could not access their chosen option they were at risk of losing funding for the support where planners interpreted this as an indication that the support was 'unnecessary'.[156]

Failure to account for people's culture, language and literacy levels can also hinder people's access to disability services regardless of location. Enhancing access to disability services for people who were born overseas and/or speak a language other than English at home requires more than translated information. Access barriers may arise from the fact that people come from places where these services are not provided by the state, and therefore they will not seek them out.[157] Overcoming this may require identifying targeted channels to alert people that these services are available in Australia and how to access them.

150. Social Ventures Australia, "SVA Perspectives: First Australians" (Sydney, 2016).
151. First Peoples Disability Network Australia, "Ten Priorities to Address Disability Inequity," 2019, https://fpdn.org.au/ten-priorities-to-address-disability-inequity/.
152. First Peoples Disability Network Australia.
153. Mavromaras et al., "NDIS Evaluation Consolidated Report - Appendix to Final Report."
154. Ernst & Young, "Thin Markets Project: Discussion Paper to Inform Consultation" (Canberra, 2019).
155. Mavromaras et al., "NDIS Evaluation Consolidated Report."
156. Mavromaras et al.
157. Mavromaras et al.

The evaluation of the NDIS in the Barkly Region in the Northern Territory, recommended that a 'culturally-sensitive model' that fits remote needs for services be applied. This was in recognition that NDIS pricing did not adequately reflect remote service provision costs, people were unable to access supports in their plans and that a holistic sense of wellbeing is a more relevant concept to the Aboriginal people living in the Barkley Region than disability or a focus on 'physical concerns'.[158]

A deep dive on Specialist Disability Accommodation (SDA)

Under the NDIS, individuals who require specialist housing solutions that are tailored to support extreme functional impairment and/or very high support needs are eligible to receive funding for Specialist Disability Accommodation (SDA). This funding is available to roughly 6% of NDIS participants, or 28,000 people, and is designed to improve the independence of participants and reduce their reliance on attendant care. It aims to increase housing supply by providing incentives for private investment in the market.[159] A range of design categories and housing types are eligible for SDA funding, with the quantum of SDA funding varying across these. SDA funding levels also vary on a location by location basis, to account for construction costs differences across the country.

SDA, as an investment class, holds the unique position of being able to deliver scaleable, long term social and financial returns. Housing providers receive annual payments for each occupied SDA dwelling from the NDIS, and a reasonable rent contribution from the resident.

In theory this income stream could catalyse significant private investment into the sector which will create the required new housing suitable for people with disability. However, there are still design features of SDA that are inhibiting new housing supply despite recent positive changes to the operation of the subsidy.

Investors seeking appropriate risk-adjusted returns have begun to invest into the market, however so far the large scale investment required to address the lack of supply has not eventuated. Unlike investment into general residential housing, a mainstream investment class, SDA housing has very specific characteristics that requires awareness and understanding from investors. These include the particular nature of vacancy risk with this resident cohort, and demand uncertainty in the market.

The SDA market is dealing with a lack of validated, granular information on supply and demand. This is both impeding the confidence of developers to build more supply, and resulting in an uneven development of supply to meet participants' needs. For example, there is currently a shortage of the 'Robust' housing type required by people with complex needs, exacerbating the problems of thin markets for this cohort.[160]

There are a number of more general concerns about the operation of SDA which we believe may be creating uncertainty for a range of stakeholders, as well as harming NDIS participants. These include delays in providing people with SDA funding under their plan; issues with the process required for people to access SDA funding; ambiguity in design category requirements; and state planning processes and tenancy rights issues.

In addition, greater market stewardship is required to guide the development of SDA. Research by SVA and the Summer Foundation has found an estimated shortage of 10,000 places in SDA, and that this shortfall may grow significantly in the future as there is greater clarity on the suitability of existing disability accommodation and as eligibility increases.[161] In such a landscape, there is a risk that SDA developers build new properties that are only incrementally better or perhaps the same as existing stock, and still attract substantial interest as there is such a significant shortage of supply. NDIA should play a more active role in shaping the development of a market to ensure all supply that is built will be something to be proud of for many years down the line. This will not only ensure improved outcomes for people with disability but also improve the cost-effectiveness of SDA funding.

The recommendations announced in early 2019 have provided some clarity around the issues highlighted above. However, the policy settings governing SDA require further attention to ensure that the high quality, well located housing, at the numbers required can be delivered into the market.

Outside of SDA, there is also a role for the NDIA to play to encourage or provide investment in housing for the other 94% of NDIS participants not eligible for SDA, and for broader reform to social and affordable housing that is accessible for the many people with disability who are not NDIS participants (see Section 2 for more on this).

158. Mavromaras et al.
159. SGS Economics & Planning, "Specialist Disability Accommodation: Market Insights" (Canberra, 2018).
160. NDIS, "COAG Disability Reform Council Quarterly Report" (31 March 2019).
161. Social Ventures Australia, "Specialist Disabilty Accommodation: Supply in Australia" (Sydney, 2019).

Case study: Understanding the supply pipeline for Specialist Disability Accommodation

One of the major barriers to private investment in SDA is a lack of detailed data on the supply and demand in the market. The Summer Foundation and Social Ventures Australia have partnered to develop a new understanding of new SDA housing and SDA housing currently in the pipeline.[162]

The report is based on a survey of SDA providers across Australia undertaken in late 2018. The survey collected data about new SDA projects under development to understand how many SDA places are in the pipeline (i.e. being planned or constructed). The data presented in the report came from 55 SDA providers who responded with details of their SDA development projects. The survey indicates that there are 1,518 SDA places in development around Australia, with the most activity in NSW, Victoria and South Australia.

The Specialist Disability Accommodation Supply in Australia report was created to provide much-needed data on the nascent SDA market to encourage further investment and speed the creation of specialist housing for people with disability. The report indicates that a solid start has been made in the new SDA market, with more than 2,000 new SDA places either enrolled (registered with the NDIS) or in the development pipeline. This takes into account 718 places of newly built SDA enrolled with the NDIA as at 31 December 2018.

However, with around 12,000 new SDA places needing to be created to meet the anticipated demand from NDIS participants with SDA funding, increased market confidence to encourage further investment is essential. The survey has revealed that:

- The current SDA development pipeline is dominated by High Physical Support designs, with very little Robust capacity being built
- The most common building types are apartments and group homes
- More than 80% of places are at pre-construction or construction stages of development
- Three-quarters of the reported supply would be delivered by early 2020
- The estimated undersupply of SDA is concentrated in the major cities, except for South Australia where Adelaide already has significant new supply in the pipeline

A range of provider types responded to the survey, with not-for-profit providers dominating activity, mainly community housing providers (the latter responsible for nearly 60% of the reported supply).

162. Social Ventures Australia.

A deep dive on the quality of supply of disability services

A key ambition of the NDIS was to increase the quality of services and the degree to which services are more responsive to consumers' needs. This is achieved by putting purchasing power into the hands of consumers and introducing competition into the market.

This fundamental shift from block-funding to consumer-directed funding has indeed altered market dynamics, with the entrance of new providers with entirely different business models, an increase in mergers and acquisitions, and a recognition by existing providers of the need to change. Existing providers have begun to adapt their operations in response such reorienting business and operating models to adapt to the financial implications of delivering services under price caps, with those that have failed exiting the market.[163]

The challenges faced by existing providers are significant. Providers have had to adapt from the relative predictability of block funding to payment in arrears and build capabilities to monitor and manage costs at a unit level. Additionally, providers have had to build new capabilities, such as marketing and client acquisition for the first time. Culturally, many organisations are trying to make the shift from a culture of 'caring for' to 'doing with.'

It is important to understand too that these challenges have been further compounded by implementation challenges that have come with the roll-out of the NDIS. Difficulties in securing payments for services rendered have meant that for some organisations, up to 10% of their revenue was delayed. In addition, many existing providers have taken upon themselves to provide unfunded support to existing clients to help them access and navigate the scheme in the wake of confusion about the NDIS. Consequently, both from a financial and an effort perspective, resources have been stretched as providers have sought to transition to the new scheme while continuing to support their clients.

While the nature of the challenges faced by these providers should not be underestimated, the still limited incorporation of client voice into organisations is disappointing. Research by SVA found that in a survey of 18 disability service providers representing Australia's largest and most innovative providers and ~40% of NDIS revenue, only 1 in 18 disability service providers was collecting client feedback in line with best practice and 3 providers were not collecting any feedback at all.[164]

It has been our experience that many organisations claim they have become more customer-centric, yet few organisations have instituted formal processes that will enable them to learn effectively and efficiently. (Refer to case study on page 37.)

This is a serious gap for the sector. Without adopting a more rigorous and systematic approach to collecting client feedback, it will be difficult for organisations to truly drive the learning and cultural change required to adapt their operations to meet the needs of those they serve.

163. Paul Bigby, "Staff laid off, services cut ahead of NDIS rollout" (21 March 2018).
164. Social Ventures Australia, "Harnessing the Power of Client Experience: The Collection and Use of Client Feedback in the Social Sector" (Sydney, 2019).

Case Study: Harnessing the power of client feedback

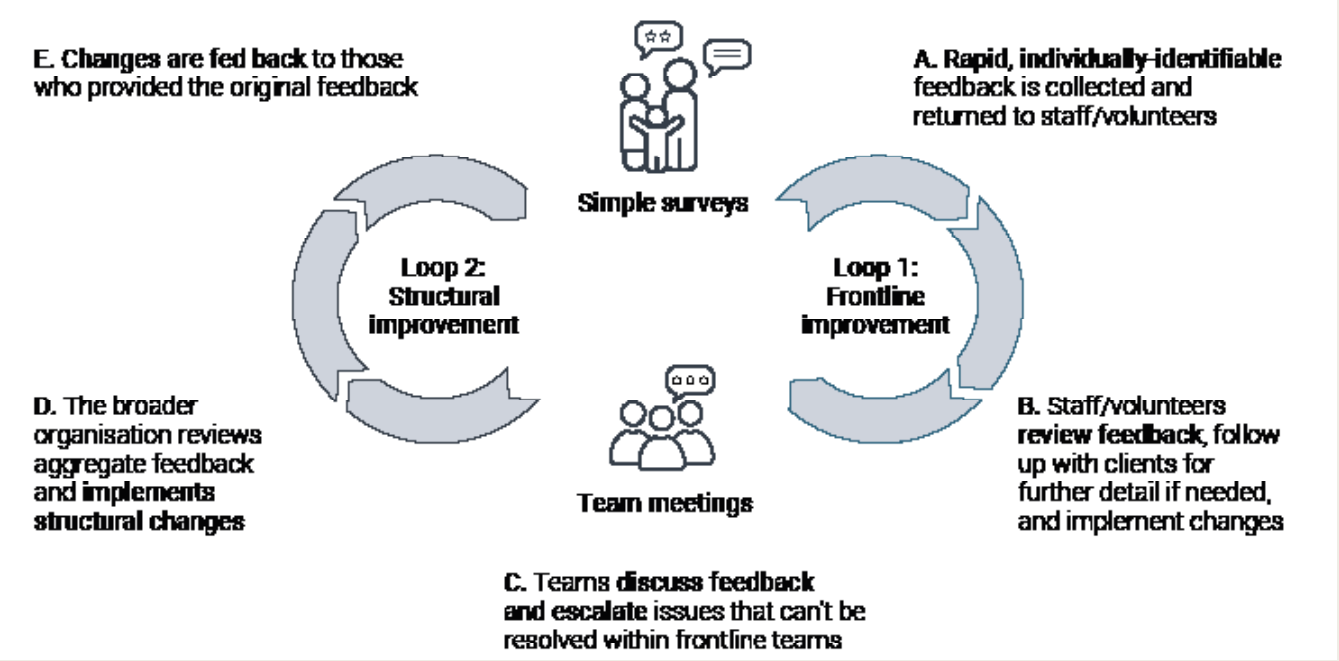
The importance of listening to clients seems obvious. It is difficult for any service to achieve positive outcomes for dissatisfied clients: dissatisfaction reduces engagement, and without engagement, it is hard to have positive impact. In light of the NDIS, client feedback is even more critical. Providers cannot deliver outcomes or achieve financial sustainability without acquiring or retaining clients. Consequently, we expected the disability sector to be one of the most advanced sectors at using client feedback.

Yet our survey of Australia's largest and most innovative disability service providers shows the sector to be underdeveloped.[165] Only 1 of the 18 providers surveyed exhibited behaviours close to best practice: it collected feedback weekly and shared it the same day. Three providers collected no feedback at all.[166] This is a missed opportunity for insight and for impact.

Organisations are often tempted to design complex surveys to learn as much as they can. In practice, these surveys are too expensive and too cumbersome to conduct regularly. What's more, their response rates are low, limiting the reliability of findings. Alternatively, some organisations point to the presence of a board member with lived experience or an advisory group of a small set of customers as their source of customer feedback or insight. However, in all cases, feedback is neither regular nor rigorous enough.

A systematic approach to collecting and acting on client feedback can be a powerful tool to help organisations improve outcomes for clients and improve their financial sustainability.

Drawing on best practice from the social and corporate sectors, SVA has distilled the key principles for a high-velocity client feedback model, one that focuses on collecting feedback frequently and disseminating it quickly to those who can act on it (see below).



165. Respondents included established providers with at least $20 million per annum in revenue and smaller providers experiencing triple-digit growth. Collectively, they represent $2 billion in annual disability revenue, or about 40% of total paid NDIS supports in FY18.
166. Social Ventures Australia, "Harnessing the Power of Client Experience: The Collection and Use of Client Feedback in the Social Sector" (Sydney, 2019).

The model starts with developing a simple survey: one that is easy to conduct, easy to answer, and will produce actionable insights (A in the diagram). The specific questions are less important than the ability to conduct and answer them easily.

The other key design feature of a high-velocity client feedback system is the inclusion of two complementary 'learning loops' to listen, learn, and act. Loop 1 aims to understand and act on feedback at the front lines (e.g. to improve the way the organisation responds when clients inquire about a service) (B); and Loop 2 aims to understand, escalate, and act on feedback that requires structural changes and the involvement of functions outside the frontline team (e.g. the redesign of major services, policies, or procedures) (C&D).

The best systems also 'close the loop' by communicating back to those who initially provided feedback, to understand the issues more deeply and let them know what actions are being taken (E). This shows responsiveness and encourages further feedback in the future.

Successful organisations embed these feedback loops and the associated 'listen-learn-act' disciplines deeply into their day-to-day operations. Two factors make this possible: strong leadership commitment and cultural reinforcement, and robust measurement methodology and systems.

Ultimately, embedding client feedback loops into the way disability organisations work requires a significant shift in daily behaviours and operating disciplines. This is a change in culture, and requires concerted, visible senior leadership. Organisations which become truly effective at using client feedback are those whose senior leaders make it a clear priority. These leaders have a genuine desire to learn and improve and are willing to stay the course even when progress seems slow.

Client feedback can lead to a wide array of improvements in service design and delivery – from inexpensive and obvious refinements to fundamental changes requiring real effort. While sometimes the feedback system uncovers unexpected insights, some of the greatest benefits come from acting – at last! – on issues which were already well known but somehow went unaddressed.

Flexible funding

The flexibility and certainty of funding can have a significant impact on the ability of people with disability to exercise true choice and control. While the NDIA must be judicious in controlling spending to ensure the scheme remains financially sustainable, such caution must be balanced with the issues it may cause for NDIS recipients.

For example, the previous SDA rules contained a number of conditions that limited the choice and control of participants, including disincentives for families to live together in SDA and a lack of certainty around whether SDA funding, once granted, would remain in people's plans in the future. The rules also previously required SDA applicants to demonstrate that they had first found a suitable home – limiting their ability to work with providers looking to develop new builds – and to demonstrate that SDA was a 'last resort' – which often required significant time and using a lot of support coordination funding just to document the lack of alternative suitable options.

The new SDA framework announced in February 2019 has thankfully resolved many of these issues, however the NDIS will need to continue to ensure it actively monitors and seeks feedback from people with disability and their families and carers to identify issues that limit the flexibility of funding and therefore participants' abilities to exercise choice and control.[167]

167. Summer Foundation, "Summary of Changes to Specialist Disability Accommodation Framework" (Melbourne, 2019).

Enabler: data and evidence

Quality data and evidence are critical to support better outcomes for people with disability. Any data collection and analysis should take into account the perspectives of and ideally by driven by people with disability. The design and implementation of services, programs and policy for people with disability should be informed by the best available evidence and data, including the voice and varied perspectives of people with disability. However, the use of data and evidence should not undermine the choice and control exercised by people with disability in determining what is right for them.

Historically, incomplete or ambiguous data have meant that people with disability have not been identified as a priority population group, and many experiences of discrimination and disadvantage have remained invisible. This has reinforced social attitudes of disability and contributed to entrenching disability in a medical model rather than social model.[168]

Currently, there are insufficient rigorous and comparable data and research related to disability nationally and globally.[169] The World Health Organisation's Global Disability Action Plan states that good quality data and research are essential for providing the basis for sound policy and programmes and for efficient allocation of resources in the disability space. Data and evidence are critical to deepen society's understanding of issues faced by people with disability, including identifying ways to successfully remove barriers so that people with disability can participate in and contribute to society on an equal basis.

Australia has distinct challenges in presenting a complete picture of the experiences of, and outcomes for, people with disability. Various data sources define disability in differing ways depending on the type of data and the purpose they were collected for, and data from mainstream services rarely includes a mechanism to identify whether a person has disability.[170] For example, more work is required to keep and share data on the housing needs of people with disability to ensure there is the right mix of housing being built and people's needs are being met.

The AIHW is currently continuing its work towards improving the quality and availability of national data on disability, including developing a standardised disability flag for use in mainstream services.[171] However, there is serious concern that the National Disability Agreement (NDA) disability services collection is at risk without the highly desirable, but not yet achieved, coordination between the NDIA and AIHW.[172] Without agreed and stable data standards, it will remain difficult to understand long-term trends in disability and the need for and impact of changes to policy and service design. A lack of long-term data may prevent better outcomes for people with disability being obtained which is unacceptable.

The Centre for Disability Research and Policy's Audit of Disability Research in Australia Update Report 2017 found that the policy topic gaps identified in the 2014 audit unfortunately remain the same:

- Aboriginal and Torres Strait Islander disability research
- rural and remote disability research
- structured policy evaluation
- policy studies addressing CALD populations with a disability
- multidisciplinary approaches to policy evaluation and
- research on lived experience bringing the perspectives of people with disabilities, families and carers to policy critiques.[173]

The report also suggests there is a real need for an Aboriginal and Torres Strait Islander disability research agenda to meet community need as currently most research is undertaken with limited direction and input from communities.[174] Culture is Inclusion is the first publication to distil a research agenda for Aboriginal and Torres Strait Islander people with disability to elevate and promote their voices within research and translate this into policy and practice.[175]

168. Anne Kavanagh, Lauren Krnjacki, and Monica Kelly, "Disability and Health Inequalities in Australia: Research Summary" (Melbourne, 2012).
169. World Health Organization, "WHO Global Disability Action Plan 2014-2021: Better Health for All People with Disability" (Geneva, Switzerland, 2015).
170. AIHW, "Disability: About," 2017, https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/disability/about.
171. AIHW.
172. Gwynnyth Llewellyn, "Audit of Disability Research in Australia Update Report 2017" (Sydney, 2017).164. Anne Kavanagh, Lauren Krnjacki, and Monica Kelly, "Disability and Health Inequalities in Australia: Research Summary" (Melbourne, 2012).
173. Llewellyn.
174. Llewellyn.
175. Avery, Culture Is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability.

There are some current methods which are considered good practice for the collection of data and improving outcomes for people with disability. Inclusive evaluation is a practice where people with disability are involved in evaluating a service that they use, including by acting as lead evaluator. Taking on this role challenges people's expectations and demonstrates what people with disability are able to contribute. For people with disability who have participated in inclusive research, the method reports many benefits, the primary advantage being people with disability are able to uncover the most salient issues and identify options to overcome issues raised throughout the evaluation process.[176]

The Cooperative Research Centre for Living with Autism is another good example of an organisation that prioritises inclusive research that genuinely involves autistic people and their advocates in all stages of the research process. This is a significant development given that people with autism were historically assumed to be incapable of contributing, misunderstood, ignored and excluded from decision-making processes and campaigns.[177]

The University of Melbourne undertook a participatory research approach when examining the perspectives of NDIS service users.[178] People with disability were engaged in all stages of the process from study design to collecting and analysing data to writing up the findings. This methodology allowed the combination of lived experience and academic perspectives to enhance the validity and relevance of research findings and produced rich and nuanced stories about NDIS experiences to inform both policy and practice.[179]

Despite some pockets of good practice, there is an urgent need for people with disability, government, non-government organisations, advocacy groups and the community to work together to ensure Australia has a robust and fit-for-purpose data collection and surveillance system for people with disability. This will enable Australia to provide better options and care to ensure all people with a disability can lead fulfilling lives.

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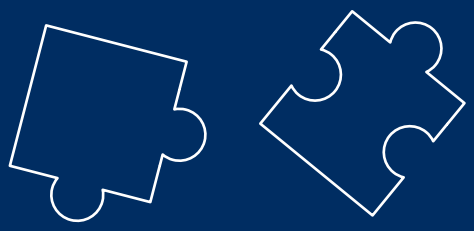

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176. Robinson, Fisher, and Strike, "Participatory and Inclusive Approaches to Disability Program Evaluation."
177. Liz Pellicano, "Autism Advocacy and Research Misses the Mark If Autistic People Are Left Out," The Conversation, April 11, 2018.
178. Warr et al., "Choice, Control and the NDIS : Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme."
179. Warr et al.

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