

# SVA Perspectives: Disability

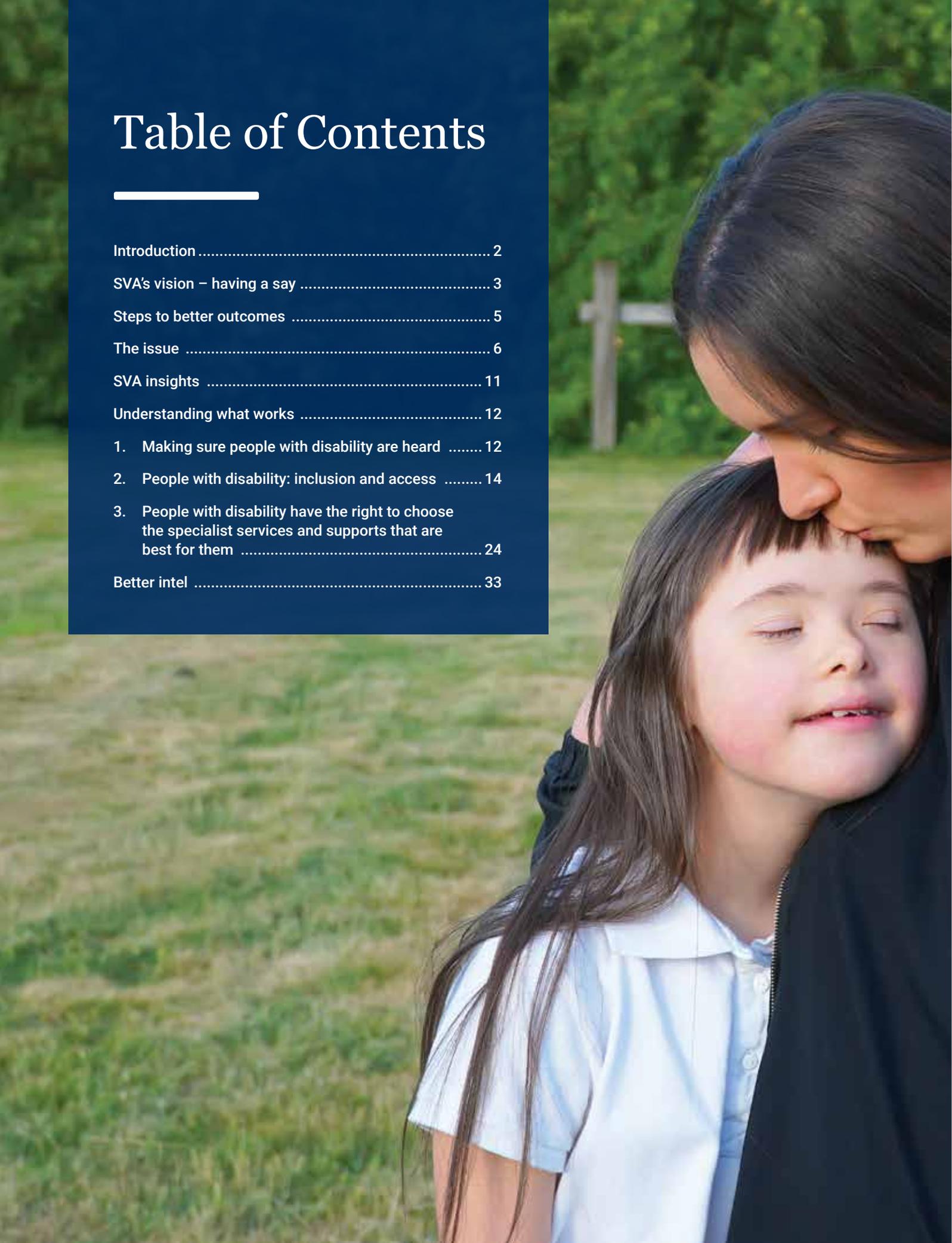
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Plain English version  
November 2019

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# Introduction

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Social Ventures Australia (SVA) is working towards an Australia where everyone is leading a fulfilling life.

While there has been some great work done, one in four people in Australia experience disadvantage.

SVA is committed to finding solutions and bringing about change. Since 2002, we have developed an understanding of what it takes to tackle disadvantage.

In 2016 SVA released a series of Perspective Papers on education, employment, housing and the things that improve the lives of First Australian people and communities.

We have used these insights to focus on two new areas: disability and mental health and to look at those greatly at risk of being disadvantaged: children in out-of-home care, Aboriginal and Torres Strait Islander children, and children and young people not attending school.

We hope that these papers start people talking and getting together to come up with new ideas that will lead to an Australia where everyone has a fair go.

**Suzie Riddell**

CEO

Social Ventures Australia



# SVA's vision – having a say

SVA has a vision for Australia where all people and communities are doing well.

We believe that all Australians should have the same rights and opportunities and that people with disability should have a say in the things that impact on their lives.

In the past, the approach to disability in Australia has been more about disability as the problem, looking at changes to the life of a person with disability (such as therapy, specialist services and in some cases even segregation) with no changes to society.

A new approach to disability looks at community attitudes as the problem. In this light, disability stems from a community filled with barriers to those living with an impairment, and the focus is placed on changes to society.<sup>1</sup> This includes a breakdown of those barriers, including discrimination, that is needed if people with disability are going to get on with their lives.

This new approach to disability is a central part of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that Australia signed up to in 2007. The UNCRPD sets an international standard for the human rights and fundamental freedoms of people with disability.

A national survey of people with disability 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.”<sup>2</sup>*

Transforming the lives and rights of people with disability is a big win for all Australians. People with disability in Australia represent about 20% of the overall population, so a lot of people are at risk of being excluded. Reports estimate that reducing unemployment rates for people with disability by just one-third would provide a \$43 billion increase to Australia's GDP over a decade.<sup>3</sup> There should be no reason for people with disability to be excluded if all the barriers are removed.

Different types of disability, including physical disability, sensory disability, intellectual disability and psychosocial disability, need to be considered when designing policies and services to make sure that everyone is included, and services are available to all. 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 different cultures who speak different languages (CALD) must be considered.

In Australia, there is a commitment to the rights outlined in the UNCRPD, and the National Disability Strategy (NDS). The NDS sets out a big agenda for reform, the most well-known of which is the National Disability Insurance Scheme (NDIS). We recognise that people with disability and their families and carers must have a big say in what happens if any positive changes are to take place.

We have used evidence to help us come up with what we believe is necessary for all people with disability to participate fully in the Australian community.

## Aims of this paper

This paper aims to look closely at disability in Australia, at the same time we do recognise that there are big differences between people with disability in Australia.

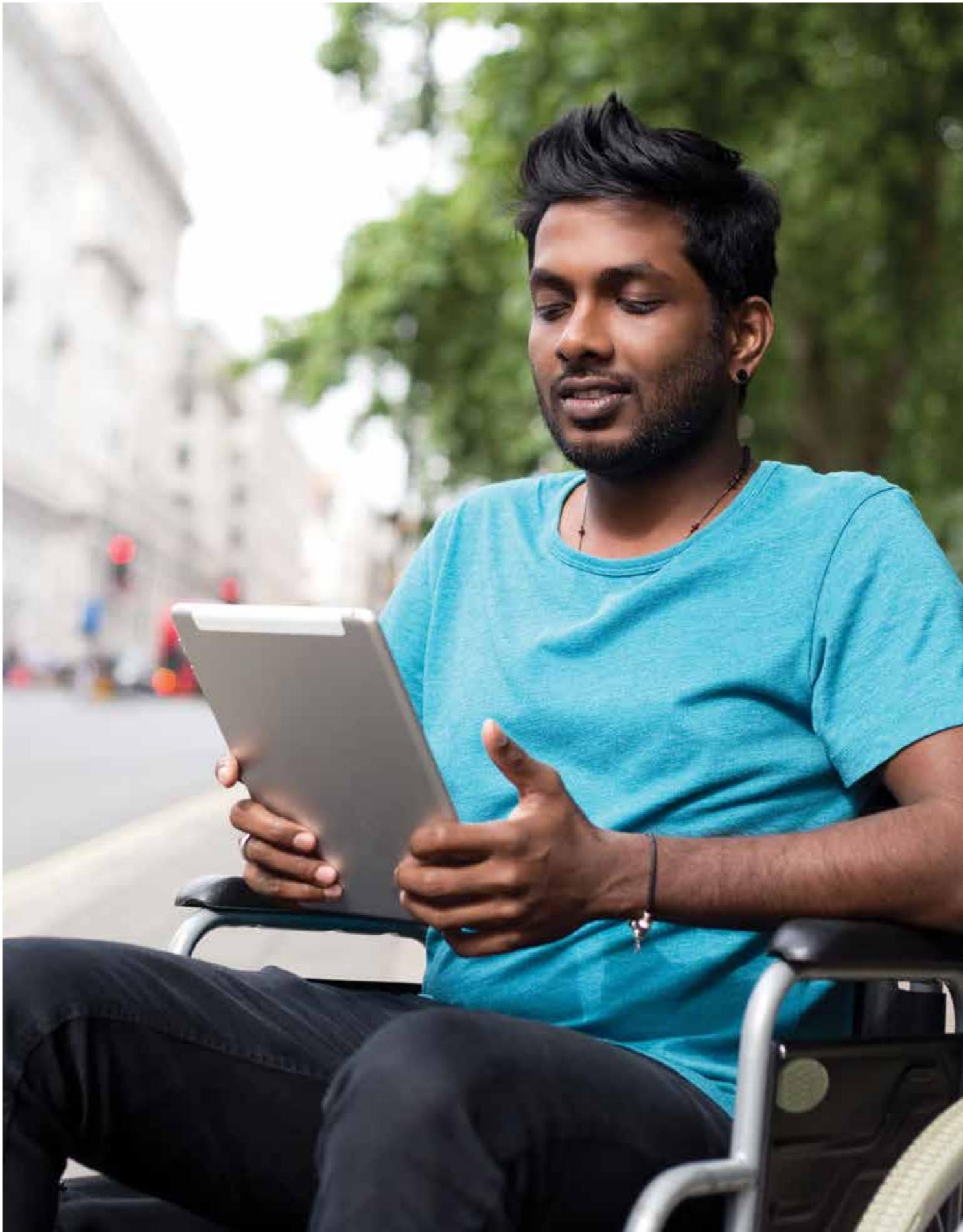
We also recognise that better outcomes for people with disability is not just up to the disability sector, but the responsibility of the whole of society.

While we have done our best, it is not possible to identify every single aspect and experience in this one paper.

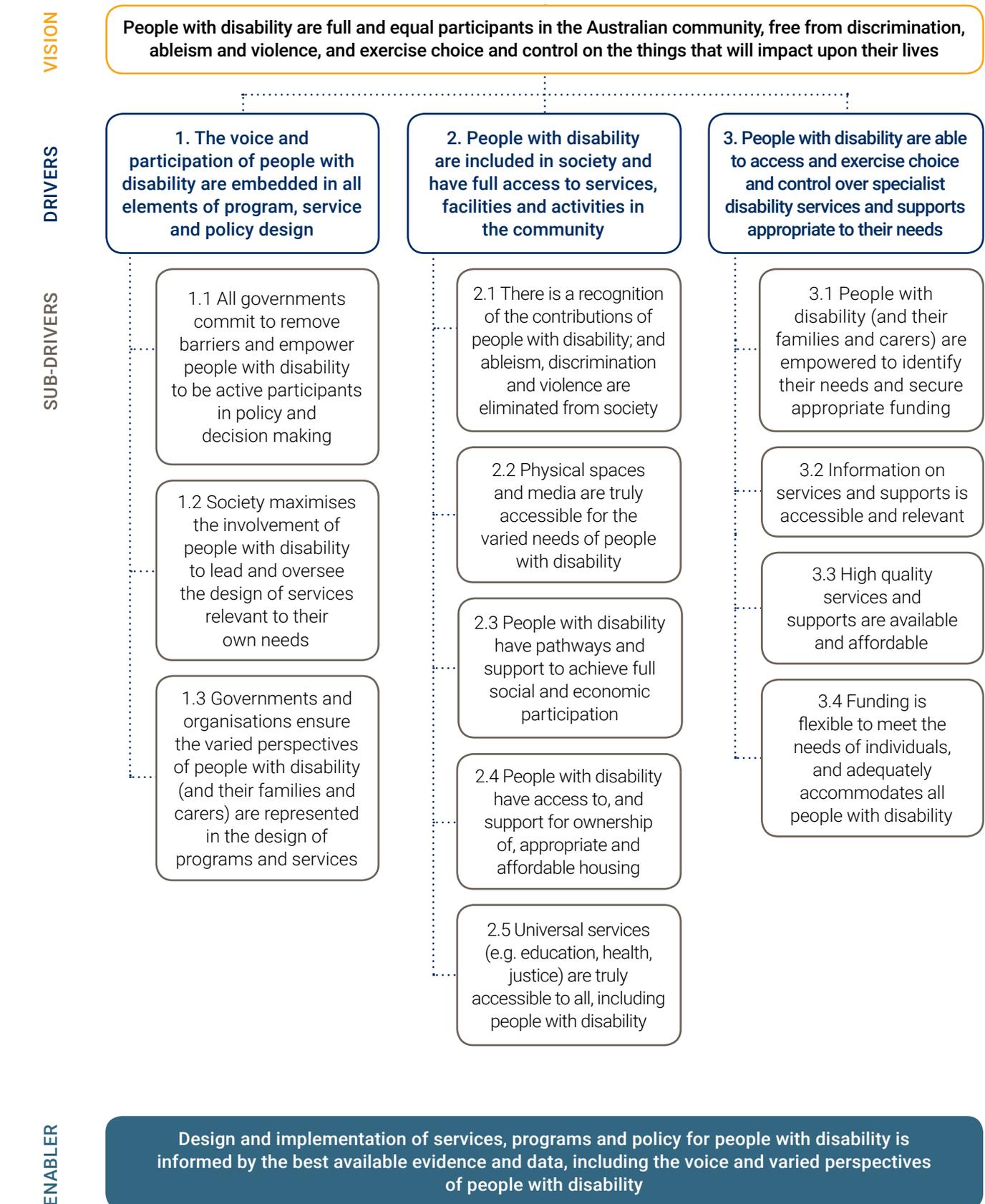
1. People with Disability Australia, "Social Model Of Disability," 2018, <https://pwd.org.au/resources/disability-faqs/social-model-of-disability/>

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).



# Steps to better outcomes



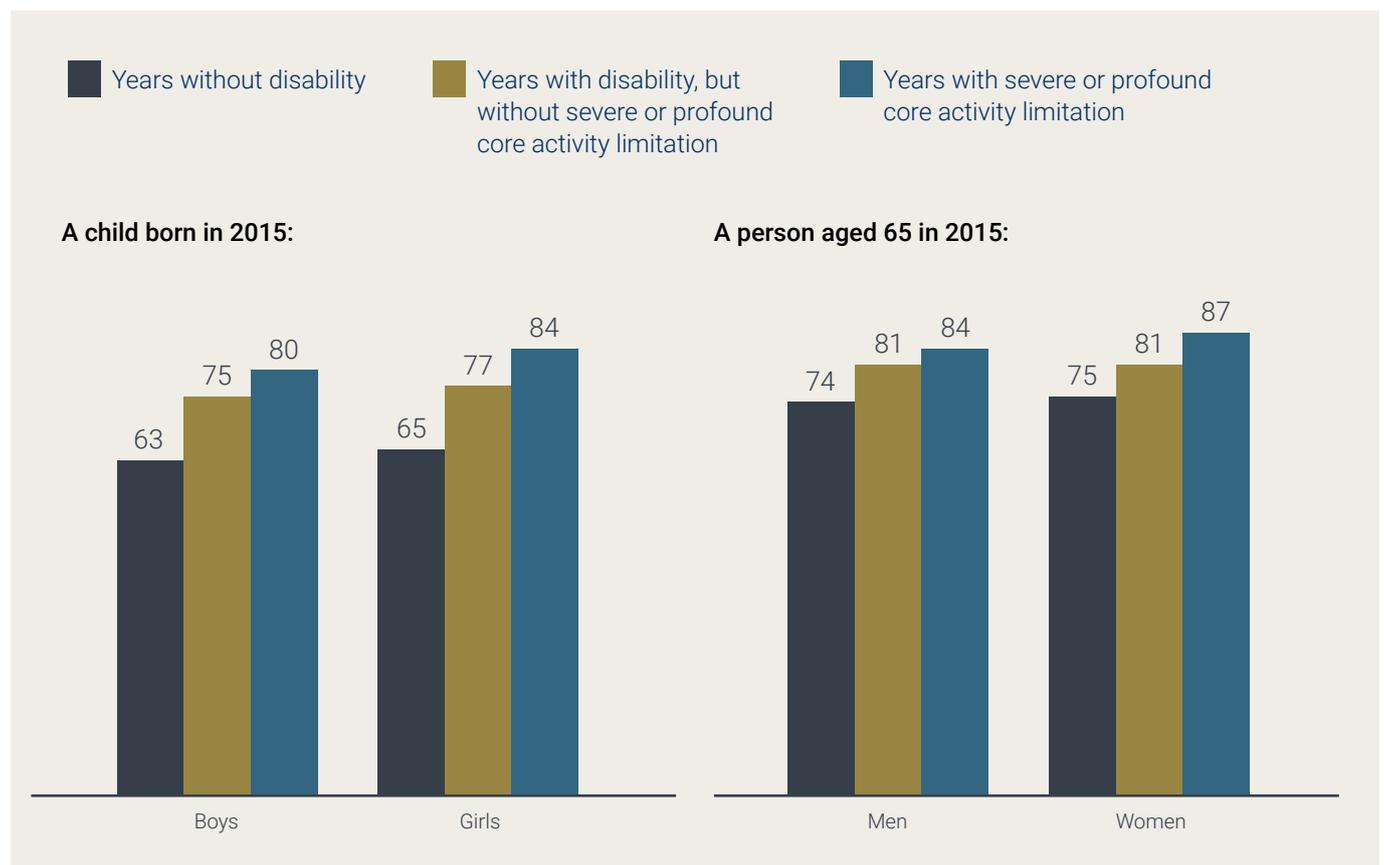
# The issue

## 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 stable since 2001.<sup>4</sup> 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.<sup>5</sup>

At birth, Australians can expect to live, on average, over one-fifth of their lives with some level of disability. By age 65, Australians can expect to live, on average, over half of their remaining years with some level of disability (Figure 1).<sup>6</sup>

Figure 1: Life and health expectancy in years



4. R Reeve et al., "Australia's Social Pulse" (Sydney, 2016).

5. ABS, "Disability, Ageing and Carers: Summary of Findings, 2015, Cat. No. 4430" (Canberra, 2016).

6. 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 policies and services.

People with intellectual disability may have difficulty learning, applying knowledge or making decisions. They could struggle with decisions at key life moments (from home to school to adult life), and require support during times of change so they can make their own choices. For children experiencing development delay, specific early intervention and therapeutic support is often required.<sup>7</sup>

The needs of people with psychosocial disability can change over their lifetime and there are some big challenges involved in making sure they fully participate in life. There is a strong focus on recovery for people with psychosocial disability and this is dependent on the type of care they receive.<sup>8</sup>

For people with physical disabilities the main challenges are in mobility, transport and self-care. Because of these challenges, they often need home modifications and technologies to assist them. However, a key barrier is the lack of access to 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 they can access.<sup>9</sup>

## What are the impacts of disability?

The way in which society views disability can have significant negative impacts on people with disability as well as their family members, friends and carers, and the wider community. It can lead to isolation, discrimination and stigma as well as health issues. For many, there are connected experiences of poverty, social exclusion, unemployment and homelessness as well as limited opportunities to have a say in what happens to them.

People with disability tend to be excluded and have poorer outcomes when compared to other members of society, including education, employment, housing and health and wellbeing. Some groups face several 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.<sup>10</sup>
- 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.<sup>11</sup>
- 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%).<sup>12</sup>

### Violence:

- 70% of women with disability have reported being victims of violent sexual encounters at some time in their lives.<sup>13</sup>
- 90% of women with 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.<sup>14</sup>

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7. ABS, "Disability, Ageing and Carers: Summary of Findings, 2015, Cat. No. 4430."

8. ABS.

9. ABS.

10. The Brotherhood of St Laurence, "Social Exclusion Monitor: Health," 2018, <https://www.bsl.org.au/research/social-exclusion-monitor/who-experiences-social-exclusion/health/>.

11. AIHW, "Disability in Australia: Changes over Time in Inclusion and Participation Factsheets: Community Living, Cat. No. DIS 67" (Canberra, 2017).

12. AIHW.

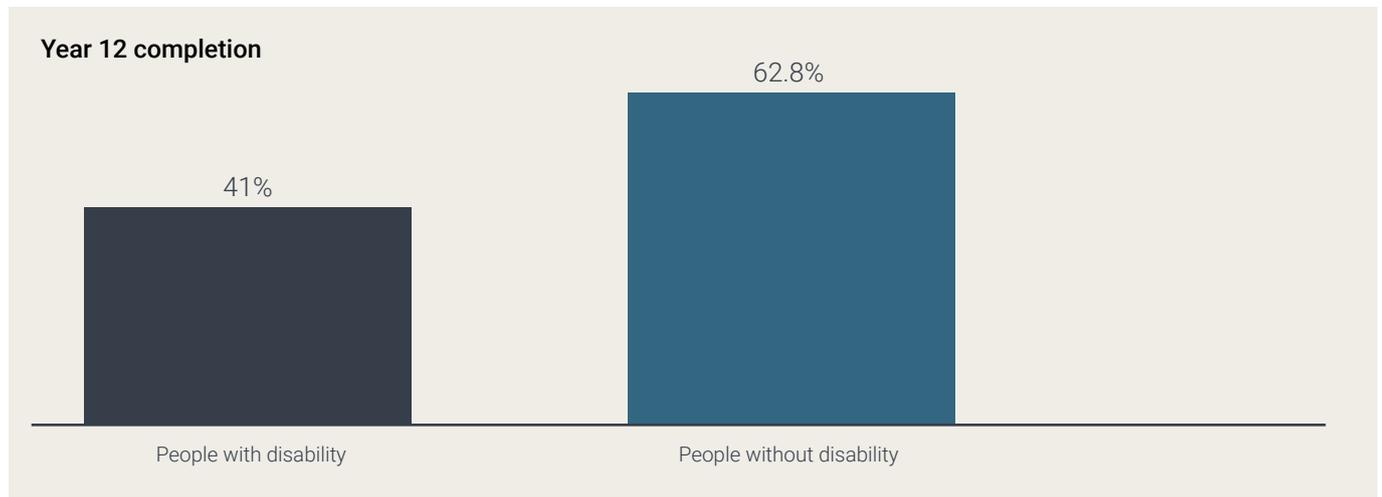
13. C Frohmader and T Sands, "Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings" (Sydney, 2015).

14. Frohmader and Sands.

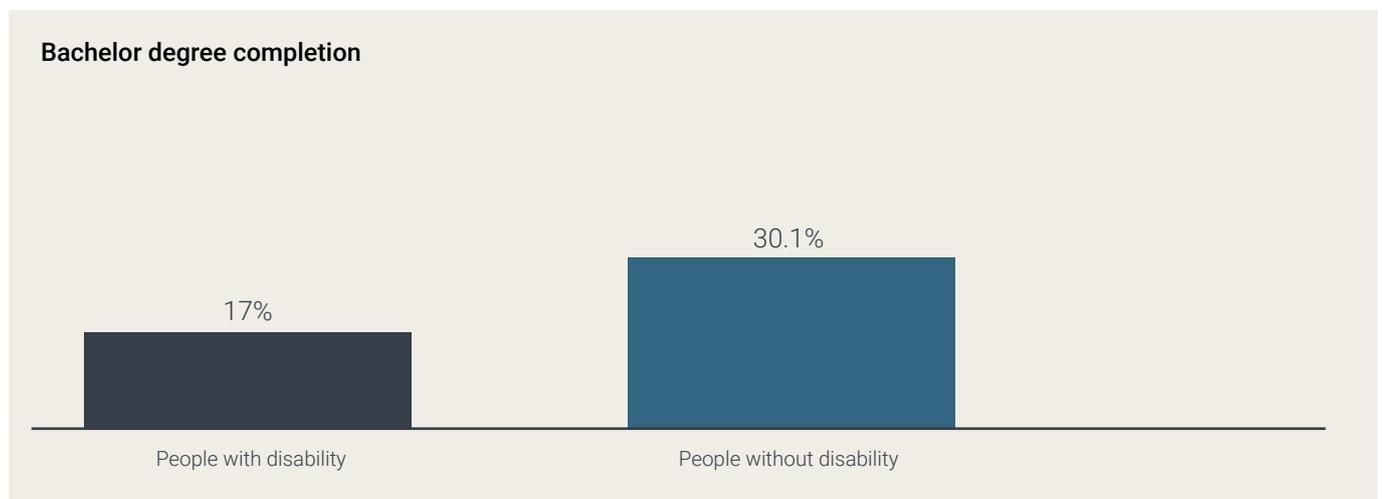
## Education:

- Only 41% of people with disability have completed year 12, compared with 62.8% of people with no disability (see Figure 1).<sup>15</sup>
- Just 17% of people with disability have a bachelor's degree, compared to 30.1% of people without disability (see Figure 2).<sup>16</sup>

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



**Figure 2:**  
Bachelor degree completion rates, by disability status



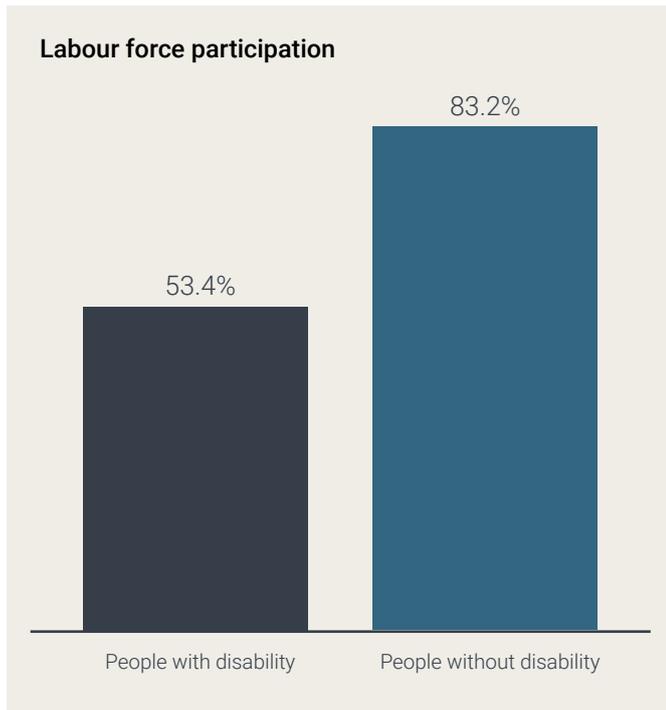
15. People aged 15-64, living in households (i.e. not in care institutions). ABS, "Disability, Ageing and Carers: Summary of Findings, 2015, Cat. No. 4430."

16. People aged 15-64, living in households (i.e. not in care institutions). ABS.

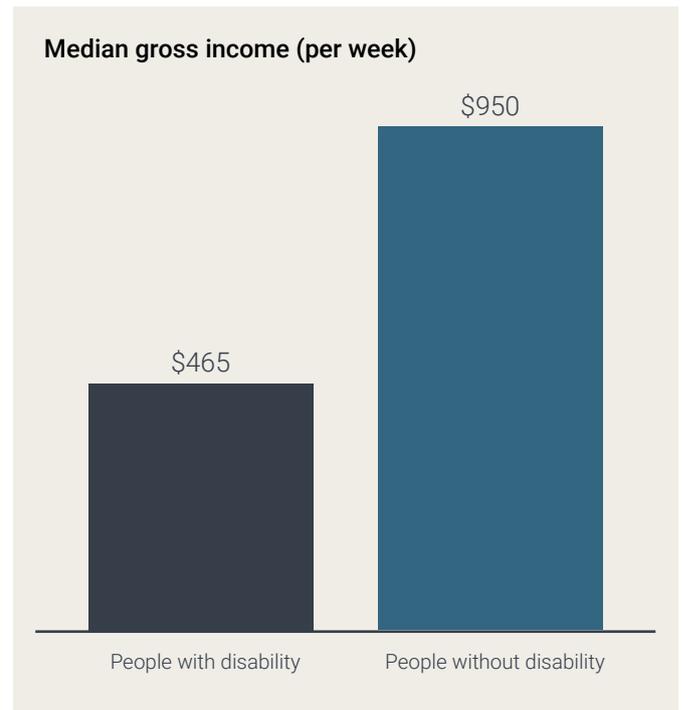
## Employment:

- 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.<sup>17</sup>
- Median gross income for people with disability is \$465 per week, compared to \$950 per week for people without disability (see Figure 4).<sup>18</sup>

**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.<sup>19</sup>
- 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.<sup>20</sup>
- 45% of Aboriginal and Torres Strait Islander people have a disability or long-term health condition.<sup>21</sup>

Many of the poor outcomes experienced by people with disability are not because of the person's impairment, but because of the failure of society to make our communities, buildings, services and public spaces easier to access. In the past, people with disability have had their basic human rights ignored and have experienced high levels of discrimination. Being left out and lacking choice and control over their lives has also resulted in a less tolerant and inclusive society where people with disability were hidden, forgotten and purposely shut out of life.

17. People aged 15-64, living in households (i.e. not in care institutions). ABS.

18. People aged 15-64, living in households (i.e. not in care institutions). ABS.

19. AIHW, "Access to Health Services by Australians with Disability, Cat. No. DIS 70" (Canberra, 2017).

20. AIHW.

21. First Peoples Disability Network Australia, "Policy Platform Federal Election 2019."

## What's happening with disability in Australia right now?

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 big shift in attitudes.<sup>22</sup> This included introducing the National Disability Insurance Scheme (NDIS) which was a landmark event for Australia.

The idea 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).<sup>23</sup>

While this has been a welcome change, there have been many teething issues and problems. Within this market, people with disability are expected to operate as consumers – choosing the services they wish to use and having control over how they are delivered. In the early life of the NDIS, more work is needed to ensure the disability and mainstream services can deliver options in sufficient numbers, variety and location to provide people with disability every opportunity.

There is also evidence that men and those with higher incomes have greater choice than the most vulnerable, such as those with intellectual disability or complex needs, substance abuse, mental health or forensic issues, socially isolated older carers and those from CALD backgrounds.<sup>24</sup> (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 people with disability in Australia.

Most people with disability want to access the same things that people without disability do: a suitable job, a good education, housing that suits their needs and transport around their community.



22. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments" (Canberra, 2011).

23. Productivity Commission, "Disability Care and Support, Report No. 54" (Canberra, 2011).

24. 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 many organisations and governments throughout Australia, we have come up with a few ideas on how the disability sector can change for better results.

- The **rights, voice and participation of people with disability are super important in discussions and decisions** which affect them. Where possible, people with disability should have a say in the policies and services that affect them. However, this does not mean that other approaches, such as advocacy, do not work.
- The government must play a more active role in developing **a quality disability services market** that 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
  - Ensuring information about services is available to all people with disability, and that individuals make meaningful informed choices
  - Employing, monitoring and adjusting appropriate pricing and investment to ensure an adequate supply of quality services for all people with disability, in particular to those living in smaller, more remote places and providers of last resort
  - Continuously monitoring and ensuring a rapid response to addressing problems and funding to ensure that a robust market develops
  - 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 organisations must focus on getting better, not just bigger. This includes **putting the needs of consumers first** and collecting and acting on client feedback. Our research found that only 1 in 18 of Australia's largest and most advanced disability services providers collected and used feedback in line with best practice, while 3 had no formal process for collecting and acting on feedback at all. This is a missed opportunity for insight and for impact.
- Social policy and programs must enable and reward any amalgamation **between the disability sector and other universal services** (such as housing, employment, education, health and justice) which reduces the risk of people missing out on services.
  - For example, there has not been enough thought about how housing support could improve outcomes and reduce the need for and cost of NDIS supports.
  - There needs to be a broad approach to education and employment pathways, with a range of options to suit the needs, abilities and desires of people with disability.
- Service delivery organisations should work 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 the majority of people with disability are not the sole responsibility of the NDIS, and that all people with and without disability need to work together for better outcomes as do all government, private and not-for-profit organisations.

# Understanding what works

## 1. Making sure people with disability are heard

The voice and participation of people with disability in all things that will impact upon their lives is at the heart of any improvement in the experiences of people with disability in Australia. Voice and participation means both inclusion in decisions, as well as equal opportunity to have choice and control over things that impact on someone's life.

Empowering voice and participation will ensure better designed programs and services and means not repeating the mistakes of the past that led to discrimination, marginalisation, violence, segregation and isolation. It is vital that people with disability, including those such as Aboriginal and Torres Strait Islanders, people from CALD backgrounds, LGBTI people, 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, not just as clients or participants but as citizens.

The experiences of people with disability in Australia in the past have involved discrimination, isolation, segregation and a loss of personal power and independence. Many people with disability continue to experience these problems, as well as ongoing 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 policy, law and decision-making.<sup>25</sup> Meaningful participation is essential if the needs of people with disability are to be met.

Despite Australia's commitment, there is still further work to be done to ensure all people with disability are involved in these processes.

Despite some opportunities and progress, it remains difficult to assess the degree to which the advice of people with disability has been considered in decision-making.

Beyond the limited formal mechanisms, much work remains to be done to build the ability of organisations to engage people with disability in policy and decision-making processes.

Many organisations display a general lack of understanding of disability and how they can change their approach to promote the inclusion and participation of people with disability.<sup>26</sup> They often do not consider the different types of disability and varied perspectives and needs.

It has also been 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 take part in advisory groups have reported being spoken down to or being ignored.<sup>27</sup> Other barriers 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.<sup>28</sup> If the right steps are taken to reduce the barriers, then people with disability can add real value – as shown in the positive example below.

25. United Nations, "Convention on the Rights of Persons with Disabilities" (2007).

26. 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>.

27. 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>.

28. 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."

## 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 take part in decision-making. They run training to help develop leadership skills and encourage people in the art of speaking up.<sup>29</sup> People with intellectual disability play key roles in the organisation and more than half of all Board positions must be held by people with intellectual disability.<sup>30</sup>

CID is active via public campaigning and policy, also offering disability awareness training, translation of materials into Easy English and consulting services.<sup>31</sup> As part of their advocacy work, CID has brought together people with intellectual disability, academics and government decision-makers to highlight good practice and seek positive change. While roundtables are not new, 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.'<sup>32</sup> 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.<sup>33</sup>

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 at all levels.<sup>34</sup>

Greater recognition of the different types of disability and the opinions of people with disability is needed, as well as the chance for them to be heard. 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 so that people are clear on how to engage with the content discussed and how to contribute meaningfully.<sup>35</sup> Otherwise, people may feel their involvement is token and they may drop out.

Among the different types of disability, there are not enough people with intellectual disability on bodies providing advice to governments - so do government policies and services really reflect what people with intellectual disability want and need?<sup>36</sup>

While the participation of people with disability in decision-making should be encouraged where possible, it is important to recognise that some people cannot or may not want to participate themselves. For those people, advocacy can be vital to ensuring their views are included.

Unfortunately, from June 2020 State Governments will no longer fund independent disability services, including funding for disability advocacy. Without certainty of funding, 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 or advocate on their behalf.

This is unacceptable and the funding for advocacy either needs to be rectified, or other mechanisms to 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 their needs, but also all universal services, to ensure an end to the social barriers and attitudes that reinforce discrimination.

29. Council for Intellectual Disability, "NSWCID: What We Do," accessed June 5, 2019, <http://www.nswcid.org.au/what-we-do/what-we-do.html>.

30. 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).

31. Council for Intellectual Disability, "NSWCID: What We Do."

32. 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."

33. Bigby and Henderson.

34. Bigby and Henderson.

35. Frawley and Bigby, "Inclusion in Political and Public Life: The Experiences of People with Intellectual Disability on Government Disability Advisory Bodies in Australia."

36. 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: inclusion and access

### 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 end discrimination and exclusion. 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."<sup>37</sup>*

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.<sup>38</sup>

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."<sup>39</sup>*

Essential to a more inclusive society is public awareness of the fundamental human rights of people with disability, and recognition 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. To achieve this, 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.<sup>40</sup>

Sadly, there remains a high incidence of violence against people with disability with more than 70% of women with disability having reported being victims of violent sexual encounters at some time in their lives.<sup>41</sup> 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.<sup>42</sup>

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 devaluing 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 through 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.*

37. 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."

38. AHRC, "Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability," 2016.

39. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."

40. 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>.

41. 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."

42. Frohmader and Sands.

*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.”<sup>43</sup>*

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is an important step towards making people aware of the experiences of people with disability and 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.”<sup>44</sup>*

## Physical spaces

The physical environment is an obvious barrier for many people with physical disability taking part 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.<sup>45</sup> Access difficulties often involved stairs, internal doors, corridor widths, ramps, handrails and lighting.<sup>46</sup>

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.<sup>47</sup> There is certainly a need for these standards to be applied as they were intended to make it easier for people with disability to enter public spaces. Barriers to access exist even in places not legally required to be upgraded. 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.<sup>48</sup>

The first step in removing barriers is to introduce a standard in the design of parks, houses, shopping centres and sporting arenas so that they can be accessed, understood and used as much as possible by all people regardless of their age, size, ability or disability.<sup>49</sup>

Australia has taken some important steps towards doing this and reducing barriers, including the adoption of minimum accessibility standards for public transport and buildings. However, there is certainly more work to be done.

## Transport

The ability to move around the community is a basic right for people with disability and is essential to taking part 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.<sup>50</sup>

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. Also, people with disability are often still unable to use 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.<sup>51</sup> 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.

Australia has improved its public transport but more needs to be done. 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.

## Media and information

People with disability require information that is easy to find and delivered in ways that suits everyone’s needs. Digital, web and broadcast content should be able to be used, read or viewed by people with disability, especially those who are blind, vision impaired, deaf, hearing impaired, or who have a cognitive condition or mobility disability.<sup>52</sup>

43. 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).

44. National People with Disabilities and Carer Council, “Shut Out: The Experience of People with Disabilities and Their Families in Australia.”

45. AIHW, “Access to Health Services by Australians with Disability, Cat. No. DIS 70.”

46. AIHW.

47. 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.

48. 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.

49. Centre for Excellence in Universal Design, “What Is Universal Design?,” *Universal Design*, 2014, <http://universaldesign.ie/What-is-Universal-Design/>.

50. COAG.

51. COAG.

52. <https://mediaaccess.org.au>.

Creating access to media and online information, with the aid of technology, helps people with disability to be more independent, to gain knowledge, make their own informed choices, and be active members of our society.<sup>53</sup>

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.<sup>54</sup> This 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.<sup>55</sup>

This shows that access to websites, online information, digital communications, streaming services and broadcast television, as well as access in the classroom, cinema and the arts is important to the inclusion of people with disability and should be compulsory across all formats.<sup>56</sup>

## Making friends and finding work

### Being included

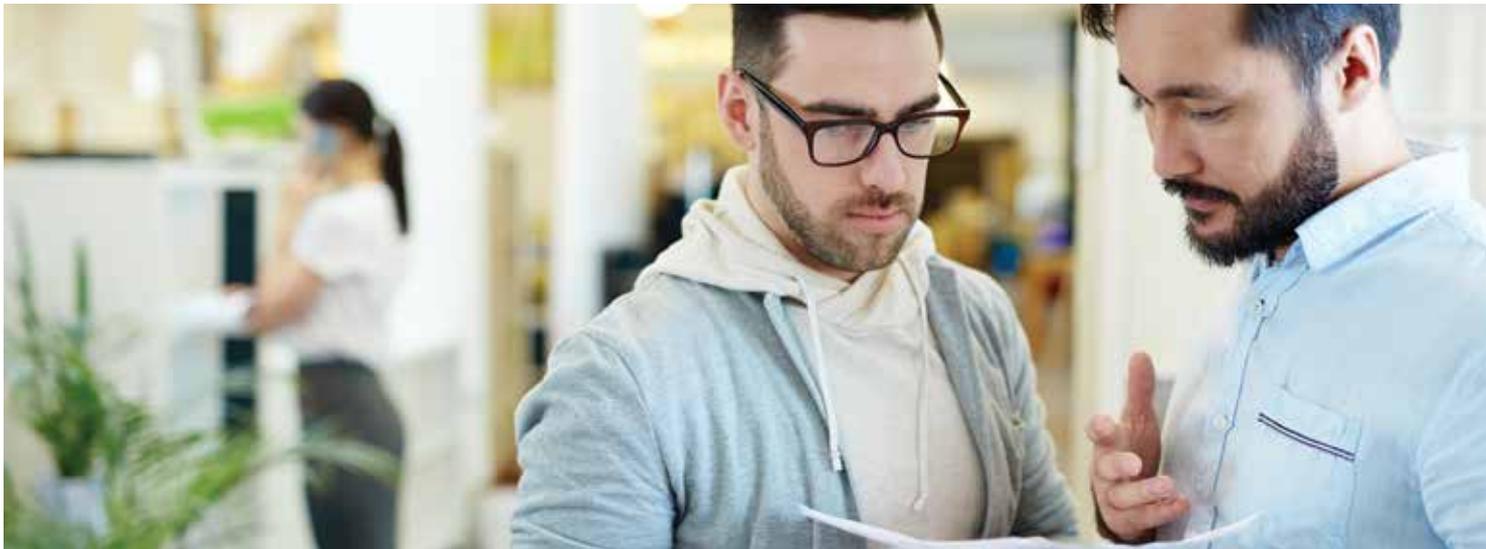
We already know that social networks and relationships with other people are very important to people with disability and to their sense of wellbeing and belonging. Children with a disability however, are often excluded from a very young age and miss out on a lot of life's activities. Alarming, children 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.<sup>57</sup>

Supporting people with disability in having meaningful relationships is more about recognising the other valuable and varied roles they play. One NDIS study suggests that policy needs 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.<sup>58</sup>

There has been a shift towards supporting people with disability to live at home or in the community, rather than in institutions.<sup>59</sup> In 2015, most 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.<sup>60</sup> 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.<sup>61</sup>

### 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.<sup>62</sup> The unemployment rate for people with disability was also higher at 10% compared to 5.3%.<sup>63</sup> These rates have barely shifted since 1998 and the gap in employment rates is significantly wider in Australia compared to other OECD countries.<sup>64</sup> While not all people with disability are in a position to be able to do paid work, the contrast 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.



53. <https://mediaaccess.org.au>.

54. <https://www.theguardian.com/australia-news/2019/jun/29/ndis-sent-letters-to-vision-impaired-and-blind-people-in-format-they-could-not-read>

55. <https://www.theguardian.com/australia-news/2019/jun/29/ndis-sent-letters-to-vision-impaired-and-blind-people-in-format-they-could-not-read>

56. <https://mediaaccess.org.au>.

57. Telethon Kids Institute, "Children with Disabilities 3 Times More Likely to Be Maltreated but Risk Varies by Disability Type," 2017.

58. Ariella Meltzer and Laura Davy, "Supporting NDIS Participants' Interpersonal Relationships," The Mandarin, March 21, 2019.

59. AIHW, "Disability in Australia: Changes over Time in Inclusion and Participation Factsheets: Community Living, Cat. No. DIS 67."

60. AIHW.

61. AIHW.

62. ABS, "Disability, Ageing and Carers: Summary of Findings, 2015, Cat. No. 4430."

63. ABS.

64. 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.

HGJTC uses a demand-led brokerage model that starts with the employer to build their confidence to employ people with a disability. Over a two-year period, the program achieved outcomes for both employers and job seekers. For job seekers with disability, the program supported 39 placements with very high retention rates.

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.

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.

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.

### Job options

For some people with disability, open employment or employment in mainstream jobs may not be what they want. 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.<sup>65</sup> At their best, ADEs can offer work opportunities to people who might otherwise be entirely excluded, and can lead to getting other jobs. However, many ADEs have been criticised, because they may have segregated workplaces and pay low wages. These features of ADE employment can increase feelings of isolation and low expectations of people with disabilities.<sup>66</sup>

Social enterprises are another path to employment for people who have been locked out of the general workplace or need a way to find 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.<sup>67</sup>

However, the opportunities for employment in social enterprises are limited right now. Further work is needed so that social enterprises can be an employment option for more people, and provide people with intellectual disability with more options.<sup>68</sup> Several Australian governments are currently seeking to expand social enterprise development, including where government gives preference to goods and services from organisations with a social benefit.

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 negative effects of income support that lead to poverty and reduce access to housing, health and other supports must be recognised and addressed. There also needs to be a broader approach to disability employment to reflect the varied needs of people with disability and more opportunities for employment for those looking for it.

65. 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>.

66. 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>.

67. 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>.

68. Meltzer, Kayess, and Bates.



### **A happy ending for James: case study**

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.

## Prejudice in the workplace

The Disability Discrimination Act 1992 (Commonwealth) requires all employers to make reasonable adjustments so people with disability can have jobs that match their skills.<sup>69</sup> However discrimination remains a big 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.<sup>70</sup>

The Australian Network on Disability's (AND) 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'.<sup>71</sup> AND has developed the Access and Inclusion Index which provides workplaces with the tools to measure their practices that foster better access and inclusion.<sup>72</sup> The online tool helps workplaces by investigating their progress in 10 areas including workplace adjustments, recruitment and selection and career development.<sup>73</sup> Workplaces that have been rated highly have improved inclusion by ensuring that mentoring and training is delivered in an accessible manner. Annual awards for exceptional inclusion practices are held and have a diverse team who provide career support and development to staff members with disability.<sup>74</sup>

The Commonwealth Government's Job Access website provides information for employers about how to employ people with disability and about financial assistance and incentives. Despite these positive actions, there is clearly much more that needs to be done with employers to ensure that people with disability 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 benefit 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."<sup>75</sup>*

## Money, Money, Money

For people with disability who cannot work, income support is vital. Unemployment 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.<sup>76</sup>

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 mean fewer people are getting this payment. It has been reported that 73,000 DSP claims were rejected in 2017-18, a rejection rate of 70%.<sup>77</sup> The Commonwealth



69. AHRC, "Disability Discrimination Act Guide: Earning a Living," 2012, <https://www.humanrights.gov.au/our-work/disability-rights/dda-guide-earning-living>.

70. Stancliffe, "Inclusion of Adults with Disability in Australia: Outcomes, Legislation and Issues."

71. Australian Network on Disability, "Access and Inclusion Index Benchmark Report 2017-18" (Sydney, 2018).

72. Australian Network on Disability, "Access and Inclusion Index," 2019, <https://www.and.org.au/pages/access-inclusion-index.html>.

73. Australian Network on Disability.

74. Australian Network on Disability.

75. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."

76. OECD, "Sickness, Disability, and Work - Breaking the Barriers (A Synthesis of Findings Across OECD Countries)."

77. Luke Michael, "Disability Groups Weary as DSP Appeals Skyrocket," Pro Bono Australia, February 22, 2019.

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.<sup>78</sup>

New work requirements for younger DSP recipients and the introduction of eligibility reviews have also contributed to reduced DSP numbers.<sup>79</sup> Reduced access to DSP for people with disability has increased the risk of poverty and therefore made it more difficult for many to secure suitable housing, health services and other support.

*"Disability support recipients live in 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?"<sup>80</sup>*

An increasing number of people with disability 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 stricter job search and activity obligations.

### **A roof over your head**

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.<sup>81</sup>

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.<sup>82</sup>

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. It's estimated 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.<sup>83</sup>

In addition to financial 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 suitable housing stock and of information about accessibility.<sup>84</sup> 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.<sup>85</sup> 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..."<sup>86</sup>*

There are some approaches emerging that show promise in helping people with disability to find their own housing. Shared ownership, 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.<sup>87</sup> Some people with disability have 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 possible option for some.<sup>88</sup>

78. Commonwealth Ombudsman, "Department of Human Services: Accessibility of Disability Support Pension for Remote Indigenous Australians, Report No. 05/16" (Canberra, 2016).

79. Australian National Audit Office, "Qualifying for the Disability Support Pension, ANAO Report No. 18 2015-16" (Canberra, 2016).

80. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."

81. Ilan Wiesel et al., "Moving to My Home: Housing Aspirations, Transitions and Outcomes of People with Disability, AHURI Final Report No.246" (Melbourne, 2015).

82. Disability Housing Futures Working Group, "People with Disability Living in Inadequate Housing: Prevalence, Trends, and Health and Workforce Participation Outcomes" (Brisbane, 2016).

83. Laurence Troy, Ryan Van Den Nouweland, and Bill Randolph, "Estimating Need and Costs of Social and Affordable Housing Delivery" (Sydney, 2019).

84. 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>.

85. AIHW, "Specialist Homelessness Services Annual Report 2017–18" (Canberra, 2019).

86. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."

87. 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>.

88. Wiesel et al.



### **Case Study: Project Independence**

SVA has worked with Project Independence, a not-for-profit community housing provider, to provide people with 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 will likely 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 ideas 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 a new program that brings together short-term accommodation, individual outreach and a warm line of support to people, with the aim to avoid hospitals unless 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 that shows the benefits of early intervention, 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.

Another example, the NSW Housing and Accommodation Support Initiative (HASI), has been great at supporting people to live independently in the community. HASI applies a client-centred approach to provide support that includes providing social housing at the same time as 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.<sup>89</sup> Many of the people assisted through the HASI scheme had dual diagnoses that included physical and intellectual disabilities. The aim was to provide support to access and maintain residency, recover, stay connected with and participate in their communities, and experience improvements in the quality of their life.<sup>90</sup> The HASI evaluation showed positive health and housing outcomes for those who took part, 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.<sup>91</sup>

Ensuring that people with disability have affordable access to suitable housing requires an adequate and appropriate supply of housing, the right support services to help people maintain tenancies and improve their quality of life, and pathways to positive change and progress. To achieve this, governments must provide the right combination of funding, regulation, and service provision.

It is beyond this paper to consider the full range of challenges and opportunities for the Australian social and affordable housing market; more on this can be found in SVA's Housing Perspective Paper.<sup>92</sup>

There is a great opportunity for the state and Commonwealth governments to work together to streamline funding and support for housing for people with disability, not least because having suitable and affordable housing reduces the need and cost for more support services. As we've said, 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 way social and community housing is run, to work jointly with the NDIS on an investment approach that sees an investment in accessible, suitable social and community housing stock that reduces the need for NDIS supports.

### Universal services

A major goal of the NDS is to get more people with disability involved in mainstream services. However, to achieve this aim, the majority of these services which include education, health, housing, and justice need to change to become more inclusive and accessible.<sup>93</sup>

### The Magic of Education

People with disability continue to experience lower levels of schooling, both in secondary and tertiary education, compared to other Australians, limiting employment prospects for many and contributing to the continued exclusion of people with disability from our society.<sup>94</sup> 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%).<sup>95</sup>

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.<sup>96</sup> This has slightly increased since 2003 but more needs to be done to ensure Australia creates inclusive and accessible education. There is a need to improve the ability of all education providers to deliver inclusive high-quality educational programs for people of all abilities.<sup>97</sup> There is also a need to ensure that NDIS-supported services work more easily with educational services, so that children are not denied access due to disputes about which agency is responsible for supporting them.

89. 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>.

90. Muir et al.

91. Muir et al.

92. Social Ventures Australia, "SVA Perspectives: Housing" (Sydney, 2016).

93. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."

94. AIHW, "Disability in Australia: Changes over Time in Inclusion and Participation in Education, Cat. No. DIS 69," 2017.

95. AIHW.

96. AIHW.

97. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."

There is new research in early learning settings that tells us 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.<sup>98</sup> 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 than people without disability and this is often due to a health system that does not meet their needs. People with disability tend to lack access to health services, endure lengthy waiting times, impossible costs and discrimination by health professionals.<sup>99</sup> Because more often they have several ailments at once, 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.<sup>100</sup> 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."<sup>101</sup>*

Sticking to the traditional medical approach to providing disability services has unfortunately created dependence rather than independence for people with disability and a health system that is not equipped to properly cater to their needs.<sup>102</sup> 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.<sup>103</sup>

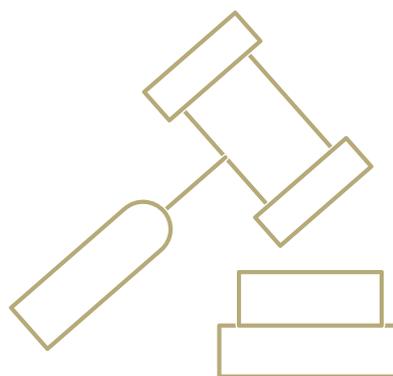
Australia's health system therefore needs to be responsive to the needs of people with disability and there is a great deal more to be done to provide suitable health services for people with disability. There is a need for an overall co-ordinated approach and the fusing of disability and health services 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.<sup>104</sup>

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 leaving jail to go back into the community, to ensure continued support. Many states and territories have committed to court diversion programs for people with disability to respond to both their disability and offending needs.<sup>105</sup>

People with disability need equal access to justice which may require aids and equipment so they can fully take part in all legal proceedings. Disability awareness training for the judiciary, legal professionals and court staff would help to ensure they can participate and help protect their rights.<sup>106</sup>



98. 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>.

99. AIHW, "Access to Health Services by Australians with Disability, Cat. No. DIS 70."

100. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."

101. National People with Disabilities and Carer Council, "Shut Out: The Experience of People with Disabilities and Their Families in Australia."

102. 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>.

103. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."

104. 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).

105. COAG, "2010 - 2020 National Disability Strategy: An Initiative of the Council of Australian Governments."

106. COAG.

### 3. People with disability have the right to choose the specialist services and supports that are best for them

#### 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 are essential for many people with disability to be full and equal participants in society.

The NDS is the 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.<sup>107</sup> 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.<sup>108</sup>

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

Clearly, more needs to be done to ensure better cooperation between governments, advocacy bodies, services and individuals including greater political will and leadership to ensure the NDIS is successful.<sup>109</sup>

#### Services that match people's needs

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 suitability of services and supports is super important to make sure people with disability can fully participate in our community.

For many people with disability in Australia, specialist services and supports have always meant a loss of personal independence 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".<sup>110</sup> While there have been improvements, 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."<sup>111</sup>

The introduction of the National Disability Insurance Scheme (NDIS) in 2013 represented a big 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 mostly run by professionals.<sup>112</sup> Including choice and control, the objectives of the NDIS are the provision of reasonable and necessary supports, 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 become disabled
- All people with disability – Providing information and referrals to services in the community
- Eligible people with disability – Providing individual funding to people with significant care and support needs, as a supplement to the roles played by family and community.<sup>113</sup>

At full roll-out, 460,000 Australians with disability or around 10 per cent of people with disability are expected to receive individual supports.<sup>114</sup> While it's not yet been rolled out in all states and territories, it is already the primary funder of services to people with disability in Australia. But the design and application of the NDIS faces major challenges to adequately:

107. COAG.

108. COAG.

109. 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>.

110. 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."

111. Productivity Commission, "Disability Care and Support, Report No. 54."

112. 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).

113. Productivity Commission, "Disability Care and Support, Report No. 54."

114. National Disability Insurance Agency, "What is the NDIS?," 2019, <https://www.ndis.gov.au/understanding/what-ndis>.

*“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.”<sup>115</sup>*

## Needs, choice, control, funding

The NDIS was designed with choice and control for people at the centre. Generally, people with disability have moved from block-funded disability services that offered little choice or control due to funding limits and budgets held by service providers, to being the “holder” of personalised funding to access supports that are approved by the National Disability Insurance Agency (NDIA).

With this approach, 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 are not always possible for people with disability for a variety of reasons including the complexity of systems, not having enough support to exercise it,<sup>116</sup> not knowing the new systems, inexperience of making choices and/or undeveloped communication tools needed for planning and decision-making. While the new consumer-oriented approach has created greater satisfaction among those who are able to exercise choice and control, sadly, NDIS has not worked for everyone.<sup>117</sup>

The NDIS set-up 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 evidence that those least able to navigate the system are more likely to receive less funding.<sup>118</sup>

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.<sup>119</sup> 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.”<sup>120</sup>*

As well, 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’.<sup>121</sup>

Local Area Coordinators (LACs) are the best contacts for people who would like to access the NDIS with information and support. LACs can assist people to: understand and access the NDIS; create and realise 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 and to advocate for the supports they need. There is a big difference in the skills and capabilities of individual LACs, particularly around their understanding of the 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 financial challenges.

Also, NDIS planners who are responsible for approving NDIS plans have also shown they have an inconsistent understanding of the different types of disability and of what ‘reasonable and necessary supports’ means. All these challenges can present big barriers to people with disability getting the right support for their needs, and particularly affects people with lower cognitive abilities or those who do not have strong advocates.

115. Warr et al., “Choice, Control and the NDIS : Service Users’ Perspectives on Having Choice and Control in the New National Disability Insurance Scheme.”

116. Warr et al.

117. Kostas Mavromaras et al., “NDIS Evaluation Consolidated Report” (Adelaide, 2018).

118. Malbon, Carey, and Meltzer, “Personalisation Schemes in Social Care: Are They Growing Social and Health Inequalities?”

119. Mavromaras et al., “NDIS Evaluation Consolidated Report.”

120. Productivity Commission, “National Disability Insurance Scheme (NDIS) Costs, Study Report” (Canberra, 2017).

121. 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.

## Who qualifies for NDIS?

Discussions continue about who should qualify for the NDIS and who is actually able to access it.<sup>122</sup> While the NDIS provides greater access to disability services for some, those found not to qualify have experienced reduced access to services or a rise in the cost of services that had been free before.<sup>123</sup>

This is particularly obvious for people experiencing psychosocial disability.<sup>124</sup> 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.<sup>125</sup>

The good news is that a progress report recently 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 works better for everyone.<sup>126</sup>

But even if the psychosocial disability stream is modified, by its very design, the scheme (which is based on an insurance model) must intentionally exclude certain groups of people with disability to ensure the overall financial health of the scheme. A challenge that has popped up already is ensuring adequate coverage and supports for those who may not qualify for the NDIS. This requires the NDIA and the federal and state governments to work together more to ensure those who don't qualify for the NDIS do not fall through the cracks.

## It's never too early...

It is well established that the best time to step in to improve a person's 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."<sup>127</sup>

Since children with disability face more social exclusion and barriers to taking part in many of life's activities, and childhood is a critical time for development, the NDIS has introduced the Early Childhood Early Intervention (ECEI) approach which is available to all children aged 0-6 years with a developmental delay or disability.<sup>128</sup> This is vital

for children with disability if they are to achieve the best possible outcomes throughout their life. The ECEI approach aims to ensure that parents or primary caregivers provide these young children with experience.<sup>129</sup>

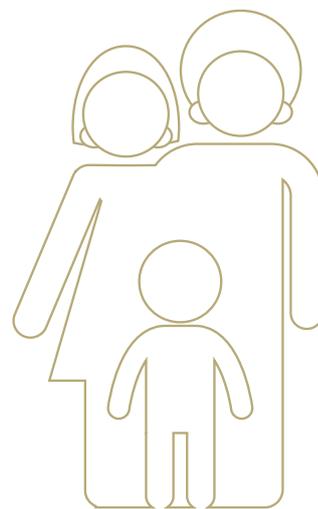
## Finding out about services and supports

Given the barriers people with disability face in having input into disability services, there is a big debate over what it means for a disability service system to be driven by consumer choice.<sup>130</sup> Flexible systems, that take account of a person's specific disability, culture, communication and literacy levels, are important in delivering disability services that achieve positive outcomes for all people who qualify for them.

Information needs to be accessible and relevant for people with disability to be able to use it. This will only come about as the scheme grows and develops, and through talking with the people it's meant for.

Officially, NDIS participants can get help from LACs and, if eligible, from Support Coordinators to understand what's available in their area. However, knowing what different services and supports are in place depends on the performance and knowledge of individual LACs or Support Coordinators. There is also a big variety in outcomes for people based on their capacity to interpret the various options and self-advocate for their needs.<sup>131</sup> New organisations are trying to help with this, typically in the form of online directories with user reviews.

However, challenges will continue to remain for some, for instance people with sensory or intellectual



122. Karen R Fisher, "Understanding the NDIS: Many Eligible People with Disabilities Are Likely to Miss Out," The Conversation, 2016.

123. Kostas Mavromaras et al., "NDIS Evaluation Consolidated Report - Appendix to Final Report" (Adelaide, 2018).

124. 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).

125. Smith-Merry et al.

126. Joint Standing Committee on the National Disability Insurance Scheme, "Progress Report 2019: General Issues around the Implementation and Performance of the NDIS" (Canberra, 2019).

127. 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>.

128. 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.

129. National Disability Insurance Agency, "Help for Children under 7," 2019, <https://www.ndis.gov.au/understanding/how-ndis-works/help-children-under-7>.

130. Warr et al., "Choice, Control and the NDIS: Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme."

131. Mavromaras et al., "NDIS Evaluation Consolidated Report."

disability, people from culturally and linguistically diverse backgrounds, or people who identify as Aboriginal or Torres Strait Islander. For example, improving access to disability services for people who were born overseas and/or speak a language other than English at home may require translated information, targeted channels to alert people that these services are available and how to access them, and targeted campaigns to remove the stigma of having a disability.

A survey of 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; and people with intellectual disability and psychosocial disability were the least satisfied that their supports were reasonable and necessary.<sup>132</sup>

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

Disability in Aboriginal and Torres Strait Islander communities is both more common and more complex compared to other Australians. The high rates of disability are partly because of colonisation, intergenerational trauma and ongoing social, cultural and political isolation and neglect as well as a major lack of public infrastructure in remote Aboriginal communities. It's complicated because of a high number of co-existing disabilities and that these multiple disabilities crop up within a life expectancy that is much lower than other Australians.<sup>133</sup>

An evaluation of the NDIS found the number of Aboriginal and Torres Strait Islander people with disability taking part in the scheme was less than the actual high levels of disability. While awareness of the NDIS has improved, Aboriginal and Torres Strait Islander people have struggled with the complicated NDIS processes and documentation and their understanding of the NDIS remained low throughout the evaluation.<sup>134</sup>

Other barriers for Aboriginal and Torres Strait Islander peoples 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 the lack of a dedicated Aboriginal and Torres Strait Islander support unit within the NDIA.<sup>135</sup>

The First People's Disability Network's Culture is Inclusion project found that Aboriginal people with disability are subject to discrimination related to their disability as well as their race.<sup>136</sup> So, Aboriginal and Torres Strait Islander people face more challenges in accessing both disability and universal services than non-Indigenous people with a disability.

The diagram below shows how the experience of intersectional discrimination for Aboriginal and Torres Strait Islander people accumulates over the life course.<sup>137</sup>

### 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 overshadowing	Inadequate public infrastructure especially in remote communities.

■ Aboriginal and Torres Strait Islander    ■ Disability

132. Mavromaras et al.  
 133. Scott Avery, Culture Is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability (Sydney: First Peoples Disability Network Australia, 2018).  
 134. Mavromaras et al., "NDIS Evaluation Consolidated Report - Appendix to Final Report."  
 135. Smith-Merry et al., "Mind the Gap: The National Disability Insurance Scheme and Psychosocial Disability. Final Report: Stakeholder Identified Gaps and Solutions."  
 136. Avery, Culture Is Inclusion: A Narrative of Aboriginal and Torres Strait Islander People with Disability.  
 137. Avery.



The right to self-determination and empowerment of Aboriginal and Torres Strait Islander people is a must if the lives of Aboriginal people with disability are to improve. Self-determination must be driven by Aboriginal people. While state and federal governments have a role in setting a coordinated national policy, they must be prepared to give up 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.<sup>138</sup>

First Peoples 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.<sup>139</sup> 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.<sup>140</sup>

138. Social Ventures Australia, "SVA Perspectives: First Australians" (Sydney, 2016).

139. First Peoples Disability Network Australia, "Ten Priorities to Address Disability Inequity," 2019, <https://fpdn.org.au/ten-priorities-to-address-disability-inequity/>.

140. First Peoples Disability Network Australia.

## A high-quality disability service and support system that works for everyone

High-quality disability services and supports in sufficient numbers, variety, and location is critical to ensure people with disability are to have choice and control. The introduction of the NDIS has already seen tremendous growth in the number of providers operating, however big challenges remain to ensure a fair distribution of supply and a high quality of all services and supports.

Areas where there is an inadequate supply of services to meet needs, have started to emerge. These thin markets present a serious challenge to users exercising choice and control, as without options, choice and control becomes a theory only.<sup>141</sup>

Thin markets have arisen in rural and remote areas and among people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, people requiring specialised supports, and people with complex needs such as early childhood intervention, behavioural intervention, and specialist disability accommodation.<sup>142</sup>

For example, at the time of the NDIS trial, people living in remote Aboriginal communities in the Barkly Region of the Northern Territory experienced shortages of disability workers – so it was choice and control in theory only.<sup>143</sup> Also, where people in rural areas could not access their chosen option they were at risk of losing funding for the support where planners viewed this as meaning that the support was ‘unnecessary’.<sup>144</sup>

Failure to account for people’s culture, language and literacy levels can also obstruct people’s access to disability services no matter where they lived. Improving access to disability services for people who were born overseas and/or speak a language other than English at home requires more than translation. 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.<sup>145</sup> Overcoming this may require campaigns to alert people that these services are available in Australia and how to access them.

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, that people were unable to access supports in their plans and that an overall sense of wellbeing means more to the Aboriginal people living in the Barkley Region than disability or a focus on ‘physical concerns’.<sup>146</sup>

## A deep dive on Specialist Disability Accommodation (SDA)

Under the NDIS, individuals who need 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.<sup>147</sup> A range of design categories and housing types are eligible for SDA funding, with the amount 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 expandable, 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 result in major private investment into the sector which will create the necessary new housing suitable for people with disability.

However, there are still design features of SDA that are limiting new housing supply despite recent positive changes to the subsidy.

Investors have started to invest in the market, however so far the large-scale investment needed to help the lack of supply has not happened. Unlike investment into general residential housing, SDA housing has very specific characteristics that requires awareness and understanding from investors. These include the particular nature of vacancy risk with this resident group, and demand uncertainty in the market.

The SDA market is dealing with a lack of information on supply and demand. This is putting the brakes on the confidence of developers to build more, as well as resulting in an uneven development of supply to meet needs. For example, there is currently a shortage of the ‘Robust’ housing type required by people with complex needs, worsening the problems of thin markets for these people.<sup>148</sup>

141. Mavromaras et al., “NDIS Evaluation Consolidated Report - Appendix to Final Report.”

142. Ernst & Young, “Thin Markets Project: Discussion Paper to Inform Consultation” (Canberra, 2019).143. Mavromaras et al., “NDIS Evaluation Consolidated Report.”

144. Mavromaras et al.

145. Mavromaras et al.

146. Mavromaras et al.

147. SGS Economics & Planning, “Specialist Disability Accommodation: Market Insights” (Canberra, 2018).

148. NDIS, “COAG Disability Reform Council Quarterly Report” (31 March 2019).

A number of more general concerns about the operation of SDA may be creating uncertainty for a range of stakeholders, as well as harming NDIS users. 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 supervision 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 even bigger in the future as there is greater clarity on the suitability of existing disability accommodation and as eligibility increases.<sup>149</sup> So, there is a risk that SDA developers build new properties that are only slightly better or perhaps the same as existing properties, and still attract substantial interest as there is such a big shortage of supply. The NDIA should play

a more active role to ensure all that is built will be something to be proud of for many years to come. 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 to a certain extent cleared up the issues highlighted above. However, the policy settings governing SDA need more attention to ensure that enough high quality, well located housing can be built.

Outside of SDA, there is also a role for the NDIA 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).

### **Case study: Understanding the supply pipeline for Specialist Disability Accommodation**

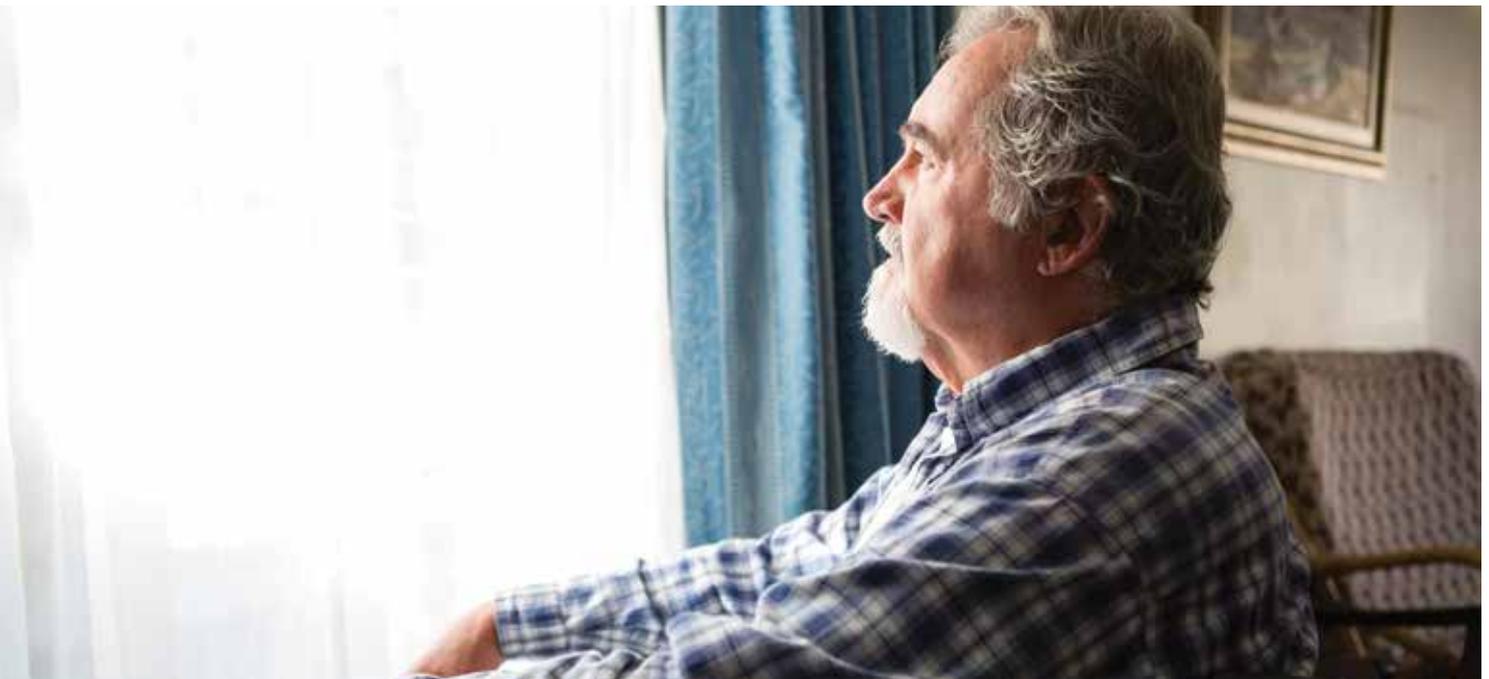
One of the major barriers to private investment in SDA is a lack of detailed data on the supply and demand in the market. The Summer Foundation and Social Ventures Australia have partnered to develop a new understanding of new SDA housing and SDA housing currently in the pipeline.<sup>150</sup>

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

149. Social Ventures Australia, "Specialist Disability Accommodation: Supply in Australia" (Sydney, 2019).

150. Social Ventures Australia.



### **A deep dive on the quality of disability services**

A key ambition of the NDIS was to increase the quality of services and the degree to which services respond to people's needs. This is done by putting purchasing power into the hands of consumers and introducing competition into the market.

This basic shift to consumer-directed funding has indeed altered the market, with the entrance of new providers with entirely different business models, an increase in mergers and acquisitions, and existing providers agreeing they need to change. Existing providers have begun to adapt their operations, reorienting business and operating models to adapt to having to deliver services under price caps, with those that have failed exiting the market.<sup>151</sup>

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 to work out new ways to monitor and manage costs at a unit level. Also, some 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 added to by challenges that have come with the roll-out of the NDIS. Difficulties in securing payments for services have meant that for some organisations, up to 10% of their revenue was delayed. As well, many existing providers have given unfunded support to existing clients to help them in the wake of confusion about the NDIS. As a result, resources have been stretched.

While the challenges faced by these providers should not be underestimated, the still limited inclusion 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 – and 3 providers were not collecting any feedback at all.<sup>152</sup>

It has been our experience that many organisations claim to have become more customer-oriented, yet few have formal processes to learn effectively and efficiently. 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 and insight. Other organisations have complex surveys that are too expensive or large to conduct regularly or collect feedback in a makeshift manner. In all those cases, feedback is neither regular nor careful enough.

This is a serious gap for the sector. Without adopting a more careful approach to collecting client feedback, it will be difficult to truly drive the change required to adapt and meet the needs of the people these organisations serve.

151. Paul Bigby, "Staff laid off, services cut ahead of NDIS rollout" (21 March 2018).

152. Social Ventures Australia, "Harnessing the Power of Client Experience: The Collection and Use of Client Feedback in the Social Sector" (Sydney, 2019).



## The Wishing Well - Flexible funding

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

For example, the previous SDA rules contained some 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 took a long time and used a lot of funding just to document the lack of suitable options.

The new SDA framework announced in February 2019 has thankfully fixed many of these problems, however the NDIS will need to continue to actively monitor and seek feedback from people with disability and their families and carers to identify issues that limit the flexibility of funding and therefore people's abilities to exercise choice and control.<sup>153</sup>



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

# Better intel

Quality data and evidence are critical for better outcomes for people with disability and should ideally be driven by people with disability. The design and application of services, programs and policy for people with disability should be based on the best available information, including the voice and varied opinions 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.

Traditionally, incomplete or confusing 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 towards disability and contributed to making disability a medical model rather than social model.<sup>154</sup>

Currently, there is insufficient information related to disability nationally and globally.<sup>155</sup> The World Health Organisation's Global Disability Action Plan states that good quality data and research are essential in providing the basis for sound policy, programs and distribution of resources. Data and evidence are critical to society's understanding of issues faced by people with disability, including identifying ways to successfully remove barriers so that people with disability can take part in and contribute to society on an equal basis.

Australia has challenges in presenting a complete picture of the experiences and outcomes of people with disability. Ways of defining disability differ depending on the type of data and the purpose it was collected for. Mainstream services rarely identify whether a person has disability.<sup>156</sup> 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 continuing its work towards improving the quality and availability of national data on disability, including developing a disability flag for use in mainstream services.<sup>157</sup> However, there is serious concern that the National Disability Agreement (NDA) disability services collection is at risk without the not yet achieved coordination between the NDIA and AIHW.<sup>158</sup> Without agreed data standards, it will remain difficult to understand long-term trends in disability and the need for changes. This may prevent better outcomes for people with disability 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.<sup>159</sup>

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 involvement from communities.<sup>160</sup> *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.<sup>161</sup>

154. Anne Kavanagh, Lauren Krnjacki, and Monica Kelly, "Disability and Health Inequalities in Australia: Research Summary" (Melbourne, 2012).

155. World Health Organization, "WHO Global Disability Action Plan 2014-2021: Better Health for All People with Disability" (Geneva, Switzerland, 2015).

156. AIHW, "Disability: About," 2017, <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/disability/about>.

157. AIHW.

158. Gwynnyth Llewellyn, "Audit of Disability Research in Australia Update Report 2017" (Sydney, 2017).

159. Llewellyn.

160. Llewellyn.

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

A current approach that is improving outcomes is inclusive evaluation, a practice where people with disability evaluate 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 there are many benefits, the primary one being people with disability are able to uncover the major issues and identify options to overcome problems raised.

The Cooperative Research Centre for Living with Autism is another good example of an organisation that prioritises inclusive research that genuinely involves people with autism and their advocates in all stages of the research process. This is a major development given that people with autism were always assumed to be incapable of contributing, misunderstood, ignored and excluded from decision-making processes and campaigns.<sup>162</sup>

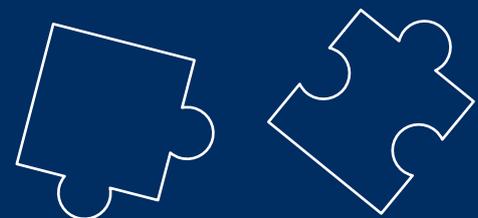
The University of Melbourne undertook a participatory research approach when examining the perspectives of NDIS service users.<sup>163</sup> People with disability were engaged in all stages of the process, from study design to collecting and analysing data to writing up the findings. The combination of lived experience and academic perspectives produced rich and nuanced stories about NDIS experiences to inform both policy and practice.<sup>164</sup>

However, there is still 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.



## Thank you

This paper was funded through a Sector Capacity Building program grant, by the following trusts; James Raymond Hartley Charitable Trust, Louisa Henty Estate, Harold Moreland Oldham Perpetual Trust, Arthur & Mary Osborn Trust and the Theodotus John Sumner Charitable Trust, managed by Equity Trustees.



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162. Liz Pellicano, "Autism Advocacy and Research Misses the Mark If Autistic People Are Left Out," The Conversation, April 11, 2018.

163. Warr et al., "Choice, Control and the NDIS : Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme."

164. Warr et al.

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