NDIS 2.0

A DISABILITY-LED PLAN FOR THE NDIS

Get Skilled Access

FOREWORD

This plan aims to put people with disabilities and their perspectives first in conversations about the future of the NDIS. It is meant to amplify the exceptional work already going on in the sector. With the NDIS turning ten next year, it seeks to be the start of a conversation about the future of the NDIS.

Several important themes have emerged in our conversations with NDIS participants. Trust in the NDIS needs to be restored by making vital changes to the Scheme. As part of this process, the NDIS must return to its original purpose, which includes providing community or "tier 2" supports. The experience of participants throughout the NDIS needs to be prioritised, meaningful choice and control must be provided for participants, and vulnerable participants need to get the support they deserve.

We're very grateful to all the people who shared their story. Some people have had great experiences with the Scheme. Others have not. Many of the people who shared their story have been consulted time and time again about improvements to the NDIS without having their advice listened to, and are sick and tired of feeling unheard.

Along with other people with disabilities and their supporters across the country, Get Skilled Access and I are calling on the Australian Government to renew its contract with people with disability.

Dylan Alcott AO

In the spirit of reconciliation Get Skilled Access acknowledge the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

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THE NDIS EXISTS TO HELP AUSTRALIANS WITH DISABILITY LIVE ORDINARY – AND EXTRAORDINARY – LIVES

The National Disability Insurance Scheme is a $32.9 billion annual investment to help Australians with disability be fully included in the community. [1,2] At its core, the NDIS exists to help Australians with disability live normal, fulfilling lives, just like other Australians.

The Scheme is the backbone to Australia's commitment to uphold the United Nations Convention on the Rights of Persons with Disability (CRPD), especially due to its emphasis on enabling people with disability to exercise their rights, individual autonomy, freedom to make their own choices, and ensuring the full participation and inclusion in society. [3]

The NDIS was created in 2013 by the Federal and State Governments to overhaul the disability support system that saw Australians with a disability face very high costs and poor quality services that did not meet their individual needs.[4] The Scheme promised better access to mainstream government services in areas like health, education, transport, and employment; improved community services for people with disability; and to give people with significant and permanent disability meaningful choice and control over the reasonable and necessary individualised supports they need to live a normal, fulfilling life in the community.[5]

It was meant to take an investment and early intervention approach to community and economic inclusion things like getting a job, participating in education and training, building social connections and independence.

It also sought to transform attitudes towards Australians with a disability – building a culture of understanding, acceptance, inclusion, and the recognition that what is good for people with disability is good for Australians overall.[6]

Perhaps most importantly, many of the people the NDIS is designed to help are some of Australia's most vulnerable. These participants live in challenging circumstances and experience layers of structural disadvantage in their daily lives – let alone in their interactions with government and the NDIS. Historically, many people with disability who are particularly vulnerable have not been able to exercise their rights. Prioritising these most vulnerable people – and their ability to control their decisions – in the next 10 years of the NDIS should be a critical starting point for any reform.

> *I believe that the NDIS is there to support people who are living with any kind of disability, to be able to live just like anybody else. Just be normal. We're just a person, take the disability out of it.*

> *I think the main purpose of NDIS is to fund supports and aids that work towards eliminating the person's disability, in a sense. Eliminate the inaccessibility of the diagnosis to improve the person's quality of life, access to community, independence, and relationships. And also reducing the dependency on the person's informal supports.*
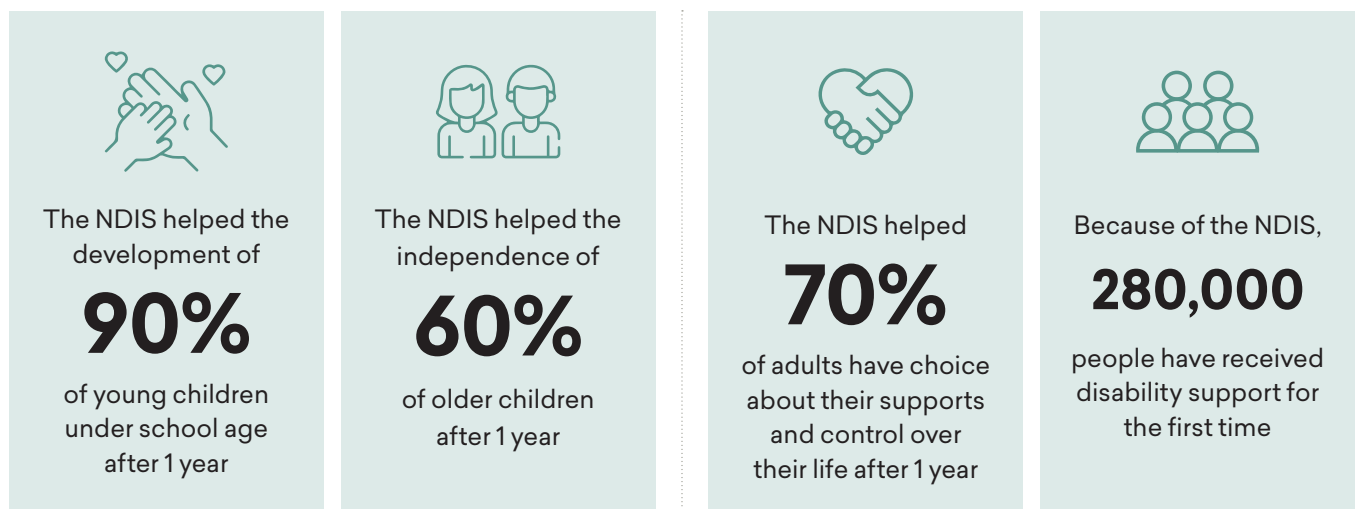
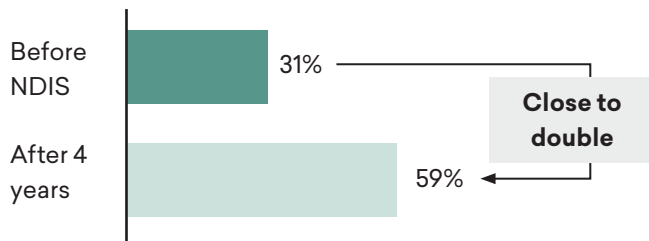Source: Participant and sector interviews (2022).

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THE NDIS HAS MADE A POSITIVE IMPACT ON SOME PARTICIPANTS, FAMILIES, AND THE ECONOMY

The NDIS provides some benefits to participants, their families and carers, and the wider Australian community and society. Some participants have improved health, social participation, and employment outcomes due to the NDIS. Families are more able to advocate for the participant and have improvements in their own wellbeing and employment outcomes. The economy is benefitted because of the jobs created in the NDIS and providers, and communities all throughout Australia benefit from the spending in their local area.

Benefits for participants

The NDIS helped the development of

90%

of young children under school age after 1 year

The NDIS helped the independence of

60%

of older children after 1 year

The NDIS helped

70%

of adults have choice about their supports and control over their life after 1 year

Because of the NDIS,

280,000

people have received disability support for the first time

Young children having friends to play with

Before NDIS — 31%

After 4 years — 59%

Close to double

Young adults working 15 or more hours a week

Before NDIS — 27%

After 4 years — 57%

More than double
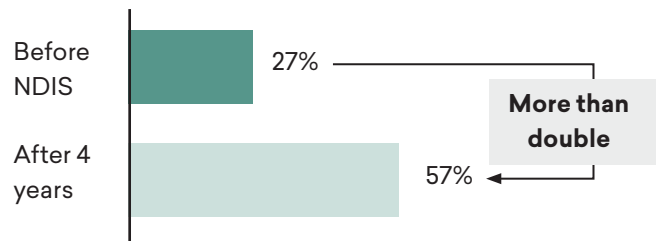
Benefits for families and carers

Families and carers of children having a paid job

Before NDIS — 31%

After 4 years — 59%

+10
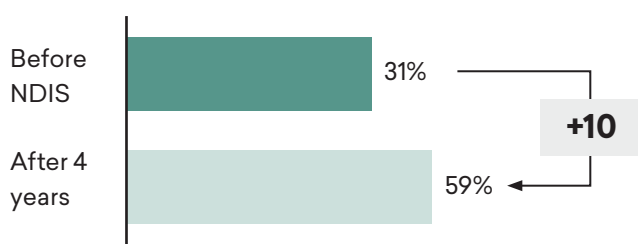
Families and carers have been helped by services to care for an adult participant

Before NDIS — 56%

After 4 years — 79%

+23

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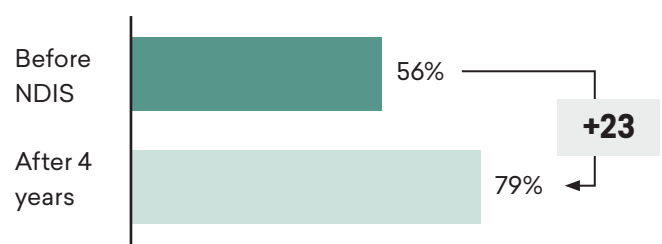
The NDIS has helped participants' independence and wellbeing

My plan let me be independent. It gave me support with cooking, shopping, all that sort of stuff.

I couldn't work without the NDIS, and that lets me support my son to go to university. He wouldn't be there if the Scheme wasn't helping me.

Previously I would make do with basic continence supplies or catheters because they cost a bomb. Now I don't have to cut corners or skimp on supplies, which has created great health benefits.

It makes us on equal footing, not left behind, isolated in the deaf world. We belong to the wider community now, not just the deaf community, and the NDIS enables that to happen.

I've had to get support in many aspects of my life to be able to regain and retain those skills I've had to learn again. And much of that support... has been made possible by the DIS funding.

I'm currently in a position where I'm housebound again and I'm really struggling, but knowing that there's someone who can come to your house... to support you... that makes a massive difference.

Source: Participant and sector interviews (2022).

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The NDIS has helped families and carers feel supported

It has changed my relationship with my family. When my sisters come over, I don't have to ask them to change the bed, because the cleaners do that.

I don't have to worry about my husband driving me places. I can do things I couldn't do before. Because I am blind, navigating to new places was previously very difficult.

It has taken the weight off our relationship.

Source: Participant and sector interviews (2022).

OVERALL ECONOMIC IMPACT

While the NDIS also affects the wider economy, more work is needed to fully quantify this impact and how much the Scheme is delivering on its potential. This assessment should focus on direct impacts for people with disability and their families, especially their ability to work in open employment, build businesses, and spend and save like other Australians.

The indirect impacts on the broader disability support workforce and economy are important, but this should not distract from the Scheme's core goal of including people with disability in the economy, just like everyone else.

Preliminary estimates by Per Capita suggest the NDIS may generate $2.25 of economic benefit for every $1 invested in it, which would mean there was a $52 billion economic impact in FY20-21. This is significant. It shows that despite the unrealised potential of the Scheme, it could already be delivering an outsized economic contribution to some people with disability and the wider economy.

3

BUT THE NDIS HAS NOT YET REACHED ITS FULL POTENTIAL

3.1 The NDIS must define its fundamental purpose

The NDIS has demonstrated that its principles can work, but they haven't worked for everyone. This may be because the Scheme was not always clear about its fundamental purpose: whether it exists to find government cost efficiencies, act as a pure insurance scheme, or deliver on the Australian Government's promise to empower people with disability to exercise their rights outlined in the Convention on the Rights of Persons with Disability.[7] The result of this confusion is that it has not fully delivered better individualised, community, and mainstream services.

In its first ten years the NDIS has come to focus on individualised supports, but still hasn't delivered meaningful choice and control, independence, and social and economic inclusion for everyone.[8][9] It's true that the Scheme's individualised funding has given many people the ability choose supports, service providers, and activities for their first time in their lives.[10] For example, some people can select the wheelchair they want, or have a say about which carer comes into their house.[11] But the promise of empowering participants to purchase high quality and innovative supports from a competitive and consumer-driven market has not come to be.[12][13] Instead, the Scheme has tightly controlled what services are available in the market for half of all participants while doing little to ensure the other half of participants are receiving quality supports at all. Around 40% of the Scheme's funds are also spent on Supported Independent Living, but participants receiving these supports have little choice and control over their roster or format of care, or daily activities.[14]

The NDIS has also failed to give many people with disability any choice over supports at all. There are significant market gaps for some people, especially Aboriginal and Torres Strait Islander people, people who are Culturally and Linguistically Diverse, people in rural and remote areas, and people with intellectual and psychosocial disabilities.

The NDIS was also supposed to increase the quality and quantity of community services for all people with disability – not just participants. However, decisions over the first ten years of the scheme have created a situation where individualised funding is an "all-or-nothing" oasis in the middle of a desert of community disability support services.

This is similar to the Scheme's promise to improve mainstream services for people with disability: not enough progress has been made. Participants report that their experiences with healthcare, education, employment, transport and other services is often disconnected and at-odds with the supports they can access through the NDIS. Until mainstream services are equally accessible for people with disability as other Australians, the NDIS will not have delivered on its fundamental goals of access and inclusion.

3.2 Too many decisions are made without Participants at the centre

The promise of the NDIS was that it would be person centric: the voice of participants is often unheard in decisions about how the scheme operates, and the Scheme is not always designed and run in a way that prioritises participants' experiences, either.

Participants have not been sufficiently included in decision-making

Participants have not been sufficiently included in important policy or operational decisions that affect them. Including people with disability in important decisions that affect them is one of the key principles of the NDIS[15], but it has not been fully realised in practice.[16]

For example, participants were not included enough in the decision-making about whether Independent Assessments or budget 'personas' would happen.[17] Participants should have been involved in if the Independent Assessments policy was a good idea, instead of how it could be implemented.[18] The lack of consultation when creating the proposed changes undermined trust in the NDIS for participants and the disability community.[19] To give participants a true voice in decisions, they should have been included in more discussions when the proposal was being created.

Whilst attempts are made to talk with the disability community about NDIS policies, there is often not enough time allocated to listening to participants. After Independent Assessments were proposed, the disability community was given 4 weeks to provide feedback. However, the NDIS was given advice that 8 weeks would be needed for detailed feedback.[20] If participants are going to be truly listened to in decision-making, there will need to be enough time and priority given to these conversations.

There is a particular need to include young people and families of children in policy decisions such as the proposed Independent Assessments.[21, 22] Children and young people are the majority of NDIS participants, and so they should be meaningfully represented in decisions about the NDIS.[23]

Not only are they insufficiently consulted on scheme design, many participants also feel unheard in the assessment of their individual needs. Complaints about the NDIS have risen, with a 400% increase in new AAT cases in the six months to January 2022, with the proportion of new cases to active participants also increasing.[24] Defending against AAT cases has contributed to the NDIA's rising legal fees, and having to resort to the appeals process can cause stress for participants.[25] An increase in appeals has coincided with decreases in average plan budgets for participants, driven by lower plan budgets for participants not in Supported Independent Living who joined the scheme since 2021,[26] and widespread stories of cuts to plan budgets. The increase in appeals suggests that participants do not feel they have been heard in the assessment of their needs.

The Scheme's systems and processes do not put Participants' experience at the centre

When participants engage with the Scheme, they experience a lengthy process that doesn't take account of their needs or day-to-day timelines.[27] Participants find long waiting times can leave them without the support they need, particularly when they experience changes in circumstances. Plans can be slow to change when needed, and home approvals can take a particularly long time.[28] For example, 24% of home and living applications open in March 2022 had been in progress for 90 days or more.[29]

The pathway of participants throughout the NDIS is too complex,[30] and can create barriers for participants in accessing supports.[31] An access and planning process that is too complicated and not appropriate enough for participants needs can mean some participants are not able to access the scheme, don't receive adequate funding, or don't receive the supports they need.[32, 33] An inappropriate access or planning process can be a particular barrier for participants who have complex support needs or less ability to advocate for themselves, as they may not be able to successfully navigate the participant pathway.[34, 35]

Participants' different needs across their lifetime has not been built-in to the Scheme's design either. This includes the experience of children and young people up to the age of 25 in the NDIS. Although Early Childhood Operating Guidelines are being developed, there is no operating framework for all the other children and young people up to the age of 25.[37] People up to 25 can have very different needs to adults, such as the need for family capacity building, or the need to have their development supported in natural environments.[36, 37] As people up to 25 make up the majority of participants, it is important that their experience throughout the NDIS pathway has been thoughtfully designed.

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I had a plan of $50,000 spread across 2 years. Then I had a plan review, and now my plan is $30,000 spread across 3 years. I'm legally blind, so it's a pretty significant disability. Other disabilities require even more support, but you hear stories of those people getting their funding cut as well. It seems to be spread across different categories of disabilities.

My plan ran out 4-5 weeks ago and I don't have a new plan. I have renewed it, but I don't know when I will get a new plan. Since I've moved and don't know the local area, I need more support right now.

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There is a woman I know who needs home modification in the bathroom, but it is taking so long to modify, that they said she could use the gym bathrooms. She was told that if the house were to be modified, she would have to stay there for many years. Since she is young, that is a long time to be locked into a place.

It seems that with reviews, we can only get money for funding when things aren't working. So, if we've had 12 months of something working, and we go, 'we've reduced behaviors of concerns, or reduced this, reduced that', then the funding gets cut.

SOURCE: Participant and sector interviews (2022);
Herald Sun (March, 2022)

3.3 Accessing the right support at the right time can be challenging

Accessing supports requires participants to navigate a complex process of assessment before trying to find services in their local area that meet their needs. This process often takes too long, and information and services are often hard to find. Sometimes participants can only access poor quality services or cannot find any services at all.

Participants often feel let down by the officials who are supposed to help them navigate the NDIS

The NDIS is complex and complicated,[38] and several "navigator" roles have been created to help participants find their way in the Scheme.

Examples include Partners in The Community (PITC) – which consists of Early Childhood Early Intervention (ECEI) and Local Area Coordinators (LACs) – and Support Coordinators, and Plan Managers. PITC are the first contact point between the NDIS system and people with disabilities.[39, 40] The role was designed to play a key part in helping people with disability access the scheme, planning and plan reviews, and connecting with services and supports in their local

area.[41] Support Coordinators and Plan Managers also help participants implement their plan, manage their plan budget and connect with supports, in addition to building participants' capacity to navigate the system themselves.[42]

While each of these navigators play a slightly different role, participants report that these navigators often let them down. Staff in these roles often appear to know too little about people with disability; be disconnected from the local community and services; and unable to build trust with people with disability and participants.

This creates a poor experience for participants and ultimately leaves them unable to access the supports they need. It prevents the scheme overall from delivering on its promise and potential.

While participants get choice over some navigators, their PITC are assigned to them. This undermines the purpose of the NDIS to provide meaningful choice for participants about their own lives. Firstly, LACs and ECEIs are appointed by the NDIA to deliver coordination services within a particular jurisdiction.[43] Then, Participants do not get a choice about which

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There is a lack of awareness from LACs about the complexities and diversity within disability. If they don't understand that, then whatever they submit isn't going to be a true reflection of your experience.

The LAC I had in 2019 seemed much more attentive and knowledgeable about disability and my personal requirements. And in 2022, the LAC I was given did not... I think just the biggest differences that I felt was just a general lack of understanding and knowledge on blindness.

I have an LAC keep cancelling on me, so I got another one. I think it was his first day, because he had no idea how things worked. Also, he was more interested in hearing about how I went to the Paralympics than he was in talking about my needs.

You must be very persistent and well-spoken... to advocate for yourself.

My first Local Area Coordinator helped a lot in getting funding for me. The next LAC I had was not engaged, did not care, and was happy to keep my plan as it was. The standard of quality between person to person is reliant on their passion for that they are doing.

This one particular LAC just didn't fully understand what being deaf was. They kept on saying, well you don't need this, that, and what have you. I told them, I said, 'Look, I need translation services.' They said, 'no... that's for people who come from overseas, they have to pay and learn English.

I think that they're given very limited training. The training they get given... is poor at best. They're not paid very well. They probably take a lot of grief from clients and probably internally from management. But as a result, people move on very quickly. There's adverts all over the place to be a NDIS coordinator.

SOURCE: Participant and sector interviews (2022)

organisation they are allocated to. Third, participants are often assigned a staff member from the PITC rather than getting a say about who within the organisation works with them.[44] These staff members can change without notice. This undermines the trust that people with disability have in the scheme from the very start of their journey; PITC play a vital role in determining the types of supports a participant receives and whether their needs are met, and yet participants do not have choice about this foundational part of their NDIS experience.

Participants report that some navigators don't have enough knowledge about people with disabilities to be truly helpful. Participants have reported experiencing PITCs, Support Coordinators, or Plan Managers who don't have sufficient knowledge about participants' disabilities or training about how to engage with people with disability; many report insensitive and demeaning questions about their disability.[45] This creates a poor experience for participants, but also means navigators often struggle to effectively communicate participants' needs to the NDIA, or help participants access the resources they most need.

Some navigators are disconnected from the communities and local areas they are supposed to serve. Participants report that this can be true in both a practical and a cultural sense.

For example, LACs often fail to link participants to community or mainstream services because they are not sufficiently connected to the local area.[46] [47] Families of young participants report that a key strength of ECEI organisations is their knowledge of early childhood education and disability services, but the system for appointing LACs created by the NDIA weakens the ability for well suited specialist disability organisations to help with access and planning.

At the same time, these navigator roles also need to be culturally safe in order help participants achieve their goals, yet participants report that navigators often struggle to understand the family and community context in which participants live. This leads to difficulty defining goals, and understanding what supports are most appropriate for achieving them. For example, some Aboriginal and Torres Strait Islander participants report that planners and Support Coordinators lack cultural awareness.[48] As a result, participants are sometimes offered supports that do not allow them to be included in their communities[49].

There are several examples of community integrated models that could exist. These includes ACCHOs operating as LACs in relevant locations, KPIs about cultural representativeness or cultural accreditation, or enhanced role for community liaison officers such as Aboriginal Disability Liaison Officers (ADLOs).

There are not enough support options

Participants are still not able to utilise their total plan budgets because there aren't enough supports available locally. While participants spend a bigger share of their plan as they become more familiar with the NDIS, plan utilisation has stabilised at around 70% in 2021, meaning each year participants are not spending 30% of the funds allocated.[50, 51, 52, 53, 54, 55]

This is particularly a problem for participants in regional and remote communities, with plan utilisation for participants without Supported Independent Living decreasing across all plan numbers as remoteness increases.[56] In the Northern Territory, there are fewer providers to choose from for each participant than other regions, because provider concentration is higher.[57 58] The Northern Territory also has lower plan utilisation than other regions for participants not in Supported Independent Living.[59, 60]

Participants in rural areas have a particular struggle in getting allied health support, because allied health workers are not located in rural areas, and they are not paid fully for travel. The shortage of allied health workers in remote or rural Australia means that participants have to travel to health providers, or health providers have to travel to them.[61, 62] Whilst participants do have a travel budget, that money can run out quickly, especially in rural areas.[63, 64]

Aboriginal and Torres Strait Islander participants face additional barriers in receiving support, as they are over-represented in rural and regional areas, and there are limited culturally appropriate supports available.[65] Aboriginal Community Controlled Health Services (ACCHSs) are one of the key sources of culturally appropriate supports for Aboriginal people, but many organisations have found it is not feasible to become registered NDIS providers.[66, 67] Other barriers to accessing services for some Aboriginal people include potentially not having access to online services or the internet, transport to get to appointments, or translation services.[68]

Aboriginal and Torres Strait Islander participants, and Culturally and Linguistically Diverse participants over the age of 25, were less likely than other participants to respond that the NDIS has helped them.[69, 70] Aboriginal and Torres Strait Islander participants were also less likely than other participants to be satisfied with their knowledge of what happens next with their plan.[71] In addition, the families and carers of culturally and linguistically diverse participants over 15 had a larger decrease over time in feeling able to advocate for the participant when compared to other families and carers of participants over 15.[72]

The range of support options that the NDIS promised to deliver to meet participants' diverse needs does not exist.[73, 74] While the scheme was intended to produce a diverse range of innovative supports to choose from[75], the prescriptive price guide may have restricted innovation.[76, 77] The promise of support for people with disabilities who don't have an NDIS plan, along with better integrated community and mainstream supports, also hasn't been fully realised.[78, 79, 80, 81, 82, 83, 84]

The market-based design of the NDIS was meant to enable a wide range of support options for participants to choose from.[85] These innovative and diverse supports were meant to suit different participants needs and preferences,[86] which includes local culturally appropriate programs[87], new methods of service delivery[88], and new types of provider technology.[89] There is some development of new programs, such as initiatives for Indigenous people with disabilities[90], but a range of innovative support options is yet to fully emerge.[91, 92, 93] There are several practical reasons that may be causing this: the definition of supports in the price guide and support catalogue, along with fee-for-service prices, may create more standardised and similar services and discourage risk-taking innovation.[94, 95]

Many local community organisations also report difficulty becoming providers that can service their local community. Specialist organisations like Aboriginal Community Controlled Organisations (ACCOs) and Aboriginal Community Controlled Health Organisations (ACCHOs) want to help their communities but find the registration process costly and lengthy. These burdensome rules for local community organisations also effectively prevent participants from exercising freedom of choice and meaningful control. This problem is especially acute in thin markets, where allowing organisations to "stack" the services they provide in the NDIS would help participants get the support they need in a more effective and efficient way than an approach that can force separation and individualisation of access, planning, and provision of NDIS supports.

The NDIS was supposed to be accompanied by a Tier 2 of community-based supports for people with disabilities who don't have NDIS plans, but this has never fully happened.[96, 97, 98, 99, 100, 101] Since Tier 2 was intended to be funded, many previous support options for people with disabilities were shut down, but have not been replaced for those who don't have NDIS plans.[102, 103, 104] This has created a 'desert' of support for anyone not in the Scheme, including for many with psychosocial disabilities.[105, 106] The Information, Linkages and Capacity Building grants program was intended to deliver these community supports, but the current system is not the most effective way to develop connections to services for all people with disability.[107, 108, 109] A cohesive strategy for mainstream and community based investment is needed, with longer term investments made.[110] The NDIS has responded recently to the disability sector with a statement that it will expand Tier 2 supports,[111] but so far it is unclear whether this will effectively support people with disabilities without NDIS plans.

> "A lot of the state funding that was there pre-NDIS, that's all gone now. What are the states doing to support in that area? They just go, "Well, we've offloaded over it to NDIS and if you don't make the scheme, then you're not supported." There needs to be a real growth in that second tier, even if it's state based or federal, because there's a lot of people, especially young people, kids that are misdiagnosed as not having autism or being on the spectrum when they probably are, and they're not receiving that early intervention support that they need that's going to set them up for the rest of their life. So, there's a lot of people falling through the cracks.

SOURCE: Participant and sector interviews (2022)

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> *I was horrified to find that the agencies don't interconnect. I have psychologist sessions and receive a rebate back from Medicare. I tried to claim the gap back from the NDIS, but I found I could not do this.I'm lucky I have a full-time job and can afford the $120 gap but just think of all the people who miss out on services because they can't put their unused NDIS funds to work.*
>
> *Support workers should be allowed in schools to support their participants of NDIS who are also students, but they currently aren't allowed.*

SOURCE: Participant and sector interviews (2022)

This is especially challenging for young children and their families. The access process that young children and their families go through when children reach 6 years of age represents another challenge to accessing supports. Not only does a lack of community and mainstream supports make this process feel like an "all-or-nothing" moment for their child's supports, but the nature of the children's different developmental pathways and access to the diagnostic tools necessary to test for a permanent disability both represent significant barriers to giving their kids the best chance of a normal, fulfilling life in the community and economy.[112]

Participants also report that they face barriers to accessing supports outside the NDIS because the Scheme is not well integrated with mainstream services.[113] There is a particular lack of clarity about the roles and responsibilities between systems.[114] Some work was done through pilots and ILC grants to connect the NDIS to mainstream systems,[115, 116, 117, 118] but integration between the NDIS and mainstream services has not fully happened yet.[119, 120, 121] These mainstream systems include the justice, mental health, child protection, and education systems, amongst others.[122] Opportunities exist to integrate the NDIS with Medicare and employment services, such as by improving communication between NDIS and mainstream service providers or allowing NDIS funding to pay for mainstream services.

Participants are not provided with enough meaningful choice about supports

Participants do not always have the information to find supports. Participants find that it is difficult to understand the services that are available to them, which means they cannot access the support they need. Information about available services can be hard to find. There is a lack of knowledge about available services from the agency and Local Area Coordinators. In addition, information on the website and portal is insufficient and hard to navigate. There has also been insufficient effort in building the capacity of participants to navigate their plans and choose supports,[123] despite the intentions for the Support Coordinator role.[124] When participants cannot find out what services are available to them, they may underuse their plan budgets, or may miss out on a service that would better fit their needs.

Despite navigation support helping many people with additional disadvantage get better outcomes in the NDIS, it isn't widespread. One existing, successful form of this is where participants have 100 hours of culturally safe navigation support – sometimes in the form of support coordination – automatically included in their plans. For example, automatically connecting CALD and ATSI participants in certain geographies with culturally competent support coordinators has helped those participants, their families and communities to better exercise choice and control and be included in the community than without supports.[125]

There is a lack of knowledge about what services are available to me. Instead, I get very standard answers. For example, I met a NDIS LAC who only had knowledge of one sporting program for people with a disability, and they have 14,000 clients. It would be great if within those roles, people had the knowledge about what is available locally.

It is not just a list of services needed, but there is a shortage of LAC workers being savvy and knowing what is available. In regional areas, an LAC knows about what is available from them, but they don't know what is available outside their program. If your LAC doesn't know and it's not on the Disability Gateway, it is very hard to understand what is available.

The portal about what is in the area has bad functionality, and when the LAC also doesn't know providers, it is very difficult. I had to contact individual training and services providers to find out what they have.

During the first year of self-managing, I only spent a quarter of my plan because I didn't know how to navigate the system and find available services.

The information on the website is very technical and not easily accessible.

Local government is where a lot of good support comes from, but they don't have much knowledge about what is available.

SOURCE: Participant and sector interviews (2022)

There hasn't been enough investment in building participants' capacity to engage in the support market. This creates several issues. For example, it makes it more difficult for participants to critically select between supports in the market. It also dulls the signals that participant choices send to providers in the market. When participants are not empowered to select the supports that best meet their needs, then providers will not be able to understand where to invest more, less, or change their offering.[126]

The quality of supports is still an issue

While almost all people and organisations involved in the NDIS are highly passionate and dedicated, the system overall still experiences problems in the quality of supports. This includes inconsistent quality supports and the persistent use of restrictive practices.

Complaints about NDIS providers and their workers increased by 8% in the second half of 2021, with over 4,000 complaints being made in the 6-month period.[127]

Too often, the NDIS has approached challenges and solutions for people … who already have the most resources, probably also the most informal supports and the most ability to access information if we needed it. The most privileged. But the challenges and solutions shouldn't be built for these people, they should be built for the people with psychosocial disabilities, living in regional Australia, who have been institutionalised for 20 years. If the solutions can meet their needs, then they will meet other people's needs.

SOURCE: Participant and sector interviews (2022)

This indicates that many participants and their families are unsatisfied with the quality of supports. About a third of complaints were about provider practice, and another third were about worker conduct or capability. A fifth of complaints were about alleged abuse or neglect.

Insufficient resources for providers, including training and monitoring of work, contributes to the use of restrictive practices against people with a disability. Restrictive practices are anything that restricts the rights of freedom of movement of a person with a disability[128], which includes chemical, physical, and other restraints[129]. The unauthorised use of restrictive practices made up 98.7% of all reportable incidents to the NDIS Commission during the reporting period[130].

There can also be a disconnect between evidence-based best practice and what the NDIS system incentivises providers to deliver. For young children for example, some participants report providers adopting a medical-model of therapy and capacity building support provision.[131] This is despite evidence that supporting families to support their children in their everyday environment delivers the best results. But because of the structure of ECEI rules and the lack of best practice guidance, providers are instead incentivised to over-therapise young children, often in environments segregated from other children their own age, which sets them up for segregated schooling and segregated employment – rather than meaningful social and economic inclusion as the scheme was meant to deliver. The purpose of the NDIS for children should be about full social and economic inclusion, instead of othering and segregating that comes from medicalised service delivery that the system is bringing about.[132]

3.4 The Scheme is too focused on transactions not transformations

NDIS plans and funding are focused on the day-to-day costs of transactions not the opportunity the scheme brings for transformations in people's lives. Funding participants based on the individual service costs and paying providers on a fee-for-service basis contributes to a system that overemphasises scheme costs instead of benefits. A scheme that is too transactional could also contribute to negative attitudes towards individual people with disabilities.

> "

> *If you go for a massage or if you see a chiropractor or things like this, and they find out that you have NDIS, you'll get a different price to somebody who isn't on the NDIS. So there's a bit of like a two-tier pricing sort of system happening.*

> *Dollars could go a lot further if suppliers were held accountable.*

> *The DIS has a list of costed items and they've got a maximum fee. For example, they have a max fee that you can pay for interpreters or counselors. Now, if they were to charge the maximum, then it's easy for us to actually run out of our funds, you see? And because they advertise this maximum. Now I don't know if it's such a good idea having each line item allocated at a maximum fee charge. I mean, we need a competitive market. We need it to be competitive, because the more competitive it is, the cost will actually be reduced, which means our money will go further.*

SOURCE: Participant and sector interviews (2022)

Providers are paid for services instead of outcomes for participants

Providers are paid based on the amount of support they deliver. This means providers are not incentivised to create positive outcomes for participants. This can cause several issues, such as encouraging higher amounts of services to be provided, and not encouraging providers to work together.[133] Rewarding providers for giving more services doesn't match the investment aims of the NDIS, which are to build up the capabilities of participants over time.[134, 135]

This could mean the Scheme underdelivers on outcomes for participants. For example, post-school transitions and other pathways to employment are a challenge. Participants report that if the Scheme's investment approach was working well, they would expect to see much better formal education and employment outcomes.[136]

Many participants who want relationship-based supports report that the current fee-for-service transactional system often fails to deliver them. In settings such as SIL, complicated rules for shared and individual supports can distract participants and providers from focusing on delivering high quality supports.

Aboriginal and Torres Strait Islander Participants also report difficulty accessing culturally safe and community-based supports, despite the presence of organisations that participants would happily go to for services.[137] For example, Aboriginal and Community Controlled Organisations (ACCOs) could deliver these supports but, on top of the administrative burden of registration, the financial structures for payment act as barriers to service delivery: commissioning services in persistently thin markets, rather than fee-for-service would ensure participants get the support they need in regional and remote areas.[138 139]

The use of price caps and a rigid price schedule also makes delivery of quality services difficult, regardless of whether prices are set too high, too low, or at the average market rate.

If prices caps are set too low, the quality of services may be reduced to make offering a service possible,[140] or there may be a shortage of providers willing to offer support at that price there are reports in some sub-markets of limited availability of allied health services, which could be due to price caps being set too low.[141] As another example, there is a low availability of culturally appropriate supports in the NDIS for Aboriginal people provided by Aboriginal Community Controlled Health Services (ACCHSs), likely because these supports are priced too low.[142]

If price caps are set too high, providers may raise the price of their services, 'bunching' around the price cap.[143] Some stakeholders report that providers raise their prices once they know someone is an NDIS participant.[144]

There are issues stemming from price caps even if prices are set at the average level for the market. This is because specifying a particular service and price for that service drives standardisation in the supports that providers offer in the market, instead of a diversity of supply to meet participants' different needs. Price caps can also reduce incentives to invest, and reduce the entry of competitive providers into the market.[145] It is also unlikely that regulators will have all the information needed to continue to set the right price.[146]

> " *There is a mentality that people want gold plated wheelchairs.*
>
> *When people see my prosthetic, they have an attitude of 'how much did that cost me in taxes'.*

SOURCE: Participant and sector interviews (2022)

Scheme costs are overemphasised relative to benefits

Policymakers and politicians overemphasise the costs of the NDIS relative to the benefits in the day-to-day administration of the scheme and their poor communication of the social and economic benefits of the NDIS in the public debate. This creates wariness and mistrust with participants and providers.[147]

In the day-to-day administration of the scheme, policymakers focus too much on annual costs and not enough on investing over the long-term to improve outcomes for participants. Practically this plays out in a planning process that focuses on 12-monthly needs not what participants need at different stages of their lives, and on allocating funding based on input costs not on the value of benefits. Some people report that more funding in a budget, for example for disability support-workers, could reduce unauthorised use of restrictive practices. The focus on a 12-monthly budget cycle also creates anxiety for participants over their future funding and uncertainty for providers who face changing price rules and levels that prevent them from making decisions about their businesses more than one year in advance.

Politicians' contribution to the public debate also focuses too much on costs and not enough on benefits. While the NDIS has enabled 540,000 more Australians with disability and their families and carers to access individualised supports,[148] it has generated significant wider social and economic benefits too. This includes more people with disability and their families and carers in education and jobs, more investment in Australia's care sector – which has flow on benefits for health, aged care, and early childhood education and care – and significant additional economic activity in the economy. But as long as the public debate is about how much one government is funding the NDIS relative to another, the benefits of the NDIS for all Australians will remain unknown and unacknowledged in the wider conversation. This focus on costs makes many participants feel that much of the NDIS is caught in a rationing and welfare mindset.

Many people with disability still report experiencing negative attitudes towards them.[149] Discrimination against people with disabilities is still widespread,[150] especially in employment.[151] Young people report that the attitudes and misconceptions of employers were the biggest barrier to them gaining employment.[152] A scheme that is too focused on the transactional nature of supports risks losing sight of the broader goals of rights, fairness, and inclusion.

4

THE AUSTRALIAN GOVERNMENT SHOULD RENEW ITS CONTRACT WITH PEOPLE WITH DISABILITY

The NDIS exists to ensure people with disability can live ordinary – and extraordinary – lives just like other able-bodied and neurotypical Australians.

The first almost-10 years of the Scheme have delivered many benefits, but it is also clear that it's not working for everyone.

Overall, Government should work to develop a renewed contract with people with disability to rebuild trust that people with disability will get a fair go. The most important commitment Government can make is working meaningfully with people with disability and the sector to make the next 10 years of the scheme deliver on its promise.

The goal of this report is to amplify the voices of participants about key priorities for the next decade. It seeks to to be the start of the conversation, not the end. The following ten commitments highlight what we think Government should deliver.

4.1 Do not make decisions about us without us

High level decisions about the NDIS do not include participants enough. The NDIS governance and decision-making must meaningfully include a Participant voice. This should include:

- **Disability-led:** The Chair of the NDIA Board should be a person with disability, and a majority of the NDIA Board should be people with disability or people with lived experience of disability.

- **More representative:** The leadership team should have the same proportion of people with disability or lived experience of disability as the wider community, where almost 20% of Australians live with a disability.[153] There should also be a greater representation of the diversity of people with disability throughout the NDIA. This includes Aboriginal and Torres Strait Islander people and people who are Culturally and Linguistically Diverse. In addition, people with lived experience

of psychosocial or intellectual disabilities should be represented in decision making. It is also important to note that the number of people who self-report disability may underrepresent the total number of people who live with disabilities as some people choose not to self-report.

- **Stronger voice:** There should be a stronger Participant voice in other NDIS and NDIA decision-making through mechanisms like a Participant Compact, an expanded Participant Vision, and a meaningfully consultative Youth Council. There should also be extended consultation on policy and operational changes, such as 2 rounds of 6-8 week consultations. The NDIS and NDIA should make the most of the representative organisations that Governments already fund to provide a voice for people with disability. However, there may be urgent matters where the IAC or the new disability led board determines shorter consultations are appropriate.

4.2 Remember what the NDIS is for

Policymaker and politicians should clarify the fundamental purpose of the NDIS. This could require frank conversations about difficult trade-offs, but the goal of helping people with disability living normal, fulfilling lives just like other Australians should be front-and-centre in the Scheme. This includes people with disability who do not receive individualised funding, for whom the NDIS was supposed to invest in community supports and deliver more accessible mainstream services. This should lead to a scheme that is more values-based and focused on impact for people with disability. This should include:

- **Contextual:** More recognition of the role of the NDIS in Australia's broader Disability Strategy is required. The Scheme should not be the be-all and end-all of disability support services. It should exist within a broader framework of vibrant community supports and accessible mainstream services that include people with disability just like other Australians.

- **Tier 2:** Deliver the promised community or tier 2 supports with States and Territories for people with disability who do not qualify for the NDIS but still need services..[154]

- **Mainstream integration:** Improve the integration between the NDIS and mainstream supports like health, education, and employment services. A strategy is needed that outlines the roles and responsibilities between the NDIA and other systems.[155, 156] Since many children and young people engage with many mainstream services, it is vital that interfaces between services meet their needs for inclusive education.[157]

4.3 Put Participants-first at the NDIA

The operation of the NDIA does not prioritise participants' experience with the Scheme enough. Making the NDIA better will have outsized impact in making the scheme better, because all money and so many decisions flow through the Agency. This should include:

- **Empowering:** The NDIA should make improvements to the access and plan review process so participants feel empowered during the process, instead of shamed about what they can't do. It should give participants a chance to review the draft of their plan from the Local Area Coordinator before it is sent to the assessor at the agency. The NDIA should also work more efficiently so that the timelines can keep up with people's changing circumstances.

- **Age-appropriate:** Ensure the NDIS takes a tailored approach to people with disability at all stages of their life, especially for children so they do not feel like they are operating in a system designed for adults.[158]

- **Independently reviewed:** Government should launch an independent review of the NDIA to identify improvements in structure, processes and especially organisational culture needed to put participants first. This should include an internal culture review or health check, using a tool like the Global Disability Equality Index, to ensure the NDIS culture is inclusive and respectful of all employees, including those with disability.

- **Appeals:** A new, participant-focused appeals process should be introduced so participants can avoid legal processes if they feel their needs have not been properly assessed.

4.4 Improve the role and performance of Scheme "navigators"

The current role for Partners in the Community (including LACs), Support Coordinators, and Plan Managers to help participants access and navigate the scheme is not working. Participants' experiences of these services is often disjointed, disrespectful and fails to give them access to the supports they need in a timely way. Instead, these roles should be improved by :

- **Locally connected:** Explore ways to make navigators more closely connected to local areas so they have a comprehensive view of available services. This should include better training about the supports available in participants' areas.

- **Independent:** Ensure support coordinators are independent and / or integrated in the participant's own community.

- **Experienced:** Hire more people with lived experience of disability (such as people with disability, or family members of people with disability) as LACs.

- **Skilled:** : Have more training so that navigators like planners, PITC, support coordinators, and plan managers better understand the diversity of needs that people with disability can have, for example young people, ATSI and CALD people, those in rural and remote areas, those with complex psychosocial and intellectual disabilities.

4.5 Change the narrative about costs to benefits

Too much of the conversation about the NDIS focuses on costs, with not enough discussion about the benefits of the Scheme. The NDIS should be helping participants and their families and carers get into paid employment and be able to consume more mainstream goods and services.[159]   Benefits are likely heightened for large-scale initiatives like the NDIS, because there should ideally be improvements in productivity and innovation.[160, 161]

- **Investment-oriented:** The Scheme's original investment-based approach should be better embedded in decision-making, especially overall Scheme funding and participant planning.

- **Quantified:** Government should commission an independent study on the benefits of the NDIS, including the benefits of early investment through the NDIS. No detailed analysis on the benefits of the Scheme has been done.[162] However, work by Per Capita suggests that the NDIS returns at least $2.25 for every $1 invested in it, with the actual return potentially being higher than this.[163 164]This would better inform public debate than the Productivity Commission's five-year-old report on costs or the NDIA Scheme Actuary's cost-focused Annual Financial Sustainability Report that was released in 2021.

- **Effective:** Efforts to reduce fraudulent costs should be focused on improving internal NDIA systems, rather than restricting participant choice about supports. For example, data systems should be improved so they can identify trends in behaviour and find fraudulent activity.

4.6 De-politicise the Scheme's institutions and rebuild trust

The existing relationship between the Government and the NDIA has eroded trust in the NDIS and created an environment where decisions about access and service delivery are politicised and intermingled with decisions about financial sustainability.

Many participants have lost trust in the Scheme due to the political narrative around rising costs and perceived responses to this issue – independent assessment and plan cuts. Government needs to match words around the Scheme being "fully funded" with actions. Government should commit to a fully-funded, demand-driven scheme that does not unfairly restrict access or services to rebuild trust with participants, the sector, and the Australian people. This will require Government to be explicit about how it will ensure funding rises with demand in future.

- **Funded:** There needs to be an independent process with clear and defined roles that determines overall scheme funding levels that informs the NDIS's own dedicated funding stream. It is important that financial sustainability questions are resolved separately from questions about who has access to the scheme, or the way services are delivered.

- **Transparent:** Improve the transparency of the scheme by publishing more data to allow for independent analysis and community debate. This includes transparency around the interactions between LACs and plan assessors, such as how many plans assessor and LACs both agreed on first time, the number of plans in dispute, and number of plans proposed by LACs that assessors either increased or decreased funding for before approval.

- **Beyond annual cycles:** Transition away from transaction-based, annual budget cycles in as much of the Scheme's decision-making as possible. Participants should be more easily able to receive supports that have benefits over time, especially for participants who have more stable needs.[165] This constant change and unpredictability also creates significant anxiety for participants – who are constantly worried about their budgets changing – and difficulty for providers in investing in innovation or taking risks because of prices and pricing rules that can change significantly every 12 months.

4.7 Improve the availability of supports

Many participants in the NDIS cannot access the supports they need, either because the support is not in their local area, or they don't have information about the supports available.

- **Market development:** Increase the focus on market development,[166] including workforce development, especially where access is an issue for participants such as in rural and regional areas. There also needs to be enough supports available for children and young people, people with complex needs, and intersectional disadvantage. New ways of delivering diverse and innovative services to these communities should be explored through pilots.

- **Local collaboration:** Work with local community leaders and organisations to ensure that there are sufficient local supports available and the Scheme is flexible enough for these community developed options to operate. This could include reducing the administrative burden for local community organisations to become providers of culturally safe providers in the NDIS, especially ACCOs and ACCHOs.[167]

- **Accommodation options:** Consider developing market-based options other than SDA for people with intellectual disability to live independently. This will provide people with intellectual disability a more appropriate living environment, especially as their families age, and will increase the capacity of their families and carers to work.

- **De-medicalised early childhood:** De-medicalise ECEI service provision to better uphold children's rights and improve their inclusion in the community.[168]

4.8 Increase the ability of Participants to make choices

The NDIS was intended to provide meaningful choice and control for Participants about their supports and their lives,[169] but many feel the Scheme has not lived up to its promise of providing true choice.[170] Not only does insufficient support availability reduce options for participants, but some Participants find the design of the Scheme does not provide meaningful choice, such as in choosing a LAC or making decisions about the supports received from a SIL provider.[171] In addition, Participants need adequate information about what supports are available in order to make a decision, and more Participants need capacity building to improve their ability to make decisions about their own lives.

- **Flexibility:** Plans should be more flexible for Participants. This could include full flexibility and fungibility so Participants can choose how to spend an overall reasonable and necessary funding envelope on the services they need, and allowing Participants to roll over their budgets from plan to plan.

- **Supported decision-making:** There needs to be improved information and supported decision making through practical measures like a participant marketplace and independent support coordination, except where participants and the local community agree otherwise.[172]

- **Navigation, planning, and connection support:** Ensure consistency, and choice and control in the navigation supports that are available to participants so they can get the most out of their funding. Consider including additional supports for participants who face additional barriers to navigation, like the 100 hours of support coordination automatically available to some participants.[173]

4.9 Focus on the impact for Participants

Currently providers are paid based on the services they provide, rather the benefits of those services to Participants.[174] Providers should be rewarded for helping to achieve Participant goals. This would benefit the providers who provide high-quality services, and it increases the focus for Government, the NDIS and providers on building the long-term capabilities of Participants.

- **Blended payments:** Government should trial blended payment models. Blended payment models would allow participants to pay providers in another way instead of only fee-for-service, for example paying more for a provider who can demonstrate high quality service delivery, or paying a provider for meeting a participant's needs for trust, stability, and relationships over a period of time instead of service-by-service.

- **Quantitative targets:** As part of an effort to focus on the impact for Participants, the Government should be more ambitious in its commitments to achieving Participants' goals. This should include a target of supporting 10,000 people with disability into open employment in five years, and reducing home & living application wait times to less than three months for all participants. The Commonwealth and State & Territory Governments should also commit to better outcomes for people with disability across all services, not just disability supports. This should include outcomes for people with disability in schools, transport, health, employment, and other areas.

- **Post-school pathways:** Government should develop a specific youth employment strategy and DES reform. Every young person in the scheme who wants a tailored post-school transition plan should have one, and they need to be sufficiently supported to achieve their plan before their 25th birthday.

- **Do better on employment**: Make employment – especially open employment – for people with disability a priority. Give everyone, and especially young people, the opportunity to set and work towards employment-related goals like finding meaningful work and developing their careers.

- **National Disability Data Asset:** Fund the National Disability Data Asset to improve the monitoring of outcomes over time, with data separated by demographics (for example, age group).[175]

4.10 Connect Participants with their communities to improve safety

There is more that needs to be done to improve participant safety. Prioritising participant safety should not undermine the dignity of risk for people with disabilities, as people should have choice and control over their own lives, instead of "being placed in bubble wrap" against their will.

- **Simpler registration:** Streamline the registration process to reduce the regulatory burden on providers who become registered, encouraging more providers to register with the Scheme in the process.

- **Follow advice:** Government should commit to responding to all findings of relevant safety-related reviews, including acting on ongoing Quality & Safeguards Commission findings and recommendations.[176]

- **Community connections:** Priority needs to be given to efforts to improve participants' connections with their local community, to ensure people have an informal network who could help identify safety issues.

- **Appropriate housing:** Increased effort is needed to ensure participants are in appropriate housing, as inappropriate housing is a main cause of safety issues.[177] Housing that is appropriately designed and located has been found to improve safety, reduce the risk of accidents, and reduce the ongoing costs of support.[178, 179] To improve housing availability, new estimates will be needed for the supply and demand of housing.[180]

ENDNOTES

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