



NDIS Review – A strong, effective, sustainable NDIS

Submission – Volume 1

Policies and services

About Advocacy for Inclusion

Advocacy for Inclusion incorporating People with Disabilities ACT¹ (AFI) is a leading independent organisation delivering reputable national systemic advocacy informed by our extensive experience in individual advocacy and community and government consultation. We provide dedicated individual and self-advocacy services, training, information and resources in the ACT.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. Advocacy for Inclusion speaks with the authority of lived experience. It is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

Advocacy for Inclusion operates under a human rights framework. We uphold the principles of the United Nations Convention on the Rights of Persons with Disabilities and strive to promote and advance the human rights and inclusion of people with disabilities in the community. Advocacy for Inclusion is a declared public authority under the Human Rights Act 2004.

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Advocacy for Inclusion acknowledges the Aboriginal and Torres Strait Islander peoples as Traditional Custodians of the lands where we live, learn and work. We respect and celebrate the diversity of individuals, including those amongst the lesbian, gay, bisexual, trans, and intersex communities and we value and promote inclusion and diversity in our communities.

¹ On March 24, 2021, Advocacy for Inclusion (AFI) officially merged with People with Disabilities ACT (PWDACT), a systemic advocacy organisation based in the ACT. Herein, reference to 'AFI' also acknowledges the values and philosophies of PWDACT.

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Executive Summary and Introduction

Opening reflections

*"I really hope that this review allows us to get back toward the original vision... **It's time that we're allowed to dream big.**"*

*Sarah, NDIS Participant (*Names changed)

"Before we got one shower a week, we didn't get to choose who was the one with showering us. We didn't get to choose on what day that shower would actually happen.

But what the NDIS has actually meant us having choice and control and saying what days you want to have a shower, having the dignity of being able to have more than one shower a week, you know, you got a maximum of three showers per week, but only if you were incontinent.

Every second day you can imagine we lived a life of living in our own mess. The NDIS has meant we don't live like that anymore. It has given us dignity over our lives. It has given us, you know, respect within our own homes, ... personal hygiene, having clean sheets on beds, all of those sorts of things. That's what the NDIS has meant for us. It's meant from us going from block funding ... to actually knowing we can cover the gap..."

Nicole – at the NDIS 10 Forum

Now that my wheelchair fits into the bathroom and I have a bench seat, I am able to shower almost completely on my own. I now have a shower every second day, instead of once a week as I had been doing previously.

You always feel so much better after a shower. I'd love to make my garden more accessible too, so that I can make my way outside on my own.

You have to get around your house safely and be clean, and everybody needs to spend some time outdoors.

*I think those are **the sorts of basic things that people should be able to expect in life.** They're things we all deserve.*

Susan - NDIS participant

"All of the skills I have learned from having access to the NDIS have helped me to gain meaningful employment. It has also helped me build skills in participating in the community and in sport and life skill programmes and also social connections.

Without the NDIS funding, I would not have been able to do any of the things I've done.

Both of my parents work full time and I have three other siblings. They would not have been able to help me to access all the programmes or training I have over the years. My mum always says that she is so grateful that the NDIS was created because it helped me to be an active member of our community and live a full life."

Charlotte – at the NDIS 10 Forum

About this submission

Advocacy for Inclusion (AFI) welcomes the opportunity to make a submission to the NDIS Review, which is both timely and welcome. This submission is the result of extensive policy work and local consultation including a forum, an appreciative inquiry, a series of depth interviews and a social media forum.

To appropriately reflect this feedback our submission to the Review will comprise of two volumes:

- Volume 1: *Policies and Services*, this volume, contains key elements and themes from AFI's interactions with the NDIS across the last 10 years through a frame of what we expected and what we received. It discusses
 - Funding and sustainability
 - Participant experience
 - Culture, capability and innovation
 - Planning and funding
 - Market and workforce
 - ACT specific issues
- Volume 2: *Voices for Change* to be delivered during September and informed by the consultation process managed by the Australian Government Department of Social Services with Women with Disabilities Australia.

Volume 2 will give volume to participant voices and will be published to contribute to public understanding and include additional qualitative and quantitative detail, lived experience stories and evidence from our lived experience consultations for the review. It will be our contribution to public discussion.

Volume 1 – which is this submission, prepared for the public submission process, focuses on recommendations for change to address well-known issues which cover three main areas: seeking equilibrium between NDIS and non-NDIS services; what we expected from the NDIS; and areas where the NDIS is delivering and underdelivering.

The NDIS and the ACT at a glance

- The proportion of people with disability in the ACT **has increased over time**, rising from 15.8 per cent in 2012 to 16.2 per cent in 2015, and 19.4 per cent in 2018.
- Approximately 22,400 people, about 5.5% of the ACT's population, live with profound or severe disability. Across Australia, 5.7% of the population live with profound or severe disability
- The ACT has a **greater prevalence of reported disability** across all age groups compared to Australia. For example,
 - 11.3% of children aged 0-14 (compared to 7.6% Australia-wide)
 - 15.4% of people aged 15-64 (compared to 12.9% Australia-wide)
 - 50.5% of people with disability are aged 65+ (compared to 49.7% Australia-wide)
- Patterns emerge if we consider the gender splits across these age groups. For example,
 - Of the 0-14 age group with disability in the ACT, approximately 65% are male and 35% female. This is similar Australia wide (64 and 36 percent, respectively).
 - Of the 15-64 age group with disability in the ACT, approximately 49.4% are male and 50.6% female. This is similar Australia wide (48.7 and 51.3 percent, respectively)
 - Of the 65+ age group with disability in the ACT, approximately 47% are male and 53% female. This is similar Australia wide (47 and 53 percent, respectively).
- As of December 2022, **9793 people in the ACT on the NDIS**:
 - 3253 (34.0%) participants with autism
 - 1484 (15.5%) participants with intellectual disability
 - 1138 (11.9%) participants with psychosocial disability
 - 1059 (11.1%) participants with other including neurological or physical conditions
 - 983 (10.3%) participants with (global) developmental delay
 - 696 (7.3%) participants with sensory disabilities
 - 598 (6.3%) participants with cerebral palsy, spinal cord injury or acquired brain injury
 - 216 (2.3%) participants with multiple sclerosis
 - 141 (1.5%) participants with stroke
- Of NDIS participants in the ACT:
 - 4349, or 45.5%, are plan-managed
 - 3405, or 35.6%, are fully self-managed
 - 846, or 8.8% are partly self-managed
 - 922, or 9.6%, are agency-managed
 - 45, or 0.5%, are not recorded

Funding and sustainability

AFI supports the notion that the quantity, timeliness and targeting of mainstream responses need to be dramatically improved to ensure that the NDIS is not the only response working to improve the lives of people with disability.

Greater, more intense and focused government and inter-governmental effort should be directed to ensure that health, housing, justice, transport, employment, government and community services and the urban realm are able to provide a welcoming community to relieve the pressure on NDIS sustainability. Disability services that reach where the NDIS cannot and does not reach must be maintained and – in many cases – reinstated.

Among other things, this requires an equilibrium of effort and investment between the NDIS and the Australian Disability Strategy. We suggest a new settlement between jurisdictions designed to shift investment towards lasting social and community infrastructure. This should be the main sustainability outcome from the NDIS Review – caps, cuts and exclusions from the scheme are an inferior and problematic way of achieving sustainability.

What we expected from the NDIS

The NDIS has delivered disability supports to hundreds of thousands of Australians and over 30,000 Canberrans who had not received supports previously. It has allowed people to participate in the community, work and normal family life. It should be reformed, but the basic elements and principles should remain.

Where the scheme has fallen short of its promise is in delivering choice and control through autonomy, a seamless system, connection with mainstream services and an approach based on delivering early intervention and supports when people need them regardless of impairment. The scheme is too difficult and complex and sometimes makes simple transactions harder than they need to be.

As individuals, we expected:

- To be supported to live a normal life;
- Individualised funding which grew consumer power;
- A friendly participant lead process to decide support types and amounts;
- Flexible, responsive and timely supports that respond to changes in peoples impairment;
- Focus on early intervention especially with children and young people;
- Meaningful conversations with participants to build understanding of support possibilities.

As a consumer group, we expected:

- Expansion of quality and quantity of providers in the disability services market;
- Better, more responsive services;
- A funding environment which caused good services to prosper and poor services to fade;
- More consumer control and influence in service design;
- More funding and quantity of disability supports through a demand driven uncapped scheme available across the life of plans;
- Over time less red tape, more integrated access to supports and fewer gaps and referrals between providers;
- More responsive and adjacent mainstream supports, ILC supports and level 2 supports;
- Less attention to diagnosis and impairment types and more attention to meeting support needs at a point in time to access community, employment, family and education;
- Common sense, flexibility and responsiveness to changing circumstances and in times of crisis;
- Decent up to date information and referral services to support empowered consumers.

As a disability community, we expected:

- An independent National Disability Insurance Agency that was closely engaged with the disability community and was accessible to feedback, partnerships and genuine co-design (not replicating known deficiencies in delivery by large Commonwealth agencies);
- A comprehensive funded program of allied work by the Australian Government, States and Territories, with municipal Government to create a more welcoming community for those who benefited from improved specialist supports (including 'tier 2' supports);
- Information and referrals services that were functional, consumer controlled, modern and effective in supporting consumers to be empowered and discerning;
- Genuine opportunities for joint collaborative work and projects with an agency that was a known and trusted partner;
- Close engagement with the disability community at a local, territorial and national level;
- Quality local area coordination.

Areas where the NDIS is delivering

For individuals, the NDIS is delivering:

- Better and more consistent baseline supports for a wider group of people;
- Timely plans for some people in crisis and in post hospital discharge;
- More generous supports than under the state system for some people.

As consumers, the NDIS is delivering:

- An increased number of plans after a slow start.

For the disability community, the NDIS is delivering:

- Improved engagement with DPO/DRO sector since COVID.

Areas where the NDIS is underdelivering

For individuals, the NDIS is underdelivering through:

- Inconsistent decision-making about type and nature of supports;
- Incidents of poor customer facing interactions across the call centre, shopfront and with planners;
- Lacking a risk appetite to respond to individual circumstances outside of a narrow framework.

As a consumer group, the NDIS is underdelivering:

- Stewardship, flexibility and proactive outreach in times of crisis – a big insurer should be there to help in times of crisis (COVID is an example);
- Formation of trusted relationships and corporate memory holdings with participants;
- A culture of active listening across agency and LAC staff;
- Investment in consumer capacity for people with disability to become empowered and discerning consumers;
- Investment and policy intent to create quality information and referral resources;
- Development of market stewardship – sound knowledge and actions to ensure the continuation and health of a viable market to deliver the NDIS to participants. The NDIA lacks knowledge and an appetite to intervene in troubled markets.

As a disability community, the NDIS is underdelivering:

- Consciousness and knowledge of levels of satisfaction and dissatisfaction with the agency (and tools to do this – lots of surveys and superficial collection of data but lack of deep customer satisfaction effort) i.e., the Citizens Jury in 2014/15 which was never repeated;
- Proactive engagement as a known and trusted partner.
- Leadership of people with disability and disability rights understanding in the agency.

Following is a list of key recommendations to address the concerns raised together with a deeper analysis of these issues.

Recommendations

AFI's key recommendations are:

Funding and sustainability

1. That work be undertaken towards a new disability funding settlement designed to secure matched effort and investment between NDIS and non-NDIS efforts for people with disability.

New measurement tools and agreements should strive to match actions and resourcing between the Australian Disability Strategy and the National Disability Insurance Scheme.

This might include requirements for NDIS top ups by the States and Territories where they do not meet investment targets in mainstream areas.

A new equilibrium could be the centrepiece of a drive towards true sustainability for the NDIS, better outcomes for people with disability that meet our CRPD obligations and a legacy of better services for all Australians.

Participant experience

2. All NDIS legislation and NDIA operations, policies and processes need to be reviewed and amended so they enhance rather than reduce choice and control for people with disability under a human rights framework.
3. Ensure that every front facing member of staff in the NDIA is exposed to regular direct candid feedback from consumers which highlights positive and negative scheme interactions.
4. Create State and Territory consumer feedback groups.
5. Hold regular meetings with DPO's and DRO's.
6. Co-design and create at least one shared project to improve consumer engagement.
7. Develop a clear framework which describes co-design.
8. Establish an independent quality assurance and continuous improvement unit within the NDIA to build partnerships.

9. Activate the five NDIA customer charter principles and test these against lived experience (our Appreciative Inquiry report in Volume 2 contains extended feedback).

Culture and innovation

10. Create a cycle of deep citizen and participant engagement and openness through mechanisms like a periodic Citizens Jury along the lines of the joint DPO/NDIA project 2014/15.

Support Coordinators

11. Support coordination is one way to reduce administrative burdens on individuals. NDIS participants should be granted funding for a support coordinator in their first plan, unless they choose to opt-out.

Local area co-ordination

12. LACs need to be trained in working with NDIS participants to empower their choice and control to utilise their plan.
13. The selection of Local Area Coordination should prioritise organisations managed by disabled people who are grounded in their local communities. The ACT's LAC should be sent to market again.

Capabilities and Efficiencies

14. That the NDIA prioritise the creation of total quality control mechanisms for all key planning documentation going to clients and identify needed process improvements and targets for improvement.
15. That the NDIA connect and initiate community partnerships with the DPO and DRO sector to create genuine opportunities for co-design projects.

NDIA Communications and Partnerships

16. Clarify and promote the role of State and Territory managers.
17. Create positions for State and Territory NDIS decision makers.
18. Develop State and Territory consultative mechanisms for improved sector engagement.
19. Create advisory committees to engage with local Disability Peak Organisations.

20. The NDIA should undertake work on values and culture which builds understanding of social model – it should model best practice with other agencies.
21. The NDIA should feel present in the disability community with a learning culture and a curiosity about disability in its staff through shared projects, learning opportunities, embedded staff and collaboration between the Agency and organisations of people with disability – it shouldn't look like another Commonwealth agency, it should be the lighthouse agency that does disability really well and walks its own talk.

Planning and funding

22. There should be minimum standards for the time planners allocate to planning conversations.
23. There should be improved training and information available to planners. Planners should have deep knowledge about local context and the state of the market for people with disabilities in the location of the person being planned for.
24. There should be a simplification agenda to make the language around planning easier to understand.
25. Reasonable and necessary should be retained but work should be undertaken to better interpret this.
26. Individualised funding under NDIS should be retained. We do not support a return to block funding.
27. Pricing work by the NDIA should ensure that baskets of goods and services used to determine pricing are realistic and preference quality – for instance avoid costing in low quality products that do not meet Australian standards or have the potential for customisation and which contribute to an unrealistic pricing standard.
28. The NDIS should adopt a policy goal of ensuring a better alignment between the actual life goals and funding preferences of individuals and the goals and allocations in peoples plans. 'Do we have enough funding in the right areas for you and are these goals your actual goals?' should be a regular question in quality assurance work.
29. The NDIS should develop a better more nuanced approach to funding one off high value and high impact items which includes consideration of their wholistic benefits to individuals.

Market and workforce

30. The NDIS should see itself as a steward of an immature market and undertake responsible stewardship, industry development and guiding to create a viable, healthy and responsive market in those areas where it has failed or where it is denuded.
Features of this should include:
 - a. Preferential pricing and offers to quality providers
 - b. Proactive assistance to new and emerging providers where the market has completely failed
 - c. Startup grants
 - d. Workforce development interventions
31. The NDIS should continue to allow participants to use providers of their choice.
32. Ensure pricing is accurate, bends towards quality and allows the maintenance and growth of a viable market.
33. The NDIS should avoid practices, regulations and behaviours which hamper the market like mandatory qualifications on providers and support workers.

Information and referral

34. That the NDIA commission DPO's and DRO's in each State and Territory to audit its provider list as an interim measure.
35. That the NDIS fund an independent, comprehensive, detailed and consumer curated information and referral portal and phone service for private, government and non-government providers which is permanently updated and sits outside of government so that consumers can become informed, knowledgeable and discerning consumers. It should help people find providers, find products and make decisions about which provider might be able to deliver for them. It should be detailed, specific and provide feedback about quality.

ACT specific issues

36. The agency should have regular mechanisms for engagement with peaks and DPO's in each State and Territory.
37. Attention should be paid to better responses for people with disability in the greater Canberra region starting with advocacy.

PART 1: FUNDING AND THE FEDERATION

Funding, sustainability and the Federation

“Prior to 2013, people with disabilities in my area were relying on small group community services, and over time we had established really strong friendships with each other. We enjoyed doing things together.

*After the NDIS was established, the community services we used tried to adapt to the new funding models and it was a bit of a disaster. **They just axed all the disability programs”.***

Sarah – NDIS Participant

We note that this review takes place in the context of much commentary around sustainability and funding shares for the NDIS within the Federation. It has been noted that the NDIS has become an ‘oasis in the desert’ or a ‘magic pudding’ which has needed to assume a greater level of disability supports while States and Territories moved away from disability supports, but also haven’t improved mainstream responses.

In several regards the ACT is a crucible for these issues having been established as a launch jurisdiction for the Scheme and having one level of government which provides a level of transparency and visibility of mainstream supports and accessibility across areas like transport, education, health, local community services and physical and digital infrastructure and the urban realm.

While the ACT made sensible provision for non-NDIS services through the health system, including the Community Assistance and Support Program (CASP) AFI notes that these are fragile. Most recently the CASP program has undergone changes and a likely narrowing of scope as it transitions into another program.

The ACT on paper has polished systems and frameworks to improve mainstream responses for people with disability. These include a government commitment to an ACT Disability Strategy, a Disability Justice Strategy, a Disability Health Strategy and an Inclusive Education Strategy. The ACT is also moving towards a more formalised commitment to disability action and inclusion plans and strategies through a pending Disability Inclusion Bill issued by a Government backbencher which is set to be introduced in coming months.

Yet only one of these strategies – the Disability Justice Strategy – actually has multi-year funding (outside of administrative funding) and many of the markers of mainstream progress for people with disability in this jurisdiction are either poor, worsening or very slow to improve:

- One-third (33%) of people with disability identify wages or salary as their main source of personal income. Compare this to more than two-thirds (71%) of people with no reported disability
- Nearly one-third (30.8%) of people with disability aged 15+ are in the lowest income quintiles. Compare this to 10.4% for people with no reported disability.
- A single person aged 21 years or older on DSP receives just over \$500 a week. The median rental price for all dwellings in the ACT is \$625 a week
- A DSP recipient could not afford any of the 1,553 private rentals advertised for rent in the ACT and Queanbeyan in March 2023. The median rental price for a unit or house was more than their entire primary income.
- The employment rate is 20% lower for people with a disability aged 15-64.
- People with disability are less likely to complete year 12: 56.1% compared to 77.3% of people with no reported disability
- The ACT has the highest rate of rental stress for low-income private renters of any Australian jurisdiction (73% compared to 50% nationally)
- People with disability report poorer access to all types of health services on average compared to other ACT residents.
- The ability of many Canberrans to access health services declined between 2019 and 2020. People with disability reported poorer access to all types of health services on average compared to other ACT residents.
- This finding is replicated in the Disability Strategy’s Listening Report: 63% of survey respondents rated finding and using health care services that are needed as a big or very big issue.
- The ACT also suffers from a shortage of specialists, especially specialist services for children with disability. In the ACT, of the people most likely to report poor health at the end of 2021:
 - 57.5% of people with physical disability
 - 57.2% of people with any type of disability
 - 46.4% of people with mental health disability
 - People with disability are more likely to develop preventable and/or treatable conditions, such as cancer, diagnosed at a stage where a good health outcome is significantly less likely
 - The ACT have relatively low levels of access to bulk-billed GP services
- 31% of AMC detainees identified as having a disability in 2022.

Towards funding equilibrium

AFI supports the notion that investments in mainstream services need to be lifted to ensure that the NDIS is not the only engine for improving the lives of people with disability. More government and inter-governmental effort should be directed to ensure that health, housing, justice, transport, employment, government and community services and the urban realm are able to provide a welcoming community. This is the only way to relieve pressure on NDIS sustainability while retaining the promise made to all Australians by all Governments to deliver and maintain a national lifetime entitlement based care and support scheme for people with disabilities.

This is easier said than done. The NDIS is a shared investment and undertaking as is the Australian Disability Strategy (ADS). The Australian Government is a funder of the NDIS and the States and Territories are minority funders of the NDIS. The States and Territories fund most of the non NDIS services but they do this with a mixture of their tax takes and through tied grants. The Australian Government also delivers non NDIS services and funds the States to provide them.

A sustainability solution requires greater funding equilibrium from both the States and Commonwealth – not just *between each other* but *between* the NDIS and the ADS. A problem is that funding in the NDIS is relatively transparent but funding in non NDIS responses is blurred. Opacity and a lack of clear owners make it hard to design, enforce and track implementation.

One option might be for Governments to agree and define clearer benchmarks and expectations around non NDIS funding, how this is described, reported and measured and what happens when it doesn't step up. As the major funder for the NDIS Commonwealth has a fiscal interest in stepping up to design measures and instruments capable of achieving this. It would take effort, but as with Wellbeing Budgeting, it is not impossible. As the jurisdiction with the greatest stake in sustainability – and much data capability - the Commonwealth should lead the project of designing them.

Bilaterals could identify arrangements whereby Governments met non NDIS disability investment targets which are measured by these instruments. Where they failed to do so Governments might be required to top up the NDIS sovereign fund in a way that acknowledged the contribution the scheme was making to gap supports. Over time the aim would be to shift the balance between more investment towards social and community infrastructure focused on accessibility, inclusion and non NDIS services provided by Governments as part of their universal service obligations.

This outcome would also be in the national interest as it would grow social inclusion and viable infrastructure across the community, including for people who are ageing. It would leave a positive legacy and address other great national concerns – especially intergenerational equity.

Under this model States and Territories might have a new settlement carved out where they initially top up more of the NDIS but also have the option of offering a substitute investment for some portion of their 'side' of the balance sheet - more money towards inclusive education, accessible transport, warm discharge from hospital and long duration post hospital disability supports, early childhood supports, improved physical and digital infrastructure and better aged care.

The sovereign fund should also be managed carefully and protecting against raids with money retained in the scheme.

This is a superior model than other changes mooted to address sustainability which will not work without walking away from the Scheme Australians asked for. There are some measures we specifically warn against

- Capping the scheme which would create a rationed scheme
- Returning to block funding or vastly limiting the scope of providers
- Requiring people to agree Budgets before planning sessions as in the UK which would thwart the scope, usefulness and effectiveness of plans
- Removing basic service elements from the scheme, such as gardening and domestic services and restricting it to specialist services – the scheme is about living an ordinary life. A clean house and a clean body are both ordinary and reasonable expectations.

Recommendation

1. *That work be undertaken towards a new disability funding settlement designed to secure matched effort and investment between NDIS and non-NDIS efforts for people with disability.*

New measurement tools and agreements should strive to match actions and resourcing between the Australian Disability Strategy and the National Disability Insurance Scheme.

This might include requirements for NDIS top ups by the States and Territories where they do not meet investment targets in mainstream areas.

A new equilibrium could be the centrepiece of a drive towards true sustainability for the NDIS, better outcomes for people with disability that meet our CRPD obligations and a legacy of better services for all Australians.

PART 2: PARTICIPANT EXPERIENCE

The participant experience can be divided into three key areas: choice and control; participant/staff interactions; and NDIA values and principles.

Choice and Control

The participant experience must reflect the core principle of the NDIS – choice and control. To do this, the NDIA needs to re-frame its policy reform and service system design and provision within a human rights framework. Participant choice and control must underpin such reform to be ‘exercised in ways that enable freedom and power, not just participation in a market’.²

Examples of this include participants being:³

- Recognised equally before the law and supported to exercise their full legal capacity;
- Able to exercise their choice and control in every aspect of their lives relating to their NDIS experience. For example, their supports; choice of where they live and choosing their own form of personal mobility.

Recommendation

2. *All NDIS legislation and NDIA operations, policies and processes need to be reviewed and amended so they enhance rather than reduce choice and control for people with disability under a human rights framework.*

Participant / Staff interactions

A twin feature of the participant experience is how participants and NDIA staff interact. The NDIA culture needs to improve. To do this:

- Staff development activities within the NDIA could focus on enhancing and building understandings of the effects of customer interactions on people with disabilities. A co-design model could be the service improvement work undertaken in the early 2000’s within Centrelink under the leadership of Sue Vardon including value creation workshops and exposure of staff to intensive client experience feedback.
- All staff should be exposed to reflective feedback from clients to understand how interactions impact them – sessions could be designed for State and Territory staff to observe clients providing candid feedback about what it was like to engage with the NDIA.
- We need specific NDIA mechanisms to enable people to give feedback about the NDIS at a State and Territory jurisdiction level. While the NDIS might be organised in a national way it

² ACTCOSS, op cit., page 11.

³ Ibid.

has not abolished State and Territory boundaries which still govern what non NDIS resources are available. Providing this feedback is not realistically the role of State and Territory appointed advisory councils like the ACT Disability Reference Group, as they do not have the access, proximity and resourcing to provide advice on the NDIS. They also have a busy work agenda around State and Territory responses.

Recommendations

- 3. Ensure that every front facing member of staff in the NDIA is exposed to regular direct candid feedback from consumers which highlights positive and negative scheme interactions.*
- 4. Create State and Territory consumer feedback groups.*
- 5. Hold regular meetings with DPO's and DRO's.*
- 6. Co-design and create at least one shared project to improve consumer engagement.*
- 7. Develop a clear framework which describes co-design.*

NDIA Values and principles

The NDIA needs more administrative focus on quality assurance to oversee its functions and highlight deviations from its values and principles to push the agency to do better.

This could mean an embedded but independent unit within the NDIS with independence, authority and capacity to challenge and drive innovation and continuous improvement in participant engagement, participant experience and building true partnerships with the sector.

Recommendations

- 8. Establish an independent quality assurance and continuous improvement unit within the NDIA to build partnerships.*
- 9. Activate the five NDIA customer charter principles and test these against lived experience (our Appreciative Inquiry report in Volume 2 contains extended feedback).*

PART 3: CULTURE, CAPABILITY AND INNOVATION

Culture

*“My biggest challenge with the NDIA is that **you ring the 1800 number and you may or may not talk to someone**. Someone may or may not ring you back. Then if you need to follow up on that specific concern, you end up talking to a new person, and **there's often no paper trail** in the office about what was discussed before.” – From the AFI Appreciative Inquiry*

NDIS Staff

There are many thousands of staff working for the NDIA. Staff at the NDIA are dedicated, responsive, professional and care about outcomes for people with disability. However, there is room for improvement when it comes to the communication, flexibility, and responsiveness of the NDIA's current operational processes and procedures.

Ambitious community engagement projects that allow NDIS participants and the public to be part of the process of driving cultural change should be resumed. A very good example from the early days of the scheme was the NDIS Citizens Jury Scorecard project from 2014/15 which was the winner of a global IAP2 Award in 2015.

Recommendation

10. Create a cycle of deep citizen and participant engagement and openness through mechanisms like a periodic Citizens Jury along the lines of the joint DPO/NDIA project 2014/15.

Support Coordinators

The NDIS needs to make support coordination available earlier in the planning process.

What we've seen: We have seen participants being required to submit the same documents over and over again, unnecessary hoops for receiving support coordination and requirements for reports for small cost items.

AFI has witnessed instances in which participants are not granted support coordination, despite requesting or requiring it. In one situation, a client who did not have support-coordination was unable to access most of their supports for six months, due to the lack of support regarding their difficulties in self-management. This caused angst and difficulty in their subsequent plan review, as they were required to prove why they didn't access all their funds.

Recommendation

11. *Support coordination is one way to reduce administrative burdens on individuals. NDIS participants should be granted funding for a support coordinator in their first plan, unless they choose to opt-out.*

Local Area Coordinators

*“... Sometimes I feel like the **LACs definitely don't understand their own role**. Being gatekeepers when it's not their place and not stepping up when they should. Within all of these roles there seems to be either **a lack of training** or varying amounts of training amongst staff. Some are excellent and some are well, terrible. This affects participants' quality of life dramatically. Inconsistent approaches by LACs with a lack of clarity around their roles is limiting, and potentially damaging, participants to achieve the best outcomes from their plans.”*
– Michelle, Social Media Forum .

*“I would like to see a central resource of a shared file, so that if staff leave, everything's on file. So if we have to continue with having LACs when somebody leaves their job, I want something like a handover and having the participant involved in the handover process, if they want to participate, so that there is a **continuity of understanding and care**.”* – from the Appreciative Inquiry.

What we've seen: A client did not know how to begin organising supports in their first plan, and they were unaware that support coordinators could be funded. Despite them asking for assistance, their LAC did not show them how to organise supports for the first few months of their plan.

There are persistent quality issues with Local Area Coordination in the ACT. This should be returned to market. Preference should be given to local organisations who have good knowledge, networks and local capability.

Recommendations

12. *LACs need to be trained in working with NDIS participants to empower their choice and control to utilise their plan.*
13. *The selection of Local Area Coordination should prioritise organisations managed by disabled people who are grounded in their local communities. The ACT's LAC should be sent to market again.*

Capabilities and Efficiencies

“They lost my plan for two years.” Anon, NDIS participant

The following sections focus on the broader areas of the NDIS where we suggest improvements for the Scheme’s capabilities and efficiencies including enhancing the interaction between the NDIA and related policies and systems; the planning process and funding levels.

High quality assurance: Improving the interaction between the NDIA and related policies and systems

The NDIA needs to take steps to improve the quality of document management, handovers between staff and other quality assurance procedures.

What we’ve seen: There has been a small but regular stream of issues around the management of information and documents with our clients. AFI has interacted with clients where it appears the NDIA has lost participant’s documentation or where there have been errors in documents (wrong names, wrong conditions and other basic details incorrect).

There is room and opportunities for improvement in terms of the NDIA’s capabilities – including capacity to connect and drive community partnerships and genuine co-design with the DPO and DRO sector. There is limited appetite for risk and innovation. This could be strengthened by focusing on cooperation, partnership and exchange with the sector and communities of disabled people in order to cultivate goodwill.

Recommendations

14. *That the NDIA prioritise the creation of total quality control mechanisms for all key planning documentation going to clients and identify needed process improvements and targets for improvement.*
15. *That the NDIA connect and initiate community partnerships with the DPO and DRO sector to create genuine opportunities for co-design projects.*

NDIA Communications and Partnerships

Communications

Communication between the NDIA and disability community needs to improve at a State / Territory and grassroots level. Following is a discussion and recommendations on these issues.

State / Territory Communications

The national nature of the NDIA, as well as headquartering in Geelong, has made it hard for State and Territory based advocates to problem solve with the agency, to understand who is in charge and to build rapport. Welcome initiatives like the NDIA monthly briefings are focused on information sharing.

While the NDIS is national, Australia is still a Federation – public services like justice, education and health remain organised on State and Territory lines. Markets which serve NDIS clients contain providers and provider networks which exist solely within that State or Territory. The NDIS needs to have some decision makers and consultative mechanisms in place at a State and Territory level.

Recommendations

16. *Clarify and promote the role of State and Territory managers.*
17. *Create positions for State and Territory NDIS decision makers.*
18. *Develop State and Territory consultative mechanisms for improved sector engagement.*

Grassroots level communication

There would be value in regular grassroots advisory committee groups and the relevant NDIA State or Territory managers engaging with groups of peaks – like the Disability and Carers Policy Group in the ACT.

What we've seen: Over time it has become clear there is mixed local market knowledge from staff at the NDIA and sometimes with Feros who do not have a good grasp of thin market issues in our region. Sometimes clients are referred to services that are full, do not provide services in the ACT or for service types that are not offered here.

Recently the NDIA's engagement with AFI has improved with monthly catchups with the advocate and policy team working through a 'traffic light' register of issues. This could be a good engagement model for other jurisdictions.

Recommendation

19. *Create advisory committees to engage with local Disability Peak Organisations.*

Innovation and Collaboration with the disability community

*“A lot of people don’t fully understand my disability either because it’s quite rare. It might help if the **NDIS had the resources, time and capacity to get to know people, and to learn about them.** But right now, it seems like **they just don’t.**” Anon, NDIS participant*

A NDIA more disability aware, confident and grounded in disability issues is required. Specific areas of focus could include:

- Diversifying NDIA staff to include more people with disability, and more people with broader experiences in the disability sector including people grounded in rights-based work.
- Exploring other ways of coworking and collaborating with disabled people and our organisations, for example, embedded staff, shared projects, secondments and other mechanisms.
- Developing a culture of learning about disability, its impacts and the nature of impairments.
- Targeting efforts to increase the culture and safety of the NDIA for staff with disability. In turn, this will help attract more staff members with disability.

What we’ve seen: Sometimes decisions reflect a poor knowledge of the impacts of particular disabilities on a person’s need for supports – for instance accessing transport or health services. Sometimes comments about disability in planning conversations have a medical, rather than a social model approach.

Recommendations

20. *The NDIA should undertake work on values and culture which builds understanding of social model – it should model best practice with other agencies.*
21. *The NDIA should feel present in the disability community with a learning culture and a curiosity about disability in its staff through shared projects, learning opportunities, embedded staff and collaboration between the Agency and organisations of people with disability – it shouldn’t look like another Commonwealth agency, it should be the lighthouse agency that does disability really well and walks its own talk.*

PART 4: PLANNING AND FUNDING

*“The NDIS basically has its **own language and vocabulary**, with all different terms and nuances that you won’t know unless you were familiar with it, so it I found it confusing.” Angela, NDIS participant*

*“Luckily, I didn’t have much trouble getting accepted, but it just took a really long time. I think **seven months went by before I heard that I’d been approved**, despite the dossier of medical reports that I provided.” – Susan, NDIS participant*

Plan Quality

There is a need to lessen administrative burdens both on staff and for people on the Scheme as well as fraying trust, collaboration and problem solving at a State and Territory level. Participants are much more likely to feel satisfied with a plan that they have had meaningful input into where their choice and control heard, respected and acted on accordingly by NDIS staff.

To do so, the planning process must be more collaborative.

NDIA staff members and LACs must dedicate and allow adequate time to speak with the person with disability about the reasons for decisions, at all stages of engagement with the scheme. Together with staff being equipped with correct and up-to-date knowledge of the NDIS. Further, the call centre must be subject to greater quality control.

The paperwork, language and vocabulary around the NDIS is too confusing.

To restore participants confidence in the planning process, the NDIA must not:

- Reintroduce independent assessments;
- Cap plans;
- Remove the capacity to ask for a plan review;
- Make all plans roll over year on year without review (this needs to be an option only).

Recommendations

22. *There should be minimum standards for the time planners allocate to planning conversations.*
23. *There should be improved training and information available to planners. Planners should have deep knowledge about local context and the state of the market for people with disabilities in the location of the person being planned for.*
24. *There should be a simplification agenda to make the language around planning easier to understand.*

Funding levels

The funding architecture of the Scheme is basically sound in our view. By and large the reasonable and necessary test is a sensible one but the interpretation of this needs work. Individualised funding under NDIS should be retained. We do not support a return to block funding. We do not support a cap on funding so that runs out at a particular time of year. A capped and rationed system would be a return to the dysfunctional system that failed people with disability before the NDIS.

We have however encountered a number of issues which point to insufficient and poorly arranged funding, inconsistent funding, misallocated funding and poor pricing. The most problematic issues are:

- Unrealistically low and averaged prices for some pieces of equipment or services – these have created viability issues for small quality providers and have reduced choice and control in the scheme as large providers have come to dominate the market. Some of the pricing for equipment for instance has been based on low quality off the shelf items (like Pharmacy quality mass produced wheelchairs which are not intended for ongoing use and are not able to be customised). Quality providers are not able to produce equipment at that cost and some of them have faded from the market leaving consumers unable to source quality product in local areas or needing to source the same equipment at higher costs.
- Funding appears to be misallocated in some peoples plans with people getting funding for services and supports they do not need while getting insufficient funding in areas that are important to them. Over time our goal should be to ensure that the goals and the funding levels in peoples plans align to their goals in real life.
- The scheme appears to resist funding high value one off items – like specialised walking devices even when they are transformative and high value to individuals when set against multiple investments in low-cost items.

Recommendations

- 25. Reasonable and necessary should be retained but work should be undertaken to better interpret this.*
- 26. Individualised funding under NDIS should be retained. We do not support a return to block funding.*
- 27. Pricing work by the NDIA should ensure that baskets of goods and services used to determine pricing are realistic and preference quality – for instance avoid costing in low quality products that do not meet Australian standards or have the potential for customisation and which contribute to an unrealistic pricing standard.*

28. *The NDIS should adopt a policy goal of ensuring a better alignment between the actual life goals and funding preferences of individuals and the goals and allocations in peoples plans. 'Do we have enough funding in the right areas for you and are these goals your actual goals?' should be a regular question in quality assurance work.*
29. *The NDIS should develop a better more nuanced approach to funding one off high value and high impact items which includes consideration of their wholistic benefits to individuals.*

PART 5: MARKET AND WORKFORCE

*“Even then there are not many builders who are doing accessible modifications and so the wait lists are long. When it was finally my turn to get started, **the business that I was working with had collapsed. I had to start all over again.***

*It’s definitely been difficult to access health services and find support workers too, and when you do, they’re also **overrun with requests.** I don’t have a Canberra based LAC at the moment, so the advice that I can get from them is limited.” Angela*, NDIS Participant*

“A major struggle I have is in finding support workers and specialists who are willing to cater to my needs in the same way.

Unfortunately, I’m sensitive to conventional cleaning products, so I can’t employ someone who has just cleaned someone else’s house and used spray and wipe.

The service agencies that I use keep sending people who are properly briefed, but who don’t take the risk seriously. Some agencies just seem to throw up their hands and say “yeah, that’s a bit too hard”, Susan, NDIS Participant

Market Failure

In other areas of the economy where the market fails to produce an essential good or service government intervenes to ensure that it does. This includes the energy market, telecommunications, manufacture of health devices and transport. Yet the NDIS has been introduced with almost no market development and an expectation that if we build it they will come. Likewise the Government intervenes to ensure that workers are available in key industries using a range of levers from immigration policy, the transfer system and even key worker housing.

“One of the major services I rely on to support my recovery is brain training. Twice a week I attend an exercise physiology studio that specialises in brain injury and has a program set up for me.

I find that their services help me tremendously. After a session my brain just feels so much clearer. I feel calmer.

*At the same time, I believe the clinic I go to is the **only neurological training service in Canberra.** That’s a **single point of failure right there.***

There is definitely quite a bit of demand, so the clinic is frequently busy.” Peter, NDIS Participant*

The Review has already noted that there is no real market of disability services. But there *should* be and our response to this should be to look at why a market has not flourished and how we can gain the benefits that a market could bring to people with disabilities in those areas where it is important. We must also urgently respond to consequential market failure which has meant that, in some areas, the market has been vacated entirely.

Limiting choice and control to particular providers in a market prevents people with disability having the full range of real and meaningful choice in their lives. This has the cascade effect of limiting participant’s ability to have control over their own life.⁴ Following, market failures will be discussed through examining the current categories of providers: registered, equipment and diagnostic.

Registered providers

“I wouldn’t even know where to start if I had to use a registered provider” – Angela, NDIS Participant*

Taking into consideration the thin markets and poor-quality services by some registered providers, the NDIA should not remove small bespoke providers in favour of larger providers. Additionally, participants should not be required to:

- only use registered providers;
- use the cheapest available or generic products;
- use State or Territory services to replace a service currently funded by the NDIS when that service does not exist.

Further, registered providers and support workers should not be required to undertake mandatory qualifications. There is no evidence this will improve quality participant experiences and will instead limit options, choice and control for participants.

⁴ ACTCOSS report, op cit., page 8.

Recommendations

30. *The NDIS should see itself as a steward of a young immature market and undertake responsible stewardship, industry development and guiding to create a viable, healthy and responsive market in those areas where it has failed or where it is denuded.*

Features of this should include:

- a. Preferential pricing and offers to quality providers*
- b. Proactive assistance to new and emerging providers where the market has completely failed*
- c. Startup grants*
- d. Workforce development interventions*

31. *The NDIS should continue to allow participants to use providers of their choice.*

32. *Ensure pricing is accurate, bends towards quality and allows the maintenance and growth of a viable market.*

33. *The NDIS should avoid practices, regulations and behaviours which hamper the market like mandatory qualifications on providers and support workers.*

The provider list

“It really is a matter of Googling until I find what I’m looking for.” – Susan, NDIS Participant*

The NDIS provider lists are confusing, inaccurate, out of date and unhelpful. They contain no useful information about what providers perform what functions and whether providers are actually operating in a jurisdiction. There are ‘dead listings’ of defunct providers. Some providers types, like equipment, seem to be exceptionally poorly served. NDIS participants report using search engines to try and find services. People without access to digital platforms are simply lost. The next section on information and referral recommends a longer term approach but we also need interim work to avoid harm.

What we’ve seen: AFI did our own audit of the service providers listed for mobility aids and equipment in the ACT and found that only around a third of the providers listed for the ACT *actually serviced the region at this point in time.*

Recommendation

34. *That the NDIA commission DPO’s and DRO’s in each State and Territory to audit its provider list as an interim measure.*

Information and referral

*“Lots of the **information and recommendations** that I have received have come from informal sources, rather than from the NDIS website” – Angela*, NDIS participant*

People do not know where to go to get information about NDIS services or how to find out what the good services are. Clients get a long list of services and are then required to go off and do their own research without any context, peer review, quality assessments or detailed information. Lists are confusing, inaccurate, out of date and insufficient.

Resources are printed and inaccessible and there is no alternate way for people to get information over the phone or on the web.

There is a **desperate need for an independent, comprehensive, detailed and consumer curated information and referral portal and phone service** for private, government and non-government providers which is funded by the NDIA and sits outside of government so that consumers can become informed, knowledgeable and discerning consumers. It should help people find providers, find products and make decisions about which provider might be able to deliver for them. It should be continuously updated.

The Disability Gateway is limited and cannot perform this function. It either needs to be reformed and turned over to a dedicated DPO with expertise and information referral holdings with ongoing annual funding to manage so that it can become a useful one stop shop for both NDIS providers, support workers and general accessibility information or a new resource created.

This resource needs to include the following features:

- To be continuously updated and permanently updated
- To provide detailed and up to date information by goods, services and equipment type
- To be independent and able to offer robust feedback on quality and value for money from the point of view of consumers
- To allow services to be rated and described by users
- To sit outside of government but be funded by government so it can list private companies
- To be available via web, smartphone application with a phone option
- To allow consumer ratings and feedback
- To make good use of technology and modern apps including geo tracking, but also have a basic level of accessibility and wayfinding.

In time the resource should cover NDIS and non-NDIS spaces, places, people and services that provide accessible goods and services and inclusion for people with disability including suppliers of accessible equipment; accessible accommodation listings; sports and recreation, arts, services and community facilities. Instead of dozens of poorly maintained sites we need a reliable navigable one stop shop that supports people with any kind of disability and diverse information access needs to identify services that can help them, equipment they need, places to stay and things to do.

Recommendations

35. *That the NDIS fund an independent, comprehensive, detailed and consumer curated information and referral portal and phone service for private, government and non-government providers which is permanently updated and sits outside of government so that consumers can become informed, knowledgeable and discerning consumers. It should help people find providers, find products and make decisions about which provider might be able to deliver for them. It should be detailed, specific and provide feedback about quality.*

ACT specific issues

Relationship with local NDIS office

There are areas of best practice and signs of improvement with the local NDIS office. The NDIA's engagement with AFI over recent months have been more outward looking, engaged and focused on problem solving. The virtual NDIS updates and briefings started during COVID are a great initiative.

We note that some complex matters are being resolved outside of AAT and dispute contexts. This is welcome but further cultural and market improvement is needed to sustain change.

There is a need for greater focus on Canberra, Queanbeyan, Yass and Goulburn as a region in the provision of NDIS and non NDIS supports. Taken as a whole this region includes clusters of socio economic disadvantage, regional disadvantage and high numbers of people with disability. There is considerable and obvious cross border needs that ACT agencies are unable to service. There is very little advocacy available outside of Canberra city to serve the wider region.

Recommendation

- 36. The agency should have regular mechanisms for engagement with peaks and DPO's in each State and Territory.*
- 37. Attention should be paid to better responses for people with disability in the greater Canberra region starting with advocacy.*