

Advocacy for people with disability

NDIS Review

Submission by **Queensland Advocacy for Inclusion**

to

NDIS Review Panel

1 September 2023

About Queensland Advocacy for Inclusion

Queensland Advocacy for Inclusion (**QAI**) (formerly Queensland Advocacy Incorporated) is an independent, community-based advocacy organisation and community legal service that provides individual and systems advocacy for people with disability.

Our purpose is to advocate for the protection and advancement of the needs, rights, and lives of people with disability in Queensland. QAI's Management Committee is comprised of a majority of persons with disability, whose wisdom and lived experience guides our work and values.

QAI has been engaged in systems advocacy for over thirty years, advocating for change through campaigns directed at attitudinal, law and policy reform.

We also provide individual advocacy services in the areas of human rights, disability discrimination, guardianship and administration, involuntary mental health treatment, criminal justice, NDIS appeals, and non-legal advocacy for young people with disability including in relation to education. Our individual advocacy experience informs our understanding and prioritisation of systemic advocacy issues.

Since 1 January 2022, QAI has also been funded by the Queensland Government to establish and co-ordinate the Queensland Independent Disability Advocacy Network (QIDAN). QIDAN members work collaboratively to raise the profile of disability advocacy while also working towards attitudinal, policy and legislative change for people with disability in Queensland.

Contents

About Queensland Advocacy for Inclusion	2
QAI's recommendations	4
Background	6
Introduction	7
Solutions built on success	7
1. Applying and getting a plan	8
Solutions: Getting access to the NDIS	8
Solutions: Planning	11
2. A complete and joined up ecosystem of support	13
Solutions:	13
3. Defining reasonable and necessary	17
Solutions:	17
4. Early childhood supports	19
5. The support and service market	19
Solutions:	19
6. Measuring outcomes and performance	20
Solutions:	21
8. Help accessing supports	21
Solutions:	22
9. Supported living and housing	23
Solutions:	24
10. Participant safeguards	26
Solutions:	27
Conclusion	29
Appendix A: Prior Submissions by QAI on the NDIS	30
Appendix B: Case Study	32
Choice and control in housing	32
Appendix C: Case commentary on reasons	33
Appendix D: Template – How your plan has been calculated	35
[Name]: NDIS Plan [Plan start date] – [plan end date]	35

QAI's recommendations

QAI's submission contains several small and large-scale reform ideas.

Our large-scale reform ideas include:

- 1. Introduce a **new governance structure** which includes the NDIA, the Commonwealth and all States and Territories to provide oversight and accountability for all disability related supports, services and funding. The new structure must consider the ecosystem as a whole rather than continuing a siloed approach in which certain Ministers or bureaucrats have responsibility for either the NDIS or state and territory funded mainstream services.
- 2. Increase supports available to people with disability through **Medicare**. Provide access to funding for comprehensive assessments and reports from a medical professional and relevant allied health professional. Provide access to 20 rather than 10 psychology sessions and 10 rather than 5 allied health sessions, with the Medicare rebate matching the NDIS price limits for these services. The current system is inequitable and better Medicare services could reduce reliance upon the NDIS.
- 3. Create a **no-wrong door approach** so that where service duplication may exist between service systems, the onus is on the service systems to settle funding responsibilities. The NDIA should take a precautionary approach with funding supports for participants where it views those supports should be covered by another service system. Like other insurance schemes, the NDIA should be able to seek recovery of costs from other government services where those service systems have failed to provide the necessary services.
- 4. Every state and territory must have a well-equipped, well trained, and person-centred **provider of last resort**.
- 5. Increase transparency and improve planning processes, for example by providing all participants with draft plans, detailed reasons and a clear breakdown of funded supports (see Appendix D for an example). Provide flexible planning processes that **support families with multiple NDIS participants**. Stop the practice of changing plans without notice, consultation and proper reasons.
- 6. Create a separate, **independent support organisation** to provide information, advice and support regarding plan implementation obligations, such as **obligations when directly engaging/employing support workers** and negotiating or managing disputes with service providers.
- 7. Introduce a **new model for auditing service providers** that centres the expertise of people with disability who are participants of the scheme. Reform registration and accreditation processes so they move beyond compliance and reporting measures and include criteria that evaluate the extent to which services provide person-centred care.
- 8. Introduce a mechanism to regularly **review the accessibility of mainstream services** for people with disability. This could include the development of an inclusion scorecard used to review discrete aspects of a service, such as the competency of staff in supported decision-making practices or the accessibility of information provided to all service users. This could be linked to and included in the Outcomes Framework of Australia's Disability Strategy and/or state and territory disability action plans.

- 9. Redesign and **simplify the home and living supports** offered to NDIS participants. Adopt a rights-based approach towards housing that will facilitate the full deinstitutionalisation of people with disability. Implement a '**housing first'** approach that separates consideration of housing and support arrangements.
- 10. Overhaul the **monitoring of Restrictive Practices**, with a view to eliminating their use entirely. Transition away from an approach that focuses on regulation, authorisation and positive behaviour support to an approach that addresses the 'ecological system of violence, coercion and control' that Restrictive Practices operate within.

Background

This submission is primarily informed through our experience delivering advocacy for people engaging with the National Disability Insurance Scheme (NDIS) through our NDIS Appeals Support Program, our previous Decision Support Pilot and our Young Peoples Program. It also draws upon our previous submissions regarding the NDIS going back to 2017, all of which are listed and linked at **Appendix A** of this document.

QAI is funded by the Department of Social Services (DSS) for our NDIS Appeals Support Program and the Queensland Government for our Youth Peoples Program. Both programs are currently experiencing a huge demand for our services.

Our NDIS Appeals team:

- Represents people with a disability at the Administrative Appeals Tribunal (AAT) appealing a
 decision of the NDIS. Our advocates and solicitors regularly appear for clients at case
 conferences and conciliations at the AAT.
- Provide individual advice sessions to people with a disability at all stages of their NDIS AAT appeal. We work to assist clients to self-advocate at the AAT, for example assisting clients to understand legal documentation and to articulate their needs to the Agency.
- Develop community education, for example by speaking at events and creating fact sheets.

Our Young Peoples Program provides individual advocacy for children and young people with disability to support them to uphold their rights interests and increase control over their lives. We assist people who are navigating systems such as education and the NDIS and who are experiencing discrimination, conflict or unfair treatment. Our advocacy often involves informing people of their rights, attending complex stakeholder meetings with multiple departments, supporting young people with NDIS reviews and gathering relevant documents and information.

Up until 30 June 2023, our NDIS Decision Support Pilot team provided advocacy and decision-making support for people with disability who had limited decision-making capacity who required assistance to engage with the NDIS. Operating within a supported decision-making framework, our advocates assisted with gathering evidence for access requests, preparing for and attending planning meetings, supporting clients to choose a support coordinator or problem-solve issues during the implementation of their plan.

Funding for this program was discontinued by DSS despite its evaluation being incomplete and notwithstanding positive feedback from participants across the country.

Introduction

QAI welcomes the opportunity to contribute to the NDIS Review. Despite several inquiries into the scheme and multiple opportunities for reform, key challenges remain unaddressed and are stopping the scheme from realising its true, life-changing potential for Australians with disability.

The introduction of the NDIS has undoubtedly changed the lives of many people with disability living in Australia. It is providing critical support that facilitates the rights of people with disability to be independent and to live full social and economic lives. The NDIS is a world leading scheme that supports Australia to fulfil its international human rights obligations, including those under the Convention on the Rights of Persons with Disabilities (CRPD) and the recently released Guidelines on deinstitutionalisation, including in emergencies.¹

However, ten years since its inception, the NDIS is now at a crossroads. Inadequate implementation of certain aspects of the scheme has weakened its ability to support all those who need it. Many clients have also told us that accessing support from the NDIS can be very difficult. One said:

"For someone with high and complex physical, health and communication support needs, everything about the NDIS is hard work...it is excessively bureaucratic with so many repetitive reports that it is difficult to find time to actually live life".

Further, the increasing political focus on costs and scheme sustainability is putting the future of the NDIS at risk, leaving people with disability in danger of losing their hard-fought, essential disability related supports. To reach its full potential, there is much work to be done to cement the scheme's foundations and to preserve its distinguishing feature of participant choice and control.

QAI's submission will respond to several of the areas identified in the NDIS Review Panel's 'What we have heard' report. Our suggested solutions are a combination of small and large-scale reform ideas. Some of the challenges experienced by our clients could be addressed with small, practical changes, while other problems require more significant structural reform. There is also some overlap between our proposed solutions, with some solutions addressing more than one area.

Solutions built on success

Despite the many challenges identified by the NDIS Review, QAI believes there is still a lot that is working well within the scheme. Any proposed reforms should therefore build upon these successes, use them as a starting point and ensure they remain while the scheme is reformed.

While preparing our submission, QAI surveyed our clients and members and asked what was working well with the NDIS. Responses included the following:

- The NDIS is transforming people's lives. Some people are receiving support for the first time.
 Some people previously had no choice but to live with their parents into adulthood but now have access to life-changing supports that are facilitating their independence.
- There are new and innovative services available to NDIS participants that did not exist prior to the NDIS.

¹ CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies (2022)

- The NDIS has enabled people to access services that were previously financially inaccessible or unreasonable for a person or family to pay for.
- The NDIS has helped young people residing in nursing homes move into homes that better meet their needs.
- Children with complex disabilities are accessing therapeutic supports that are making a big difference to their lives.
- The NDIS gives participants independence. The ability to receive an individualised plan means participants can work towards living an ordinary life on an equal basis with others.
- Support coordination, when provided by an independent, knowledgeable and efficient professional, can make a big difference to a participant's outcomes.
- The ability to choose who provides supports and to use funding flexibly.
- People with disability are more visible in our community than ever before. This is due to the NDIS facilitating people to be a part of their community. The NDIS has also raised awareness of disability which has led to an increase in accessibility being a proactive measure rather than an afterthought.
- The ability to access in-home supports means that family members and friends can remain present and enjoy connecting with their loved ones as informal supports. Some carers have been able to enter the workforce and increase their own community participation.

1. Applying and getting a plan

Notwithstanding the above successes, not everyone who needs support from the NDIS can currently access it. Many of QAI's NDIS appeals advocacy clients seek help due to difficulties gaining access to the scheme. Too often, people are prevented from accessing the help they need because of arbitrary rules, bureaucratic or inaccessible planning processes, or because of a lack of understanding about disability within the Agency. Some people need additional assistance to apply or participate in the planning process yet struggle to find appropriate support. Others experience financial barriers to obtaining the evidence they need for their access request.

Solutions: Getting access to the NDIS

- Provide all prospective participants with a single point of contact within the Agency to provide information, assistance, and updates on their access request.
- Embed 'NDIS Access and Support Officers' or 'Disability Support Officers' into all key mainstream services, such as schools, prisons, hospitals, child safety service centres and housing service centres, to identify and assist people who may be eligible to access support from the NDIS, disability related support from other mainstream services or who are in receipt of NDIS funding but are struggling to navigate the system.
- All states and territories to fund access and referral programs to support individuals to
 access the NDIS. Queensland currently has an Access and Referral Team (ART) program
 which supports at-risk children and young people aged 7-25 years to gather evidence and
 submit an access request. The program previously assisted other at-risk groups for brief

periods of time, including people living in rural and regional areas and people exiting the criminal justice system. The program has largely worked well but should be available to all age and priority groups and receive ongoing funding.

- Provide access to **funding for comprehensive assessments and reports** from a medical professional and relevant allied health professional (e.g., occupational therapist, clinical psychologist, speech pathologist, physiotherapist). Reports and assessments should be available through Medicare:
 - by treating medical practitioners, and
 - o by allied health professionals, with the appropriate level skill.

As a minimum, this should be available to anyone seeking access who receives an income support payment.

The **cost of obtaining reports** to demonstrate that a person meets the criteria is significant. Those that cannot afford comprehensive reports from their doctors and allied health professionals are severely disadvantaged in the application process. There have been times where, knowing a person cannot collect the evidence required from allied health or medical professionals, appealing to the AAT (where the Agency is prepared to pay for a report) is the only option. This is both time consuming and costly and a good example of where early identification and support could result in better outcomes.

- Provide clear report templates for General Practitioners and other allied health professionals for the purpose of providing evidence for an access request. Provide more clarity on the type and quality of information required.
- **Provide proper reasons** in an **access decision**. We need decisions at first instance and at the internal review stage which correctly apply the evidence and the law. Too often we see poorly written decisions that include errors, poor reasoning and inappropriate language. See **Appendix C** for recent AAT commentary on this issue.
- Apply the law when determining whether an impairment is permanent: Commonly, we see access decisions:
 - o which dispute that an impairment is permanent when a diagnosis is not on List B,
 - reference an allied health therapy (or even regular massage) which the Agency says could be further considered when in practice it is not a treatment but a therapy to provide symptom relief, and/or is not available to the person, or is simply unaffordable, and
 - which fail to consider how a psychosocial impairment can impact on the 'availability' of a treatment for a physical impairment.

The Federal Court made an important decision on 29 August 2022 in *Davis*² on this issue. At paragraph 136 it says:

"In this context, "remedy" should be understood to <u>mean more than just relieve or improve.</u>
That is because r 5.5 recognises that an impairment may be permanent notwithstanding the severity of its impact on a person may fluctuate, or there are prospects for

9

² National Disability Insurance Agency v Davis [2022] FCA 1002

improvement. These changes in the impacts of an impairment may occur because of, amongst other matters, treatment. Therefore, in r 5.4 the word "remedy" should be understood to mean something approaching a removal or cure of the impairment. That is consistent with the meaning I consider should be given to the statutory phrase "permanent impairment", as an impairment which is enduring and, while its impacts on a person from time to time might fluctuate, is not an impairment which is likely to be removed or cured."

The solution:

Amend and update the current <u>operational guideline</u> regarding whether an impairment is **permanent** (it has not been updated since 30 June 2022).

The following statement needs to be amended:

Your impairment will likely be permanent if your treating professional gives us evidence that indicates there are no further treatments that could relieve or cure it.

It does not reflect the Davis decision and should be amended as follows:

Your impairment will likely be permanent if your treating professional gives us evidence that indicates there are no further treatments that could <u>remedy the</u> <u>impairment</u>. A treatment that can remedy your impairment means one which will do more than provide some relief or improvement. relieve or cure it.

The following statement is concerning to us and needs to be deleted:

The word treatment should be understood in a broadest sense and may include changes to your diet and lifestyle. So, for example, conditions such as obesity are unlikely to be found to be permanent.

Too often we see people in larger bodies discriminated against at access. There appears to be a view held by the Agency that a person who is medically obese is in control of their size and that they have made a choice. The medical research suggests otherwise.

Further, if a person is medically obese, the Agency view (as demonstrated in *Davis*) has been that the person's physical impairments could be remedied if the "person just lost weight." In appeals we see people being knocked back at the application stage because of their size and an assumption that their impairments are not permanent because they could be relieved if a person lost weight. The judgement and questioning around a person's size by lawyers and case managers at the AAT who are unqualified to understand the complexity associated with obesity, is appalling.

As an example, in a recent matter, during conversations in a case conference, lawyers acting for the NDIA openly questioned a client as to whether she was following a "validated diet" and she had to explain her difficulties following a diet (notwithstanding a very long history of struggle with weight including failed bariatric surgery). Other cases have seen the NDIA raise the argument that physical impairments could not be permanent because surgical solutions had not been fully explored, even when medical evidence was provided to show otherwise.

The operational guideline needs to include provision for **available treatments** to account for **an individual's personal circumstances** in line with the *Davis* decision that available treatments are treatments that are actually appropriate and really available to the person seeking access.

Additionally, **amend the** Becoming a Participant Rules to include a definition for "available" treatment as being **actually available to the person seeking access** (see paragraph 140 of *Davis*). For example, if a treatment is not available through Medicare, then it is not considered a standard treatment for the purpose of establishing permanency of an impairment.

Amend rule 5.8 of the <u>Becoming a Participant Rules</u> to provide that when considering a
person's 'functional capacity', reference can be made to <u>all or a combination</u> of a person's
impairments. The current wording incorrectly implies that each impairment is to be
considered separately.

Rule 5.8 requires the following amendment (shown underline):

An impairment, <u>or impairments in combination</u> results in substantially reduced functional capacity of a person to undertake one or more of the relevant activities—communication, social interaction, learning, mobility, self-care, self-management (see paragraph 5.1(c))—if its result is that:

This amendment will ensure that people who have multiple impairments, from which the **combined impact** is substantially reduced functional capacity, can access the scheme. This is similar to the approach taken when considering a person's eligibility for the Disability Support Pension. In other words, focus less on the diagnosis itself, and more on the impact of the person's (potentially multiple) impairments.

Solutions: Planning

- Increase funding for **individual independent advocacy** to assist participants to navigate their NDIS services and planning process.
- Provide funding for independent, decision-support advocates to support participants with complex support needs to navigate the NDIS.³
- Remove Local Areas Coordinators from the planning process and ensure only NDIA planners
 with decision-making authority are involved in planning discussions to remove an
 unnecessary third person. Participants often attend a planning meeting only to find that the
 final decision does not reflect the discussion that occurred at the planning meeting. Planners
 should be locally based where possible and available to participants for face-to-face
 meetings. Where possible and if requested by the participant, planners could also be
 assigned to participants.
- Increase transparency around the planning processes through the following:
 - o all participants to receive a draft plan.
 - o detailed **reasons** for **planning decisions are always given**, including any decision to **change the management of a plan**.

³ QAI previously received funding from the now defunded Decision Support Pilot. This service was not funded because the NDIA now has a Supported Decision-Making policy. This is welcomed but clients with cognitive impairments need support which is **independent** from the NDIA given the NDIA is a decision maker and cannot provide independent decision-making support.

- plans and reasons for decisions are written in plain English and include a clear breakdown of funded supports (see Appendix D as an example).
- consistently offer separate plan implementation meetings where participants discuss what has been included in the plan and how the funding can be used. This is particularly important if the person does not have funding for a support coordinator.
- Improve planning meetings by:
 - providing options for the location of the meeting including neutral spaces such as community centres, schools or at the participant's home if that is the person's preference. See our proposals under Section 2 below.
 - o giving participants **sufficient notice** of the meeting and flexibility to reschedule.
 - o ensuring **adequate time** is allocated to planning meetings.
 - always speaking to the participant.
- Provide flexible planning processes that support families with multiple NDIS participants.
 For example, offer families with multiple NDIS participants a support coordinator to oversee the coordination of the family's supports and to ensure their lives and daily supports are considered holistically rather than in silo from each other. Funding for therapy and capacity building must remain with each individual, however core funding for support workers could be better utilised if it was able to be used to meet the family's needs as a whole.
- If a participant has supports approved following a decision made by the AAT, place an alert on the participant's file with a copy of the outcome (agreement by consent or published decision). Require planners to justify any divergence from the outcome achieved at the AAT. This requirement would not fetter a planner's decision-making powers but rather remind planners of their duty to provide reasons to the participants who are impacted by their decisions. See for example, paragraph 34 of the case of Sharp4 in which the AAT noted its concern that:

'an Agency of the Commonwealth with responsibility for administering the NDIS appears to have failed to adhere to the requirements of the legislation it administers, as well as the basic tenets of contemporary procedural fairness and administrative decision-making, which requires an administrative decision-maker provide reasons for a decision to a person whose rights, entitlements or reasonable expectations are adversely affected by it.'

This simple practical solution will ensure participants don't have to go through internal review and external review processes multiple times (entering what the NDIA have coined the 'revolving door to the AAT') to access the same supports.

We acknowledge information sharing between two different service areas within the NDIA (the NDIA AAT case management branch and the NDIA planning team) is currently impacted by the implied undertaking that documents obtained during the proceedings cannot be disclosed for another purpose (the Harman undertaking). However, this can be managed by the NDIA AAT case management branch **introducing a step at the end** of their case management process to invite the participant to consent to the disclosure of reports or other evidence filed in the proceedings to be used in future plan reviews. This would assist

⁴ Sharp and National Disability Insurance Agency [2023] AATA 1323 (25 May 2023)

NDIS planners to make fully informed decisions at the participant's next NDIS plan reassessment.

This should be a **positive obligation** on the **NDIA AAT case management branch** and aligns with the NDIA's general obligation to act as a model litigant. Protections should be put in place so that consent is confined to the release of documents only to the NDIA's planning service area for the purposes of informing subsequent NDIS planning decisions (and not to any other parties including any other government agencies).

2. A complete and joined up ecosystem of support

Since the introduction of the NDIS, state and territory governments have diverted most, if not all, of their funding for disability services into the NDIS, despite approximately only 10% of people with disability being eligible for the scheme.⁵ This means that approximately 90% of people with disability now struggle to access disability support services. Many services simply no longer exist or only offer a service to people with NDIS funding who can pay for it through their plan.

There must be a greater investment in services outside of the NDIS and particularly in mainstream services so that it is no longer the "oasis in the desert" or a person with disability's only hope for support. This is critical to the scheme's sustainability and to ensuring Australia's compliance with its international legal obligations which requires the full and equal enjoyment of human rights for <u>all</u> people with disability⁶, not just NDIS participants. Inclusion must be embedded throughout the entire community and it must begin with schools and childcare services.

Solutions:

- Urgently review the COAG agreement and the <u>Agreement of Principles to Determine the</u>
 <u>Responsibilities of the NDIS and other Service Systems</u> which has not been reviewed since
 November 2015. The effectiveness of its key principles require evaluation and further clarity
 on the respective roles and responsibilities of state and federal governments is needed.
- The NDIA to take a **precautionary approach with funding supports** which it views should be covered by another system. In our experience, the NDIA will reduce or stop important supports which it considers should be funded by another service system. Most often we see this with health, allied health services and mental health services, but we have also experienced it with regards to child safety (refusing support workers because it is reportedly the responsibility of child safety) or prisons (refusing supports in prison because it is reportedly the responsibility of the prison service). Where the precautionary principle applies, the **NDIA should, like other insurance schemes be able to seek recovery** from the Commonwealth, states and territories **for services the NDIS has provided due to a failure by another service system**.

In doing so, create a 'no wrong door approach', such that when potential duplication exists, the onus is on the service systems to settle funding responsibilities between themselves, while the individual accesses the supports they need and which are most readily available to

⁵ As per statistics provided by the National Disability Insurance Agency; https://www.ndis.gov.au/understanding/how-ndis-works/who-ndis-supports

⁶ Convention on the Rights of Persons with Disabilities, Article 1

them. A similar approach occurs when people with private health insurance are admitted to public hospitals. Their access to healthcare is not impacted and the hospital administration liaises with their insurer to claim the relevant rebate. If there are two service options available, the default service that should provide support to the person with disability in the first instance is the NDIA. If the Agency is of the opinion that the service is more appropriately funded elsewhere, the onus should be on the Agency to recover those funds from the respective state and territory government department.

- Require states and territories to make a specific financial commitment to investing in disability related supports outside of the NDIS in the next NDIS bilateral agreement, appropriate to their population size and taking into account factors such as remote populations and marginalised communities.
- States and territories to improve and expand state-based schemes to support people with disability in their homes and communities who are not eligible for the NDIS. In Queensland, this support is predominantly provided by the Queensland Community Support Scheme. Do this by:
 - an immediate injection of funding that increases the state or territory government's investment to provide sufficient funding for existing people accessing the schemes and those on the waiting lists to access at least 5 hours per week of in person support.
 - o **improve and expand eligibility** to these schemes, for example remove any requirement that a person must have first applied and been refused access to the NDIS before being eligible for support. Such a requirement means many people are applying for the NDIS unnecessarily. An application takes time and money from the person, health services and the NDIA to process.
 - ensure the schemes are flexible enough to be able to provide sufficient support to people with a disability. This is particularly relevant for the approximately 10,000 asylum seekers from the 'Legacy Caseload' who arrived by boat between 2012 and 2013 and who for various reasons, will not be eligible to convert to permanent visas.⁷
 - o remove any requirement for **co-payment** from people in receipt of income support.
 - o require consistency in the accountability and availability of services.
- Embed an **early intervention approach into the ecosystem** of support that focuses on children and young people and the education, child safety and youth justice systems.
- Provide additional disability related supports for people with a disability through the health system and Medicare. The following would provide significant benefit:
 - access through Medicare to 20 (rather than 10) psychology sessions. The Medicare rebate should match the NDIS price limits for psychology, and

14

⁷ For more information on this cohort, see "<u>Factsheet – The 'Legacy Caseload</u>' and <u>statistics</u> provided by the Refugee Council of Australia

access through Medicare to 10 (rather than 5) allied health sessions (for example, podiatry, physiotherapy and dietitian). The Medicare rebate should match the NDIS price limits for these allied health services.

The above could have significant cost savings for the NDIS. Providing better support to people with a disability outside the NDIS through Medicare will potentially lead to a reduction in the need for those supports through the NDIS. Maintaining and optimising a person's health and well-being will potentially delay and/or reduce NDIS related costs in the future.

- Embed 'NDIS Access and Support Officers' or 'Disability Support Officers' into all key
 mainstream services, such as schools, prisons, hospitals, child safety service centres and
 housing service centres, to identify and assist people to access disability related supports
 from the NDIS or other mainstream services.
- Schools are an underutilised support network. They provide both a social connection and infrastructure for children with disabilities and their families to access integrated supports. According to the Australian Institute of Health and Welfare, 80.4% of all students with a 'severe or profound' disability attended a mainstream school in 2018.8 Most, if not all of these children will be eligible for the NDIS and forcing them to separate their therapy support and support workers from the education system is a lost opportunity.

Solutions:

- Offer in-person planning meetings at schools where parents have an option to attend planning meetings hosted at their child's school. NDIS child-focussed planners could be assigned to a local area. Planning meetings could be held on set days at the schools in their area throughout the year.
- Access to therapy on school grounds: Many children with disabilities attend therapy outside of school and their schedules can be very chaotic. Opportunities to attend therapy on school grounds before and after school or during the school day (within reasonable limits) should be encouraged. Benefits include:
 - Less travel for children and their parents,
 - Therapists are able to work with children in the school environment, meet teachers and learning support officers and provide better integration with the school, and
 - Potential for less school refusal by children with disabilities.
- Permit allied health assessments to occur on school grounds, allowing allied health professionals to more accurately identify challenges and provide effective strategies for the school environment. At present it appears this access is dependent on the individual school, so occurs for some schools but is not permitted for others.
- Childcare and outside school hours (OSH) care: Children with complex disabilities are currently excluded from most mainstream childcare and OSH care services. Special schools don't typically provide before and after school care and accessing NDIS funding to pay for specialist (expensive and segregated) programs can be incredibly difficult for families.

⁸ Australian Bureau of Statistics' (ABS) 2018 Survey of Disability, Ageing and Carers (SDAC)

Children with disability should be entitled to access the childcare subsidy to attend any mainstream childcare or OSH care setting of their choice, with the NDIS able to provide a 'top up' funding to that service to cover the additional support needs of the child. Childcare and OSH care is an everyday expense that should be subsidised through current arrangements, including for children with complex support needs, with additional disability related supports required to facilitate the child's attendance funded by the NDIS. This would ensure children with disability are fully included in mainstream settings and offers a solution that shares the costs between the NDIS and the federal government. It requires a creative and collaborative approach to funding; something that is currently desperately lacking.

- Child Safety: Require a proactive approach by the NDIA to work with the child protection system so that any child with a disability in their care (even short term) is appropriately connected to the NDIS and appropriate supports are arranged to assist with any transition home. The NDIA should have a specialist team in each state and territory working with the relevant Child Safety Department. This includes ensuring that NDIA workers working within the child protection system are sufficiently skilled and trained to support young people with disability. All states and territories must ensure they are providing appropriate disability supports to children with a disability in their care, whether or not that child is eligible for, or has access to, the NDIS.
- Youth Justice: NDIS supports must be available to young people within the youth justice system. A service provider of last resort may be required (see our proposed solution in Section 5). Plans need to provide flexibility to account for supports whilst in the youth justice system and outside the system. Further, processes must be in place to ensure parole applications are not refused on the basis that there is not an appropriate NDIS plan in place for a young person outside of the youth justice system. The NDIA and each state and territory must have a system to alert each other when a child with an NDIS plan is entering the system.
- Provide and ensure access to NDIS funded supports in all mainstream settings, particularly closed environments such as prisons. This would remove the need for, and risk of, disability related supports for people in prison being provided by fellow prisoners and would facilitate ongoing capacity building to best support a person's release back into the community. Reducing the risk of recidivism will also reduce the costs associated with the criminal justice system. This demonstrates the intertwined nature of NDIS and mainstream service costs and exemplifies the approach needed to address scheme cost sustainability concerns.
- Facilitate greater agency collaboration of a person's supports between different service systems, with the participant's consent. Recently the Queensland Department of Child Safety have implemented an NDIS Interface team. This team primarily works with children and young people with complex disability support needs who are not receiving enough funding to have their support needs met in their own homes and consequently are at risk of being taken into care by the state. The NDIS Interface team works with the families and engaged services to gather evidence and build a case for increased NDIS funding that results in young people remining in their homes, with their families and communities rather than in institutions or being voluntarily relinquished to the State.

3. Defining reasonable and necessary

Many of our clients seek advice regarding decisions about whether a support is considered 'reasonable and necessary'. For some NDIS participants, establishing a support as 'reasonable and necessary' as per the criteria in section 34 of the NDIS Act is relatively straightforward. For clients with more complex disabilities and support needs however, the concept is far more challenging to apply in practice.

The criteria which sit behind the 'reasonable and necessary' concept is one of the core pillars of the scheme and the primary mechanism through which people with disability access individualised packages of support that are tailored to meet their unique needs. People with disability are not a homogenous group, but rather a diverse group of people, many of whom live with intersecting identities and all of whom have different support needs.

QAI considers that the criteria in section 34(1) of the NDIS Act provides a sound framework for people with disability to receive funding for supports which meet their individual needs. However, the terms 'reasonable and necessary' are widely used by the Agency, participants, and service providers, often with little understanding of the legislative criteria. It is the application of the criteria (and the rules) that we see so often fail people with disability and their families.

One incorrect application of the legislative criteria which we see repeated by the NDIA with significant impact on participants is the NDIA's <u>policy</u> of only funding supports which relate to the impairment on which a person relied to gain access to the Scheme. This incorrect application forms the basis of a separate extensive <u>submission</u> QAI and other advocacy organisations has lodged with the NDIS Review and so for the purposes of this submission we have not repeated what is outlined in that submission.⁹

QAI is concerned that if the criteria behind the concept of 'reasonable and necessary' is to be more clearly defined, it will become too prescriptive, too rigid and will lead to unjust outcomes that will fail to meet the unique needs of the scheme's participants. The criteria must retain its flexibility to meet the needs of people with diverse disabilities and intersecting identities.

Rather than provide more *definition* as to what the concept means, QAI sees much greater benefit arising from increasing peoples *understanding* of the criteria required to be satisfied by the NDIA before it can fund supports. This understanding is needed inside the NDIA as well as amongst participants and service providers.

Solutions:

- Do not change the criteria for funding supports in the legislation or rules. However, improve
 communication by moving away from using the terms 'reasonable and necessary' and
 focusing more on the criteria that need to be satisfied and how they can be addressed.
- Address commonly held myths about what is a 'reasonable and necessary' support. For
 example, produce information sheets and relevant publications to help explain what is
 meant by each of the 'reasonable and necessary' criteria in the legislation. Seek input from
 people with disability and their representative organisations to produce the content of
 these publications.

⁹ Please see https://qai.org.au/briefing-paper-for-ndis-review-panel/

- Introduce a process to update Operational Guidelines to reflect decisions made by the AAT and Federal Court relating to section 34(1) and the Participant Support Rules.
- Apply the criteria in a consistent and transparent manner which recognises the individual needs of a participant. In particular, assess the needs of a participant as a whole person, and not just the needs that relate to the impairment on which the participant relied to gain access to the scheme (see <u>submission</u>). To embed this practice, amend the "<u>Fair supports for your disability needs</u>" policy to correctly reflect the NDIS Act, case law and intent of parliament; and re-train and monitor all NDIA staff in its application.
- Provide proper written reasons for decisions made by the NDIA. This concern was addressed by the AAT in <u>Sharp</u> on 25 May 2023 where the Member said:

It is a matter of concern that an Agency of the Commonwealth with responsibility for administering the NDIS appears to have failed to adhere to the requirements of the legislation it administers, as well as the basic tenets of contemporary procedural fairness and administrative decision-making, which requires an administrative decision-maker provide reasons for a decision to a person whose rights, entitlements or reasonable expectations are adversely affected by it.¹⁰

See **Appendix C** for further information.¹¹

- Address conscious and unconscious bias in decision-making by the Agency. We have observed inequities in support packages and whilst each participant's supports are unique, we often see stark differences between plans for children where their families have higher education and financial resources as compared to children from families where there are limited financial resources, single parents or parents with a disability, CALD families who have refugee backgrounds and First Nation families. We also see inequities play out with adult participants. Unconscious and conscious biases in Agency decision-making in our view are a significant factor which needs to be addressed through:
 - o staff training, and
 - careful review of automated systems used by the NDIA, to include a human rights framework and to test assumptions in the systems which perpetuate bias in resulting decisions.
- Incorporate long-term thinking into funding decisions. We see the NDIA quibbling at the
 AAT over funding for supports like assistive technology, assistance animals and home
 modifications where the evidence clearly demonstrates that the upfront cost will have a
 long-term benefit for participants and the potential to increase independence and reduce
 reliance on supports over time, with a subsequent cost saving to the scheme.
- Understand **complex trauma**. The NDIA often demonstrates little understanding of complex trauma and its impact on health outcomes, which lead to further disability. A better approach could lead to improved health outcomes for participants with complex trauma.

¹⁰ Paragraph 35 in Sharp and National Disability Insurance Agency [2023] AATA 1323 (25 May 2023)

¹¹ A further critique of the quality of written reasons given at the internal review stage was made by the AAT in a case on 21 August 2023 - BLZQ and National Disability Insurance Agency [2023] AATA 2629 (17 August 2023) (austlii.edu.au)

4. Early childhood supports

While not specifically responding this section of the 'What we have heard' report, many of our proposed solutions in sections 1 and 2 address the question of how best to support children with disability in ways that will lead to better outcomes for children and their families.

5. The support and service market

At its core, the NDIS is about choice and control. However, unless you have the resources, support, and knowledge to navigate what can be an inaccessible market, choice and control can remain elusive. Too many people with disabilities, especially those with complex support needs, suffer because of the significant power imbalance in the market. Providers can act solely in their own interest and can leave people with disabilities' needs unmet without consequence.

People with complex support needs experience particular challenges accessing support. Service providers can terminate service agreements when challenges arise and have been known to prefer to support people with less complex needs. In the absence of a provider of last resort, this leaves vulnerable people without essential services. Attaining vital supports for people with disability cannot be left to providers, particularly ones with a monopoly on the market who are primarily motivated by profit.

The context of the market must not be forgotten. The goods and services under examination relate to the daily lives of people living with significant disability and can involve the 'purchase' of supports that restrict a person's liberties. There must be sufficient mechanisms in place to ensure that a person's human rights and basic support needs are not left to the interests of capitalism. The scheme must be designed so that a person with complex disabilities, including cognitive and intellectual impairment, can access the supports they need on an equal basis with others.

Solutions:

• Every state and territory must have a well-equipped, well trained, and person-centred **provider of last resort**.

The grave impact of the use of Restrictive Practices, for example, requires a safety net that the free operation of the NDIS market cannot always provide. The inability of the NDIS market to provide high quality, timely, evidenced-based, and innovative positive behaviour support plans (PBSPs) has been demonstrated in inquiries such as the Queensland Productivity Commission's inquiry into the NDIS market. People with disability subject to such practices require a level of certainty that they can access appropriate supports, including high quality and evidence-based PBSPs, from a government provider if the market cannot provide one. The provision of these last resort services should be regarded as an obligation of government similar to the provision of public health services.

• Resolutely address conflicts of interest in NDIS transactions. For example:

¹² QPC Final Report – The NDIS market in Queensland, April 2021; https://s3.treasury.qld.gov.au/files/NDIS-final-report-volume-1.pdf

¹³ Link to our submission to QPC inquiry

¹⁴ See page 19 of <u>QAI's submission</u> to the QPC Inquiry into the NDIS Market in QLD for more information. (https://qai.org.au/ndis-market-in-queensland-draft-report/)

- Require support coordinators to be independent of and separate to other service providers that deliver supports to the participant, except in situations where this is unavoidable or is the informed choice of the participant. Ensure this rule is adequately enforced and adhered to by providers and all relevant stakeholders, including the NDIA.
- Prohibit the delivery of 'wrap around' supports by a single service provider, except where this is unavoidable or is the informed choice of the participant.
- Ensure blanket consumer law protections to NDIS participants, including access to specialised legal advice, regardless of the contents of individual NDIS service agreements.
 Ensure the Australian Competition and Consumer Commission (ACCC) is adequately resourced with a specialist team to respond to NDIS consumer related issues.
- Allow participants to employ family members in situations where this is appropriate. For example, when employing a family member is the most culturally appropriate support option for a First Nations participant. Or when a family member has received specialist training from a health service to provide a support in a regional or remote area where there are no specialist support workers available. This would ensure the concept of choice and control remains at the core of the scheme. Specifically, legislate the exceptional circumstances listed in the operational guidelines that outline when participants can engage family members to provide support. This will bring much needed clarity and make these decisions reviewable.
- Ensure a well-resourced and sustainable independent disability advocacy sector that
 ensures people with disability can access face-to-face, local, and trauma-informed disability
 advocacy. This requires at a minimum, five-yearly funding cycles and a shared commitment
 from both Commonwealth and state and territory governments to fund disability advocacy
 into the future, notwithstanding the implementation of the NDIS.
 - This should include access to specialist decision-making support from independent, professional advocates who are trained in working alongside participants to elicit their will and preferences and to maximize their autonomy. This kind of decision-making support is materially different to the supported decision-making practices that a participant might utilize from paid support workers and is very different to the decision-support that DSS envisage the NDIA will provide following the cessation of the Decision-Support Pilot.

6. Measuring outcomes and performance

Better measurement of outcomes and performance is vital to ensuring safe and high-quality services and the scheme's financial sustainability. As the NDIS is fundamental to Australia's implementation of the CRPD, and to the realisation of Australia's Disability Strategy, QAI also considers that greater oversight of the whole disability ecosystem would bring about much needed accountability to ensure everyone is playing their role in creating an inclusive society for people with disability.

Solutions:

- Introduce a **new governance structure** that provides oversight of all disability related supports and services, considering the ecosystem as a whole rather than continuing a siloed approach in which certain Ministers or bureaucrats have responsibility for either the NDIS or state and territory funded mainstream services. Ensure this new governance structure includes people with lived experience of disability. Allocate responsibility to oversee expenditure on all disability related supports and services made by state, territory and federal governments, enabling gaps to be identified, and include oversight of the investment made by governments to make mainstream services accessible to people with disability. This governance/oversight body could be connected to and involved with overseeing progress under Australia's Disability Strategy as well as state and territory disability action plans.
- Introduce a new model for auditing service providers that centres the expertise of people
 with disability who are participants of the scheme. Reform registration and accreditation
 processes such that they move beyond compliance and reporting measures and include
 criteria that evaluate the extent to which services provide person-centred care. Audit
 reports should be publicly available and accessible to all participants.
- Introduce a mechanism to regularly review the accessibility of mainstream services for
 people with disability. This could include the development of an inclusion scorecard used to
 review discrete aspects of a service, such as the competency of staff in supported decisionmaking practices or the accessibility of information provided to all service users. This could
 be linked to and included in the Outcomes Framework of Australia's Disability Strategy
 and/or state and territory disability action plans.
- Lead innovation, research and best practice. The NDIA, with its size, data and experience is
 in a unique position to lead innovation, research and best practice to improve outcomes for
 people with a disability. It has the potential to invest in innovative programs which improve
 outcomes and facilitate community connection. To date the potential of the NDIA to be a
 leader has not been explored or prioritised.

8. Help accessing supports

NDIS funding alone is not enough to ensure people with disability can access the support they need. For some people with disability, accessing support has become more complicated than ever before and there are additional responsibilities that some participants might not even be aware of, such as needing to ensure appropriate insurance cover is in place. The quality of support coordination is particularly variable and yet this is a critical support that, when provided well, can positively impact the lives of people with disability.

Some participants are denied access to psychology support or support coordination when they receive funding for a recovery coach, with the planner viewing the recovery coach as being capable of providing all three roles. This is despite there being key differences between each of the roles, including different skill sets. There appears to be no minimum qualifications for recovery coaching or support coordination.

Many clients have also told us that accessing support from the NDIS can be very difficult. One said:

"For someone with high and complex physical, health and communication support needs, everything about the NDIS is hard work...it is excessively bureaucratic with so many repetitive reports that it is difficult to find time to actually live life".

Others have remarked that the system is confusing and only workable if you have a legal or professional background. The NDIS must better support participants to implement their plans and be empowered to achieve their goals. The system must be accessible to all participants, including people with decision-support needs.

Solutions:

- Create a separate, independent support organisation to provide assistance to participants on matters that relate to their plan implementation, such as their obligations as an employer if self-managing their funding or terminating a service provider's contract. The NDIA could focus on providing information to, and building the skills of, participants to self-manage their plans where appropriate. For example, creating targeted resources that inform participants of the benefits of self-management, provide a user-friendly checklist on the steps required to successfully self-manage, and training sessions to upskill participants interested in self-managing. This would also help to reduce scheme costs by reducing unnecessary spending on plan or NDIA management when the person with disability, with appropriate support, could competently perform this role themselves.
- Ensure **funding can be used flexibly** in a way that suits participants and their families. Families with multiple participants could benefit from a support coordinator to oversee all their core supports and to ensure their needs are considered holistically rather than in silo from each other. They would also benefit from plan reassessments occurring with the same planner to avoid inconsistent decisions being made for family members.
- Professionalise the role of support coordination, including by introducing mandatory
 qualifications and training for support coordinators. The training (both initial and ongoing)
 should be co-designed with people with disability. Provide better oversight of support
 coordinators to ensure they are not embedded within service providers that are delivering
 other services to participants and develop a Code of Conduct that support coordinators
 must adhere to in order to increase the quality and accountability of this critical role. The
 Agency should play a driving role in supporting the professionalisation of this role, including
 supporting the establishment of professional accreditation.
- Redesign the pricing structure for support coordination to implement an outcomes-based model. Consider alternatives to allocating funding on a per hour basis to improve support coordination for participants whose funding can be quickly used up due to their complex needs, an emergency or crisis or when the person has additional decision-support needs.
- Ensure a well-resourced and sustainable independent disability advocacy sector that ensures people with disability can access face-to-face, local, and trauma-informed disability advocacy. This requires at a minimum, five-yearly funding cycles and a shared commitment from both Commonwealth and state and territory governments to fund disability advocacy into the future, notwithstanding the implementation of the NDIS. This includes reinstating and expanding funding for independent, decision-support advocates to support participants

with complex support needs to ensure decision-support does not become a task or responsibility of the NDIA.

- Provide **regular training on disability awareness** and the impacts of living with disability to all NDIA staff, facilitated by people with lived experience of disability to increase the awareness and understanding of NDIA staff.
- Roll out comprehensive and regular training on supported decision-making for all NDIA
 workers and providers, including competency-based assessments. It would be preferable if
 the NDIA employed people with disability and or their advocates to deliver training on
 supported decision-making.
- Clarify that support provided by a psychosocial recovery coach is not equivalent to support provided by a registered psychologist.
- Stop the practice of changing the management of plans without notice or warning or reasons, and without consultation with the participant first. In our experience, it is common for the NDIA to, without notice issue a new plan for a participant changing self or plan management to NDIA Managed. The consequences of which can be devasting and dangerous for participants. In one case, the NDIA changed a plan to NDIA management without notice. The immediate impact for the participant was that none of the 11 workers supporting him could work (due to our advocacy this decision was reversed however, no proper or written reasons for the change have been given).

9. Supported living and housing

Despite policies of deinstitutionalisation over the last couple of decades, many people with disability continue to live in segregated settings and remain excluded from mainstream housing. Long waiting lists for public housing, unaffordable private rentals and inaccessible dwellings all contribute towards the continued segregation of people with disability in group homes and other congregated living environments.

While the NDIS reportedly assists participants to live independently and to choose where and with whom they live, in reality many participants continue to be denied this right.

'Individualised Living Options' (ILO) focus on shared living arrangements such as living with a host or a housemate, while 'Supported Independent Living' (SIL) funding is typically provided in group home settings. Both can deny a person with a disability choice and control over their living arrangements. In particular, they can remove a person's right to choose to live alone if that is their preference, irrespective of their support needs.

QAI has supported a number of participant's living in their own home who have had their support funding calculated on the assumption that they share their supports with 2 or more participants. The reasoning given by the NDIA is often "there is no disability related reason" why the person cannot share their supports with another person. The decisions wilfully ignore the will and preference of a person to continue to live in their own home, sometimes with family members. The

¹⁵ This is a direct quote from home and living decisions we have seen and Statements of Issues provided by the Agency in AAT proceedings.

decisions also fail to consider the impact and disruption that may be caused by a change to a person's home environment. Please see case study in **Appendix B**.

The NDIS Act states that one of its objects is to "give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities." Choosing where to live is a basic human right that lies at the heart of the deinstitutionalisation movement and to the realisation of the rights enshrined in the CRPD. If the NDIS is to truly give effect to the CRPD, it must ensure it does not continue to institutionalise people with disability through new and contemporary forms of congregated living by providing funding in a way that forces people to live with other participants, when that is not their choice.

Home and living supports in the NDIS must genuinely facilitate a person with disability choosing where they live and with whom, including on their own if that is their preference. A person's support needs should not dictate or influence whether they need to live with other people with a disability to share their supports. While simple, this change in approach would have a profound positive impact on the lives and rights of people with disability, removing the risk of abuse inherent in congregated living environments and genuinely affording people with disability opportunities on an equal basis with others.

Solutions:

- All governments to urgently address barriers in mainstream housing that deny people with
 disability their ability to live in a home of their own, in a location of their choice and with
 whom they wish to reside. For example, increase investment in public housing to increase
 stock and reduce long waiting lists. Introduce measures that will genuinely address the
 housing affordability crisis, such rent increase caps and freezes. Ensure all states and
 territories commit to implementing minimum accessibility standards and to upgrading the
 National Construction Code. QAI supports the following recommendations made by the
 Australian Network for Universal Housing Design:
 - 1. All new social and affordable housing to be built to the ABCB Liveable Housing Design Standard: Beyond Minimum now.
 - State and Local governments to incentivise the housing industry to build to ABCB Liveable Housing Design Standard: Beyond Minimum as soon as practical, and
 - The Australian Building Codes Board (ABCB) to mandate the ABCB Liveable Housing Design Standard: Beyond Minimum for all new housing in the National Construction Code (NCC) in 2028.¹⁷
- Redesign and simplify the home and living supports offered to NDIS participants. Design a new system that begins with identifying the person's vision for a home (whether that is to live independently, with family, friends or if their choice other participants) and build a package of supports to facilitate the person achieving this goal. This may or may not include funding for specialist disability accommodation. It must provide funding to support people with disability to live alone or with their family, if that is their preference, irrespective of

¹⁶ National Disability Insurance Scheme Act 2013 (Cth), section 3(1)(a)

¹⁷ Submission to the NDIS Review - Accessibility in all new housing construction, Australian Network for Universal Housing Design and Building Better Homes, 5 July 2023.

their support needs. The will and preference of the participant must be respected and upheld.

This reflects a rights-based, transformative policy shift towards housing that is required to facilitate full deinstitutionalisation of people with disability.¹⁸ It separates consideration of housing and support arrangements by taking a 'housing first' approach:

"Emphasising housing first creates circumstances more like those experienced by the rest of the community. Starting with housing means an initial consideration of modification and adaptation, housing design, assistance for rental or purchase, and then the provision of adequate support. When support services are the starting point, appropriate and typical housing is not the emphasis and there are discussions about economies of scale achieved through group approaches and sharing of support." 19

Though this will have financial implications for the scheme, there are undeniable benefits from investing in the rights and lives of people with disability that occur over time. While some individual packages may be costly, they should be seen as part of a public investment in a policy that brings about greater social and economic participation of people with disability and their families and the associated financial benefits this brings. For example, greater independence leads to greater overall well-being which reduces costs of health services.²⁰

As the Independent Living Institute says, we need to "shift the existing focus on costs on to viewing expenditure on independent living options as a form of social and economic investment with the potential to bring about universal benefits."²¹

To retain the current model due to cost concerns is to effectively put a price on freedom.

There are also other opportunities to save money in the scheme. For example, initiatives could be introduced to repurpose and reuse pieces of assistive technology that are no longer required by a participant. Money could be saved by removing requirements for participants to undergo unnecessary allied health assessments to continue proving their eligibility and need for support when their circumstances have not changed.

The new home and living supports model should:

- o Provide funding for daily living support that can be used flexibly by the participant.
- Provide clarity about how the NDIA will fund supports, such as home modifications, in relation to rental properties and owner-occupied homes.
- Remove the need for the NDIA to approve a participant's prospective purchase of a property.
- Provide independent support to all participants to explore their home and living options prior to a planning meeting.

¹⁸ Research Report - Restrictive Practices: A pathway to elimination, page 257

¹⁹ Chris Fyffe, Jeffrey McCubbery, & Dymphna Laurie, *Research project: experiences of inappropriate accommodation support for people with a disability*, Research report prepared for the Disability Advisory Council of Victoria, May 2004, pp 16-17.

²⁰ Zarb, G (2003) 'The economics of independent living', Independent Living Institute

²¹ Ibid

- Refrain from using the word 'individualised' to describe home and living supports when this
 word infers a participant can choose to live alone when in reality, participants continue to
 be forced to live with others to access daily living support.
- Until such time that group homes and congregated living arrangements are eradicated, introduce an inspecting mechanism for people with disability living in group homes that is compliant with Australia's obligations under the Optional Protocol to the Convention Against Torture (OPCAT).²²
- Commission independent research into how countries have successfully deinstitutionalised people with disability as per the standards set in the United Nations guidelines on deinstitutionalisation.

10. Participant safeguards

The Disability Royal Commission has heard extensive evidence of violence, abuse, neglect, and exploitation of people with disability occurring in the absence of sufficient scrutiny. While the NDIS has brought about positive change to the way in which many people with disability now access disability supports, some of the supports are poor in quality and/or are delivered in an unsafe manner, as the tragic death of Anne Marie Smith exemplified.²³ Due to the market-based philosophy of the scheme, participants and service providers are free to make decisions in accordance with their own interests. Whilst this theoretically facilitates increased choice and control for participants, it also enables service providers to put their own needs ahead of the people they support and, in some situations, this has resulted in the exploitation of people with disability. For example, the many NDIS participants whose service providers have made applications for guardianship and administration appointments in situations where the service provider has a conflict of interest and potential to gain financially from a participant's funding.²⁴

The extent to which the NDIS Quality and Safeguards Commission provides effective oversight of NDIS-funded supports is severely limited by its establishment as a regulatory body with primarily reactive, rather than proactive, powers. This essentially passive role, which has been reinforced by the high volume of complaints received, limits the Commission's capacity to properly utilise its investigative powers.

Given the nature of the market and the vulnerability of its consumers, the need for robust accountability measures is critical. Participants need to be able to trust that dishonest service providers who fail to act in accordance with the NDIS Code of Conduct will be held to account. Without a strong oversight mechanism, or 'big stick' that maintains standards of service delivery through enforcement measures and proactive compliance strategies, the quality of a participant's service provision can depend upon whether they happen to encounter a safe and ethical service provider.

²² See QAI's position statement on OPCAT implementation.

²³ See the Robertson Review; https://www.ndiscommission.gov.au/media-centre/former-federal-court-judge-head-independent-review-circumstances-relating-death-ann

²⁴ See QAI's submission to the DRC on Increasing Guardianship Applications in the NDIS; https://qai.org.au/2021/03/26/increasing-guardianship-applications-in-the-ndis/

Solutions:

- Strengthen the remit and capacity of the NDIS Quality and Safeguards Commission to conduct independent investigations and to proactively monitor and regulate the delivery of disability supports under the NDIS.
- The NDIS Quality and Safeguards Commission establish referral pathways with National
 Disability Advocacy Program (NDAP) providers, independent state funded disability
 advocacy organisations, Community Legal Centres (CLCs) and State Legal Aid Commissions
 to ensure participants who are particularly vulnerable are supported through complaint and
 investigation processes.
- Introduce a 'Ryan's Rule' equivalent. Ryan's Rule is mechanism in Queensland Health
 facilities which provides an escalation process for patients, their families and carers to raise
 concerns if a person's condition is deteriorating and they are worried their concerns are not
 being listened to. An equivalent process could be introduced in the NDIS Quality and
 Safeguards Commission for situations where a person's life is potentially at risk. It could also
 be introduced within the NDIA for situations where a request for funding for a critical
 support has been denied.
- Proactively monitor NDIS service providers who make applications for guardianship and administration appointments for participants and introduce safeguards around this process. Many of these applications are unsubstantiated and are occurring in situations where the provider has a conflict of interest and seeks to gain financially from vulnerable participants with generous funding packages. For example:
 - The NDIS Quality and Safeguards Commission could capture data on the number and type of applications made by service providers, requiring service providers to report this activity. Monitor and record whether the applications were successful, whether there was an interim order imposed before the application was dismissed at hearing and whether the participant was advised of their right to seek legal advice and/or received representation in the process.
 - Adopt measures to deter service providers from making unnecessary and vexatious applications, such as imposing a penalty or compliance notice when applications are deemed to be unsubstantiated by the relevant state/territory Tribunal.
 - Require service providers to first liaise with another body, such as the NDIS Quality &Safeguards Commission, prior to making an application to ensure it is truly a last resort option.
- Introduce specific safeguards around the appointment of plan nominees. Despite nominees
 having comparable powers to a guardian, there are no formalized safeguards within the
 NDIS regulatory framework that minimize the risk of undue influence or exploitation of
 participants by their nominees. QAI recommends that:
 - All nominee appointments are made as a last resort.
 - All appointed nominees undergo a compulsory online training program which covers their duties and responsibilities as well as a basic overview of the NDIS.
 - Upon the appointment of a nominee, a specialist NDIA employee (outside the plan review process) should ensure that all the checks required under the Operational

Guideline have been followed and that meaningful and accessible communication has occurred with the participant whether in writing, on the phone, online or in person. The proposed nominee should not be present for this process.

- All nominee appointments are reviewed regularly and in a meaningful way, and the same thorough process undertaken at the time of appointment should be followed (minimum of every 2 years).
- Participants have access to an independent advocate where they indicate (or there
 are concerns raised) that they don't agree to or no longer consent to the
 appointment of the nominee. This should be extended to ensuring participants can
 independently (even where a nominee is appointed) review a decision relating to
 nominee appointments (including cancellations and suspensions).

In relation to CEO initiated nominee appointments, particularly those that are contrary to the stated intent or wishes of a participant, QAI is concerned about the large discretionary powers provided by the legislation and the lack of publicly available information on what, if any, safeguards exist around these appointments. For example, there is no publicly available information that explains whether the CEO would first obtain an independent capacity assessment before deciding to appoint a nominee in situations where this appointment is contrary to the stated preference of the participant. The review process for such an appointment through the AAT would seem to us to be inaccessible for a participant, given that the decision-making power has been given to the nominee.

There is also potential for a conflict of interest in these appointments, where the NDIA could benefit from the appointment of certain nominees over others, particularly where different nominees may take different views on required supports, thus providing a possible financial incentive for the NDIA. NDIA delegates may also seek these appointments due to a perceived burden associated with communicating with a participant in a supported decision-making framework.

QAI therefore recommends:

- There are clear operational guidelines published with respect to the process of CEO initiated nominee appointments and the numbers of CEO initiated appointments must be reported publicly in the NDIA quarterly reports.
- The NDIS Act is amended to require the CEO to give comprehensive reasons to the participant on the appointment of a nominee by the CEO.
- If an appointment is required as a last resort measure, a capacity assessment from an appropriately qualified, independent expert must be obtained and fully paid for by the NDIA, prior to the CEO decision.
- The appointment should be subject to regular independent review, given that a nominee has powers similar to that of a guardian.
- Amend the NDIS Act to clarify that the NDIS Quality and Safeguards Commission has power to investigate and take action against unregistered service providers.
- Ensure the Public Trustee of Queensland, when appointed as a participant's financial administrator, has the ability to access and view a participant's NDIS plan in order to identify situations where supported accommodation providers who also provide daily living supports are 'double dipping' from a participant's plan.

- Overhaul the monitoring of Restrictive Practices, with a view to eliminating their use entirely. Transition away from an approach that focuses on regulation, authorisation and positive behaviour support to an approach that addresses the 'ecological system of violence, coercion and control' that Restrictive Practices operate within.²⁵Introduce reforms in line with the eight-point action plan to eliminate Restrictive Practices proposed in the recently released research report commissioned by the Disability Royal Commission.²⁶ Consider other changes, such as:
 - Increase the capacity of the NDIS Quality and Safeguards Commission to capture high quality data on the use of Restrictive Practices.
 - Order mandatory training of support workers where uses of Restrictive Practices are not reduced or eliminated within a determined review period.
 - Require providers to demonstrate that strategies in a participant's Behaviour Support Plan have been implemented. If this is not evident, require a change of provider.
 - Where more than one review period has passed without any progress towards reduction or elimination of Restrictive Practices, require a change in service provider.
- Progress adult safeguarding reforms, such as those proposed by the Queensland Public Advocate in their 2022 reports on Adult Safeguarding.
- Ensure other government oversight agencies (for example ASIC and the Australian Charities and Not-for-profits Commission) are appropriately funded, work with the NDIS Quality and Safeguards Commission and actively monitor compliance of NDIS services providers with corporate regulations.

Conclusion

QAI thanks the NDIS Review Panel for the opportunity to contribute to this inquiry. We are happy to provide further information or clarification of any of the matters raised in this submission upon request.

101

²⁵ 'Research Report – Restrictive Practices: A pathway to elimination', p6

²⁶ Ibio

Appendix A: Prior Submissions by QAI on the NDIS

- 'Capability and Culture of the NDIA', QAI Submission, 12 October 2022.
 - o https://qai.org.au/capability-and-culture-of-the-ndia/
- 'Information Gathering for Access and Planning in the NDIS', QAI Submission, 22 July 2022.
 - o https://qai.org.au/information-gathering-for-access-and-planning-in-the-ndis/
- 'NDIS Amendment (Participant Service Guarantee and Other Measures) Bill 2021', QAI Submission, 8 November 2021.
 - https://qai.org.au/ndis-amendment-participant-service-guarantee-and-other-measures-bill-2021/
- 'NDIS Legislative Changes and the Participant Service Guarantee', QAI Submission, 7 October 2021.
 - https://qai.org.au/ndis-legislative-changes-and-the-participant-service-guarantee/
- 'Supporting You to Make Your Own Decisions, QAI Submission, 13 September 2021.
 - o https://qai.org.au/supporting-you-to-make-your-own-decisions/
- 'NDIS Amendment (Improving Supports for At Risk Participants) Bill 2021', QAI Submission, 7
 September 2021.
 - o https://qai.org.au/ndis-amendment-improving-supports-for-at-risk-participants-bill-2021/
- 'Increasing Guardianship Applications in the NDIS', QAI Submission, 26 March 2021.
 - o https://qai.org.au/increasing-guardianship-applications-in-the-ndis/
- 'Independent Assessments', QAI Submission, 15 February 2021.
 - o https://gai.org.au/independent-assessments/
- 'NDIS Access and Planning Policies', QAI Submission, 8 February 2021.
 - https://qai.org.au/ndis-access-and-planning-policies/
- 'NDIS Market in Queensland Draft Report', QAI Submission, 8 February 2021.
 - o https://gai.org.au/ndis-market-in-queensland-draft-report/
- 'NDS and NDIS Outcomes Framework', QAI Submission, 14 December 2020.
 - https://qai.org.au/nds-and-ndis-outcomes-frameworks/
- 'Inquiry into the NDIS Quality and Safeguards Commission', QAI Submission, 30 September 2020.
 - https://qai.org.au/inquiry-into-the-ndis-quality-and-safeguards-commission/
- 'Support Coordination', QAI Submission, 8 September 2020.
 - o https://gai.org.au/support-coordination/
- 'Inquiry into the NDIS Market in Queensland', QAI Submission, 28 August 2020.
 - o https://qai.org.au/inquiry-into-the-ndis-market-in-queensland/

- 'Inquiry into NDIS Workforce', QAI Submission, 7 April 2020.
 - o https://qai.org.au/inquiry-into-ndis-workforce/
- 'The Tune Review', QAI Submission, 30 October 2019
 - o https://qai.org.au/the-tune-review-2019/
- 'NDIS Planning', QAI Submission, 13 September 2019.
 - o https://qai.org.au/ndis-planning/
- 'NDIS Thin Markets', QAI Submission, 20 August 2019.
 - o https://qai.org.au/ndis-thin-markets/
- 'Supported Independent Living', QAI Submission, 20 July 2019.
 - o https://gai.org.au/supported-independent-living/
- 'Market Readiness for the NDIS', QAI Submission, 22 February 2018.
 - o https://qai.org.au/market-readiness-for-the-ndis/
- 'General Issues Around the Implementation of the NDIS', QAI Submission, 21 November 2017.
 - o https://gai.org.au/general-issues-around-the-implementation-of-the-ndis/

Appendix B: Case Study

Choice and control in housing

James, a young man in his 30s, lives with Autism and Intellectual Disability. James has lived with his elderly father his entire life in a house his father owns. His father plans on leaving that house to James. James's home is a place of comfort and predictability for him. The home is set up specially for James's needs, with a learning space, reinforced walls and his bedroom and support worker bedrooms are side by side. James has privacy and family contact in his home and can live his life on his terms, with his will and preferences respected.

The NDIA unfortunately did not agree to provide the supports James needed to live independently in his own home. The NDIA's view was that James should move from his home and live with two other participants so that supports could be shared between participants. The NDIA's view was that providing the level of support James needed to live in the home of his choice would impact on scheme sustainability. James's family felt like James was being forced into an institutional type setting, against his wishes. During the AAT process, the NDIA made assumptions about what they thought was best for James, which ran contrary to the evidence and was made without speaking with him or his family.

With the support of QAI, James was able to secure support to enable him to continue to live in his own home with his father. As a result, James does not need the NDIA to provide disability housing to him at a cost saving to the government. James now has choice and control regarding his housing and future because he has adequate supports to remain living in his own home.

James and his family do need though to be able to confidently plan for the future and the constant plan reviews create enormous stress and anxiety.

Appendix C: Case commentary on reasons

Throughout a person's journey with the NDIA, decisions are made which significantly affect their lives. In our experience, the only time a person will consistently be given written reasons for a decision is if they apply for an internal review. In our experience, the quality of those decisions is in many cases very poor and they can be difficult to understand (even for us).

In a recent AAT decision of Sharp and the National Disability Insurance Agency [2023] AATA 1323 (25 May 2023) Member Webb made the following comments:

- 33. In Ms **Sharp**'s case, the 24 November 2022 decision to approve the SOPS under s 33(2) is a *reviewable decision*. The requirement in s 100(1) and (1A) to give Ms **Sharp** a notice of the SOPS decision and the reasons for it does not appear to have been met. On the available materials, the only notice she was given is the Notice of the Plan on 24 November 2022, **which does not set out reasons** for the SOPS decision and it does not address any supports which were found <u>not</u> to be reasonable and necessary for the purposes of s 33(5) and s 34(1) of the NDIS Act. Furthermore, the Notice does not set out any particular disability or impairments to which it relates, in respect of which supports may be provided or funded, or on which Ms **Sharp** was found to meet the access criteria in s 21 of the NDIS Act. The Notice and the Plan do not refer to Ms **Sharp**'s disability attributable to impairments resulting from COPD, and no reference is made to the supports recommended by Mr Clark. On the terms of these documents, it is not possible to know if such matters were considered and decided. It is necessary to go to the Agency's interaction notes to discover what occurred, by inference at least, in the decision-making process.
- 34. It is a matter of concern that an Agency of the Commonwealth with responsibility for administering the NDIS appears to have failed to adhere to the requirements of the legislation it administers, as well as the basic tenets of contemporary procedural fairness and administrative decision-making, which requires an administrative decision-maker provide reasons for a decision to a person whose rights, entitlements or reasonable expectations are adversely affected by it. One might expect this is especially important in respect of government administrative decision-making for people with disability, when making a decision about supports for a participant in the NDIS. Otherwise, how is an NDIS participant to understand or even to know the matters decided, positively and negatively, in respect of reasonable and necessary supports, including any limits in respect of disability or impairments for which supports will not be funded, if they are not given a decision setting out such matters? The point is sharpened in the context of legislation, including s 100(2) of the NDIS Act, which prescribes a time limit upon exercise of the statutory right to request review of such a decision. It is apposite to recall Deane J's observation in *Public Service* Board of NSW v Osmond $^{[9]}$: the exercise of a decision-making power in a way which adversely affects others is less likely to be, or to appear to be, arbitrary if the decision maker formulates and provides reasons for his decision.
- 35. Nevertheless, albeit not exposing an intention contrary to s 100(1) or excusing failure to comply with the duty to provide notice of a decision and the reasons for it, s 100(8) operates to preserve the validity of the SOPS approval decision under s 33(2) and Ms Sharp's right to request review. Nonetheless, the seriousness of the apparent failure of the Agency to comply with the legal obligation to provide reasons for the SOPS decision in this case

would be elevated if the failure to provide reasons for such a decision is systemic. Providing a participant with a formulaic plan setting out supports that will be provided or funded does not satisfy the requirement to inform the person of supports that will not be provided or funded and the reasons for this. A systemic failure to provide reasons for administrative decisions made under s 33(2) of the NDIS Act would be a matter of serious concern one would expect the CEO to promptly address.

Appendix D: Template – How your plan has been calculated [Name]: NDIS Plan [Plan start date] – [plan end date]

This is an outline of the way your support budget has been calculated. Core Support can be used flexibly. This is a draft to help you understand your plan. You can negotiate lower rates with your service providers.

Core Supports \$#			
Support Item	Frequency	Unit Cost ²⁷	Total Cost
Support worker assistance – weekday daytime		\$65.47 per hour	
Support worker assistance – weekday evening		\$72.13 per hour	
A Weekday Evening Support is any support to a participant that commences not earlier than 12.00 noon on a Weekday and finishes after 6.00 pm on the same day (unless it is a Public Holiday Support).			
Support worker assistance – weekday night		\$73.46 per hour	
A Weekday Night Support is any support to a participant that commences on or after 6.00 pm on a Weekday and finishes before 7.30 am on the following day (unless it is a Public Holiday Support).			
Support worker assistance – Saturday		\$92.12 per hour	
Support worker assistance – Sunday		\$118.78 per hour	

²⁷ Rates as per NDIS Pricing Arrangements and Price Limits 2023-24: https://www.ndis.gov.au/providers/pricing-arrangements

Core Supports \$#			
Support Item	Frequency	Unit Cost ²⁷	Total Cost
Support worker assistance – Public holiday		\$145.44 per hour	
House cleaning and other household activities		\$54.07 per hour	
House or yard maintenance		\$53.09 per hour	
Inactive sleepover		\$276.27 per night	
Sub-Total			[Sum]
Continence products			
Assistive technology			

Core (Transport) \$#			
port Item	Frequency	Unit Cost	Total Cost
nsport		Level 1 - \$1,606 per year.	
		Level 2 - \$2,472 per year	
		Level 3 - \$3,456 per year	
		See <u>here</u>	

Capacity Building (Daily Living) \$#			
Support Item	Frequency	Unit Cost	Total Cost
Physiotherapist		\$193.99 per hour	
Occupational therapist		\$193.99 per hour	
Podiatrist		\$193.99 per hour	
Other therapies		\$193.99 per hour	
Psychologist		\$214.41 per hour	
Exercise physiology		\$166.99 per hour	

Capacity Building (Daily Living) \$#			
Support Item	Frequency	Unit Cost	Total Cost
Counsellor		\$156.16 per hour	
Subtotal			[Sum]

Capacity Building (Support Coordination)			
Support Item	Frequency	Unit Cost	Total Cost
Level 1 Support Coordination		\$74.63 per hour	
Level 2 Support Coordination		\$100.14 per hour	
Level 3 Support Coordination		\$190.54 per hour	

Capacity Building (Improved Life Choices)				
Support Item	Frequency	Unit Cost	Total Cost	
Plan management – Set up costs	Once	\$232.35 each		
Plan management – Monthly fee	Monthly	\$104.45 per month		