Rocks and Hard Places – The erosion of safeguards in the NDIS

The Royal Commission into violence, abuse, neglect and exploitation of people with disabilities *Issues Paper on Safeguards and Quality* (2019) highlights the necessity for systemic safeguards to protect the safety of people with disabilities (1). As the primary governing body overseeing reasonable, necessary, and safe access to disability supports in Australia, the National Disability Insurance Agency has an obligation to provide exemplary practice in this regard.

Currently, there are significant changes proposed to NDIS legislation, policy, rules and guidelines. It is timely to reflect on the role of the NDIA, including partners in the community, to ensure basic safeguards, that meet community expectations, are in place. The NDIA is responsible for 'upstream' policy in guiding the direction of reasonable and necessary support provision, while the Quality and Safeguards Commission responds to 'downstream' impacts of NDIA policy.

RECOMMENDATIONS

- The Committee ensure a clear and transparent risk assessment process be
 established and undertaken for each new NDIS Guideline development, looking at
 current, future and potential risks and associated mitigation strategies. The process
 would include representation from the NDIS Quality and Safeguard Commission, the
 Independent Advisory Council, participants and representatives, and relevant allied
 health and other peak bodies.
- The Committee ensure that co-design processes are clear and transparent, include
 inclusive recruitment methods that involve participants with complex and
 psychosocial disability, and the groups most impacted by the policy under design,
 their representative organisations, and allied health peak bodies where members are
 involved in care provision.

1. Functional Capacity Assessment

The assessment of functional capacity is an essential component of the NDIS. It forms the basis of access to the Scheme, and has the potential to enable equitable allocation of support and funding. During 2021, following piloting of 'Independent Assessments', this Joint Standing Committee commenced a Parliamentary Inquiry into Independent Assessment. This work was summarized in a report, which again highlighted the fundamental importance of appropriate assessment of functional capacity, and issued a set of recommendations for functional capacity within the Scheme(2). The Committee recommended that functional assessment be completed by allied health professionals with appropriate credentials, and that functional assessment be co-designed in collaboration with people with disability and their representatives, and the disability sector. The Committee further cautioned against assessment processes that may disadvantage cohorts of people within the Scheme, and the need to tailor assessment processes. It proposed alternative approaches, including a bulk-billed Medicare model of assessment to ensure impartiality of assessment. It further recommended "The National Disability Insurance Agency implement specific, targeted strategies to ensure that particular cohorts are not disadvantaged by such a process".

It is thus extremely concerning that current tender documents for Local Area Coordination Partners in the Community, include functional assessment as a component of the LAC role.

"(e) LAC Partners will conduct functional assessments/tools, as directed by the NDIA, to assist the NDIA to determine reasonable and necessary funded supports to be included in their NDIS Plan" (3).

This is contrary to the recommendations of the JSC Committee report on the NDIS. There has not been consultation with the disability sector on this approach to functional assessment. Most concerning, this approach holds strong parallels to Independent Assessment, which were widely condemned as unfit for purpose, lacking an evidence base, and potentially harmful.

This Submission strongly recommends the halting of plans to conduct functional assessment through LAC Partners, and that NDIA immediately commence a transparent consultation process on the future of functional capacity assessment within the NDIS.

2. Workforce

The current regulatory framework does not ensure, at a systems level, that the NDIS workforce can provide safe and high-quality services. In addition to concerns around participant safety, this is a significant issue that undermines the benefits of the NDIS.

Allied health professionals, including OT, must meet AHPRA registration standards. While the NDIA has supported the development of other critical supports such as support coordination, support workers and psychosocial recovery coaches, these roles unfortunately do not require mandatory skills and experience. Essentially, anyone who thinks they can provide supports such as support coordination. NDIS recovery coaching and many other supports, can start providing supports.

For most supports, there are no mandatory checks (for both registered and unregistered providers) to ensure that they meet relevant competencies to provide support in a way that will not cause harm to participants, in advance of commencing support.

Furthermore, the NDIS Quality and Safeguard Commission's Code of Conduct, which applies to all providers (registered and unregistered) can only be called upon after someone makes a complaint to the NDIS Commission (4). This is grossly inadequate given many participants, carers and family members experiencing harm from providers are likely to be experience significant barrier to make and follow through with a complaint.

Simply put, the current regulatory framework places the burden of ensuring basic safety on participants, carers and their families rather than providing an adequate preventative measure that minimises the possibility of significant harm in the first place.

3. Supported Independent Living

Access to appropriate housing continues to be extremely difficult, and there continues to be substantial unaddressed housing need. Supported Independent Living (SIL), Independent Living Options (ILO) and Specialist Disability Accommodation (SDA) are currently notoriously difficult to have funded in participant's plans, even when there is strong evidence of need and eligibility.

The Supported Independent Living Guideline (5), released in late 2021, included eligibility changes that made SIL a support only available to those who need 24/7 support, including 8 hours of 'active' daily person-to-person support. These changes disproportionally impacted people with psychosocial disability, who frequently need support available within their residence, but may not need, or cope with, 8 hours of direct support.

Many participants, particularly those with psychosocial disability, who have their NDIS Home and Living applications rejected, are then exposed to extremely unsuitable and often unsafe living environments. Many experience negative health and well-being outcomes as a result. It is imperative that these participants experiences are journey-mapped to understand the full implications of NDIS home and living decisions. These perspectives need to be proactively sought for inclusion in the upcoming NDIS home and Living co-design process. These participants will not be recruited for participation by social media or email call-outs for volunteers — as many do not have access to online information, due to their living circumstances; disability; or capacity. Disability representative organisations, and allied health peak bodies, must be included in co-design alongside a broad spectrum of participants who require a home and living response.

4. Local Area Coordination

An area that requires scrutiny is the role of Local Area Coordinators (LACs) in the NDIS. Local Area Coordination. If designed and implemented in a way that is consistent with the original development of the role (which emerged many years before the NDIA, during the late 1980s in Western Australia (6) and was further developed internationally), would play a crucial role in promoting safety. Not only of participants of the NDIS, but all people with disabilities and their families, in communities that they are based in.

However, as stated in an evidence review report of Local Area Coordination by the NDIA "Local Area Coordination is applied differently in the NDIS than it is internationally" (7). This is an understatement. Through its implementation, the NDIA has distorted Local Area Coordination into something that would be difficult to recognise as 'actual' Local Area Coordination on the ground. It appears that LAC has become an extension of the NDIA functions with an emphasis on bureaucratic funding related activities such as planning (for funded supports) and plan reviews over other functions.

In relation to safety of people with disabilities, what remains most concerning is that many organisations that provide LAC services have split the LAC role into different functions. For example, a participant and their family may meet one person to support with access, another person to prepare you for your planning, another person could conduct the planning conversation where funding is discussed, a different person to help you with implementation of your plan, and yet another when you make enquires. This approach, that may be a response to issues including resources and high levels of staff turnover, removes the most valued element of Local Area Coordination, a trusting relationship. Importantly, it erodes the critical safety net that is provided through a valued relationship with someone connected to a participant's local community.

5. Assistive Technology

A new assistive technology guideline, introduced March 2022, changes the process to apply, gain approval, 'script' (the process by which a suitable qualified professional prescribes assistive technology having assessed risks, benefits, future prognosis and future AT needs) and purchase midcost assistive technology, up to \$15,000 per individual item (8). A driver for the change in policy was the previous substantial paperwork needed to apply, and lengthy NDIS processing periods, meaning the participant was left waiting extended periods for much-needed AT, and for some, it was already outdated or their needs had changed by the time it arrived. Hence, reform of policy around accessing AT was merited.

The new AT guideline changes the application process, meaning a support letter from an AT advisor, replaces the previous application process. The AT support letter can be written by an allied health professional; a GP or an 'AT mentor'. The AT mentor is a new role, without established practice standards or regulation. Training to become an AT mentor can be done in as little as 4 hours, and they can then market themselves as AT experts. With a support letter, if the AT request meets reasonable and necessary criteria, the participant can go shopping for their AT.

The guideline recommends that participants seek independent advice from a suitable AT advisor, and will held accountable for any adverse AT-related outcomes based on this choice. There is no systemic process for ensuring that advice is independent of the supply industry; for ensuring that AT advisor expertise is matched to the complexity of the AT; and it appears, for ensuring that decision-making support is in place for those who need it. **Respecting individual participant 'choice and control' cannot be a defence for an absence of systemic safeguards.**

Under the new guideline, the Agency requires less information on the needs of the participant. Effectively, the Agency are left blind to assessment of risk, raising questions around preventable harm. Please refer to Appendix 2 for comparison of information required by the NDIA to make a decision on reasonable and necessary mid-cost AT supports, prior to March 2022 and under the new AT Guideline.

AT for use in restrictive practice (physical restraints; surveillance systems and alarms; bedrails etc) can be approved by the NDIS Planner, and purchased, with a brief support letter (See Appendix 2).

A decreased focus on clinical advice and allied health professional input to the process, combined with the introduction of a poorly defined and unregulated AT mentor role, escalates the risk of inappropriate AT purchases; AT being unsuited to the participants needs; AT that is out of tune with prognosis and expected changes to future functional capacity; or AT that elevates risk of preventable harm to both participants, and carers e.g. AT used in restrictive practice or used in manual handling (standing aids, hoists, mobile commodes).

The mid-cost AT budget broadly is estimated to be \$2-2.5 billion dollars. Many larger AT suppliers have been reforming their digital client management and sales systems, for compatibility with the new NDIA client management system software. Many are becoming 'digital partners' with the NDIA. Compatibility of IT systems, between the Agency and AT suppliers, will mean AT sales can occur efficiently, and at point-of-sale. Recent changes to the NDIS Act will enable AT providers to bill directly to participant plans using these digital platforms. It is unclear what data will be shared between the stakeholders; what the implications are for participant privacy; and to what extent participants will be assertively targeted by tech-enabled marketing strategies. However, what is clear, is that participants will be held accountable for their choices. It has been indicated that the Agency will strive to recoup debt from the participant if they purchase the 'wrong' AT. Proposed changes to the NDIS Act will likely further increase the Agency's ability to recover debt from individual participants. Again, respecting individual participant 'choice and control' cannot be a defence for an absence of systemic safeguards

6. Lack of in-person contact with NDIS delegates

Failure of basic safeguards can have catastrophic outcomes. With great sadness we reflect on the death of NDIS participant Ann-Marie Smith. Despite a 2017 note written in her NDIS case-notes indicating that she required direct face-to-face contact with the NDIA delegate to understand her support needs, this did not occur. Since the commencement of the COVID-19 pandemic in March 2020, there has been a shift to NDIS plan review meetings taking place by phone-call – further removing the NDIA from the daily physical reality of participant's lives. The current focus on plan 'rollovers' - largely phone-based plan review of reasonable and necessary support 'rolling over' for a further 1-2 year term of support – continues the trend of NDIA delegate distancing from physical daily reality. Robust risk assessment (of vulnerability factors, decision making capacity etc) should be conducted by the NDIA to ensure that phone-based plan review is suitable, appropriate and safe, in individual circumstances. Respecting individual participant 'choice and control' cannot be a defence for an absence of systemic safeguards. If a temporary COVID-19 measure aimed to reduce transmission of the virus, becomes a permanent approach to interactions with participants the NDIA, there are safeguarding implications.

References

- Royal Commission into violence, abuse, neglect and exploitation of people with disabilities. Interim report. https://disability.royalcommission.gov.au/publications/interim-report Retrieved 31/1/2021
- 2. Parliamentary Inquiry final report <u>Independent Assessments Parliament of Australia</u> (aph.gov.au) Retrieved 13/04/22
- 3. AusTender ATM Documents SPC00001863: AusTender (tenders.gov.au) Retrieved 10/04/22
- 4. NDIS Code of Conduct (NDIS Providers) | NDIS Quality and Safeguards Commission (ndiscommission.gov.au) Retrieved 13/04/22
- 5. <u>Supported independent living provider guidance | NDIS</u> Retrieved 13/04/22
- 6. <u>Strengths, assets and place The emergence of Local Area Coordination initiatives in England and Wales Neil Lunt, Laura Bainbridge, Simon Rippon, 2021 (sagepub.com)</u>
- 7. Evidence review: Support coordination and LAC models to inform how participants can be best supported to implement plans Support Coordination and LAC models report (DOCX 1MB).
- 8. Assistive technology | NDIS Retrieved 13/04/22

Appendix 1: Contrasting NDIA and international LAC Models

Local Area Coordination as described by a service in the UK

What is Local Area Coordination?

Local Area Coordination uses a strength based and person-centred approach to support people and their families to have a good quality of life.

It is a preventative approach which helps individuals to:

- improve their health and wellbeing
- stay safe, well and happy
- improve their quality of life
- develop confidence and independence
- make links within the local community
- reduce social isolation
- access opportunities for further support, friendship and social interaction

Local Area Coordination also uses an **asset-based** approach to community development. This involves identifying the assets, strengths, and skills that already exist within an area, including the personal skills, qualities and expertise which individuals, families and communities themselves can offer. It also includes identifying and utilising other community assets, such as local services, groups, community buildings, places of worship and businesses.

What does a Local Area Coordinator do?

- Spends time to understand a person's strengths and aspirations
- Works in partnership to develop effective networks of community based support for local people
- Normally works in community based outreach settings
- Identifies community assets and resources which individuals can access
- Supports individuals to access other relevant services where required
- Support creation of community groups
- Uses an enablement approach to prevention to help people to be and maintain their independence and be as

Local Area Coordination described by the NDIA (Accessed April 2022- <u>LAC Partners in the Community | NDIS</u>)

- "Role of Local Area Coordination (LAC) LACs can help you to:
 - Understand and access the NDIS This can include workshops or individual conversations about the NDIS.
 - Create a plan If you are eligible for an NDIS support plan, your LAC will have a conversation with you to learn about your current situation, supports, and goals to help develop your plan. It is important to know that LACs cannot approve an NDIS plan, this is done by someone from the NDIA.
 - Implement your plan Your LAC will help you to find and start receiving the services in your NDIS plan. Your LAC can also provide assistance throughout your plan if you have any questions.
 - Review your plan Your LAC will work with you to make changes to your plan through a plan review. This generally occurs 12 months after your plan is implemented.
- Linking you to information and support in your community
 - LACs will help you:Learn about support available in your local community;
 - Understand how the <u>NDIS works with</u> <u>other government services</u> – this is supports like education, health, and transport;
 - Sustain informal supports around you this is family, friends and local community members.

This is part of <u>Information Linkages and</u> <u>Capacity Building (ILC)</u>.

You can ask your LAC about the supports available in your community, even if you're not eligible for an NDIS support plan. Partners delivering LAC services will also work to make your community more welcoming and inclusive."

in control of their own lives as much as possible.

Appendix 2: Information required by the NDIA to make a decision on reasonable and necessary mid-cost assistive technology (up to \$15,000 per individual AT item).

| AT Policy prior to March 2022 | |
|--|---|
| | New AT Guideline March 2022 |
| AT advisors required to consider | |
| NDIS Quality and Safeguards Commission guidelines | No specified safeguarding |
| Professional registration under AHPRA) and/or professional registration body | frameworks identified by the |
| Australian Consumer Law | AT guideline, required to be |
| Must be aware of and observe the law relating to AT that is likely to | considered by AT advisors, |
| restrain the participant e.g. NDIS Restrictive Practices and Behaviour Support) Rules 2018. | assessors or mentors. |
| Information required by NDIA to make a reasonable and necessary | Information required by the |
| support decision: | NDIA to make a reasonable |
| Background: diagnosis, prognosis, co-existing conditions, disability, living | and necessary support decision |
| arrangements, life transitions. | (provided by letter of support): |
| Functional assessment, Functional limitation(s) related to the participant's disability | The AT you need Why the AT is the best value, |
| Summaries of relevant assessments. For example: skin integrity, cognitive assessments, positive behaviour support assessments. | over other supports, to help with your disability support |
| Current AT use - the type of AT – information on model, age, history of | needs |
| repair and ongoing suitability for the participant's need | How the AT will help with your |
| The level of independence or support the participant will need to use the | disability support needs and |
| AT | help you pursue the goals in |
| How the participant's current AT will work together with the AT being assessed | your plan An estimate of how much the |
| Any changes needed to the participant's environment, transport, or other | AT costs. |
| AT, that will be needed for the AT being assessed. AT trial | |
| The NDIS expects valid and reliable outcome measures are used for AT trial. | |
| AT trial outcome | |
| When you are able to complete a trial, please provide a detailed description including: | |
| the location of the trial | |
| • trial outcomes | |
| duration of trial | |
| participant's tolerance | |
| functional outcomes | |
| support required | |
| risks or barriers identified | |
| any other relevant information. | |
| Note: You need to include trial outcomes of each specific feature recommended in | |
| this assessment. | |
| If you are not able to complete a trial, please provide information on: | |
| why you were not able do the trial, for example: remote/rural location, | |
| availability of equipment, etc. | |

• the steps you have taken to make sure the AT is suitable in the absence of a trial.

Describe previous lived experience the participant has using this or similar AT. If this AT item is a replacement, provide details of the participant's existing AT including:

- make/model
- features
- age
- participant's independence/outcome with current AT solution
- level of support required to use AT
- reason for replacement AT.

Evaluation of other options

List all alternative supports considered to meet their disability support needs and why they are not suitable. This may include:

- repairs, modifications, therapy or AT training
- details of comparable AT items that were considered or trialled
- when trials have been conducted give information on where the trials took place, for how long, and the outcomes
- when the participant has used alternative AT in the past, give details of when the participant used this, for how long and the outcomes

Evidence

Explain the evidence for the recommended option as the most suitable and cost-effective support to:

- help the participant pursue their goal(s)
- reduce functional limitation
- facilitate participation
- improve life stage outcomes

Compare the recommend AT support to other supports considered such as:

- past participant experience of AT
- trial outcomes
- consideration of long-term benefit in both current and anticipated future needs
- changes or adjustments to personal care support need, etc.

Describe, having regard to best practice, what evidence indicates the proposed AT will be, or is likely to be, effective and beneficial for the participant? (E.g. published literature, past participant experience of AT)

Describe the long term benefits of the AT being assessed including:

- anticipated life span
- how it allows for adaptation/accommodation of likely changes to the participant's circumstances, development or function. For example, growth of child over the lifespan of the AT.

Describe how the AT will:

- Impact the participant's functional status, independence and /or outcomes over the long term
- potentially reduce the cost of funded supports for the participant in the long term.

Risk assessment

Describe any

- potential risks to the participant related to the use of this AT
- potential risks to the participant's carer related to the use of this AT
- risk mitigation strategies that are or will be implemented

Please attach a copy of a risk assessment if applicable.

Describe any potential risks to the participant/carer if this AT is not provided?

Does this AT comply with relevant AT Australian Standards (or ISO AT standards)? If yes, which standards. If no, why not and does this add to the risk?

Behaviours of concern

Describe any behaviours of concern that may impact the safety of the participant or others in relation to the use of this AT.

Could the use of this AT constitute a restrictive practice? If so, is there an authorised Positive Behaviour Support Plan (PBSP) in place to guide the implementation and reduction of restrictive practice in the future?

Please include a copy of the authorised PBSP with this assessment. Please describe all less restrictive options that were considered or trialled.

The participant must be provided with maintenance and servicing information for their AT to remain in good working order. Provide details on:

- When will this be done?
- What warranty periods apply to this AT?

About allied.org.au

We are an alliance of allied health professionals, working alongside those with lived experience and our communities. Our contributors represent a broad range of expertise, including lived experience, health, disability, law, economics and others.

Our purpose

- Our website is called Allied because our purpose is to share a broad range of perspectives. In particular, we aim to:
- Inspire allied health professionals to be more reflective, informed, and action-oriented
- Promote evidence-based practice and policy development
- Share and understand the perspectives of allied health professionals and those we work with, particularly those with lived experience.
- Encourage allied health professionals to consider co-design in their work, with the hope of building services and systems that are in tune with the needs of those who use them.

We believe

- In the potential for collaboration to generate innovative responses to health and community issues
- Health is a human right
- Health can be influenced by social determinants
- Evidence-based practice is fundamental to building needs-based policy and system response, and to change lives.