NDIS Act Review 2019

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Background: WA's Individualised Services (WAiS)

Western Australia's Individualised Services (WAiS) is a member-based community organisation working in partnership with people, families, service providers and government agencies to promote and advance individualised, self- directed supports and services for people living with disability, including psychosocial disability.

Since our inception in 2010, we have evolved to become thought leaders in this space, providing comprehensive, intentional support with integrity, passion and authenticity at our core. By leveraging our extensive local, state, and international network, we seek to lead, influence, innovate and inform to create meaningful and lasting change, supporting people to build capacity and live their lives on their own terms.

Unlike any other organisation, we partner and work with all sector stakeholders, as well as providing vital links, ensuring that disability services respond to the unique needs of people. We work to ensure that people can access and navigate the services and the sector to achieve their goals.

WAiS is the only organisation that has a specific focus and purview of supporting and developing the capacity of people, families, service providers, Local Co-ordinators and government, specifically in the area of individualised, self-directed supports and services.

WAiS membership has a focused group of people and their families and service providers who are committed to individualised supports, and people having choice and control in their life. The WAiS team also come from diverse backgrounds including people with disability, family members and people who have worked in the disability sector.

General Comments

Fundamental to the National Disability Insurance Scheme Act are the Objects of the Act. The very first object is to "give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities". In doing so, the Scheme is to "support the independence and social and economic participation of people with disability" and "enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports".
To achieve all this requires then the establishment of the NDIS in Australia to "provide reasonable and necessary supports".

The NDIS Act itself, has a strong foundation embedded with Human Rights, however, there are significant issues with how well the legislative framework is working with implementation. The legislative framework has inadvertently enabled priority to be given to 'reasonable and necessary' supports, through s34 of the Act and clause 2.3 of the Support for Participants Rules. Approval of participant plans has focused predominantly on what is 'reasonable and necessary' which is trumping other objectives and principles, for example economic and social participation.

Another concern is the intrinsically subjective nature of 'reasonable and necessary' and, therefore, the embedded risk that if the decision-maker, which in the case of approving participants' plans remains with the NDIA, does not fully understand the nature of the individual's disability, their life circumstances and experiences, their needs and preferences, what works well for them individually, a determination may be made in relation to reasonableness and necessity which actually results in participants' not being able to attain their goals and aspirations.

Understanding, however, the system rationale behind the need for reasonableness in participants' funding plans, it is suggested that a better approach would be to inverse the rule – plans will be approved unless it can be evidenced that the support is unreasonable. The onus of proof then becomes one of proving it is unreasonable with the assumption of reasonableness. The current framework suggests that the onus of proof is on proving supports to be reasonable, putting participants both under undue pressure, with a focus on evidence and also at a disadvantage. The need to demonstrate 'reasonable and necessary' via evidence, is prompting the system to move toward a more medical model approach as opposed to a social model. The social model is in line with the NDIS Act, and our community over many years has been moving away from a medical model related to disability.

Regardless, the use of reasonableness as a measure is fraught with difficulty. Entire bodies of law dedicate themselves with this issue to no singular conclusion. As such, WAiS recommends that what is also required is the elevation of other objectives and principles within the legislative framework so that 'reasonable and necessary' is not, in practice, the only yardstick used for approval of plans, and if evidence is needed, it is focussed not just on medical or functional assessments. Other objectives and principles ought to be people's human rights – independence, economic and social participation, choice and control.

Participant Service Guarantee – Principles for Service Standards

These objectives and principles in relation to people's human rights need to be front and centre with any proposed Participant Service Guarantee and highlighted in the Principles for Service Standards. WAiS supports all proposed Principles for Services Standards in the discussion paper, albeit with some reservations in relation to the standard in relation to "expert". It is critical that NDIA staff have a high level of training and understanding of disability. However, their understanding of what supports are most effective for a person's disability should not amount to them dictating what goes in a person's plan nor overpowering what may be a recommendation from a person or their family themselves. Historically, people with disability and their families have had 'experts' in their lives, to the point where self direction, choice and control was negatively impacted upon and, at times, non-existent. This principle could possibly be better stated as “informed” rather than expert, to minimise any risk of NDIS staff thinking this is an opportunity to decide for someone what they need, rather than decide with them.

None of these Principles will be practiced if they are not based on NDIS staff being aware of the objects of the Scheme and having the right values - a real understanding of people’s human rights (what they are and what they mean), a value system that upholds the dignity of and respect for people with disability and their family members, a passion for working WITH people to support them to get the best possible plan and, consequently, supports for themselves or their loved one, in order to be better able to live a good life.

At the moment, much of what WAiS has learnt through evidence from the experience of people is that the system that has lost sight of this. The NDIS has been established to support, people to live a good life. Within systems and communities, people face discrimination, exclusion, and are at risk of direct, structural and systemic abuse. The system needs to be intentionally mindful not to add further risks, or hurdles to jump that can seem and be, insurmountable. The system, and its processes needs to be as easy to access as possible, and one that chooses to facilitate a smooth, empathetic, supportive process for people to be able to get the plan, funding and supports they need.

To follow are some specific examples of concerns and possible improvements that WAiS has evidenced from the experiences of people and families we have supported. A general trend in recommendations that arise from the experience of people and families (outlined below) is that people and families require far more information from and far better communication with the NDIA or the LAC Partners. This information and communication needs to be relevant, timely, accessible and forthcoming in nature. And, this approach to information and communication needs to be underpinned by human rights, a respect for the dignity of people and families, their entitlement to the supports they need to live a good life, and recognition of their fears and vulnerability.

Eligibility and Application

- Access refusal letters are difficult to understand and with no clear reason provided for being refused. The only reference is quoting different clauses of the NDIS Act which is generic in nature. The letter also does not make it clear that people can re-apply for access.
- It is problematic that people can only select one primary disability and it can be short sighted that plans are built based only on this. People with multiple disabilities and their support needs cannot be reduced down to one disability.
- There is insufficient information provided as to what supporting documentation is required for access: for example, reports in relation to functional impact or predicting therapy needs for the next year.

- When a person turns 18 years old and nominee needs to transition from child nominee to nominee, there is insufficient information about this process, too.
- The text alert that people receive is cold and provides insufficient information. There is no timeframe provided for the phone call, no purpose stated, no caller ID.
- In relation to the NDIA's 1800 number, there are lots of examples of call centre staff being inadequately informed and providing misinformation. The experience of people has left people referencing the 1800 number as "1800 who cares".
- There is a significant lack of understanding by NDIA staff around consent and/or supported decision-making processes. Our experiences with people have shown that NDIA can go completely one-way ie people are supported to make their own decisions, but without considering what support they might need to do that, OR, they will default to a carer, family member or provider for the decision making without involving the adult person.
- People regularly complain about the impact of the NDIA requiring consent from the person to be able to speak to a family member on the phone, in the case of someone not being able to verbally communicate over the phone or who may have an intellectual disability and not understand the concept of consent.
- There is no confirmation provided that an Access application has been received and no timeframe provided for processing the application. People then lack confidence as to whether the application has actually been received and causes undue stress.
- Pastoral care component offered by the State Local Coordinators is lacking.
- There is still a lack of clarity as to the role and responsibilities of Support Coordinators and LACs.

Recommendations:

- That far more information is provided to people and families to fully inform them of what is required from them, what the process involved is, and timeframes. This is at all points of contact, whether on the NDIS website, text alerts, phone or in person communication.
- That consent is explored further by the NDIA and the requirements not a one size fits all.
- NDIA staff are aware of, and committed to Supported Decision Making principles and practice.

Creating Your Plan

- People regularly highlight that they have no trust in the planning process. Fears and stresses about not getting funded supports without significant medical or functional evidence are significant.
- People have shared with us, that they feel requests in relation to goals, outcomes, supports required are not heard or valued. People feel discounted and devalued. People feel like they have to justify everything through evidence.
- People need to be able to view a draft plan and provide feedback. This assist people to feel

in control of the process, reduce fear of ‘what did they note, did they listen’, and will actually also reduce the likelihood of reviewable decision requests.

- There is no record of planning meetings, especially when for many people the plan that they receive is not what they sought at the meeting.
- There are no reasons provided for what is in the final plan, if this contrasts with what people sought at their meeting.
- There is inadequate time dedicated to pre planning, or the planning meeting itself. One plan meeting is insufficient. If required, more should be offered. Many people comment that they actually feel like their planner is trying to minimise the amount of time required to plan with the person.
- For some people, without support with pre planning, it is challenging to be able to come up with goals and strategies. This requires time to explain what these could be and support people to develop them.
- People have difficulty understanding “NDIS speak”. More support is required to translate this into every day language.
- There is too heavy a focus on functional impact of disability and what then stems from this, without enough focus on what people need to be able to live a good life.
- There are still a lot of inexperienced LACs and Planners.
- There is a lack of understanding of plan management, especially in relation to direct employment and Capacity Building funding that can be sought for this.
- People are not informed of available planning resources that can support them with planning.
- There is no timeframe provided for turnaround from planning meeting to plan approval. This causes undue stress. This is further inflamed in cases where people are at particular risk.
- Calling the meeting a “pre-planning” meeting is confusing when it is actually a planning meeting.
- People are still very confused as to when they plan with an LAC or with a Planner, why, and if there is any impact if it is with one over the other.
- People are confused as to who determines if someone is “complex”.

Recommendations:

- Pre planning support is available through LAC Partners or other ILC funded activities. Information is actively offered to people and families that is easy to understand and supports them to feel fully informed, allay any fears of an unknown system.
- That the NDIA increase their focus and understanding that what people need in the planning process with Planners and LACs is the ability to build relationship and trust, this is reflected both in terms of the amount of time dedicated to meeting and the manner in which the Planner or LAC interacts with people.
- People and families are automatically provided the opportunity to review a draft plan.
- There is transparency as to the NDIA’s justification for decisions in relation to plans.

Using and Reviewing Plan

- LACs currently provide insufficient support to people who choose to self-manage. LACs in WA are seeking support from WAiS (as part of a WA State grant funded service) in this regard.
- People are concerned about losing funding if they don't use it, especially if, for example, they are not able to use the funding because the service is not available or if they need help with implementation.
- People are concerned about transport funding. This includes insufficient funding and lack of flexibility of use. People may get funded supports to engage socially and economically but cannot physically get there due to transport barriers. This is particularly an issue in regional and remote areas. People are being told 'you have used all your 'kilometres' this month so you can't have transport support to go anywhere". There is also an unclear age criterion so no consistency as to who gets it if the person is younger than 18 years old.
- In relation to the interim one month extension policy, there is lack of information in relation to what happens if someone has almost used up their annual budget.
- People do not understand their plans and LACs, when requested to, may read through it with someone, but this is not the same as explaining it. People don't understand budget categories and what this means practically that they can spend the budget on.
- People experience difficulty navigating what supports and services are available and implementing them, without adequate support from experienced, and focussed LAC, SC or others.
- There is lack of clarity in relation to bank accounts and confusion as to whose name the account need to be in.
- There is lack of clarity around who is determined as family for the purposes of NDIA policy that family cannot be paid to provide services.
- People are concerned they will lose funding in areas where they need it, when they seek a review of a reviewable decision, as this triggers a review of their entire plan.
- Review of reviewable decision versus change of circumstances – there is a level of misunderstanding as to the difference. The timeframes for these impact on people when they have inadequate funding and may run out of funding before the review/appeal is completed.
- There is a lack of understanding as to whether a LAC can support someone to initiate a review or change of circumstances.

Recommendations:

- That people and families are provided adequate and easy to understand information to ensure they are fully informed and any fears allayed.
- That the NDIS developed a policy in relation to who and how someone is determined a

"family member".
- That plans are easy to understand.
- That people are adequately supported to implement their plans.
- That adequate information is provided in relation to reviewable decisions, reviews and appeals, and mechanisms for amending a plan, for example change of circumstances. This information should be both about what these are and what people can expect during each of these processes.
- That people should be able to have a plan that can start with the accepted funded supports, whilst they wait for a reviewable decision on the specific strategies/ decisions being challenged.
- That people should be able to use their WHOLE plan flexibly to meet their goals and outcomes, not just elements of Core Supports.
- That people can request a review of only a specific part of their plan.
- That the NDIA explicitly states its position in response to AAT decisions.

Appealing a Decision

- It would be of great assistance to people if it is made clear people can have an advocate and where they can go to for this advocacy. It is noted that there are notable advocacy waitlists, even for situations that have been deemed requiring urgent attention.
- The timeframe for appeals is too long.
- Anything that can be done to minimise the likelihood of reviews and appeals will minimise undue stress, anxiety and fear in relation to having to go through a review/appeal.

Recommendations:
- That people are pro-actively offered advocacy support when appealing and that this advocacy is available.
- That people are fully informed as to what to expect during an appeal process and that appeals are undertaken in as short a timeframe as feasibly possible.

Plan Amendments

- WAiS fully supports this option being made available.
- This needs to actually be a swift, easy option.
- Clarity is required, however, as to the distinction from change of circumstances, or review of reviewable decisions.
- This option needs to include people seeking a change of management option.
- Clarity is required as to at what point people can request this. WAiS assumes at any time during life of plan.
- Clarity is required as to whether this impacts on the timeframe of plans. WAiS assumes the

plan duration remains the same and that this does not kick start a new plan period.

Recommendation:

- That a mechanism to enable swift minor plan amendments is offered to people.