

Submission: Review of the NDIS Act and the new NDIS Participant Service Guarantee

Submission by:

The following document is based on my own experiences, and those of close friends. I have commented on each of the key areas from the discussion paper. I have also included five short stories. These describe how the NDIS failed to act in a timely manner with participants I know personally. These stories bring actual people into the picture and highlight critical areas the NDIS needs to address immediately.

Thank you

Possible principles for NDIS services standards

Response to points in the discussion paper

The '**Expert**' model of service delivery is outdated having its origins back in the 19th Century. For the past two hundred years people with disabilities often have decisions made on their behalf by apparent 'experts'. There are some fine folk working in the NDIS, who make informed decisions and many who understand the social model of disability as opposed to the medical mode. The 'medical' model assumes a 'looking after approach' to disability where the social model assumes competency and appropriate support to lift a person's life to be on par their neighbors and community.

Currently there appear to be far too many '**experts**' who have come from the old broken system of support provided by the States. They often make decisions based on a prejudiced outdated medical model.

*Strengthening the '**Expert**' principal:*

- Source and employ people with disabilities and from the broader community. People with lived experience, and others, who have worked in related or part disability areas. i.e. Teachers' aides from regular schools for example, often have a more focused view on what may be possible. They have worked in a hands-on environment, not from an office desk in the State System making decisions on people who they have not met.

The '**Connected**' principle is flawed as it does not mention key mainstream departments or include people with disabilities themselves. Employment and Housing being crucial areas that were mentioned in the Productivity Commissions report when considering an NDIS model.

*Strengthening the **connected** principal:*

- A key recommendation from the Productivity Commission was for the NDIS or agency to work more closely with all other government agencies.
- Housing is one key area where the agency can do so much better. The NDIS could work more closely with the Housing Department in addressing the housing shortfall and finding suitable housing. Congregate living for four or more people with disabilities is 19th Century thinking

and does not provide good outcomes. Over 4 million people in Australia have some form of disability. That's 1 in 5 people. (<https://www.and.org.au/pages/disability-statistics.html>) Public Housing should be built with this ratio in mind to enable people with disabilities to engage with neighbors and the broader community.

- Much better outcomes for all people with disabilities including those with complex needs to live in mainstream housing with the full support of the NDIS.
- Employment is another area where people with disabilities can soar, provided they receive the right individual support from the NDIS.

Being 'Valued' and 'Decisions made on Merit' has not been part of how the agency has been operating. The term collaborative is not readily understood or used by the agency. **A solid collaborative process should be a major part of the principles and standards of the NDIS.**

- To value participants the NDIS must operate in a fully collaborative manner. This would include **respect, shared decision-making and shared responsibility** at all times. The NDIS has a history of decision making that often imposes an ableist view during the decision-making process. *Real collaboration* begins when parties talk genuinely to each other and keep communication channels open. Decisions should not be made by the NDIS until all avenues of information have been sourced, discussed and agreed on in full collaboration with participants.
- Value and decisions made on merit currently works at a bureaucratic level. This disempowers and does not provide good outcomes for participants and for the monetary investment by the NDIS and Government.

Story One:

A 33-year-old participant's mother was getting married, two weeks after his plan was finalised. On marrying the mother, due to her husband's work, would need to move elsewhere, well away from her son's area and his community. He was very well known in his neighborhood and looked out for by the local community.

The planner was advised of this fact and how it would change the dynamics of mother and son relationship. Strategies and advice on why and how this would be beneficial to the participant, including additional supports that would be required, were shared clearly with the LAC responsible for information gathering.

His plan did not address any of his needs to become more independent once his mother married. His Support Coordinator, on discussing this outcome with the planner responsible for the plan was told. 'Because his mother had not yet married, **that factor was not considered.**'

Outcome: The mother felt she had no choice but to remain with her son. The relationship with her fiancée broke down and the marriage did not eventuate. The son is still dependent on his mother and did not have the opportunity to live independently, with initial NDIS support, that could have been potentially reduced over time.

The value placed on this participants needs in this instance was low in standard. The flow on effect from this lack of support for his potential growth, also threw his family into a circle of crisis and feeling undervalued.

Planning processes 1: Creating, your plan

Response to points in the discussion paper

The NDIS has a poor record of accomplishment in supporting some people with disabilities with an effective individual plan. There does, however, appear to be some people who are satisfied and comfortable with their plan.

Challenges to improve the planning process:

- Requested and regular face to face meetings where the person is comfortable and able to relate at ease with LAC or planner.
- Phone calls from the NDIS often come with no indication as to where the call is coming from. This causes stress and anxiety as participants wonder whether to take the call or not. It may be a telemarketing call, or other call that they may not wish to take. It's understandable that NDIS numbers do not show. This could be readily managed if it came up showing NDIS on the screen.
- I am aware of a number of people with disabilities and their nominees who prefer to have all communication in writing by emails or letters. There are various reasons for this. Personal preference. hearing impaired people and others with cognitive difficulties who may find it difficult to talk directly on the phone.
- There are many examples of people who have specifically asked for email or letter correspondence who are called regardless of their preference.
- Planners are not always proficient at what they do and overlook or ignore cues that may come up during the planning process. i.e. person becoming stressed, pushing to finish as they may have to get their car back to the office.
- Planning is completed on a computer using specific questions with a set of algorithms to run through the various planning stages. This is an impersonal approach to planning and does not readily engage or create a good final plan.
- Notes and material shared with the planner are often ignored or lost in the system, when back at the office.
- The LAC may have a very responsive meeting with a participant, but the final plan is missing key aspects of what was discussed and agreed on.
- Plans are sometimes finalised with aspects that have not even been requested or needed.
- Some participants have been unable to use their plans effectively as they have not covered what they really require.

- Planning decisions are often not in line with the NDIS Act.

Section 4 - General principles guiding actions under the Act.

(8) People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as [equal partners in decisions](#) that will affect their lives, to the full extent of their capacity.

- Collaboration is key to people with disabilities being treated as [equal partners](#) in the planning process and for the duration of their plans. Collaboration with participants needs to be stronger with [shared decision making](#) at the center of the process. Just talking to a participant does not make a process collaborative. Planners must meet participants with a completely open mind. Ask a question, receive a response, discuss the response and allow the participant to feed further information in as needed. Collaboration can be a back and forward approach by coming up with decisions that both parties can understand and are comfortable with
- There needs to be thorough training and full understanding of how collaboration works with a set of clear guiding principles that planners must abide to.

Planning processes 2: Using and reviewing plans

Response to points in the discussion paper

- There are a many challenges for participants to use their plans effectively. Sometimes a lack of services in their area, training staff effectively and/or agencies unable to support people adequately.
- Plan reviews, when needs change, must be held within a more reasonable timeframe. I am aware of people needing critical reviews, who have been put on hold with no outcome flagged by the NDIS, or a planner even if the person is fortunate enough to have direct contact.
- Participants needs can change dramatically over time. That is the reality for many people with a disability. Often it may be a small change that should be able to be readily fixed without creating yet another plan. This causes unnecessary stress for participants and or their nominees and is a huge waste of Government funds.

Story Two:

A participant with complex needs waiting on a review, had her plan escalated after her nominee spoke to the local member of parliament. In good faith the planner was notified that the local member had been approached. This resulted in her plan being finalised within days, yet it was missing a number of items that had been discussed as needing more work prior to being finalised.

This is not good planning or an effective way to work with others. It appeared to be a reaction from a bureaucrat and/or her team to finalise it quickly to avoid scrutiny from a member of parliament. She had simply been asked to let the nominee know what were the

sticking points to finalizing the plan. The nominee was purely asking if more information was needed in some areas to allow the NDIS to make an informed decision.

Whilst this rushed plan effectively addressed a number of crucial points. The points that were missed now need to be picked up in another reviewed plan within three to four weeks' time.

Just another plan on top of currently six plans for this participant in just under three years. Her needs have changed little within that time. Her first plan was very adequate yet her second and third plans were underfunded resulting in her provider having to cover costs themselves. Costs which have not yet been recouped from the NDIS who underfunded plans two and three. This was despite being told on several occasions' funds would run out prior to the plans finishing.

Appealing a decision by the NDIA

Response to points in the discussion paper

This can be an onerous task for people receiving support from the NDIS. For many they need to be able, strong or have adequate and solid informal supports from family or friends. People who rely on formal support every day are conflicted when they need more support or have not received appropriate support initially. There is often a feeling of 'if I ask for more and have to go to the tribunal this might impact on my support in the future'. From my dealings with the NDIS it appears to me that the 'system relies on this' often. Knowing it can be difficult for many to appeal decisions.

This is wrong and unfair. If the NDIS worked effectively in the first instance, through the planning process, the need for appealing would significantly reduce. Savings for the NDIS for its legal team would also reduce. There is an obscene amount of money being used by the NDIS just for teams to fight appeals brought to the tribunal. Many it appears are finalised and agreed on just prior to going to the tribunal.

There needs to be more emphasis on getting plans and required supports right the first time.

The Legislative Framework

Response to points in the discussion paper

Sections of the legislation are absolutely strong and should not be changed or reduced in intent.

The NDIS Act. Section 4 - *General principles guiding actions under the Act.* This is clear and provides a solid framework for the NDIS to respond to.

- I would be concerned if this was changed and weakened.

The NDIS Act. Section 31 *Principles relating to Plans, Part 2.* Participants Plans needs to be stronger and spell out how **collaboration** between the agency and participants should work.

- A definition of collaboration could be included in the legislation so that all are clear on how this is to work.
- In-servicing of the NDIS team and providing them all with a full understanding of the NDIS legislation, including collaboration and how working in partnership with people with disabilities gives good outcomes.

The NDIS Act. Section 34 *Reasonable and necessary supports*

(c) the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;

- Reasonable and necessary supports is very clear. What occurs in practice however is many staff at the NDIS look at the cost of alternative support and go directly to the lowest common option. This process uses cost as central to the planner's decision making. Cost is clearly important and necessary to ensure the financial viability of the scheme, but planners **often ignore** what a person may specifically require for his or her disability needs.
- There is often a one shoe fits all approach to NDIS decision making. People with Down Syndrome, Cerebral Palsy, Intellectual disability etc. are NOT all the same. This has been a constraint placed on individuals by society and a 19th century health model. Many people with the same disabilities may require X supports and many may require Y supports. Again, it is the absence of real collaboration in the decision making that causes this divide and inadequate support.

Story Three:

A participant in a wheelchair, single parent with a young son, waited over two years for her very necessary home modifications. A comprehensive report by an Occupational Therapist, including architectural drawings and quotes, was submitted to the NDIS. Her Support Coordinator contacting the NDIS at every opportunity seeking a response as to when this would be actioned. She requested a Review of a Reviewable Decision to have the situation rectified as soon as possible. Even then this took up to ten months before it was considered by the NDIS

Her Mother died in the early stages of this process, and the participant wished to live in her Mothers home while the modifications were under way. This would have been very appropriate for her, with no extra rent to pay and her son continuing at his local school.

This did not occur with the 'process' seemingly stalled, with no meaningful outcome.

It was only when her physical situation deteriorated, and she began to have consistent falls, daily, that the NDIS began taking her situation seriously. Several of the requests of the build were to widen doorways and replace the flooring with vinyl. Both requests designed to minimize her falls, as she moved around her home and for chair transfers.

It took several major falls and visits to hospital for surgery to her spine on two occasions for the NDIS to start to address her home build needs seriously. A lead planner was allocated to assist her. She was brilliant. However even she could not hasten the bureaucrats in the building department with their decision making. They were so focused on cost and

considering cheaper options that the participants needs took second place in the decision making.

When the build and costs were finally approved, she had to rent accommodation at a local motel for her and her son costing her around \$1,500. A huge cost for her given she relied on a disability pension. This could have been avoided, had the NDIS acted in a timely manner in the first instance. She would have been able to stay in her Mother's home, and the falls and hospital visits would have been avoided.

The delays from the NDIS experienced by this participant amount to abuse by neglect.

Story Four:

A participant with complex support needs had an OT assessment at her home by an Occupational Therapist over two years ago. The OT identified two clear areas that were unsafe and placed the participant in danger. Formal reports and requests for necessary home modifications were submitted including quotes and clinical justification.

1. A safety gate required at the top of a flight of stairs and
2. A short safety fence at the top of a steep drop.

The participant is mobile and has numerous epileptic seizures resulting in falls. As a result of these falls, she has had many emergency runs to hospital. After being in danger and waiting two years for these areas to be addressed she was advised the requests were not reasonable as she already had a full-time worker with her at all times.

There was no discussion on how to best manage this situation prior to the decision being made, despite it being part of a Request for a Reviewable Decision. Having a worker with her 24/7 does not guarantee she or the worker will be safe from harm.

Her seizures are severe, and her worker could be pulled down with her if he/she had to support her and restrain her during a seizure. Both could be seriously injured.

If the worker restrained her in her home from standing at the stairs or wall, this would be viewed as a restraint for this person. She enjoys looking at her garden when on her veranda standing near the stairs and outside near the drop. To physically move her every time she gets near these dangerous areas is restrictive. It is a different scenario when outside in the community and worker vigilance is crucial at all times. Her home should be a place to be at ease and safe.

She has one worker only supporting her at her home 24/7. The worker is entitled time to herself and breaks under the award including toilet breaks. The workers are committed to this participant and ensure she is safe as much as possible They have to perform house duties when their eyes may be off the participant on occasions.

This drawn out process placed both participants at high risk for over two years, with minimal or no action by the NDIS. Both examples amount to neglect and abuse of care by the NDIS. If either participant had to now go to the tribunal to appeal this, the process would be drawn out even further, continuing to place both participants at further risk.

Plan amendments

Response to points in the discussion paper

Amendments to participants plans must be far more responsive to their changing needs. The introduction of a new plan for the smallest change to a person's plan is bureaucracy gone mad. The additional cost to the agency in implementing a new plan, is often above what the item or change might be in some instances. If it is identified as a major change a new plan may be justified. If it is for an additional item not noted on a current plan that is a small cost, it should just be approved and added accordingly.

Story Five:

A participant requiring a weighted blanket to assist her to settle in bed had a full assessment and report submitted by an Occupational Therapist. This blanket was strongly recommended. The item had not been identified in the participant's plan, but the plan manager could not pay for the blanket. The plan manager could pay for the Occupational Therapists report.

This participant had just gone through a complex Review of a Reviewable Decision, and now had another plan with many key areas resolved. She had received up to seven plans over a three-year period, which was in itself unsettling and difficult for her to keep track of.

Because the blanket had not been on the radar at the time of the Review, it would mean yet another plan for the participant. She and her family decided the blanket was important, and staff had had good results with a blanket loaned to her by the Occupational Therapist. She purchased the \$180 blanket herself from her own savings.

It would have been far simpler and easier for the participant if the blanket could have just been added to her current plan.