

Submission:

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

The NDIS ACT

The NDIS Legislation provides a clear framework for Government and NDIS bureaucrats to address the needs of people with disabilities. Some sections tend to be interpreted to benefit Government alone, often failing the very people it is meant to serve, people with disabilities themselves.

I am a parent of an NDIS participant who has extremely complex needs/ My background spans some 46 years not only as a parent, but also a professional in planning, education, disability and one who has worked collaboratively with professionals and many others including:

- People with disabilities.
- Parents and family members of children and adults with disabilities.
- Other professionals in the field of disability.
- State and local Government.
- Minister of Education.
- Deputations to various ministers with the Victorian Parent Collective
- Department of Human Services.
- Numerous bureaucrats at varying levels.

I shall not comment on or attempt to go through the entire legislation. I shall focus on three key sections of the legislation that I see as crucial to retain and build upon.

1. **Section 4** - *General principles guiding actions under the Act*
2. **Section 31** *Principles relating to Plans*
3. **Section 34** *Reasonable and necessary supports*

The interpretation by those in the NDIS of parts of these three sections, has been inconsistent since the NDIS came into being. This has resulted in cases of people with disabilities being thrown into a circle of crisis, and often, denied what is commonly referred to as reasonable and necessary supports. The Productivity Commission identified the previous system as broken and fragmented. The NDIS is in danger of losing its way in this regard and in some cases moving back to a system more broken and fragmented than before.

Part of this seems to be as a consequence of the following situation I have experienced firsthand from several overzealous bureaucrats. They see their role as saving money for Government, rather than providing a framework to allow individuals to grow and develop alongside and with others in society, as prescribed in the legislation.

I have worked alongside and with people with disabilities in crisis. I have experienced firsthand the NDIS requesting numerous reports from Allied Health Professionals, and then disregarding their professional recommendations.

I have experienced individuals requesting necessary equipment and home builds recommended by Allied Health Professionals that have been denied. This then goes through an extensive review

process, in some cases one to two plus years. This process, in the end, sometimes provides a good outcome for the participant but at huge unnecessary cost to the Government. In some cases, I have observed the NDIS spend excessive bureaucratic time and wages, way above the initial cost of the piece of equipment requested.

I could continue with many other examples, but to me this is a system in crisis.

- Part of the crisis may come from current and past NDIS training.
- Part from bureaucrats who were part of the previous broken system.
- Part from bureaucrats who have never been involved in disability before and understand nothing of its complexities.
- Part directly from direct and indirect prejudice and a perception of 'doing good'. A view that people with disabilities should be 'grateful' to the NDIS for what they might receive.

I have spoken and worked with many in the NDIS who fully understand disability and are totally committed to making it work. It appears to me they are sometimes hamstrung by others either in their own team or blocked by their superiors.

I shall now discuss sections of the NDIS ACT which I mentioned earlier, that are important to me, explain why these should be retained and where they need to be strengthened.

General principles guiding actions under the Act, Principles relating to Plans and Reasonable and necessary supports. **The sections I agree with and should be retained will receive a comment in green.**

Where I see the legislation needing more clarity, or where it needs to be strengthened, I shall comment in red

NDIS Legislation

The NDIS Act.

Section 4 - General principles guiding actions under the Act

4 General principles guiding actions under this Act

(1) People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development.

Retain. This is crucial and enables the intent of the NDIS to be fully addressed.

Some planners / decision makers view people with physical disabilities as having more potential than people with cognitive or perceived intellectual disabilities. This often creates a divide in the decision making by treating both groups as distinctly 'different' The 'rights' that the NDIS should be focused on become blurred when differing attitudes come into play.

(2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability.

Retain. Essential and doable with the right support and planning process.

Personal prejudice often gets in the way in terms of perceived capacity and ability.

(3) People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime.

Retain. Absolutely essential and important.

People with disabilities, families and carers have no certainty or confidence in how the NDIS is operating at the current time. Plans are often short term with no ability for people to plan for their future as essential supports are provided one year and changed or removed the next year. Apart from the uncertainty, the stress level on individuals and ageing parents in particular are a constant. As a parent over seventy years old I have worked tirelessly to ensure my son is secure for when I and my wife die. The stress level in working with the NDIS currently has impacted on my own health and wellbeing. The current situation does not give my wife, our son or myself certainty his future will be secure with the current NDIS.

(4) People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.

Retain. Absolutely essential and important.

This support and choice is not always apparent or provided for many participants.

(5) People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.

Retain. Absolutely essential and important.

(6) People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation.

Retain. Absolutely essential and important.

(7) People with disability have the same right as other members of Australian society to pursue any grievance.

Retain. Absolutely essential and important.

Having to appeal through a legal process at a tribunal is a stressful process for people who are already marginalized by society. This is not made any easier by the NDIS spending millions on legal teams to fight grievances. It may assist the NDIS and bureaucracy but if the NDIS got it right the first time, it would save millions and enable the NDIS to perform effectively in the first instance as intended.

(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.

Retain. Absolutely essential and important.

Equal partnership and real shared decision making is not how the NDIS has been operating.

(9) People with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximized in a way that is appropriate to their circumstances and cultural needs.

Retain. Absolutely essential and important.

(10) People with disability should have their privacy and dignity respected.

Retain. Absolutely essential and important.

(11) Reasonable and necessary supports for people with disability should:

(a) support people with disability to pursue their goals and maximize their independence;
and

(b) support people with disability to live independently and to be included in the community as fully participating citizens; and

(c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment.

Retain. Absolutely essential and important.

(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.

Retain. Absolutely essential and important.

(13) The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognizing that advocacy supports people with disability by:

- (a) promoting their independence and social and economic participation; and
- (b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
- (c) maximizing independent lifestyles of people with disability and their full inclusion in the community

Retain. Absolutely essential and important.

Advocates are not always welcome by the NDIS as part of a shared process or seen as equal partners in the decision making.

(14) People with disability should be supported to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme.

Retain. Absolutely essential and important.

(15) Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.

Retain. Absolutely essential and important.

I have not seen much evidence that this is occurring at a fast-enough rate. Lack of qualification and the number of staff employed by the NDIS, appears to be a constraint in this and other areas.

(16) Positive personal and social development of people with disability, including children and young people, is to be promoted.

Retain. Absolutely essential and important.

(17) It is the intention of the Parliament that the Ministerial Council, the Minister, the Board, the CEO and any other person or body is to perform functions and exercise powers under this Act in accordance with these principles, having regard to:

- (a) the progressive implementation of the National Disability Insurance Scheme; and
- (b) the need to ensure the financial sustainability of the National Disability Insurance Scheme.

The NDIS Act

Section 31 Principles relating to Plans

Part 2 – Participants Plans

The preparation, review and replacement of a participant’s plan, and the management of the funding for supports under a participant’s plan, should so far as reasonably practicable

(a) be individualised; and

(b) be directed by the participant; and

(a) and (b) above often does not occur with some planners who push their own personal view above that of the individual. Collaboration (see following) rarely occurs in a format that will have meaningful outcomes. I will discuss collaboration, so it is clear how it actually works.

There are many definitions of collaboration online. This quote describes key elements of what it is, and how it should work:

‘Collaboration is often seen as an activity that involves team members working on a project together. True collaboration is more than an activity, however. It is a process with associated behaviors that can be taught and developed. It is a process governed by a set of norms and behaviors that maximize individual contribution while leveraging the collective intelligence of everyone involved. It is the way in which a group of people collectively explore ideas to generate solutions that extend beyond the limited vision of a single person (Maynard, n.d).’

- **Collaboration is working together**
- **Collaboration is about information sharing. From all sides**
- **Collaboration is about listening.**
- **Collaboration is about asking questions and seeking answers from all parties.**
- **Collaboration is asking for more information if not all the facts are fully known.**
- **Collaboration is ensuring all people are on the same page.**
- **Collaboration is understanding where others are coming from**
- **Collaboration is not one person doing just what he/she wishes to do.**
- **Collaboration is not judgmental.**
- **Collaboration is not decision making on the run.**

(c) where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant; and

On occasions respect often disappears as bureaucrats ignore process and act only in the NDIS's interest.

(d) where possible, strengthen and build capacity of families and carers to support participants who are children; and

if the participant and the participant's carers agree—strengthen and build the capacity of families and carers to support the participant in adult life; and

(e) consider the availability to the participant of informal support and other support services generally available to any person in the community; and

(f) support communities to respond to the individual goals and needs of participants; and

(g) be underpinned by the right of the participant to exercise control over his or her own life; and

(h) advance the inclusion and participation in the community of the participant with the aim of achieving his or her individual aspirations; and

(i) maximise the choice and independence of the participant; and

(j) facilitate tailored and flexible responses to the individual goals and needs of the participant;

Retain all above points. They are all absolutely essential and important.

The NDIS Act

Section 34 Reasonable and necessary supports

34 Reasonable and necessary supports

(1) For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:

(a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;

Retain. Absolutely essential and important.

Often planners change the wording and put their own opinion into a participant's goals and outcomes. They change the wording to save funding so that it no longer reflects the participants wishes or what they wish their goal to address.

(b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation;

Retain. Absolutely essential and important.

People placed into Supported Independent Living (SIL) often are not fully supported to address their goals effectively. Social participation for those in SIL often relates to group activities that deny them real access to community. It is usually those who can access advocacy and individual support during the planning process who may have an opportunity to begin to have a meaningful life.

(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;

Retain. Absolutely essential and important HOWEVER:

Point (c) is the elephant in the NDIS room and often the one planners only focus on. It is usually addressed on it is own without any consideration of the other two sections already discussed. 'General principles guiding actions under the Act' and 'Principles relating to plans'. If these two areas have been addressed correctly it should be fairly straight forward to determine if Reasonable and Necessary requests are just that 'Reasonable and Necessary'.

If the principles are understood and effectively used by planners when dealing with participants, this sets the scene for a meaningful planning process. But only if the planning process uses a fully informed and thorough Collaborative Process.

It is essential that money is not wasted, and all outcomes are value for money.

What occurs in practice is often supports are pushed down to the lowest common denominator by NDIS planners. This does not necessary give good outcomes. What may be appropriate for some individuals, is not necessarily appropriate for others.

Collaboration is key to determining what is reasonable and necessary for an individual. Many planners and bureaucrats appear to not be trained, or understand collaboration, disability and how to work effectively and productively with others. I have worked with a number of planners and seen firsthand variations in approach with both good and bad practice.

I have attended numerous review planning meetings with several participants. One was with a woman in a wheelchair. This lady was articulate and able to engage in the conversation. The planner's first question was 'How was everything going?'

Followed by 'Is there anything that is not working well and what might we need to do to make it better?'

At a following review meeting with my son who had initially received a good individualised plan from the NDIS.

He is nonverbal with cognitive difficulties, epilepsy, autism and apraxia. None of the earlier positive questions above were asked. This planner had no knowledge of how to communicate or relate with him. She was inexperienced, and despite knowing his needs were complex, was intent on starting the whole planning process again. This approach did not create a good proactive environment for plan development and impacted negatively on his next plan. It was insufficient and had a shortfall of around \$23,000. His provider is still waiting, six months later, for reimbursement from the NDIS. This was a planning decision by an inexperienced planner and one that impacted directly on the provider. This provider is committed to providing good support and positive outcomes for their clients. Their job is not helped with such poor planning decisions.

The NDIS is currently following up to address these inadequacies. The person assisting us with these areas is committed and has been able to work proactively with us. He, however, is still constrained by a system that continues to work in isolation and at arm's length from an individual's reality.

(d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;

If a good planning process is used, including the element of collaboration as discussed earlier, this in itself, will lead to good practice. Listening and working with someone in this manner can only lead to good outcomes. If parts of the discussion lead in the wrong direction or toward bad practice, it is often rectified along the way with positive communication channels being kept open.

(e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;

Provided the supports are fully discussed and understood by planners and are appropriate for ageing parents of an adult who requires support. It is not reasonable to expect elderly parents to have to fill in gaps due to bad planning decisions based on saving money.

(f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:

(i) as part of a universal service obligation; or

(ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

(2) The National Disability Insurance Scheme rules may prescribe methods or criteria to be applied, or matters to which the CEO is to have regard, in deciding whether or not he or she is satisfied as mentioned in any of paragraphs (1)(a) to (f).