

Feedback to the NDIS Review

What defines Reasonable and Necessary?

The NDIS Review 'what we have heard' Report has identified the definition of Reasonable and Necessary as a key issue to be resolved.

We write to provide feedback, as requested, to the NDIS Review concerning what we believe should be defined as Reasonable and Necessary and what should be identified as not reasonable or necessary.

We are the parents of, and NDIS Nominees for, a 41 year old woman with profound intellectual, physical, and sensory disabilities and complex support needs who act as her voice for all her needs as she is unable to hear or speak and does not possess the cognitive skills to negotiate her daily activities and supports.

Comments reported in the NDIS Review Report are unfortunately consistent with our experience as we have found NDIS Planning processes to be unclear, highly stressful, and very time consuming with communication about planning decisions being at best opaque but generally totally unintelligible. NDIS Plans have consistently failed to fully fund the Reasonable and Necessary supports, at the level our daughter needs, requiring us to seek multiple plan reviews and we are currently in the process of working through an Internal Review of a Decision [previously known as a S100 Review of a Reviewable Decision].

The NDIS processes we need to follow to secure our daughter's support funding are repetitive and very time consuming [preparation for the request for an Internal Review of a Decision has taken more than 50 hours of our time] and are personally distressing to the extent that they are now starting to affect our mental health.

What is not reasonable or necessary?

Following the confirmation of our daughter's current NDIS Plan we received a NDIS letter which stated, *"For a reassessment of your current funding at the next meeting further reports will need to be submitted"* then lists 6 different reports already provided to the NDIA. Additionally, her current NDIS Plan [core supports narrative page 7] states *"this will help me build my skills to live as independently as possible"*. Our daughter, unfortunately, does not, and never will have, the capacity to build her skills as evidenced in her Functional Capacity Assessment provided to the NDIA. At best she will, with the help of allied health professionals, preserve the limited capacity she has.

The need for us to have to continually prove our daughter's disabilities and their impact on her functional capacity is, in our opinion, disrespectful, unreasonable, and unnecessary.

Proof has been provided multiple times that her disabilities are lifelong and permanent, and we are very concerned at the NDIA Planners' apparent lack of understanding of the permanence of our daughter's disabilities and her total reliance on personal support for her to complete every aspect of her daily activities and to keep her safe.

We do not believe that it is reasonable or necessary that any person with lifelong permanent disabilities should be required to consistently need to prove their levels of disability and that this view is consistent with public remarks made by Minister Shorten confirming that he does not believe it is reasonable or appropriate for a person with permanent lifelong disabilities to be required to reprove their disabilities. Furthermore, it adds unnecessary cost to the NDIS and causes trauma for

participants, parents and carers who are simply trying to enable the reasonable and necessary supports needed to allow them to live an ordinary life with dignity and safety.

What is Reasonable and Necessary?

We believe that it reasonable and necessary for our daughter to be able to have fully funded support for each of the basic daily activities to enable her to live an ordinary life:

- to get out of bed,
- to get dressed,
- to transfer between her bed, wheelchair, casual seating, change table, and shower chair as required for each part of her daily activities, identified in her Functional Assessment as up to 16 times per day,
- to prepare her food and to be fed,
- to manage and prepare her medications and be medicated according to a medically prescribed timetable,
- to be able to safely move around the community [someone to push her wheelchair and provide transport for her for community access and activities],
- to anticipate and respond to her needs as they vary throughout the day,
- to manage her personal hygiene care,
- to be showered,
- to reposition her,
- to change her clothes as needed,
- to help her get into bed,
- to launder her clothes,
- to purchase her food, medications, and personal care supplies,
- to assess risk and keep her safe.

These are the ordinary daily activities of everyone in the community but people with disabilities need help to complete them.

Permanent lifelong disabilities

Our daughter has been diagnosed with:

- Cerebral palsy
- Profound developmental delay
- Profound hearing loss
- Epilepsy
- Doubly incontinent of bowel and bladder
- Severe oropharyngeal dysphasia
- Severe gastroparesis

Her disabilities are lifelong and incurable. She will not get better or 'develop her capacity' and her cerebral palsy is degenerative in its impact on her health and wellbeing as she ages.

- She cannot hear or speak.
- She does not have the cognitive skills to manage her daily needs, or to assess risk to manage her personal safety and requires full assistance from others to manage her life's needs, her personal dignity and safety.
- She cannot sit unassisted or walk and uses a customised wheelchair for her seating and mobility and requires full assistance with transfers to and from it and for moving throughout the community.
- She cannot feed herself and needs full assistance to prepare her nutritional needs, manage her medications, and to feed them to her.

- She cannot manage dressing and changing of clothes and requires full assistance with dressing and changing.
- She is doubly incontinent and cannot manage her personal hygiene, bathing, or toileting, requiring total assistance from 2 people on average 5 times per day to change her incontinence pads, shower her, and manage changing of clothes as required.
- She has 7 different specialised assistive technologies to support her basic daily needs and keep her safe.

Our daughter’s functional capacity assessment clearly describes the support levels she requires to maintain her personal care and safety and provides a clear explanation, including medical definitions as appropriate, of her disabilities and a detailed timetable of personal supports and equipment to keep her well and safe.

Nationally accepted assessment tools were used by a qualified allied health professional to assess the extent of her disabilities on her Functional Capacity which confirm that she best fits the criteria for Higher Needs Level of support which provides 24/7 support. These assessment tools are:

- **The FIM™ (Functional Independence Measure).** Her FIM™ score for Motor Items was 13/91 and her FIM™ score for Cognitive Items was 5/35. These are the lowest scores that can be attained using the FIM™. These scores indicate that our daughter requires total assistance overall with completion of motor tasks and total assistance for cognitive tasks.
- **The Care and Needs Scale (CANS; Tate, 2004)** is an 8-level categorical scale that is designed to measure the level of support needs of older adolescents and adults with traumatic brain injury. The CANS comprise of two sections: a Needs Checklist and Support Levels. The Needs Checklist evaluates the type of care and support needed ranging from basic needs through to instrumental activities of daily living and social participation activities. The Support Levels assess the length of time that one can be left alone, the extent, intensity and frequency of care and support needed. She was administered the CANS and was rated as a level 7 = Cannot be left alone – needs support 24 hours of the day.

Despite having provided this information we have been told we will need to submit proofs of disability for our daughter’s next plan review?!?!??

Our proposed definition of Reasonable and Necessary

Reasonable and Necessary should be defined as:

- **Personal supports to help a person with disabilities to complete the basic daily tasks of an ordinary life and to keep them safe.**
- **Assistive Technologies to enable the basic activities of an ordinary life.**
- **Capacity Building supports to enable a permanently disabled person to maintain their health and wellbeing and to improve and / or preserve their current functional capacity.**

Reasonable and Necessary should include the right to have the permanence of a Participant’s disabilities and their effect on their functional capacity clearly identified and never questioned:

Consistent with Minister Shorten’s comments that people with permanent lifelong disabilities should not have to continually prove their disabilities; **We propose that it is Reasonable and Necessary that a category of NDIS Participants be established for people with permanent lifelong disabilities, that has resulted in a reduction in functional capacity requiring them to have assistance to complete everyday tasks to live an ordinary life, which includes the condition that once they have established their functional capacity and support needs they never have to prove their level of**

disability or functional capacity. Additional proof should only be required if the person has a change of circumstance which unfortunately tends to mean that they now have further reduced functional capacity requiring higher levels of support.

Immediate change is Reasonable and Necessary.

The proper definition of what is and is not Reasonable and Necessary is, we believe, an urgent and critical priority for the health and wellbeing of people with permanent lifelong disabilities and their families and carers and, furthermore, that these changes will prove to be more cost effective for the good governance of the NDIS.

With appropriate common sense, good will, and sense of urgency these are simple changes that can and should be made immediately.