



Reasonable and necessary supports

Background Paper – NDIS Review Engagement Project

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This paper was prepared by Helen Dickinson and Anne Faulkner to support Inclusion Australia's engagement with people living with intellectual disability, their families and allies, and other stakeholders as part of consultations to inform the NDIS Review.

Introduction

The NDIS is a universal scheme that is not subject to income or asset tests. In order to prioritise claims for support and to allocate resources the NDIS uses a principle of 'reasonable and necessary' to determine what will be funded.

The aim of the NDIS Independent Review is to assess the NDIS for opportunities to improve the experience of participants and ensure that the scheme is sustainable. As of June 2023, the Review has identified five major challenges, one of which is resolving the planning and funding problems that the poor definition of 'reasonable and necessary' creates for the purposes of defining supports.

The Review has found that it is difficult for NDIA decision-makers to be consistent across a range of participants, disabilities, and circumstances. Participants are confused, feel decisions are not transparent and believe the planning process creates inequities. There is also insufficient guidance for clinical professionals on providing evidence as part of considering what is reasonable and necessary for the participant and it is not clear why their views are not always considered. The combined result of these factors is that cases relating to the interpretation of reasonable and necessary continue to create demand at the Administrative Appeals Tribunal (Bonyhady & Paul, 2023).

As a next step in the review, the NDIS review is calling for ideas about 1) how reasonable and necessary could be more clearly defined for participants and the National Disability Insurance Agency (NDIA) and 2) what processes could support practice and implementation of the principle of reasonable and necessary so that decisions are consistent and fair and there is certainty about future funding.

What is the problem?

The documents that set out how the principle of reasonable and necessary should be interpreted are the NDIS Act 2013, the NDIS Rules 2013 and the NDIA Operational Guidelines.

The NDIS Act provides for the National Disability Insurance Scheme Rules (NDIS Rules) to set out methods or criteria to be applied or matters that the Chief Executive Officer should consider in deciding whether to approve supports. The NDIS Rules most relevant to reasonable and necessary decision-making are the National Disability Insurance Scheme (Supports for Participants) Rules 2013.

The concept of 'reasonable and necessary support' is not defined in the NDIS legislation but criteria are set out under Section 34 of the NDIS Act. In order to fund a support, the decision-maker must be satisfied:

- (a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;
- (b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation;

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

As this list suggests, the NDIS takes into account any informal supports available (e.g., through friends, family and community services) and formal supports through mainstream services (e.g., health, education) in determining what is reasonable and necessary. The NDIS differs from a number of other international schemes given that the principles in the Act are broad and so planners and other decision-makers are reliant on the operational guidelines and taking into account a wide range of factors in the lives of participants and families without detailed legislative guidance.

The difference between what is established by law and the factors set out for the administrative decisionmaker to consider in the Operational Guidelines are the location of significant points of contention for the implementation of the principle of reasonable and necessary supports. The detail in the guidelines about establishing value for money, the requirement for NDIA decision makers to align with financially sustainable practice, the budget and a consideration of when day-to-day living costs are not related to disability are directed by policy, require significant skill to assess and are often a point of debate between planners and NDIS participants and their families who are experts in their own lives. The potential for these Rules and Guidelines to be interpreted in different ways creates space for disagreement and leads to inequity in decisions and is at least one driver of increasing cases being heard by the Administrative Appeals Tribunal in recent years (Cross, 2022).

Challenges in determining what is reasonable and necessary in NDIS plans no doubt plays a role in determining the outcomes a participant gains within the scheme. Evidence shows that people with intellectual disability are at greater risk of receiving inadequate levels of support through the NDIS, and experience more unmet need and relatively poor outcomes (Mavromaras et al., 2018).

In recent years the NDIS has faced demands to be more financially sustainable as a greater number of participants than expected has entered the scheme. This has created pressure for reforming what supports can be considered “reasonable and necessary” (Cross, 2022). Although the NDIS is sometimes described as an ‘uncapped scheme’, a cap does exist in the form of the willingness of the Australian taxpayer to fund it (Productivity Commission, 2017). There are pressures on the NDIS relating to entry, and decisions around what constitutes ‘reasonable and necessary’ supports (Evans et al., 2021).

What does the evidence say?

The way that reasonable and necessary support is interpreted by decision-makers is critical to whether the objective of choice and control is met (Horsell, 2020; Olney & Dickinson, 2019). The lack of clarity around these concepts mean that they can be interpreted differently by different individuals and also planners and NDIS participants. Significant evidence suggests that the principle of reasonable and necessary is being applied inconsistently within the scheme and some participants and professionals lack clarity in terms of meaning of these concepts. This means that some people fail to get the services and support they need, while others are able to secure the same supports. Evidence also suggests that the scheme works better for people with support needs that are less complex and can receive support from less specialised, more generic services and support workers (Smith-Merry et al., 2023).

The role of planners

The NDIS is designed so that planners should work in a consistent, transparent and accountable way (Foster et al., 2016). This can be a challenging process given that planners are trying to make decisions that try and align the expectations of participants and working to expectations of cost effectiveness and sustainability (Venning et al., 2021). Planners may have limited experience of diverse forms of disability, the experiences of people from culturally and linguistically diverse backgrounds or Indigenous people (Smith-Merry et al., 2023).

The process of planning has been described as being underpinned by an ethic of justice, where similar people are treated in the same sort of way (Carney et al., 2019). One of the ways that consistency has tried to be addressed is through the development of typical participant profiles and reference packages that are used to determine funding allocations. But these processes often do not put individuals at the centre of these decisions in deciding what is reasonable and necessary and planners work to more abstract standardised principles.

NDIS planning processes do not always take account of communication or decision-making challenges for people with intellectual disability (Bigby, 2021). This means it can be difficult for people with intellectual disability to express what is reasonable and necessary for them in terms of their lives and aspirations. Advocacy often plays an important role in these discussions, either in terms of self-advocacy or that provided by family and other supporters (Mavromaras et al., 2018). However, people with intellectual disability are at risk of being without strong self or family advocacy (Bigby, 2021), which means it can be more difficult to make a case around what is reasonable or necessary.

However, just the presence of advocacy in planning discussions will not guarantee what is determined as reasonable or necessary from the NDIS participant will be gained. Studies show that the views of carers or advocates are sometimes given more weight than those of people with intellectual disability (Collings et al., 2019). This can be problematic because informal supports can sometimes be overly protective and risk-adverse, they may not always reflect the preferences of individuals, and there may be a reluctance to talk about sensitive topics (e.g. sexual relationships) (Carney et al., 2019).

Boundaries of the NDIS

In deciding what is reasonable and necessary the NDIA needs to decide whether a support is most appropriately supported by the NDIS and not by other mainstream services, but the boundaries in terms of what different government agencies should provide is not always clear (Productivity Commission, 2017). Research shows significant challenges in areas such as health (Dickinson & Carey, 2017), education (Yates et al., 2021) and criminal justice (Dickinson et al., 2022).

In determining what is reasonable and necessary, consideration also needs to be given to what families and communities might typically provide. It may therefore not be considered reasonable or necessary for a particular support to be provided as families might be seen as usually providing this support for an individual, such as attending a social event or providing a certain proportion of support hours within a given week. There are debates over whether it is reasonable and necessary for carers to provide very high levels of care over extended periods of time without being supported, for example through respite services (Carers Australia, 2018).

What does it mean to live an “ordinary” life?

An analysis of 35 appeals to the AAT and one Federal Court Appeal relevant to the application of the principle of reasonable and necessary (Venning et al., 2021) highlighted ambiguities and challenges for scheme decision-makers as well as the values and priorities evident in the decision-making relevant to reasonable and necessary supports. While the predominant argument put by NDIS participants was that their requested supports were reasonable and necessary according to their personal aspirations, the NDIA’s responses were generally based on arguments that the requested supports were beyond what constituted an ordinary life and/or the requested supports were not directly linked to the individual’s disability. For example, Collings et al. (2019) in a study of NDIS planning of people with intellectual disability find: “For some NDIS planning helped with socialising when it otherwise may have been challenging to the participant as being supported to go to community events. For others it didn’t even when it was a goal - some experience planners exercising judgement about what did and did not constitute reasonable and necessary support to increase social participation. Emily said: “I don’t really have friends ... I wanted to mix [and] to go out with a friend. My planner said to make friends is up to us. I can’t get enough funding to help me at all.” In Emily’s case, transport assistance to meet up with another person with disability was not considered a “necessary” disability support and so was not funded in her package of supports”.

The analysis revealed two major issues, being 1) ambiguity and contestation around the responsibilities of families and 2) negotiations over the legitimacy of supports and the role of evidence and personal choice to legitimise support. Regarding family involvement, the authors concluded that this demonstrated the criticality of family involvement to the sustainability of the scheme as well as poor assumptions about it (Venning et al., 2021).

Decisions about what is reasonable or necessary can also lead to people with disability missing out on opportunities to engage with the community. For example, Purple Orange (2023) give the example of an NDIS participant who wanted to attend a local art class but was refused because it was not a disability-related expense. Instead, they were offered funding for one-to-one art therapy. This is both a more expensive option, but also meant that this individual missed out on opportunities to connect with the local community, which they would have gained in their local art class. This example illustrates an issue often seen in determining what is reasonable and necessary, especially

for people with an intellectual disability, where the support provided is a disability specialist response rather than one that fosters genuine connection with community.

Another typical response in balancing what is reasonable and necessary for individuals with concerns around efficiency can be to facilitate community interaction by taking multiple NDIS participants to an event or activity (e.g., bowling or to the zoo). While this gives the opportunity to get out into the community there is generally insufficient support for individuals to genuinely connect with others as they are part of a group (Purple Orange, 2023). Some individuals find that the only ways they are able to attend activities (e.g., going to the football) given what has been determined reasonable or necessary for them is to attend as part of a group. Some people with intellectual disability may need support to help them engage with social participation in a way that those with physical disabilities may not and where physical accessibility barriers may be more of a challenge. But this does not mean that this social interaction is less reasonable or necessary for social inclusion.

What is the solution?

Capacity building of participants

Given that the NDIS was launched and mainstreamed quickly and many participants are still on annual plans, there has been a high demand on planners (Productivity Commission, 2017). Planners have not always had enough time to work with individuals and this is particularly a challenge for individuals who may have difficulty expressing their needs. Pre-planning processes can be helpful in working with individuals to express their goals, aspirations and support needs in a way that demonstrates that they meet the criteria of being reasonable and necessary. Similarly building the capacity of individuals through mentoring or training may also be a positive way for individuals to engage more in planning processes and would also act as a safeguarding mechanism in other areas of the scheme (Bigby & Douglas, 2020). There is considerable evidence about the needs of people with intellectual disability in engaging with self-direction of supports and decision-making and this should be drawn on supporting individuals within the NDIS (Bigby, 2021; NSW CID, 2016).

Standardised packages

One way in which issues of interpretation of reasonable and necessary have attempted to be made more consistency is through the use of reference or standard packages. However, as indicated above, such an approach can create issues for equity as it does not deal with the specific preferences and goals of an individual and seeks to standardise across what are perceived to be similar individuals (Carney et al., 2019). Individuals do have different needs; this is the very underlying ethos of an individualised funding scheme like the NDIS. There need to be approaches that recognise and enable this.

Capacity building of planners

What is more important than having access to reference packages is the skill level of planners and ensuring that these are sufficiently supported to understand the needs and lives of NDIS participants (Bigby, 2021). People with intellectual disability often have quite different needs to other NDIS participants. Establishing teams of planners who are skilled and experienced in working with people with intellectual disability may be one way to better understand the lives, aspirations, and

reasonable and support needs of this group. More time needs to be taken with planning and the voice of the individual should be distinguished from that of their family (NSW CID, 2016).

In addition, allowing planners to use more judgement and discretion may enable more effective determinations of what is reasonable and necessary in the life of the individual (Australian National Audit Office, 2017). Without a high level of skill and understanding within the planning workforce, participants or carers are required to do significant advocacy work. Carney et al., (2019) reports that it is commonly felt by NDIS participants that families with high levels of experience and persistence will succeed in negotiating packages above the baseline, while participants lacking confident family members or other advocacy support tend to lose out.

Better guidance on what is reasonable and necessary

One of the key recommendations from the Review of the National Disability Insurance Scheme Act 2013 (Tune, 2019) was that the NDIA should be more explicit in how reasonable and necessary support decisions are made. Tune noted that there was no clear definition of what the principle means and, in combination with complex criteria regarding what is in scope for NDIS funding and the implications of other support the participant received, this created confusion and inconsistency.

An example of this is in relation to what might be reasonable and necessary in relation to community engagement. The provision of specialised supports might not always be the most appropriate means through which to ensure that individuals are socially connected. Where these duplicate existing opportunities, through activities including choirs and art classes, it might be considered more reasonable to provide supports to help an individual engage in these community activities. Where people with an intellectual disability are well supported to engage in these activities, this can be a way to develop deeper social connections, developing the range of potential informal supports and making people feel more included in the places they live. This is also an important factor in safeguarding. Similarly, requiring individuals to engage in activities through a group of people with disability may be seen by some as more reasonable on the basis that it is more efficient than one-to-one support. Yet these types of approaches limit opportunities for social and community interaction and may mean participants with an intellectual disability are offered different opportunities and choices to participants with other disabilities.

Improving NDIS data and IT systems may provide support for better decision-making by the NDIA. Tracking decisions and data about outcomes alongside any issues arising through review mechanisms may help develop a better data set that demonstrates the evidence base for different sorts of supports.

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