



## **REVIEW OF THE NDIS ACT AND THE NEW PARTICIPANT SERVICE GUARANTEE**

**Submission from:**

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## Introduction

Scope (Aust) Ltd (“Scope”) is a leading provider of services to people with disability in Victoria, and one of the largest not-for-profit organisations in Australia. Our origins stretch back to 1948, when a group of parents who wanted better lives and opportunities for their children with disability established the Spastic Children’s Society of Victoria.

Scope’s mission is to enable each person we support to live as an empowered and equal citizen.

Scope provides services including Supported Independent Living (SIL), therapy and Day & Lifestyle Options to over 7,000 people across metropolitan and regional Victoria. We also work with corporate and community organisations to improve inclusiveness for people with disability.

Scope is a strong supporter of the National Disability Insurance Scheme (NDIS). We embrace the benefits the NDIS will bring to our customers and will actively contribute to its success.

## Possible principles for NDIA service standards

Principle	Description
Timely	The NDIS process will be easier to understand and use, enabling decisions about access, planning and review to happen promptly.
Engaged	The NDIA engages with people with disability, their family, carers and other support persons when developing operating procedures and processes.
Expert	NDIA staff have a high level of disability training and understand the impact particular disabilities have on people’s lives. They understand what supports are most effective for a person’s disability.
Connected	The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with disability have coordinated and integrated services.
Valued	Participants, their families, carers and other support persons feel valued in their interaction with the NDIS, and know where to go if they need further assistance.
Decisions are made on merit	The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.
Accessible	All people with disability can understand and use the NDIS, and the NDIS ensures its services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse (CALD) backgrounds, LGBTQIA+ and other individuals.

**Which of the above principles do you think are important for the NDIA to adhere to, and why?**

The timeliness of NDIS processes related to access, planning and review are important for all participants and families. Moreover, there are particular life stages and transition points where timeliness is crucial. Families engaging with the NDIS for the first time because their child has been diagnosed with a disability or developmental delay are often experiencing grief, and anything that alleviates their distress, including timely interactions with the NDIS, would be appreciated. Similarly, for Early Years participants, there are compelling reasons to ensure that planners have the expertise needed and to involve appropriately skilled Early Childhood Intervention practitioners in accordance with best practice.

These themes are explored further throughout our responses to other questions below.

The connection of the NDIS with the range of stakeholders listed under the proposed 'Connected' principle is essential, in particular the interface with mainstream health services. There is a significant cohort of participants with physical and multiple disabilities, many of whom have complex health support needs that are continually changing. The extent to which these changes are attributable to a person's disability, or to their medical needs is often unclear, and the specific responsibilities of disability service providers and health providers in these situations remains contentious. The Victorian Healthcare Association has expressed concern 'that the poorly defined interface between the NDIS and health services may result in people losing access to community-based disability services and requiring more costly, acute health services leading to poorer outcomes for people with disability'<sup>1</sup>.

**What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?**

There needs to be a greater emphasis on individual outcome measurement for participants. This may translate into a key principle: 'Outcome focused'. The data collected by the NDIA around commencement of plans is useful, but data related to the completion of plans, and outcomes achieved, would be more meaningful and related to what the NDIS seeks to understand. This needs to be more nuanced than asking participants whether the NDIS 'helped' them.

**What are some of the significant challenges faced by NDIS participants in the access process?**

Participants with complex disability seeking access to the NDIS often face significant challenges that prevent them from even starting to negotiate the access process. Complex disability refers to families that experience an interplay of individual,

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<sup>1</sup> Joint Standing Committee on the National Disability Insurance Scheme: Transitional Arrangements, Victorian Healthcare Association, Submission 11, p.4.

community and societal factors that diminish their quality of life. Such factors include any combination of disability and medical conditions, mental health problems, challenging behaviour, alcohol or drug issues, contact with the criminal justice system, Aboriginal or Torres Strait Islander background, use of augmentative and alternative communication, child protection or homelessness. The continual fluctuation of one or more of these factors may seriously impede the capacity of families to exercise choice and control in decision-making.

Something as simple as having a suitable interpreter available at the outset of a participant's NDIS journey can be a critical element; and that may be prior to any contact with the NDIA. This means that the access process should commence with the agencies that have been involved with the participant and their family up to that time. While the complex needs pathway addresses many concerns with how these hard-to-reach cohorts are engaged, there is still the possibility of participants and families missing out if there is not some continuity in the transition from existing service systems to the NDIS.

The waiting list for some medical specialists is extensive. The existing 28 day timeframe in which to obtain information requested by a planner to support an access decision may be exceeded just waiting for an appointment. There needs to be flexibility in setting timeframes that takes account of these types of delays.

### **What are some of the significant challenges faced by NDIS participants in the planning process?**

In respect of children aged 0-6 there has been significant disruption to the established service model, and this has affected the way that families are engaged in planning. Instead of being referred to interdisciplinary teams, there is now greater reliance on therapy 'treatments' to address deficits identified through the planning process. This has resulted in poorer outcomes for many children, including children who have been excluded from the NDIS owing to eligibility criteria that do not consider babies and toddlers at risk of developmental delay. NDIS planning does not always foster a family-centred, strengths-based approach. The negative connotations of being associated with 'disability' has also deterred some families of children with developmental delay from seeking support.

While implementation of the Early Childhood Early Intervention (ECEI) Pathway has the potential to improve access and planning, this does not address issues associated with the expertise of ECEI Planners. The use of ECEI practice leads should improve local knowledge and capability but this is not a substitute for best practice as outlined above. While there are families receiving plans that are more appropriate to their child's needs, these tend to be families with the resources, networks and knowledge to negotiate the; and families that experience disadvantage or dysfunction are worse off overall.

Participants with complex disability continue to experience the same types of challenges with planning as they do with access.

**Are there stages of the planning process that don't work well? If so, how could they be better?**

NDIS Planners are responsible for developing plans that enable families to seek supports for their child with a disability or developmental delay. But the plans are not always developed with input from someone who has the expertise required. Planning for children aged 0-6 should always be undertaken in collaboration with skilled Early Childhood Intervention (ECI) Practitioners. This may mean that planners need closer working relationships with ECI providers to facilitate evidence-based decision-making. The use of practice leads will improve organisational knowledge, but this will not necessarily translate into better outcomes, which are best achieved through coordinated interdisciplinary practice.

Eligibility assessments are not always being completed by planners with the appropriate skills, resulting in many plans having gaps, and this carries through to the review process. Early childhood is a time when the brain is incredibly plastic, and ECI may reduce the need for reliance on additional supports later in life. It is also a time when pieces of the puzzle that about a child may emerge slowly, and plan reviews are not appropriate. The delays with getting plan reviews scheduled also means that plans expire and services are discontinued until the new plans are in place.

The transition from ECEI to LAC partners is complicated, especially for children with autism. The requirement for families to obtain evidence that demonstrates the eligibility of children to access the Scheme, and then to present further evidence prior to the transition from ECEI, is often a barrier to support continuing when it is most needed. The criticality of uninterrupted support to children at this crucial phase of their development cannot be overstated.

**What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?**

The review process can sometimes extend for considerable periods of time depending on the requirements of the planner or delays with obtaining the evidence required. This may have the unintended effect of shortening the period for which the subsequent plan runs, and another review needs to be scheduled. The eventual length of the review should be considered in either extending the existing plan or approving a new plan. This type of flexibility should be reflected in the NDIS Act.

Taking a more individualised approach to scheduling reviews warrants further exploration. There is merit, for example, in limiting reviews for many participants and perhaps extending plans over two years. There are other participants, however, who may experience continual fluctuation (or gradual deterioration) of their disability. In these cases, there will usually be some urgency to any requests for review, and this should be a factor in determining how quickly reviews take place. It would be useful to adopt a triage system to assess the urgency of review requests.

**What can the NDIA do to make this process easier or more effective?**

For those participants whose disability diagnosis is permanent there should be no requirement to provide evidence that their disability is ongoing. Scope has received numerous anecdotal reports of participants with permanent disability e.g. Down syndrome, being required to provide evidence of their disability at multiple plan reviews. This leads to unnecessary worry and expense for participants and families who need to access this evidence from health professionals. The time and resource impacts on the health professionals who are providing this information also needs to be taken into consideration.

**What changes could be made to the legislation (if any) to better define 'reasonable and necessary' supports?**

The use of the term 'reasonable and necessary' supports is problematic in the context of Early Childhood Intervention (ECI) as this leads to families seeking therapies that are directed at 'treating' an impairment for the purpose of a 'cure', rather than interdisciplinary ECI that focuses on capacity building. The 'reasonable and necessary' supports in this context are about having a team in place that is responsive to the child's emerging functional capacity and developing the family's resilience rather than a prescription for therapy, based on a diagnosis that may remain subject to change. The term 'reasonable and necessary' needs to be broad enough to encompass ECI, which is related both to the child's disability (or developmental delay) and to everyday living.