

National Disability Insurance Scheme Amendment (Getting the NDIS
Back on Track No. 1) Bill 2024

Spinal Cord Injuries Australia
Submission April 2024

10 May 2024

Committee Secretary
Community Affairs Legislation Committee
PO Box 6100
Parliament House
Canberra ACT 2600
Via email to community.affairs.sen@aph.gov.au

Introduction

Spinal Cord Injuries Australia (SCIA) welcomes the opportunity to offer a submission to the Community Affairs Legislation Committee on the proposed National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024.

The submission responds to the content of the proposed legislation, considered against the backdrop of the NDIS Review¹, the Disability Royal Commission² and the Convention on the Rights of Persons with Disabilities (CRPD), specifically article 3 (a) that acknowledges respect for inherent dignity and individual autonomy including the freedom to make one's own choices and independence of persons³.

SCIA acknowledges that, a significant amount of critical detail is yet to be determined in the Act's rules and, the definition of what is and is not included as a NDIS support. SCIA as a member organisation supporting people with complex and lifelong disability strongly state the need for genuine codesign in the development of the rules and guidelines of the Act to ensure that the autonomy and independence of persons with disability is upheld as was intended in the CRPD.

About SCIA

SCIA is a for-purpose organisation working for people living with spinal cord injury (SCI) and other neurological and physical disabilities. SCIA was founded by people with SCI over fifty years ago; people with disability make up over 35% of our staff, 25% have an immediate family member with disability and the majority of our Board live with SCI.

SCIA is national and member-focussed, serving over 3,000 members made up of people living with disability, their family, carers, researchers, and other professionals in the sector. SCIA's Systemic and Representative Advocacy Team work closely with our members to understand their aspirations and concerns and to promote full inclusion for our members living with disability.

This submission was developed collaboratively through member discussions at two Representative Advocacy forums (21st February and 24th April 2024) as well as with SCIA members with personal experience with the NDIS, and SCIA individual advocates who directly work with NDIS applicants and participants in NSW.

¹ Working Together to Deliver the NDIS, Independent Review of the NDIS, Final Report, 2023.

² Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2023.

³ Convention on the Rights of Persons with Disabilities, 13 December 2006

Summary and Recommendations

This submission outlines SCIA's position in relation to the positive developments in the Act that will allow for greater autonomy, possible areas of concern and strong recommendations regarding areas that require more detail and significant codesign with people with disability.

Positive Amendments in the Act

SCIA's supports several components of the Act which we believe offer improved autonomy, independence, and consistency for people with disability, particularly people with permanent and complex disability such as people with spinal cord injury (SCI) and neurological conditions. SCIA particularly supports the following amendments:

Whole-of-Person Flexible Budgets

SCIA welcomes the inclusion of "whole of person" flexible budgets and the separation of Home Modifications and Assistive Technology. This change recognises that a person may have more than one disability, removes the breakdown of life into separate components, and allows greater autonomy for managing budgets.

Longer Participant Plans

Complex disabilities such as SCI and other Neurological Conditions are permanent and can be time consuming to manage. The opportunity for longer participant plans reduces the need to explain supports in circumstances that are unchanged. As such, SCIA welcomes the changes to include 12 month to 5-year plans where reviews are only required when circumstances change.

Payment for Additional Reports Requested by NDIS

People with disability have a greater reliance on government support, 38% of people with disability rely on government payment as their main income⁴, meaning payment for reports can be a disincentive for people with disability accessing the NDIS. This is particularly true of people in rural areas and First Nations People. SCIA's First Nations Advocate recently consulted with First Nations peoples in the three Nations of Gomeri, Wiradjuri and Gadigal and reported that many First Nations people with disability were not even trying to access the NDIS, instead replying on community members for support. Removal of financial barriers will help to improve access to the NDIS.

Amendments in the Act that require more detail and significant codesign.

There are several amendments to the Act that lack sufficient detail and protection for people with disability, particularly people with permanent and complex disability, such as many of those comprised in SCIA's membership.

⁴ Australian Institute of Health and Welfare, People with disability in Australia, Australian Government, 2020, pp. 1-3, 41, 124, 218, <https://www.aihw.gov.au/getmedia/ee5ee3c2-152d-4b5f-9901-71d483b47f03/aihw-dis72.pdf.aspx?inline=true>.

The recommendations below focus on areas where we believe that more protective detail should be incorporated and areas where significant codesign will be required in the development of the rules.

The Definition of a *NDIS Support*

People with permanent and complex disabilities such as SCI and many neurological conditions require a broad range of reasonable and necessary supports to allow them to “live and be included in the community”. SCIA is deeply concerned that the removal of the term *reasonable and necessary* supports from the Act and the replacement with a more prescriptive list of *NDIS Supports* will limit those who rely on broad and difficult-to-define assistive technology for activities of daily living.

It is understood that the change has been developed to promote consistency however many people with permanent and complex disability have spent years learning what specific assistive technology is required for activities of daily living.

It is critical that:

- a. there is sufficient flexibility within the definition of a *NDIS Support* and that the addition of a prescriptive category list does not impede the stated goal of *choice and control* that underpins the NDIS.
- b. people with disability, their family/caregivers and representative organisations are engaged to determine what is and what is not a *NDIS Support*.

Additionally, as an interim measure members and clients within the SCIA community do not feel confident that the supports outlined in APTOS will cover the supports needed *to live and participate in the community*.

Recommendation 1: the categories that make up the *NDIS Supports* must have sufficient flexibility to include the vast array of assistive technologies and supports that *NDIS* participants with complex disability use.

Recommendation 2: extensive consultation with people with complex physical disability, their family/caregivers and representative organisations is required for the development of Category A rules.

Recommendation 3: continue the use of reasonable and necessary supports rather than relying on APTOS until the category A rules are agreed.

Supports outside the System

The proposal for the new Framework Plans and Budget Framework to be developed alongside *supports outside the NDIS* can be effective if the infrastructure for such supports is developed and in place before the changes are made.

As of 2024, many services simply do not exist in parts of Australia. The Disability Advocacy Network Australia recently made a submission into the *NDIS Participant Experience in rural and regional Australia* which found that in many parts of rural, remote and regional Australia there is less choice for service provision and, in some areas, no crucial services at all.⁵ Similarly, SCIA recently surveyed

⁵ Disability Advocacy Network Australia, *NDIS participant experience in rural, regional and remote Australia* submission, 2024

168 members to understand their experience with accessing service providers, 64% stated they had challenges connecting with disability service providers⁶.

SCIA agrees that promoting integrated foundational supports outside of the NDIS is important. However, many people, particularly in rural and regional Australia are likely to be left without access to any support because of this change if foundational supports are not implemented side by side with the new NDIS supports.

Recommendation 4: NDIS, DSS, State Government and people with disability, family members/caregivers and representative organisations must work together to determine funding breakdown of supports before the new reasonable and necessary budgets of the NDIS are rolled out.

Recommendation 5: Strategies to address workforce shortages for mainstream services in all markets, but especially in *thin* markets must be developed.

Requirements and Conditions

SCIA believes that greater clarity is required in section 32H regarding specific conditions to be satisfied prior to supports being acquired or provided.

SCIA can see the positive implications for this amendment, particularly as it may relate to alternative commissioning that allows First Nations peoples to have services from First Nations providers. SCIA employs a First Nations Advocate and understands first-hand the importance of having services delivered by people who understand First Nations Culture.

Despite the possible benefits, we also see potential risks arising for people with permanent, complex and costly disabilities in cases where requirements may be stipulated by people with insufficient expertise to know what specified conditions represent *best practice* for a *class of participants* or an individual participant.

Additionally, SCIA feels that there is potential future scope within this amendment to limit access to services for people with permanent, complex or costly disabilities by placing undesired requirements on participants. To prevent misuse in the future, or even a feeling of vulnerability in the participant community, SCIA recommends amending the language in the Act to restrict the interpretation of this requirement and protect the independence of participants.

Recommendation 6: the Act must include specific detail that protects the right of people to make informed decisions regarding their supports and to provide protections to prevent restrictions on preferred support models.

The Needs Assessment Process

The assumption in the Act is that there are more prescribed categories including NDIS Supports and *Classes of Participants*, that make it simpler to determine the supports required while removing inconsistencies. SCIA supports the intention to remove inconsistencies between people with similar disabilities, however, has significant concerns about the role and training of the people making those decisions. Training is imperative for anyone making decisions relating to people with complex disability and to protect the process of supported decision making.

⁶ SCIA, Service Provider Survey Report, 2024.

There are significant variables and complexities within a single disability category that may lead to vastly different supports being required. For example, one person with quadriplegia may be able to transfer and independently mobilise while someone in a similar *class of participant* may require a two-person supported transfer or breathing/ventilation assistance. SCIA members regularly report that their plans are not accepted due to a lack of knowledge about the complexity of their disability, even regarding basic health needs such as dressings and nursing for pressure care, requiring them to seek review.

The role of the person completing the needs assessment is critical to the provision of suitable supports. SCIA members are concerned that if the person conducting the assessment has insufficient understanding about their required specialist supports, the inconsistencies that the Act is trying to avoid will in fact be exacerbated.

Recommendation 7: provision to be included in the Act about the role of the assessor.

Recommendation 8: a comprehensive codesign process needs to be developed particularly for *classes of participants* who have complex disability to ensure that the person conducting the needs assessment has sufficient training.

Monitoring compliance

Section 30A requests that information about the *functional capacity* of a participant can be requested. This needs to be managed sensitively and, as outlined above, assessors need to be appropriately trained to understand the complexities of cases of or participant's individual disabilities.

In 2021 SCIA provided a submission on general issues around the implementation and performance of the National Disability Insurance Scheme (NDIS)⁷ to recommend that NDIA staff should be “consistently trained on and audited in giving advice on appropriate medical evidence and supporting documentation for access and planning decisions”, this recommendation is particularly relevant for the monitoring and compliance for participants under the new Act.

Recommendation 9: NDIA staff should be consistently trained on and audited to understand the requirements for functional assessments.

Recommendation 10: Administrative requirements should be minimal and should incorporate the concept of supported decision-making to ensure minimal stress placed on participants.

Conclusion

The focus on choice and control has been a defining feature of the NDIS to date. The new Act through its budget flexibility and longer participant plans makes some positive steps in the direction of choice and control. However, SCIA remains concerned about the structure of the legislation that sets rigid parameters around NDIS Supports and builds a system on those supports that could ultimately make access to the NDIS for people with permanent, complex and costly disabilities less person centred.

⁷ SCIA Submission, General issues around the implementation and performance of the National Disability Insurance Scheme (NDIS), 2021

SCIA calls on the government to consider the 10 recommendations outlined above and to continue to use language which places trust on the individual rather than on the system.