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Dear Sir/Madam

**Re: Proposed NDIS legislative improvements and the Participant Service Guarantee**

As the voice of stroke in Australia, Stroke Foundation welcomes the opportunity to provide comment on the proposed NDIS legislative improvements and Participant Service Guarantee.

In Stroke Foundation's response to the 2019 Review of the NDIS Act, we put forward a number of recommendations, which were informed by discussions with survivors of stroke, their carers, and families, and health professionals.

Stroke Foundation was pleased to note that many of these key recommendations were reflected in the recommendations of the Review, which the Government has supported and is now enshrining in the legislation.

Stroke Foundation was also pleased to note that a new, person-centred assessment model to support access and planning will be co-designed with the disability sector, and would welcome the opportunity to contribute to this process.

Outlined below are key concerns that Stroke Foundation has with the proposed changes to the NDIS Act and Rules:

**1. Plan variation without participant consultation.**

We note that in Section 47A of the Amendment Bill, it is proposed that the CEO may, in writing, vary a participant's plan (except the participant's statement of goals and aspirations) on their own initiative, without the need for a formal reassessment of the plan, and without a request or consent from, or consultation with, the participant. We acknowledge that this change will provide the NDIA with the flexibility to make quick changes to plans if needed, to enable participants to access their supports more quickly and easily. Importantly however, there are few limits on the ability of the CEO to vary a participant's plan on their own initiative. This would mean that crucial changes to a plan, such as changes to the amount of funding a participant will receive, or how a participant can use funding within their plan, could be implemented without consulting with them. **As such, Stroke Foundation believes that except in very limited instances, plans should not be varied by the CEO without consultation with, or consent from, the participant.**

## 2. Changes to the 'Becoming a Participant' Rules.

We note that proposed changes to the 'Becoming a Participant' Rules now require that to meet the disability requirements for the purposes of accessing the scheme, an individual's impairment may be considered 'permanent, or likely to be permanent', or to result in 'substantially reduced functional capacity', only if there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment. This definition shows little awareness of the interrelationship between treatments to address impairments and functional capacity.

**We recommend that survivors of stroke who are applying for access to the scheme are assessed against these disability requirements by an assessor with experience working in the neurological disability sector.**

More broadly, this wording is problematic, as it indicates the NDIA is employing a medical model of disability that conceptualises disability as an impairment or deficit which health professionals are then tasked with curing. This medical model is antithetical to Stroke Foundation's strong belief that survivors of stroke must be empowered through tailored supports to grow and thrive, contribute to the community, and maximise their life after stroke. **What is needed is an empowering model of disability, where participants, together with their families and carers, determine which services they need in order to achieve their goals, and where health professionals as service providers offer guidance and help to facilitate this.**

## 3. Providing participants with reasons for decisions.

In our discussions with survivors of stroke, including those who have been unsuccessful in accessing the NDIS, and participants who have been unsuccessful in securing some or many of their requested supports, the need for greater transparency from the NDIA regarding how they make decisions has been a consistent theme. As such, we are pleased to note that in Sections 100(1B) and 100(1C) of the Amendment Bill, it is proposed that an individual who receives a reviewable decision may request, and then must be given, the reasons for that decision. However, rather than having to request this information, **Stroke Foundation believes all applicants and participants should automatically receive the reasons for decisions made about them.** This is consistent with the findings of the 2019 Review of the NDIS Act, which stated 'Providing people with disability with an explanation of a decision should be a routine operational process for the NDIA when making access, planning and plan review decisions.' **Further to this, it is critical that this requirement applies to all decisions made by an NDIA reviewer, including decisions made following a review of a reviewable decision, something which is not currently reflected in the Amendment Bill.**

Stroke Foundation appreciates the NDIS is one of the most significant social policy reforms in Australian history, and is empowering hundreds of thousands of Australians with disabilities, their carers and families, to participate more fully in society and the economy. This includes thousands of Australian survivors of stroke.

This year there will be more than 27,000 first-ever strokes in Australia<sup>1</sup>, and there are more than 445,000 survivors of stroke living in our community.<sup>1</sup> Unless action is taken, it is estimated that by 2050 the number of first-ever strokes experienced by Australians will grow to more than 50,000 strokes annually<sup>1</sup>, and there will be almost 820,000 survivors of stroke living in the community.<sup>1</sup> Importantly, approximately 24 percent of all strokes this year will occur in people 54 years of age or younger.<sup>1</sup> If trends continue this is set to increase.<sup>1</sup>

In Australia, the economic cost of stroke exceeded \$6.2 billion in 2020, with a further \$26.0 billion in lost wellbeing - due to short and long-term disability, and premature death.<sup>2</sup>

Stroke is one of the leading causes of disability in Australia, and in 2020, a third of stroke events resulted in a disability which impeded the survivor of stroke's ability to carry out activities of daily living unassisted.<sup>2</sup>

Despite stroke being one of the largest causes of disability in Australia, only 1.5 percent (6,955) of active NDIS participants with an approved plan have stroke as their primary disability.<sup>3</sup> It is likely there is a proportion of survivors who have been included under other primary disability categories, including 'Acquired Brain Injury', 'Hearing Impairment', or 'Visual Impairment'.

**It is critical survivors of stroke who are participants in the scheme are correctly classified, to ensure we get a true picture of this cohort, and are better able to understand their needs, as well as what the barriers to access may be.**

Importantly, there has also been anecdotal evidence to suggest there is a proportion of survivors with significant disability who have applied for the scheme and have been unable to gain access. As such, Stroke Foundation has concerns about the ability of the current assessment process to appropriately assess survivors of stroke who apply for access to the NDIS.

**There is a need for appropriately trained assessors who understand the multiplicity of challenges that an individual who has had a stroke may have to address in order to function well.** Many survivors of stroke have significant disability and complex needs. Issues such as neurological-based fatigue, and hidden cognitive and behavioural problems, are often missed, while those with communication difficulties (both understanding and speaking) may have trouble communicating needs. Currently, there is a belief among the survivor community that NDIA assessors do not have an adequate understanding of stroke, stroke-related disability, and the impact this disability has on survivors, their carers and family members. Survivors of stroke have indicated that one of the biggest challenges they face is getting NDIA staff to understand need.

Given the large number of new and recurring strokes annually, **we believe the NDIA should invest in developing a team of assessors that specialises in managing applications from survivors of stroke, and those who have other forms of acquired brain injury. This was one of Stroke Foundation's key recommendations in our response to the 2019 Review of the NDIS Act.** Stroke Foundation has previously worked with the NDIA to develop resources for the stroke community on navigating the NDIS, getting back to work, and grief and loss after stroke. There is an opportunity for the NDIA to build on this successful project, by partnering with Stroke Foundation to develop training resources for assessors, and help them better understand what life looks like after a stroke.


Similarly, feedback from survivors, their carers and family members, suggests that many NDIS providers, including trained health and allied health professionals, may not fully appreciate the impact stroke-related disability can have on a participant's functional capacity, if they do not have sufficient background knowledge of, and experience with, stroke. This in turn impacts their ability to determine which services or treatments participants require in order to maximise their functional gains and achieve their desired goals.

**Stroke Foundation maintains that working with participants who have suffered a serious neurological insult, such as stroke, and understanding the impact from an impairment and activity perspective, requires specialist training. As such, Stroke Foundation does not believe that all current NDIS providers have the capacity to work**

**with survivors of stroke.** To address this, Stroke Foundation could work with the NDIA to develop an accreditation process for providers delivering services to survivors of stroke. Similar work has been undertaken previously, when Occupational Therapy Australia worked with the NDIA to develop an accreditation scheme for NDIS providers delivering major home modifications.

Thank you for the opportunity to provide comment on the proposed NDIS legislative improvements and the Participant Service Guarantee.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Sharon McGowan', with a long, flowing tail.

Sharon McGowan  
**Chief Executive Officer**  
Stroke Foundation

## **About Stroke Foundation**

Stroke Foundation is a national charity that partners with the community to prevent stroke, save lives and enhance recovery. We do this through raising awareness, facilitating research and supporting survivors of stroke.

## References

1. Deloitte Access Economics. 2020. No postcode untouched, Stroke in Australia 2020.
2. Deloitte Access Economics. 2020. The economic impact of stroke in Australia, 2020.
3. National Disability Insurance Scheme. 2021. National Public Dashboard. 4 October 2021. Available at: <https://data.ndis.gov.au/explore-data>