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Dear Sir/Madam

**Re: NATIONAL DISABILITY INSURANCE SCHEME (NDIS) CONSULTATION PAPER:
ACCESS AND ELIGIBILITY POLICY WITH INDEPENDENT ASSESSMENTS**

As the voice of stroke in Australia, Stroke Foundation welcomes the opportunity to provide comment on the new NDIS Access and Eligibility Policy.

Currently, despite stroke being one of the largest causes of disability in Australia, only 1.4 percent (5,935) of active NDIS participants with an approved plan have stroke as their primary disability.¹ 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.

While Stroke Foundation appreciates the need to ensure the NDIS remains sustainable, we do have concerns about the ability of independent assessments to accurately evaluate the functional capacity of all survivors of stroke who apply for access to the NDIS.

Stroke Foundation's views on the ability of the new NDIS Access and Eligibility Policy to address challenges associated with the current access process, as well as its concerns about this new policy, are outlined below.

1. Concerns about the proposed independent assessment process.

Currently, the burden of enrolling survivors of stroke in the NDIS is largely being borne by outpatient rehabilitation services. Survivors, particularly those with communication, concentration or fatigue issues, who do not have this support, are looking for information on where to go for assistance with completing access forms. Further to this, many survivors, particularly those who suffered their strokes many years prior and do not have a current treating team, are having to find and pay for specialists or therapists to assess them and complete medical reports that explain the impact of their disability. For example, for survivors of stroke with hidden cognitive disabilities, what humanises these disabilities is a neuropsychological assessment,

which is the gold standard evidence of permanent and significant cognitive disability. These reports are comprehensive and can cost more than \$2,000. As detailed in the Consultation Paper, Australians are currently spending between \$130 million and \$170 million per annum on assessments associated with accessing the NDIS.

While the introduction of free independent assessments will help address these inequalities in the current access process, applicants will still be required to provide evidence, in the form of advice from their treating health professional, that their disability or disabilities are, or are likely to be permanent, in order to be eligible for an independent assessment.

Another key challenge of the current access process is the lack of consistency with regard to access decisions, with some survivors of stroke with relatively mild impairments deemed eligible, while some of those with significant disabilities continue to miss out. The wide variability in assessment tools used to capture information on the impact of an applicant's disabilities has been identified as one of the main reasons for the lack of consistency in decision making. As such, the use of recognised and standardised assessment tools in independent assessments will help address inconsistencies in the current access process.

While Stroke Foundation strongly supports the NDIA's efforts to reduce inequality and inconsistency in the current access process, we do have concerns about the ability of independent assessments to accurately evaluate the functional capacity of all survivors of stroke who apply for access to the NDIS:

- a) There is a need for appropriately trained independent 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. 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.

Stroke Foundation understands that as part of the new NDIS Access and Eligibility Policy, independent assessments will be conducted by trained experts, including occupational therapists, physiotherapists, psychologists, and other health and allied health professionals. **However, we are concerned that even trained experts may not fully appreciate the impact stroke-related disability can have on an applicant's functional capacity, if they do not have sufficient background knowledge of, and experience with, stroke.**

To address this, the NDIA could develop a team of independent assessors that specialises in managing applications from survivors of stroke, and those who have other forms of acquired brain injury. Stroke Foundation has previously worked with the NDIA to develop resources on navigating the NDIS, getting back to work, and on 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 independent assessors, and help them better understand what life looks like after a stroke.

- b) The independent assessment process will require a flexible approach, and the use of evidence-based, clinically relevant, validated stroke assessment tools.**

Based on information provided in the Consultation Paper, it is estimated independent assessments will take around 3 hours on average, but could take place over a number of days if that is the preference of the applicant. **Stroke Foundation is concerned about the ability of an independent assessor, with no firsthand knowledge of the applicant's medical history and disabilities, to make a thorough assessment of the impact their impairment is having on their functional capacity, in what is a limited time period.** While the assessment tools used will take into account different settings and times, and are designed to find out what 'good days' and 'bad days' look like, for survivors of stroke with complex hidden cognitive disabilities for example, these tools may not adequately capture the impact of these disabilities on their functional capacity.

- c) Given the issues raised above regarding the possible limitations of independent assessments, there is a risk that survivors of stroke who are existing NDIS participants may have their eligibility for the scheme revoked, or their plan size reduced, incorrectly.**

The Consultation Paper explains that existing NDIS participants will need to complete an independent assessment at least every five years, to make sure they continue to remain eligible for the scheme, and receive the correct funding in their plan. Importantly however, for a significant proportion of survivors of stroke who are existing NDIS participants, for whom the permanency of their disabilities has been established, there are unlikely to be substantial improvements in their functional capacity and thus reductions in the supports required in their plans.

2. The proposed independent assessment process and timeliness of the application process.

Previous feedback from survivors of stroke has been that the application process is stressful and lengthy, with applicants waiting between six and 10 months for a decision from the NDIA, highlighting the need for a more timely process that keeps applicants informed of the progress of their application. As such, we are pleased to note the NDIA is now measuring itself (where possible) against the proposed Participant Service Guarantee timeframes for key NDIS processes, including decisions about access, ahead of the anticipated legislative change. Further to this, we are pleased to note as part of the new NDIS Access and Eligibility Policy, assessor organisations will be required to contact applicants within two days of accepting a referral, schedule the independent assessment within 10 days, and complete the assessment within 90 days, in line with the timeframes included in the Participant Service Guarantee.

3. The proposed independent assessment process and transparency in the determination of eligibility for the scheme.

Survivors of stroke who have had their NDIS applications rejected have reported they were 'deemed ineligible because they did not meet the requirements'; however, no further explanation was provided. It is important that the NDIA is able to be more transparent and provide clear explanations regarding how they have come to a decision on eligibility. As such, we are pleased to note that as part of the new NDIS Access and Eligibility Policy, regardless of the access request outcome, all applicants will be provided with a summary of their independent assessment results and guidance to help them understand the results, as well as an explanation of the access decision.

For those whose applications are unsuccessful, or who are unhappy with their independent assessment, it is important there is consistent, clear and publicly available information on the grounds and process for appeal, as well as the complaints process.

Independent assessment results will not be directly reviewable by the Administrative Appeals Tribunal, and applicants will only be able to seek a second assessment if their functional capacity changes significantly or if their assessment is not consistent with the Independent Assessment Framework. As such, it is important all applicants are provided with a clear explanation of this Framework.

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 Australia², and there are more than 445,000 survivors of stroke living in our community.² 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 annually², and there will be almost 820,000 survivors of stroke living in the community.² Importantly, approximately 24 percent of all strokes this year will occur in people 54 years of age or younger.² If trends continue this is set to increase.²

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.³

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.³ Findings from a survey of Australian survivors of stroke and their carers highlighted many survivors had ongoing health issues several years after stroke.⁴ The most common health problems experienced by survivors included fatigue (78 percent), and mobility (76 percent), emotional (68 percent), memory (68 percent) and concentration (67 percent) problems.⁴ Many survivors of stroke also experience communication impairments, and face additional barriers to accessing the scheme because of these impairments.

Of the survivors who were working prior to their stroke, almost three quarters (71 percent) reported a change in their work activities since their stroke and 57 percent reported that the

change was moderate to extreme.⁴ Specifically, survivors lose an average of 3.8 full time weeks of work each year due to stroke.³ More than one third (36 percent) of respondents reported a loss in income since having their stroke and almost half (48 percent) were receiving some form of benefit.⁴ The majority (57 percent) of survivors who had a partner or spouse reported that their stroke had a negative impact on their relationship and 34 percent reported that this change was moderate to extreme.⁴

The survey results also provided evidence there was a significant impact experienced by carers of people with stroke, including reductions in the amount of work they were able to perform, and the number or type of leisure activities in which they were able to participate, as well as changes in their relationships.⁴ In Australia, informal carers provided 39.7 million hours of care to survivors of stroke in 2020.³

In summary, disability – which affects the majority of people who survive a stroke – has a significant effect on the physical, mental and emotional well-being of survivors. In addition, many survivors and their carers experience negative consequences in a number of areas including work, finances and relationships. The impact of stroke-induced disability is also felt by the wider community, as a significant proportion of survivors and the family or friends who care for them, are forced to leave paid work, with some having to rely on welfare payments.

Thank you for the opportunity to provide comment on the new NDIS Access and Eligibility Policy with independent assessments.

Yours sincerely

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

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 stroke survivors.

References

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2. Deloitte Access Economics. 2020. No postcode untouched, Stroke in Australia 2020.
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4. Monash University Stroke and Ageing Research Centre (STARC). 2013. Australian Stroke Survivor and Carer Needs Assessment Survey.