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Dear Sir/Madam

**Re: Independent Review of the National Disability Insurance Scheme (NDIS)**

*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. Stroke Foundation is dedicated to empowering health professionals to deliver high quality best-practice care to stroke patients. We advocate for better systems, processes, and resources to help health professionals deliver world class stroke care.*

In 2020, 27,428 Australians experienced stroke for the first time, and there were more than 445,000 survivors of stroke living in our community.<sup>1</sup> Unless action is taken, it is estimated by 2050, Australians will experience an additional 23,000 new strokes annually, and there will be an additional 374,000 survivors of stroke living in the community.<sup>1</sup>

Importantly, approximately 24 percent of all strokes in 2020 occurred in people 54 years of age or younger.<sup>1</sup> If trends continue this is set to increase.<sup>1</sup> Increasing rates of stroke in people under the age of 65 have also been observed internationally.<sup>2</sup> The increasing rates of stroke in younger people worldwide are thought to be due, at least in part, to an increase in the rate of modifiable stroke risk factors such as hypertension, diabetes, and obesity.

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>3</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>3</sup>

Well beyond their discharge from hospital, many survivors of stroke have yet to make a full recovery and continue to experience a wide range of health problems. Issues with strength, sensation, range of movement and coordination are common post-stroke, and can result in loss of body control and movement, impacting an individual's ability to walk, use their hands and arms in daily tasks such as showering, as well as their speech or swallowing. Changes in communication can also occur after a stroke, with many survivors struggling to express themselves or to understand others. Other common post-stroke disabilities include 'hidden' problems, such as fatigue and changes in cognition. Some survivors have difficulties with memory, learning, or focusing on, planning or sequencing tasks, which can impact their ability to complete daily tasks such as getting dressed, or more complex activities such as driving.

Findings from a survey of Australian survivors of stroke and their carers reported that the most common health problems experienced by survivors several years after their stroke included fatigue (78 percent), and mobility (76 percent), emotional (68 percent), memory (68 percent) and concentration (67 percent) problems.<sup>4</sup>

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.<sup>4</sup> Specifically, survivors lose an average of 3.8 full time weeks of work each year due to stroke.<sup>3</sup> 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.<sup>4</sup> 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.<sup>4</sup>

The survey results also provided evidence there was a significant impact experienced by carers of people with stroke.<sup>4</sup> Carers may accompany survivors to medical appointments, and care for them at home, playing a critical role in a survivor's recovery. In Australia, informal carers provided 39.7 million hours of care to survivors of stroke in 2020<sup>3</sup>; however, this support can come at a significant personal cost.

Of those caregivers who were working prior to taking on a carer role, 40 percent reported a moderate to extreme reduction in the amount of work they were able to perform.<sup>4</sup> Almost half (47 percent) of the carers who participated in leisure activities prior to taking on a carer role reported a moderate to severe reduction in the number or type of leisure activities in which they were able to participate. Almost a third (31 percent) of carers who were the partner or spouse of a person with stroke reported moderate to extreme changes in their relationship.<sup>4</sup> A significant proportion of carers reported moderate to extreme changes in their relationships with other family members (20 percent), and with other people outside the family such as friends (32 percent).<sup>4</sup> As a consequence of these pressures, carers of survivors of stroke commonly experience a decline in their own physical and mental health and a reduced quality of life.<sup>5-7</sup>

As the voice of stroke in Australia, Stroke Foundation welcomes the opportunity to provide input into the Independent Review of the NDIS.

Please see below the key areas of concern for Australian survivors of stroke, their families and carers, and the health professionals who treat and care for them.

### **Many survivors of stroke face challenges accessing the NDIS**

Despite stroke being one of the largest causes of disability in Australia, only one percent (8,819) of active NDIS participants with an approved plan have stroke as their primary disability.<sup>8</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 been unable to gain access, due to several factors.

### *Completing NDIS access request forms*

Currently, the burden of enrolling survivors of stroke in the NDIS is largely being borne by outpatient rehabilitation services and hospital social work departments. 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 request forms.

Many survivors of stroke, particularly those who suffered their strokes several 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. If an individual does qualify for the NDIS, they may ask for funding to have a neuropsychological assessment done, so that their support workers and the people around them can better understand what their needs are.

Notably, we know that Australians are currently spending between \$130 million and \$170 million per annum on assessments associated with accessing the NDIS.<sup>9</sup>

Many survivors of stroke do not realise the importance of evidence (medical reports) until their application is rejected. Survivors have spoken about needing to educate health professionals on how to write for these applications, including the importance of using plain English, even in medical reports. Importantly, not all health professionals working with survivors of stroke, who are used to the traditional medical model of disability, are familiar with the social model of disability that has been adopted by the NDIS.

Stroke Foundation is currently developing educational resources and tools to assist health professionals who complete NDIS access request forms for survivors of stroke. These resources will guide health professionals on how to write in a style, and using language, that is in line with the social model of disability, and which effectively communicates the impact specific impairments have on a survivor's ability to live well and achieve their goals.

There are a number of ways that the National Disability Insurance Agency (NDIA) and Federal Government can help address current inequalities in the NDIS application process.

### **Recommendations**

1. NDIA to provide increased support for survivors of stroke, in particular those with hidden communication and cognitive issues, during the application process, including:
  - a. greater emphasis on the importance of evidence (medical reports) demonstrating the impact specific impairments have on a survivor's ability to live well and achieve their goals, as well as more information on who to approach for these reports
  - b. for those survivors that do not have a current treating team, information on how to find specialists or therapists that will complete medical reports for the NDIS at a price that is affordable.
2. Federal Government to make funding available within the disability system to facilitate assessments for patients with hidden cognitive disabilities.
3. NDIA to partner with Stroke Foundation to co-develop exemplar completed access request forms as a guide for survivors of stroke and health professionals.

### *NDIS assessors who do not have an adequate understanding of stroke and stroke-related disability*

A key issue of concern with the current application 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.

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 their needs. Even trained experts, including health professionals, 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.

*"I was working as an occupational therapist when I had a stroke at the age of 24. I have quite a few physical deficits and require support with daily activities, such as cooking, cleaning, and shopping. I am also legally blind.*

*When I initially applied for the NDIS, I got a rejection letter simply saying I did not meet the criteria, which was very upsetting.*

*I applied again and went through a very lengthy process, working closely with all of my healthcare providers to work out ways to frame letters regarding my conditions. After multiple letters from my healthcare providers detailing my deficits and the things I need help with, I was again knocked back. Both of the times I was rejected I was not invited to an in-person meeting or spoken to over the phone, everything was done in writing.*

*It was only after my Ophthalmologist wrote to the NDIA saying I was legally blind, that I was accepted as a participant in the scheme.*

*I found the whole process extremely gruelling, disempowering and disheartening. The journey from application to finally being accepted took almost a year."*

***Survivor of stroke, Victoria***

### **Recommendation**

4. The NDIA to invest in the development of a national team of appropriately trained assessors that specialises in managing applications from survivors of stroke, and those who have other forms of acquired brain injury. These assessors will have background knowledge of, and experience with, stroke, including experience working in the neurological disability sector, and will understand the multiplicity of challenges that an individual who has had a stroke may have to address in order to function well.

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 co-develop training resources for assessors, and help them better understand what life looks like after a stroke.

### **Many survivors of stroke who are participants in the NDIS face challenges accessing the services and supports they need**

There is a concern among participants who are survivors of stroke about the level of understanding Local Area Coordinators (LACs) and NDIS planners have about stroke, stroke-related disability, and the impact this disability has on survivors. As a consequence, LACs and planners may find it challenging to build effective plans for participants, and understand which supports, providers, and assistive technologies they are likely to need.

Feedback from survivors, their carers and family members, suggests that many NDIS providers, including trained 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.

Participants who are survivors of stroke have stated one of the biggest challenges with utilising the supports in their plans is finding providers with a demonstrated ability to deliver services for stroke patients in their local area.

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.

### ***Recommendations***

5. NDIA to invest in the development of a national team that specialises in managing participants who are survivors of stroke, or who have other forms of acquired brain injury.
6. NDIA to partner with Stroke Foundation to co-develop education and training resources for LACs to help them better understand the needs of survivors of stroke.
7. NDIA to partner with Stroke Foundation to co-develop an accreditation process for providers delivering services to participants who are 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.

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 of stroke 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.

The NDIS is one of the most significant social policy reforms in Australian history and is facilitating 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.

As the voice of stroke in Australia, Stroke Foundation strongly supports the goals of the NDIS, and believes that the scheme should empower survivors of stroke 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. We have highlighted a number of ways the NDIA and Federal Government can help address current challenges that are impacting the ability of survivors of stroke to access, and fully participate in, the scheme.

Thank you for the opportunity to provide input into the Independent Review of the NDIS.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'Lisa Murphy', with a horizontal line underneath.

Dr Lisa Murphy  
CEO  
Stroke Foundation

## References

1. Deloitte Access Economics. 2020. No postcode untouched, Stroke in Australia 2020.
2. Feigin VL, Forouzanfar MH, Krishnamurthi R et al; Global Burden of Diseases, Injuries, and Risk Factors Study 2010 (GBD 2010) and the GBD Stroke Experts Group. Global and regional burden of stroke during 1990-2010: findings from the Global Burden of Disease Study 2010. 2014. *Lancet*. 383:245-254.
3. Deloitte Access Economics. 2020. The economic impact of stroke in Australia, 2020.
4. Monash University Stroke and Ageing Research Centre (STARC). 2013. Australian Stroke Survivor and Carer Needs Assessment Survey.
5. Han B, Haley WE. Family caregiving for patients with stroke. *Stroke*. 1999. 30:1478–1485.
6. Salter K, Zettler L, Foley N et al. Impact of caring for individuals with stroke on perceived physical health of informal caregivers. *Disabil Rehabil*. 2010. 32:273–281.
7. Rigby H, Gubitz G, Phillips S. A systematic review of caregiver burden following stroke. *Int J Stroke* 2009. 4:285–292.
8. National Disability Insurance Scheme. 2023. Participant Dashboard - Stroke. 31 March 2023. Available at: <https://data.ndis.gov.au/reports-and-analyses/participant-dashboards/stroke>
9. National Disability Insurance Scheme. 2020. Consultation paper: Access and Eligibility Policy with independent assessments.