

Response to the Australian Government consultation on 'Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape'

Introduction

This year there will be more than 56,000 strokes in Australia¹, and there are more than 475,000 stroke survivors living in our community.¹ Unless action is taken, it is estimated that by 2050 the number of strokes experienced by Australians will more than double to almost 133,000 strokes annually¹, and there will be 1 million stroke survivors living in the community.¹

There are approximately 142,000 (30 percent of 475,000)¹ survivors of stroke in Australia who are adults under the age of 65. While there is a lack of solid local trend evidence in Australia, increasing rates of stroke in this age group have been observed internationally.² 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.

Stroke is a leading cause of disability in Australia.³ Findings from a survey of Australian stroke survivors and their carers highlighted many stroke survivors had ongoing health issues several years after stroke.⁴ The most common health problems experienced by stroke survivors included fatigue (78 percent), and mobility (76 percent), emotional (68 percent), memory (68 percent) and concentration (67 percent) problems.⁴

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 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. 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. 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.⁴ 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.⁴ 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).⁴

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.

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 stroke survivors.

"I've had a very good experience with the NDIS.

I had a great planner, which certainly helped, but I had also done lots of homework beforehand. I worked out exactly what I wanted and what I needed to achieve with regard to goals for the following year with help from my therapists. I found out prices and collected quotes from my neurophysiotherapist and occupational therapist. I got them to write out a plan for the year, listing my goals and what I was hoping to achieve. I also invited them to attend my planning meeting to show my NDIS planner I had a great team behind me and I was very motivated to do well.

The NDIS to me has been the best thing in assisting me to get on with my life post-stroke and with recovery and acceptance."

Stroke survivor, South Australia

Currently, one percent (3,870) of active NDIS participants with an approved plan have stroke as their primary disability.⁵ It is likely there is a proportion of stroke survivors who have been included under other primary disability categories, including 'Acquired Brain Injury', 'Hearing Impairment', or 'Visual Impairment'.

It is important stroke survivors 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.

There has also been anecdotal evidence to suggest that there is a proportion of stroke survivors with significant disability who have applied for the scheme and have been unable to gain access.

As the voice of stroke in Australia, Stroke Foundation strongly supports the Australian Government's review of the NDIS Act and Rules, and their commitment to the introduction of a new NDIS Participant Service Guarantee. Stroke Foundation believes all seven of the possible principles for NDIA service standards listed in the Discussion Paper are important for the NDIA to adhere to. **During our discussions with stroke survivors, their carers, and families, it was evident the NDIA is falling short in at least three of these principles, namely, 'Timely', 'Expert', and 'Decisions are made on merit'.**

RECOMMENDATIONS

Getting started: Eligibility and application

1. **The NDIA to partner with Stroke Foundation to develop training resources for Local Area Coordinators (LACs), planners and assessors, to help them better understand what life looks like after a stroke**

The NDIA to develop a national team that specialises in managing applications from stroke survivors, and those who have other forms of acquired brain injury

Many stroke survivors have significant disability and complex needs. 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.

Recently, Stroke Foundation has 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 to build on this successful project.

2. **Increased support for participants with communication and cognitive issues during the application process**

The cost of enrolling stroke survivors with disabilities in the NDIS is largely being borne by hospital social work departments. Stroke 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.

3. **Greater emphasis on the importance of evidence demonstrating the level of disability**

Many applicants do not realise the importance of evidence (medical reports) until their application is rejected. More information is needed on whom to approach for medical reports, and for those stroke survivors that do not have a current treating team, how to find specialists or therapists that will complete medical reports for the NDIA at a price that is affordable.

“My first NDIS application was submitted in April last year, and was put in by the social worker at the hospital I was in at the time. The application was rejected, with no reason given as to why. I then put in another application, and they responded saying they wanted me to have an assessment done by an occupational therapist, with no information on how or where to find one that bulk-bills. As I didn’t know how to go about getting this assessment, I basically didn’t worry about it for a few months. But then I thought I would try again, so I put in another application at the beginning of October this year, with the help of a doctor I am currently seeing, and I am waiting to hear back, but am not holding my breath.”

Stroke survivor, South Australia

4. Funding made available within the disability system to facilitate assessments for patients with hidden cognitive disabilities

What humanises a hidden cognitive disability 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.

5. NDIA to develop exemplar reports as a guide for stroke survivors and providers

Stroke survivors have stressed the importance of writing the application in a deficit-focused way, and using plain English, even in medical reports. Survivors have talked about needing to educate providers on how to write for these applications, and speak to their function on their worst day.

6. Greater consistency in the decision-making process

An issue of concern is the lack of consistency with regard to access decisions, with some individuals with relatively mild impairments deemed eligible, while some of those with significant disabilities continue to miss out. Due to the lack of transparency in the decision-making process, applicants are reliant on the goodwill of those at the NDIA to better understand why their application may have been rejected.

“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.”

Stroke survivor, Victoria

7. A more timely application process that keeps participants informed of the progress of their application

The application process is stressful and lengthy, with participants waiting between six and 10 months for a decision from the NDIA. Some have indicated that the drawn out process would be made less stressful if they were kept informed of their application's progress.

8. Greater transparency in the decision-making process

Applicants who have had their application rejected have reported they were 'deemed ineligible because they did not meet the requirements' and 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.

If an application requires further supporting evidence (medical reports), the applicant should be notified and given the opportunity to provide this evidence, rather than have their application rejected.

Planning processes 1: Creating your plan

1. The NDIA to partner with Stroke Foundation to develop training resources for LACs and planners to help them better understand the needs of stroke survivors

The NDIA to develop a national team that specialises in managing participants who are stroke survivors, or who have other forms of acquired brain injury

Participants have indicated that one of the biggest challenges they face is getting NDIA staff to understand need. There was a concern among participants about the level of understanding 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.

“As part of my first plan, I wanted some funding for an occupational therapy assessment for home modifications that I needed to make my life easier. For example, doors with handles don’t work for me, and cupboards above my head don’t work for me. I have a foot drop, so modifications to doors to eliminate trip hazards are important. Instead, the planner I was working with suggested that to deal with my vision impairment, I could put high visibility tape around my home (because that is what she did for her elderly father). To me, living an ordinary life does not involve putting high visibility tape all throughout my house. Instead, I had an engineering solution, a one-off cost. Eventually it just became too hard. The home modification stuff was way too hard for them, so I paid for that myself.”

Stroke survivor, New South Wales

2. The need for a consistent, central point of contact at the NDIA for participants

A number of participants have raised the high rate of turnover of LACs as an issue, stating that it is important that participants have a consistent, central point of contact when developing their plans. Some participants stated that in the future they would prefer to deal with a planner rather than a LAC, viewing LACs as working at an arm’s length from the NDIA.

3. Greater transparency in the decision-making process

Many participants report that after developing a plan with a LAC or planner that they are satisfied with, and which reflects the recommendations of their providers, they receive their final approved plans from the NDIA and are very disappointed, having lost a significant proportion of their requested supports. For example, one participant was told she needed 30 hours of physiotherapy a year, which was cut back to once a month. There is often little to no explanation as to why the requested supports have not been approved. It is important that the NDIA is able to be more transparent and provide clear explanations regarding how they have come to these decisions.

4. Introduction of a 'draft plan'

This would provide an opportunity for feedback from the NDIA to be reviewed by the participant prior to finalisation of the plan. It would allow issues raised to be addressed and alterations to be made where needed. If there is further evidence that is needed to support a plan, this would be relayed to the participant, so they could contact the relevant provider and source the necessary report.

5. Increased accountability on the NDIA 1800 number

Many participants have reported calling the NDIA 1800 number on multiple occasions, asking for someone from the NDIA to get in contact with them, and never hearing back. This lack of communication and accountability is the source of much stress and frustration for participants.

Planning processes 2: Using and reviewing plans

1. NDIA to produce a list of credentialed suppliers who have demonstrated the ability to deliver neurological services for stroke patients

Participants have stated one of the biggest challenges with utilising the supports in their plan, depending on where they are located, is finding a service provider in their local area. Some participants have to travel to access the necessary services, or their therapists need to travel to them and they have to get paid for the travel time too, which comes out of the plan and quickly eats into their budget. Participants have suggested it would be useful to have a guide and checklist to understand how to make the right choice with regard to providers.

2. Greater consistency and continuity with regard to communication with guardians and nominees

Guardians and nominees, who are responsible for managing the plans of participants, have indicated that there is a lack of communication from the NDIA, and they struggle with having to deal with a new person every time they interact with the agency.

3. More information on what to expect once a plan has been created

Many participants have suggested that it would be very useful to have a description of what to expect once a plan has been created, from the perspective of a participant, carer, family member and provider.

4. Greater support coordination and assistance with finding local providers

For stroke survivors, many of whom have complex needs, it is expected that they will require at least some support coordination when they first join the scheme, and perhaps for the first few years. Some stroke survivors may have their first planning meeting while they're still in hospital, and when they transition back home, or to an aged care facility, they will be totally focused on rehabilitation. This is when they would benefit from support coordination, and assistance with finding providers in their local area.

5. More information on the role of the LAC

There are many participants that do not fully understand the role of a LAC, and how much support they are able to provide. There is an opportunity here for the NDIA to educate participants on the role of the LAC and how they may be able to benefit from their assistance.

6. Increased accessibility of information and resources to support the use of plans

While there is excellent information and resources on the NDIA website, and the agency has done well by offering alternative forms of communication and producing information in plain English, there are some stroke survivors with aphasia or cognitive fatigue, who will still struggle to access this information.

What many stroke survivors are seeking is not necessarily more information, but advice, and what the information provided by the NDIA means in the context of their own individual situation or circumstances. This is where the LACs have a role to play.

7. Consistency of language and terminology

One area that is a source of frustration for participants is the difference in terminology/language used in participant plans versus the NDIS participant portal. This can be confusing for participants when they go into the portal to pay a bill for example. While there is a resource on the NDIS website that explains the difference between NDIS language and portal language, it would be ideal if there was consistency between the two.

For those participants who self-manage their plan, navigating the portal can be challenging without assistance from a support coordinator or LAC.

8. Greater transparency around NDIA review and update of plans

Participants have expressed frustration regarding unexpected changes to their plans from year to year. One participant explained that all of her providers had written in their reports about what she needed, and the fact that she had showed gains in response to the therapy received; however, despite this 70 percent of her supports were cut in her second plan with no rationale given for the change. Similarly, another participant, after having access to a transport budget in his first plan due to a vision impairment preventing him from driving, was not given a transport budget in his second plan, with no reason provided as to why.

Appealing a decision by the NDIA

1. Consistent, clear and publicly available information on the grounds and process for appeal

There is debate amongst the participant community about whether it is quicker to appeal a decision by the NDIA or simply re-apply. It is important that participants are given advice on what the right course of action is for their particular circumstances.

There is also a lack of clarity regarding how to appeal a decision, and a misperception that you can only appeal once.

2. Introduction of a second step in the internal appeal process

Some participants have suggested that it would be useful to introduce a second step in the internal appeal process following the 'review of a reviewable decision' and before the appeal can be taken to the Administrative Appeals Tribunal (AAT). It is important participants are made aware that because of the large case load, obtaining a decision from the AAT can take three months or more, and that they are likely to need the support of an advocate to help them navigate this process.

Plan amendments

1. Introduction of a 'draft amendment plan'

Participants have suggested that the introduction of a 'draft amendment plan', where feedback from the NDIA on the amendment request could be reviewed by the participant prior to finalisation of the plan, allowing them to address the issues raised, would be very useful.

If there is further evidence that is needed to support a plan amendment, this should be relayed to the applicant, so they can contact the relevant provider and source the necessary report.

2. Greater understanding of, and communication about, supports included in plans

For some participants, there are supports that have been included in their plan that they may not use immediately, for a variety of reasons; however, a decision has been made in conjunction with a provider that they will need them. Unfortunately for many, it is a case of if you don't use it, you may in fact lose it, and these supports may disappear from subsequent plans. It needs to be clearly communicated to participants that this could happen, and that they need to be able to explain to a planner why they haven't used a particular support but will likely need it moving forward, and that therefore it must remain in their plan. It is equally important that planners have an understanding of this issue.

3. Greater efficiency and accountability around the plan amendment process

The plan amendment process can be lengthy, depending on whether a participant goes through an NDIA planner or a LAC. The process is quicker if a planner is used; however, participants are not aware of this. Regardless of which pathway is chosen, the timeframe should be similar.

References

1. Deloitte Access Economics. 2017. Stroke in Australia – No postcode untouched.
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. *Lancet*. 2014; 383(9913): 245-254.
3. Deloitte Access Economics. 2013. The economic impact of stroke in Australia.
4. Monash University Stroke and Ageing Research Centre (STARC). 2013. Australian Stroke Survivor and Carer Needs Assessment Survey.
5. National Disability Insurance Scheme. 2019. National Public Dashboard. 30 June 2019. Available at: <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

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