



Level 7
461 Bourke Street
MELBOURNE VIC 3000
Australia

T +61 3 9670 1000
F +61 3 9670 9300

admin@strokefoundation.com.au
www.strokefoundation.com.au

ABN 42 006 173 379

Patron in Chief:
Her Excellency
Ms Quentin Bryce AC
Governor-General of the
Commonwealth of Australia

Patrons:
David Brownbill AM
Sir Gustav Nossal AC
Lady Southey AM

The National Stroke Foundation (NSF) welcomes the opportunity to make this submission to the Productivity Commission's *Disability Care and Support* public inquiry on behalf of stroke survivors and their carers.

We support the general direction of the draft report particularly with regard to improving the disjointed nature of the current system and increasing consumer choice. Providing consumers with the ability to manage their own care through self managed packages, wherever possible, contributes to a sense of personal control.

Stroke survivors and carers experience the current system as confusing, overwhelming and in many instances, unresponsive. They describe long waits for services and equipment. Many are discharged from hospital with no discharge plan, waiting for services to be arranged. The result is that many survivors describe 'falling into a black hole', unable to access the services they need and unsure where to go for help.¹

The NSF commends the Commission on its forward thinking recommendations and would be happy to provide any further information on the specific needs of stroke survivors and their carers.

Impact of Stroke

Currently, an estimated 350,000 people are living after stroke in Australia. About 88% of stroke survivors live at home and most have a disability². Of those aged 16-85, **28%** of stroke survivors are **aged less than 60 years**.³

The impact of a stroke is profound:

- Stroke survivors are more likely to have profound limitations relating to self care, movement and communication than other people with disability⁴.
- Health related quality of life (HRQoL) for the majority of stroke survivors up to two years after their stroke has been rated as very poor⁵.

¹ National Stroke Foundation, *Walk in our shoes*. 2008, NSF: Melbourne

² AIHW: Senes S 2006. How we manage stroke in Australia.

³ Australian Institute of Health and Welfare, *Australia's health 2010*. 2010, AIHW.

⁴ Australian Institute of Health and Welfare, *Australia's health 2010*. 2010, AIHW.



- Depression is seen in approximately a third of survivors⁶.

Survivors of stroke report difficulties associated with stroke that impact on many facets of their lives. These range from physical to emotional problems and impact their ability to work and participate in social and family activities.⁷

Some of the common issues often faced by survivors include:

- Being discharged home and then not sure of what to expect;
- Survivors and carers need help but do not know where to find it; and
- Survivors and carers are unable to locate or have difficulty accessing the many existing service providers as they are hidden from the consumer view⁸.

National Stroke Foundation Response to the Disability care and Support Draft Report

The NSF supports the move toward a less complex process of assessment, provision of care and funding arrangements which provides for greater consumer choice and flexibility. We would like to focus our comments on 2 recommendations.

Draft Recommendation 3.1

The NSF supports the move toward a system which is more streamlined, nationally consistent and responds directly to the individual needs of consumers.

Stroke recovery is not a linear journey, but rather a complex and changing one. Many survivors (57%) will be discharged home to a carer,⁹ fifty per cent will not have a discharge plan.¹⁰ Of those that do, many will not have had their needs accurately predicated on discharge with 40% requiring more support at home than predicted by hospital staff. At six months post-discharge, 32% of these consumers will have needs that are greater than their

⁵ Sturm, J.W., et al., *Determinants of handicap after stroke: the North East Melbourne Stroke Incidence Study (NEMESIS)*. Stroke, 2004. **35**(3): p. 715-20.

⁶ Hackett, M.L., et al., *Frequency of depression after stroke: a systematic review of observational studies*. Stroke, 2005. **36**(6): p. 1330-40.

⁷ National Stroke Foundation, *Walk in our shoes*. 2008, NSF: Melbourne.

⁸ National Stroke Foundation, *Stroke Support Strategy*. 2008, NSF: Melbourne

⁹ National Stroke Foundation *National Stroke Audit Rehabilitation Services* 2010 Melbourne Australia

¹⁰ National Stroke Foundation *National Stroke Audit Rehabilitation Services* 2010 Melbourne Australia



needs at six weeks.¹¹ This provides some challenges for the new system. It is crucial that assessment of need be undertaken at various time points even when need for referral has not been identified initially.

In a pilot study undertaken by the National Stroke Foundation, survivors were referred to the National Stroke Foundation, at discharge by hospital staff. A health professional telephoned survivors to provide support and information. Referral to a local liaison officer was available for complex clients where support was provided either by phone or face to face. In addition, the local liaison officer accepted referrals from the community. Those accepted from the community were, on average, many years post stroke.

The pilot showed that whilst many survivors' needs could be met via the standard telephone consultation, 33% required additional information that could be provided over the telephone including a more detailed assessment and referral to services. In addition, those requiring more intensive local follow up doubled at 12 weeks.

Of greater concern where the numbers referred from the community where 36% required face-to-face follow-up by a liaison officer and double the time spent in service navigation assistance.¹²

In response to this the NSF has developed a follow up service, StrokeConnect, which directly addresses this issue.

The NSF would envisage referrals between the disability assessment process and StrokeConnect.

Draft Recommendation 3.5

It is encouraging to see the attention given to the transition from disability services to aged care funded services. The NSF supports the move to allow for consumer choice in this process.

We would ask that equal attention be given to those consumers who are aged over 65 years at the time of their stroke, who may require the assistance of disability funded services despite being eligible for aged care funded services. An example of this would be a 66 year old working full time who suffers a stroke. This consumer wishes to return to work and requires the assistance of a disability funded return to work program. Currently it is unclear whether this consumer would be eligible for this program, and how this eligibility would be assessed. As a result consumers in this position are left negotiating a complex system on their own, with little assistance.

¹¹ Luker, J. and K. Grimmer-Somers, *Factors influencing acute stroke guideline compliance: a peek inside the 'black box' for allied health staff*. J Eval Clin Pract, 2009. **15**(2): p. 383-9.

¹² National Stroke Foundation, *Internal report*, 2010



The older working population is predicated to increase over coming years, resulting in more stroke survivors over the age of 65 requiring assistance with return to work. Whilst we agree there is a need to keep two distinct systems, if we are to truly create consumer focused, more seamless arrangements, a greater 'blurring' of the two systems is required, both from disability to aged care and also in reverse.

The NSF requests that protocols be developed to allow consumers over 65 years, requiring the use of disability funded services to do so without undue hindrance.

Conclusion

The NSF welcomes the vision for a system of disability support which is flexible, responsive to consumer need and nationally consistent.

We look forward to working collaboratively to ensure the needs of stroke survivors and carers are responded to in the implementation of this important and innovative new initiative.