Stroke Foundation response to consultation on draft lists of National Disability Insurance Scheme (NDIS) supports

Do you think the draft list of NDIS Supports covers the kinds of disability supports you think should be included?

YES **NO**

The Consultation list currently includes a recommendation to not include “design and subsequent changes or modifications to state or territory owned public housing” under the NDIS, whereas no such policy exists for modifications to a participant’s own dwelling (page6).

We strongly believe the decision about whether home modifications are required should be guided by the level of participant’s need and not by their level of income or property ownership.

Whilst we appreciate not all home modifications may be feasible when a participant resides in public accommodation (which is operated by state/territory governments and not the Commonwealth).

An NDIS carve out for participants in public accommodation could be considered reasonable only as long as there is agreement from all state governments to take up responsibility in this area and provide participants with the required home modifications. Feedback from many current participants is that many state public housing authorities fail to assist them with required home modifications at present.

We appreciate this is a complex area with nuanced jurisdictional responsibilities, however, this issue has significant adverse and inequitable consequences for participants and fails to adequately ensure they are able to live, thrive and remain independent.

Are there goods or services on the exclusion list that you think shouldn’t be there?

YES NO

Ongoing Psychosocial recovery supports (page15) currently listed as a carve-out for certain participants, and otherwise not included under NDIS supports.

Mood disorders, anxiety and psychosocial distress are frequently experienced by stroke survivors, families and carers; but accessing counselling and psychology services is a problem, due to accessibility and affordability issues. We feel strongly that ongoing psychosocial recovery supports should be considered under the NDIS for stroke survivors, when a direct result of their disability. We would also like to

ensure that when psychosocial recovery supports are made available for stroke survivors, no costly and undue burdens are placed on participants to "prove and explain the impact of their disability". Also, we would call for NDIS delegates to have background knowledge of, and experience with, stroke to be able to understand the multiplicity of psychosocial challenges that survivors of stroke may have to address in order to function well.

We would call for a carve out included for disability-related health supports (page5), where the need arises directly from their disability and the support would assist their enhanced function and community re-integration. These supports could be delivered jointly with other parties (eg. specialist allied health or health services). One such example is Botox, where some stroke survivors require ongoing semi-regular injections to treat stroke-related upper limb spasticity (but PBS only covers 2 courses/year). This is a current gap which NDIS can step in and address for participants

Day to Day Living Costs (page 12)

"Sex Work" is currently listed as not included under the NDIS, however, no distinction is made in the definition of "sex work" and "sex therapy".

People with disability (whether physical, intellectual or mixed) have the right to express their need for intimacy and sexual release. People with disability often face additional challenges in having their sexual needs met.[1]

Professional sex therapists with specialised and appropriately-accredited training in health and psychology can provide education, guidance and counselling to couples and individuals with a disability (either in person or via telehealth in instances where such professionals are not geographically available or access is otherwise restricted).

Whilst sex therapy (which involves no touch), and sex work (which involves contact) are different, we believe assistance with sexual pleasure should not be excluded outright and be listed as a ***carve out that may be considered as "NDIS supports" for certain participants***).

Do you have any further feedback or concerns with the draft NDIS support lists?

We support this consultation and its aims to bring clarity to the definitions of what supports are covered by the NDIS, and also support all initiatives aimed at enabling more flexible use of participant's funding (as recommended by the NDIS Review). Many survivors of stroke have complex physical, mental and emotional needs. Currently, there is a belief among the survivor community that NDIA delegates lack

[1] Finally, the NDIS will fund sex therapy. But it should cover sex workers too. SBS News, 17 July 2019

adequate understanding of stroke, stroke-related disability, and the support needs of survivors, and their carers and families.

We are also concerned that the proposed update to the NDIS Support List fails to address the undue burden placed on participants to undergo onerous assessments to “prove and explain the impact of their disability”, often at significant out-of-pocket expense and with additional delays. The decision process also continues to rely on decision-making skills of NDIA delegates who may lack expertise to capture the impact stroke has on an applicant’s functional capacity and needs, or who fail to apply consistency with regard to access decisions.

To address this, we continue calling on the NDIA to develop assessors that can develop additional expertise in managing applications from survivors of stroke, and other forms of acquired brain injury.

Stroke Foundation, stroke rehab physicians and allied health professionals provide expertise in preservation of function through rehabilitation and community care, and together with consumers with lived experience can make relevant expertise available to the NDIA and the Commonwealth to help improve the NDIS.