

Thank you for the opportunity to comment on the Productivity Commission Position Paper of June 2017.

The Paraplegic and Quadriplegic Association of NSW (ParaQuad NSW) has supported people with a spinal cord injury (SCI) and related health conditions for over 56 years. Over this period we have established the organisation as a leading provider of: personal care services to clients in their own homes; specialised supported accommodation (24x7) at Ferguson Lodge, Lidcombe, NSW; specialised health products to both the SCI and wider community as well as the provision of mobility equipment and home modifications across Australia. The organisation has an extensive clinical services team which provides training to professionals across Australia and supports the daily activities of both the personal care service in NSW and advice to customers across Australia purchasing health products.

We believe we are therefore well qualified to comment to the Productivity Commission on issues we believe need to be addressed by the NDIA and related Government departments.

Since the inception of the NDIS, ParaQuad NSW initially operated in the trial area of the Hunter and in the ensuing roll out areas of NSW as well as across Australia through its commercial arm BrightSky Australia which provides health products, mobility equipment and home modifications. We have thus experienced use of the NDIS portal in many of its categories and have formed extensive relationships with many NDIS personnel as a result.

We comment as follows:

1. NDIA COMPLEXITY

An overall concern with the program is its complexity, particularly when the program is designed to support people with a disability. To engage with the portal one needs to be IT savvy and the NDIS incorrectly assumes that participants are. Many in our SCI community are neither computer literate or have limited limb movement making access and use of the portal either very difficult or impossible.

Even the simple design of the NDIS website describing the various categories of services is confusing as the service descriptions do not match the Portal Price Guide categories, thereby thoroughly confusing the participant.

The design of the portal in our view is that it seems to have been designed and predicated on eliminating fraud. Hence the design of the portal and its reporting is unnecessarily complex. With the current delays and errors in dealing with less than 80K participants, it is with considerable concern we note the intended population of the NDIS could be in the order of 460K participants eventually using the portal. There is no doubt that whenever money is involved there will be a very small element that will attempt to take advantage of the system and use allocated funds inappropriately.

To more effectively administer the allocation of funds to participants we would suggest a far simpler approach. The portal in its current form should be modified in favour of a simpler system wherein the participant has an allocation of funds to be applied against a small number of broad categories of approved expenses. This could be personal care; equipment; community engagement; transport; and education with the requirement that all charges in these categories must be billed via authorised providers. This design would then enable NDIS to audit a much smaller number of providers (spot checks) rather than 460K participants. There are already many such systems in use

(e.g. salary packaging cards) that allow expenses to be charges against established criteria and exclude non-authorised expenses. For instance, on a Salary Packaging Meals Card one can charge meals at a restaurant to the card but not buy airplane tickets.

All of the above is contingent on the participant simply being given a card and a budget to charge against. If the budget over time is inadequate, the budget can be reviewed in the normal planning review process.

A significant element of this suggested process is that the participant can really exercise “choice and control” over his/her care package.

2. THE NEED FOR SPECIALISED PLANNERS FOR SPINAL CORD INJURY – PROPOSED NDIS ENHANCEMENT

Acquired spinal cord injury has both a physiological and psychological impact resulting in the need for coordinated complex care to enhance quality of life as those with SCI experience significant impairment in various aspects of their life.

Chronic complications experienced by people with a spinal cord injury are common and have an adverse effect on their quality of life (Sezer et al. 2015). Secondary complications identified by Sezer et al. (2015) include; respiratory, orthostatic hypotension, autonomic dysreflexia, bladder and bowel dysfunction, spasticity, pressure ulcers, pain, osteoporosis and bone fractures. The authors’ further highlight appropriate management of secondary complications provides improvement in community participation.

The Australian study by Middleton et al. 2012 (p811) highlighted elevated mortality rates following onset of spinal cord injury and argued the need for “proactive attention to the way in which contextual factors, either personal or environmental, interact with age and impairment to contribute to reduce life expectancy after SCI [spinal cord injury]”. In addition research has shown that people with SCI experience earlier onset of conditions associated with ageing (Jensen et al. 2013). This necessitates the need to manage complications appropriately.

To assist in the proactive management of complications associated with SCI in the community setting, many of the Australian Spinal Injury Alliance (ASIA) associations have developed pre-planning and planning tools. However this relies on local area coordinators and planners having a solid understanding of the specific concerns of people with SCI so that plans can cater to their unique and complex needs.

Our experience to date is that we have not encountered coordinators or planners who understand the unique needs of someone with SCI and we are therefore not confident that this community will receive the quality of planning necessary to best service their needs. It should also be noted that people with SCI will have substantially greater cost to NDIS than other groups, if not the highest costs.

Concern is further increased as we note the recently released NDIS Quality and Safeguarding Framework and particularly comments in regard to building participant capacity ***“There is a risk that some participants will tend to settle for inadequate support because the alternative seems unattainable due to these transaction costs, in the same way many people tend not to change banks even when they are unhappy with their current provider.” (pg. 23).***

Our concern is that participants are potentially receiving inadequate support based on the lack of awareness of the needs of a participant with SCI by the local area coordinator and planner. As a result participants could potentially settle for a proposed inadequate plan as the current planning process is overwhelming and confusing for most.

For example we are aware that continence management is core to the needs of people with SCI and if inappropriately handled will limit their community participation and life expectancy. A recent survey by Wicks (2016) of ParaQuad NSW members under the age of 70 investigated participants’ continence management under NDIS. The survey had a 32.4% response rate and highlighted the following

- 80.9% self-identified as not experiencing urinary complications yet indicated regular urinary complication symptoms.
- 37.7% self-identified as not experiencing bowel program complications yet indicated regular symptoms consistent with bowel management complications.
- 85.5% did not know HOW to request a continence assessment and 84.7% did not know from WHOM to request a continence assessment. The results of the survey by Wicks (2016) would suggest that participants may not understand their continence management options and associated ramifications of poor continence management.
- This is further compounded by our concern that local area coordinators and planners do not have expertise in spinal cord injury management.

Our concerns regarding the needs of people with SCI are not limited to continence. We are concerned with all supports we know are needed to manage activities of daily living to allow community participation.

We therefore strongly support the appointment of a Senior Practitioner as proposed in the NDIS Quality and Safeguarding Framework and further request that given the complex ramifications of care of people with SCI that consultation commence to ensure NDIS plans meet the needs of people with a spinal cord injury living in the community.

We further note that given our team’s clinical team experience in neurogenic continence management that **all people with a neurogenic loss should be required to have a continence assessment.** Our recent survey of over 1000 people to ask whether they understood their continence needs and how to ask for a continence assessment in their

plans alarmingly found that 80.9% did not. This clearly illustrates the need for specialist support for participants in preparing their plans

References

Jensen, M. P., Truitt, A. R., Schomer, K. G., Yorkston, K. M., Baylor, C., & Molton, I. R. (2013). Frequency and age effects of secondary health conditions in individuals with spinal cord injury: a scoping review. *Spinal Cord*, 51(12), 882-892.

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Sezer, N., Akkuş, S., & Uğurlu, F. G. (2015). Chronic complications of spinal cord injury. *World journal of orthopaedics*, 6(1), 24.

Wicks, K. (2016) Neurogenic related incontinence: being NDIS ready (unpublished conference presentation). ParaQuad NSW

<https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/ndis-quality-and-safeguarding-framework-0>

3. THE POPULATION AGED OVER 65 YEARS INELIGIBLE FOR NDIS

We are extremely concerned that a group of people with SCI aged over 65 years of age will not have the opportunity to have sufficient care provided to them with their disability.

Most people with SCI aged under 65 years of age will invariably meet the criteria for eligibility into the NDIS once it is rolled out in their area.

But there are many people (estimated at over 200) who have SCI, are aged over 65 years of age and thus do not qualify for the NDIS. Their only recourse is to enter into the Aged Care reforms which provide insufficient care for their requirements. For example a person with SCI would receive a maximum of \$49,000 under the Aged Care provisions when they would typically require a package on average of \$150,000, some less others more.

This critical issue has been raised by ASIA to Ken Baker CEO of National Disability Services, the peak disability body, and he was requested to liaise with the Department of Health where this has been raised with Dr Nick Hartland, First Assistant Secretary, Aged Care Policy and Regulation; Ms Karen Pickering, Head of the Home Support Branch. However, it seems this issue was not well understood/appreciated and currently there is no provision for this group of persons with SCI aged over 65 to receive more than the upper limit of \$49,000.

ASIA believes this inequity has arisen as:

1. There was an assumption that all people with SCI would be catered for under NDIS.
2. Failing this, those over 65 who were receiving State based care package and thus not able to enter the NDIS would have their care package maintained under the Commonwealth Continuity of Support Program.

3. However the significant point missed is that these people never had a package to “continue”. They were the unlucky ones who weren’t able to secure a State care package, due principally to State budget constraints.
4. NDIS has addressed this gap for those under 65 in this situation but not for those people over 65 who never had a care package.

4. SPECIALIST DISABILITY ACCOMMODATION (SDA)

The NDIS has a fundamental principle about choice so it should let the participant decide where he or she chooses to live. Forcing participants to reside in only specific types of funded accommodation misses an important point. We understand very well that high support needs people (people with spinal cord injury and related) want to exercise their choice and some want to live in supported accommodation which meets their needs. This may or may not be the majority or minority. But it is a material proportion. Much of this cohort have very limited limb movement, cannot prepare meals for themselves and may require the constant supervision provided by specifically designed supported accommodation.

It cannot be choice and control when “very high support needs” people cannot choose to live in a “fit for purpose accommodation for people with extreme functional impairment”.

ParaQuad NSW is a member of ASIA (Australian Spinal Injury Alliance) – comprising all spinal organisations (8) across Australia.

We contend that the generalisation *“A strong desire was expressed by people with a disability, their families, carers and advocates that large residential centre style accommodation did not fit this remit”* is far from universal and even in the minority in some community areas. These findings may be reflective of other disability areas but they are not our overwhelming experience with spinal cord injuries which your statement appears to contend. We have many members (and their families), across the eight (8) organisations in Australia, that desire to include the types of facility we propose.

The complicated and contrived rules - to exclude a small shared apartment facility (10-12 persons) and dictate that 10 participants must reside in two five bedroom homes or 7 could share a parcel of land - contradicts NDIA principles and questions the underlying integrity of the NDIA. Sections 6.15, 6.16 and 6.17 in the NDIS 2 March SDA appear to exclude choice and need to be amended.

Participants should be permitted to **choose** to use their SDA package and live in a shared apartment (studio) facility which provides maximum support for people with very high support needs. We do not support expansion to “large residential centres”.

These facilities do not require capital cost contribution from NDIA, merely the ability of participants to use their SDA funding for the supported accommodation of this type. If the facility has ten accommodation units and only four (4) are used by SDA participants then only four SDA packages are utilised and the proponent of the facility bears the commercial risk of having constructed ten units.

It is respectfully requested that the current NDIS view be amended to provide the choice proposed and therefore consistent with the guiding principles.

5. CONTINUATION OF SUPPORTS (CoS) FEDERAL PROGRAM

We note that the cohort who is aged over 65 years receiving State Disability care packages now not able to join the NDIS will continue to receive the current level of support under the Federal Government CoS Program. This important program provides for the **same level** of benefits the individual received under the State program to be continued, hence its name. While this is greatly appreciated by this cohort regrettably the program does not contemplate a change in circumstances whereby the care required by the individual needs to be significantly increased. There is no mechanism currently in place to provide additional funds to satisfy this increased need.

For example a client aged over 65 has a CoS package of \$95,000 providing a specified hours of care each day. His condition has changed and he now requires care to be delivered by two support workers and an additional shift each day. His requirement is now increased to require \$135,000 to provide this essential care. The current guidelines in the CoS Program do not provide for this.

We believe provision needs to be put in place perhaps by a “Change of Circumstances” process so that additional funding is provided when care needs are increased.

6. WORK FORCE ISSUES

Much has been written about the need to augment the workforce to meet the demands of new participants entering the NDIS. There has been much debate about this issue with a significant number of additional workers reputedly required to meet the care demands brought about by the NDIS. It is encouraging that the Productivity Commission has recognised this issue and proposed relaxing the restrictions on informal carers (Pg. 39 Overview).

The assumptions for a significantly increased workforce we believe are based on an incorrect assumption that **all** new participants will require new care workers, workers not currently in the care workforce.

While new participants will be receiving an NDIS care package for the first time, most are currently being cared for by existing informal carers. In a great many cases we contend that this care provision will continue. We also believe that in many cases informal care will cease provided an alternative exists. No doubt many informal carers will welcome the opportunity to be relieved of their historical services with the participant engaging new support workers. In some cases the participant may decide to “mix and match” and use paid support workers during the week and informal carers on the weekend. Regardless, we believe it is the participants choice but both support workers and informal carers should be paid.

In short, the care workforce does exist (albeit not completely) and we believe it is unreasonable to exclude informal carers, family members, people living at the same residence, from being paid. No doubt there will be situations where some issues may arise but to exclude informal carers goes against a fundamental issue of choice by the participant and further exacerbates a known issue with workforce numbers.

There are many instances with the current limited number of care packages available through State schemes where there are no support workers available and this will continue to be the case. Our experience in many remote areas is that support workers are just not available and in many cases need to travel extraordinary distances to service a client. An obvious solution is to pay informal carers.

In most cases there would be none better to care for a participant than his/her family. Of course there would be many that would prefer an independent support worker and there would be many family members who could not render care due to their age/own health condition.. But a substantial workforce is already there, NDIA just needs to acknowledge it and provide the appropriate remuneration.

We are thus very support of the Productivity Commission recommendation with the need to remove the “temporary” nature and establish it as a matter of choice by the participant.

7. CHANGED RELATIONSHIP WITH THE NGO SECTOR

Another critical element of the design of the NDIS is that in our view it appears that there may be a lack of trust with the NGO sector and service providers. For many years the NGO sector has been responsible for the majority of service provision to the disability community. It has built up considerable expertise and infrastructure to provide specialised services, as in the case of ParaQuad NSW. For instance, ParaQuad NSW can confidently state that it knows what services someone with SCI requires on the basis of many years of experience and a significant clinical team to support its community.

However the design of the NDIS institutes inexperienced personnel who have been engaged as Planners to somehow fulfil this important role? The Planners are expected to have a wide range of knowledge of individual disability communities so they assist participants to plan for required services. In addition there are a significant number of these planners (reputedly 30 per 1000 participants) and NDIS must seriously question their ability to contribute. It would appear the reason “planners” were established is to avoid “conflict of interest” should service providers help participants complete plans.

As an existing service provider in existence for 56 years, we know what our community and participants require and can recommend accordingly. The cost of planners would be far better put to ground roots services and products.

Finally, all of the above really changes the relationship NGOs have had with the various State Departments of Disability across Australia. In the past the NGO sector has been a critical partner with Governments in the delivery of services. The structure of the NDIS portal and the introduction of unqualified planners has resulted in the NGO sector changing its role from partner status to being a supplier of services.