Response to the
Productivity Commission's
Draft Report into Disability Care and Support

from

Alliance of Spinal Injury Organisations

Introduction

In 2009 an Alliance of Spinal Injury Organisations was formed bringing together Spinal Cord Injuries Australia (NSW), Spinal Injuries Association (QLD) AQA Victoria Ltd (VIC) and more recently Paraquad SA, each committed to supporting independence, quality of life & participation after spinal cord injury, empowering people to lead independent lifestyles in inclusive communities.

The State-based organisations forming this Alliance agreed that by actively sharing information, coordinating activities, and working together on a national level, better outcomes will be achieved for people with a spinal cord injury.

We are submitting this joint response to the Draft Report into Disability Care and Support to emphasise the issues of National importance that unite us across State borders.

Each Organisation may choose to submit a separate response in their own right that emphasises their organisational and State perspective.

Overview

Firstly we congratulate the Productivity Commission on an enlightened document that puts the person with the disability front and centre and emphasises important principles of individual choice, equity of access, flexibility and nationally consistency.

We further congratulate the Productivity Commission for opening it's draft report by calling a spade a spade - the current disability support system is indeed under funded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.

Our comments in this submission do not question the fundamentals of a NDIS. We are greatly in favour of this scheme and have lent public support to campaigns aimed at ensuring that it becomes established. Our desire is to make suggestions and highlight some refinements with the aim of supporting the rollout of a full scheme that will provide much needed support for all Australians living with a disability.

We thank you for the opportunity to provide further input to the Disability Care and Support Scheme discussion.

1. One scheme: A single NDIS for all Australians regardless how they acquire a disability as opposed to the creation of a separate National Injury Insurance Scheme (NIIS) for people who are catastrophically injured.

1.1 Many of our members and clients have an impairment arising from a traumatic spinal cord injury that would fit the criteria of the proposed NIIS.

Many States share a long experience of a separate systems where access to funding and services is based on the cause of the person's impairment rather than the needs arising.

We note the reasoning for the two schemes including the 'practical realities' of there being existing State based schemes, and the opportunity in the first instance to achieve a standard approach across State jurisdictions. We also note the Commission's suggestion that this 2 scheme approach should be reviewed in 2020 with a possible view to a single system.

Our shared concern is the perpetuation of all the problems with 2 separate systems in this case a NIIS for some and a NDIS for others with different approaches to assessment, participation, quality, administration, reporting and scheme development. In addition, the introduction of a NIIS for *new injuries* as suggested in the draft report will effectively create a 3 scheme system based on the date of a person's injury - pre - NIIS, NIIS and NDIS.

A solution to the problems in such a 3 scheme system would be to initially maintain two streams of revenue in the form of a NIIS and a NDIS, however achieve a single source of service delivery, administration and development through the NDIA.

For the person with a disability, the only difference between the two schemes would be a back office recognition that some clients are funded from consolidated revenue and some are funded via state-based insurance means.
The experience of all people with a disability seeking to access the scheme would be exactly the same. This would allow the relevant state-based legislation to be progressively dismantled toward the 2020 review timeframe as laid out in the draft. This option would also leverage the administrative and service development experience currently sitting with the Transport Accident Commission (TAC) and the LTCS to help support the ongoing development of the NDIS.

1.2 People who live with needs arising from an existing injury and are currently waiting for funded supports.

Each Association has members and clients with spinal cord injury who are under 65 yrs, receive limited formal supports and are on State Government waiting lists. If these people turn 65 before the introduction of the scheme we are concerned they will then miss out on the level of support required and will be directed to the aged care sector which will not meet their high level of need. This group needs to be identified now so they can be included in the scheme when introduced. A large portion of this group have been waiting for formal supports for many years, quite often at great financial and emotional cost to family and friends and unless transitional arrangements recognise them, will be excluded forever.

1.3 People supported under current state based third party or compensation schemes.

The NDIA needs to ensure that all clients supported under state based schemes remain fully supported until a NIIS or NDIS is fully functioning and operational and that the transition is seamless across to the new system.

2. Assessment process

2.1 That any form of assessment undertaken with a person with a disability should be holistic and not based in a medical or treatment model.

The quality of the assessment process and of the individual assessors will likely have a large bearing on the quality of services provided to an individual. To ensure there is equity for all people with disabilities the assessment tools need to be person centred and encompass life goals and aims rather than prescriptions linked to a level of disability as classified in impairment tables.

The proposal for assessors to be “accredited” by the NDIA is very welcome. Assessors need to be trained in the use of the tools and in the holistic approach. With accreditation and training in place we see no reason to restrict this role to any particular group such as those Allied Health professionals named in the draft report. Assessors can be drawn from a wide range of backgrounds including relevant professions, community development and people with lived experience of disability.

2.2 The NDIS assessors should be independent in order to work in partnership with people with disability and not simply enforce scheme guidelines or act in the interests of service providers.

2.3 Flexibility in the frequency of (re) assessment

Any system of assessment needs to be flexible enough to respond to people's changing or emerging needs. These situations may be in time of crisis for an individual (ie: injury, illness, absence of a main unpaid care) where the reassessment needs to be timely. Each client or their representative needs to be able to trigger a (re)assessment in response to changing circumstances.

While the need to ensure that appropriate supports are being provided to individuals, the NDIA needs to make certain that people are not (re) assessed unnecessarily. For many years people with a disability, particularly those with lifelong disabilities, are re-assessed on many occasions when needs have not changed e.g. driving permits, taxi vouchers, personal care, equipment prescription.

3. That people over 65 years of age who acquire a severe disability should be included in the NDIS.

In any given year the highest proportion of people who sustain a spinal cord injury are between the ages of 18-25 yrs however in recent years the average age of those sustaining a spinal cord injury is 42 years of age. A greater number of people over the age of 65 yrs are sustaining spinal cord injuries. With an ageing population, people over 65 are expected to be the second largest age group acquiring a spinal cord injury, but they will be ineligible for the NDIS.

This cohort need to have access to the NDIS as the aged care system cannot support people with such high and complex needs. If people over 65 are not covered by the NDIS they will be reliant on yet another system with separate administration, eligibility, funding, policies and procedures. We feel that this is highly inappropriate and would urge the Productivity Commission to reconsider its proposal and to include people over 65 who acquire non age related disability.

4. Access to common law compensation

As the NIIS / NDIS does not compensate individuals for pain and suffering and lost wages, people should still have the option to take action for loss of earnings, pain and suffering under existing common law. These rights we believe should not be removed from the individual and in the case of catastrophic injuries such as spinal cord injury; this allows individuals to be compensated to support themselves as they would have without an injury.

5. National standards for service providers

5.1 Consistent standards across providers

To ensure that all people with a disability receive quality services the NDIA must implement consistent standards to be met across all service providers be they not-for-profit, for-profit or government.

5.2 Consolidating the number of different standards that organisations need to meet is essential as complying with different, sometimes conflicting standards make quality auditing, expensive, time consuming and onerous on clients who need to participate. E.g. National Disability Standards, State Disability Standards, HACC etc.

6. A quality approach for service delivery

6.1 Client outcomes

The draft report focuses on efficiencies and while this is important it equally needs to emphasise that services provided are of the highest quality and are meeting the individual needs of clients. There will need to be safeguards to ensure that appropriate outcomes are agreed to and achieved. This will require ongoing reviews to monitor the effectiveness of support in client outcomes.

6.2 Building client capacity

People with disability who opt for direct payment type funding packages should be offered appropriate training and resources for financial and administration management, as well as for recruiting, hiring and training personal care support workers. The NDIS should also allocate funding to enable personal care workers, who have been employed by people with direct payment type funding packages, to undertake disability awareness and personal care training.

6.3 Standards and requirements for cashing out and self-purchasing.

Many of our Associations' members and clients have extensive experience with self-purchasing and managing personal care support after being eligible for compensation or other lump sum payouts. To contribute towards quality service provision and the safety of both people with a disability and support workers our experience shows that there needs to be minimum standards met when people are purchasing supports privately ie: injury insurance, criminal history screening, and training for support workers, appropriate acquittals and financial reporting for people with a disability, as is required when purchasing through a service provider.

6.4 Workforce Preparation & Training

While as organisations we support minimum training we agree with the Commission that minimum qualifications do not necessarily provide specialist skills for staff and that many people with disability and their families have extensive experience in the training of some support workers.

Our shared experience does however point to the importance of appropriately preparing a workforce for the tasks they are required to complete including specialised pre-requisite training when working with particular client groups e.g. people with spinal cord injury, to ensure the safety of clients as well as support workers.

We believe it is essential for the development and implementation of disability awareness training for personal care support workers, coordinators and case managers that include the philosophy of being client focused and person centred.

People recruited to provide personal care support should receive both initial and ongoing training and assessment. Personal care workers should also be encouraged to undertake tertiary education in disability awareness and service delivery.

7 Portability of funding

Like other Australians, people with a disability should be allowed to move as they choose. Portability of supports and funding make this achievable.

8 Maintaining the capability of services required by individuals on an episodic basis - such as peer support and advocacy.

We fully support the philosophy of individualised funding for people with disability. However we are concerned about the unintended consequences on some disability support services that people with disability use periodically, such as Advocacy, Peer Support and Information & Referral. Our members and clients tell us that our most valuable services include information & referral, advocacy and peer support. These services are required episodically, sometimes unpredictably and may not be identified in a person's periodic plan. To be available when required these services need to maintain a capability of skills, knowledge, contemporary information, networks and relationships.

The viability of services like these is jeopardised in a fully individualised funding model of a NDIS. This would especially be the case in vulnerable rural and regional areas where a service would be greatly needed but might not have the high demand of a metropolitan area.

We note in chapter 8 of the summary the possibility of ‘block’ funding being retained for certain services. The option to retain some form of block funding would address this.

9 Aids and equipment have a pivotal role to play in supporting community living

The appropriate assessment, prescription and timely provision of aids and equipment is extremely important for people with disability, their family and carers, as it increases a person with disability's mobility, functionality, independence and quality of life. Aids and equipment are one of the vital links in the support system in conjunction with personal care support, accessible housing/accommodation and accessible transport.

We would like to bring to the Productivity Commission's attention that apart from the NDIS providing aids and equipment, it is extremely important that NDIS participants have access to aids and equipment repair and maintenance services, including an out of hours emergency backup service.

Furthermore, many people with spinal cord injury will end up with sleep apnoea and, although sleep apnoea is considered a medical condition, for many people with a spinal cord injury sleep apnoea is directly related to the disability. If the Productivity Commission has only been considering the provision of aids and equipment to assist people with mobility problems, we would like to recommend that the Productivity Commission support the inclusion of the related breathing apparatus such as, but not restricted to, CPAP and Bi-pap machines which are required to be used by people with sleep apnoea. This type of equipment should fit into the same category as ventilators, including portable ventilators, that are currently being provided to people with a high level spinal cord injury that are ventilated dependent.

Conclusion

We again congratulate the Productivity Commission on an enlightened document that puts the person with the disability front and centre and emphasises important principles of individual choice, equity of access, flexibility and nationally consistency.

We offer our response as important refinements to the fundamentals outlined in the draft report.

Thank you for the opportunity to provide feedback.

Mark Henley	Peter Perry	Peter Trethewey	James Kinghorn
Spinal Injuries Association	SCIA	AQA Victoria Ltd	PQASA