

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

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Introduction

Spinal Cord Injuries Australia (SCIA) is Australia's leading community organisation supporting people with a spinal cord injury and similar conditions. Our organisation was established in September 1967 and has a long and proud history of providing services to members, the wider community and being a voice for their concerns both socially and to government

The release of the eagerly awaited *Draft Report into Disability Care and Support* was met with much anticipation and was received by us in a very positive manner.

We congratulate the Productivity Commission on turning 600+ public submissions into an enlightened document that seeks to address many of the inequalities and inadequacies that exist for people with a disability who currently, or wish to, access disability and community services and programs in Australia.

With the Australian Government being a strong signatory of the UN Convention on the Rights of Persons with a Disability it is pleasing to see many of the UN's aims represented within this draft report. Both the portability of services and right to access services by people with a disability in Australian as a product of the establishment of a National Disability Insurance Scheme (NDIS) cannot be overlooked as a tremendous outcome.

Our comments in this submission should not be seen as a criticism of 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 highlight developmental issues with the aim of supporting the rollout of a full scheme that will provide much needed support for all Australians living with a disability. In addition, the NDIS would also provide peace of mind to all Australians should they incur a disability as the NDIS will be in place to support them.

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

Overview of Points

SCIA recommends:

- 1) 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.
- 2) The NDIS assessors work in partnership with people with disability instead of enforcing guidelines.
- 3) That any form of assessment undertaken of a person with a disability should be holistic and not medical based.
- 4) That people over 65 years of age who acquire a severe disability should be included in the NDIS.
- 5) A longer timeframe for the rollout of the NDIS in conjunction with pre-rollout research and trials.
- 6) The role of existing compensated individuals in assisting the NDIS with individual funding planning has, we believe, been overlooked.
- 7) A best practice approach to service delivery with Key Performance Indicators (KPI) to meet minimum national standards.
- 8) Common Law rights to seek restitution for damages can exist alongside an NDIS through the creation of a hybrid scheme.
- 9) The abolition of the proposed split between the NDIS and traditionally interrelated agencies, such as Health as this is unworkable.
- 10) The option of self assessment for people with existing long-term disability conditions within the assessment process.
- 11) The need for services to be person centred and client focused.
- 12) The proposal for a financial co-payment to be paid by NDIS participants is abolished.
- 13) Individualised funding for people with disability but is concerned about the possible negative impact on current and future disability support services that people with disability use periodically, such as Advocacy, Peer Support and Information. Funding should be maintained in an individually funded climate.
- 14) The capacity of the disability support services to meet the demand for both the recognised and unrecognised services is investigated.

- 15) Appropriate funding for aids and equipment, including appropriate funding for their service and maintenance, as they are essential to support people with disability to live in the community providing independence.

SCIA Response

1) The Productivity Commission proposal for two schemes

Having a NIIS operating in conjunction with the NDIS has generated concern, debate and confusion amongst the disability sector. We note the reasoning for the two schemes but we are unsure about the implementation. Given that the NIIS would cover a smaller number of injured people per year and cost around \$685 million, or \$31 per Australian, why not just have the one scheme?

The overall funding mechanism for NIIS might be complex taking into consideration all the forms of injury (transport, medical, workplace, violence, and sporting, recreational and personal injury) as well as 25 pieces of state-based legislation that would need to change. But we believe that these are surmountable.

Currently, in NSW, non-compensable people with a newly acquired physical disability due to a spinal cord injury or brain injury are assessed for eligibility to the Lifetime Care Scheme (LTCS), for people injured in motor vehicle accidents, and a variety of NSW Government provided or funded support services. The LTCS is virtually a 'one-stop shop' providing case management and/or coordination for all services and programs. People ineligible for the LTCS are required to apply for different services from different government funded or provided service providers. The service has its own administration, and although they are meant to comply with the Disability Service Standards, many services have their own policies and procedures which are often interpreted differently therefore providing inequitable services.

With the introduction of the NDIS and the NIIS, there are extra costs associated with operating separate administration, developing (and interpreting) policies and procedures, eligibility criteria, competition for service provision and the current problems of operating two schemes would continue.

According to the proposals for the two schemes there appears to be a lack of involvement by people with disability in the policy planning and development of supports planned for the NIIS that are present under the NDIS. This also mirrors our experience interfacing with the LTCS in NSW. This is a great concern as the opportunities to ensure that incorrect policy is addressed becomes increasingly limited without a formal stakeholder review.

The NSW LTCS has problems. Since it commenced, we have witnessed the prescriptive nature of many of the supports provided and the fostering of a 'they who shout loudest get what is needed' scenario. This situation was supposed to end with the establishment of the LTCS but seems to continue to

exist and has escalated as the scheme becomes more established. There are many other issues with the LTCS and the concern is that, rather than address these issues, whilst only operating in a state based environment, the NIIS would seek to roll them out across Australia with little to no service development safeguards. In contrast the NDIS seems to be appropriately structured with review panels and forums.

With two separate schemes there is the potential for conflict between them over the acquisition of services for clients. Service providers would end up receiving funding through two separate means at potentially differing levels. With NDIS clients being individually funded and potentially cashed out they are in a position to negotiate prices whereas NIIS clients would not. Should a price/service agreement between both schemes and the service providers be established, this would remove the opportunity for a 'cashed out' person to negotiate price or service extras. This is one thing that would bring greater return to the individual and the NDIS as a funding body.

A solution to this problem of two tiers would be to initially keep the NIIS as a formal sub set of the greater NDIS, with all of the administration and development being sourced through the NDIS. The only difference between the two schemes would be 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 thus be exactly the same. Under this idea the relevant state-based legislation could progressively be dismantled with the aim of supporting the 2020 timeframe as laid out in the draft for one scheme or at least the review of one scheme.

Another benefit of this proposed solution is that administrative and service development experience currently sitting with the Transports Accidents Commission (TAC) and the LTCS could be used, with correct guidance, to help support the ongoing development of the NDIS.

2) The service assessment process

Assessment via assessors seems a little out of touch with aims of the NDIS. If the aims of the NDIS are empowerment and supporting the individual with personal development then an assessor driving the funding and potential applied services seems to be aimed against this. It would be against it as little would have fundamentally changed for the individual from the current prescriptive system under this proposed assessment model for the NDIS. Individual people with disability and their families will know what needs they have and should be the key drivers for developing their support packages. But a person with an acquired traumatic brain injury, intellectual or developmentally delayed disability (or anyone experiencing disability for the first time) may require this level of assistance due to the amount of knowledge required to understand what is needed. In this instance we would hope that they could be supported in making fair choices.

3) The need for the right kind of independent assessor

Within the plan for the NDIS the use of assessors is expected to be a replacement and enhancement of the role currently undertaken by allied health professionals such as occupational therapists and social workers.

We believe that due to the large number of people who will access services who have acquired the disability some time ago, is there any real reason why the assessors are tipped to be allied health professionals? The development of an NDIS gives us the chance to move people with disability out of the medical model and into a more holistic social justice assessment. This could encompass life goals and aims rather than prescriptions linked to a level of disability as classified in impairment tables.

In addition, it is preferable if people with disability have a greater understanding of their needs so they can appropriately participate and/or drive the assessment process. We believe people with disability should be provided with appropriate resources during a 'pre-assessment' period and supported to undertake any research.

4) The situation for people over 65 who acquire a disability

As an organisation that represents people with spinal cord injuries resulting in paraplegia and quadriplegia, it would be remiss of us if we did not comment on the proposal to exclude people over 65 who acquire a spinal cord injury or similar condition causing severe disability.

The latest statistics from the Australian Institute of Health and Welfare (2007–08) state that the average age of a person injured with a spinal cord injury is 42 years, up from 38 years in 1995–96. This statistic follows the trend of an ageing population. The two age groups that recorded rises in spinal cord injuries are the 25–34 and 55–64. With an ageing population, the proposal for the NDIS to exclude people over 65 will be out of touch with the needs of people with acquired spinal cord injuries. Over time, 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.

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.

5) The proposed time frames for an NDIS and a NIIS rollout.

As previously mentioned, we recommend the Productivity Commission implement one single scheme as the NDIS, however, the proposed timeframe for the initial NDIS rollout seems optimistic when considering the size of the task to be undertaken. Many of the issues that exist in the community for

people with a disability accessing services are often created through untested crisis driven services.

We believe that the timeframe for initial rollout does not take into account certain trials or studies that are fundamental to the success of the scheme, such as the inclusion of a 'direct' and/or 'individual' funding package trial and study. The NSW Government recently announced that it will allocate \$141.2 million over the next five years for training people with a disability to manage individual funding packages. The training is in conjunction with the announcement of individual funding packages being available from 2014 as a part of the NSW Government's Stronger Together 2 disability program and service funding (2012-2016).

Currently most states have some element of individual funding linked solely to personal care packages. There have been no studies (that we are aware of) in Australia that have looked at the implications on equipment, respite and home modifications packages etc.

In NSW, there are approximately 400 people receiving individual funding packages for personal care support through the Attendant Care Program. This will increase to approximately 600+ by 2016. We are aware of a relatively small number of people with high level spinal cord injury involved in a pilot program of individualised/self managed funding packages for up to 35 hours per week personal care support. Participants we have spoken with are extremely happy with the control, flexibility and autonomy of the funding packages.

Apart from the need for pre-implementation studies of the NDIS, there is a need for NDIS policies and procedures to be developed in consultation in partnership with people with disability and their representative organisations. Appropriate policy and procedures, and their implementation, may take time to develop. Also, it is essential that there are annual reviews of the NDIS for its ongoing development with contemplation with all stakeholders.

6) The role of existing compensated individuals in assisting the NDIS with individual funding planning has, we believe, been overlooked.
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When discussing the options for people to acquire services under an NDIS, there has been no mention that we could find a group of people currently living a completely self-directed existence. People who have acquired a traumatic injury and have been fully compensated for lifetime care costs have been in the situation of sourcing their own equipment, home modifications and directly hiring carers for some years. We believe that there needs to be recognition of this group within the Productivity Commissions report and potentially a convening of a working party to assist with the development of broader individualised funding packages for NDIS clients.

One of the differences will be that an individual compensated person requires no assessor and purchases services usually outside of prescribed guidelines. It would certainly be of interest to see, as we already believe, the cost benefits

of truly self-directed funding over prescriptive funding and the true benefit that the NDIS may experience by understanding this established group.

We recognise that many of these individuals will have had to go through long and lengthy court cases to receive their compensation and usually this compensation has an estimate of lifespan and function throughout life. This initial assessment to establish costs doesn't always work correctly with people who had previously been assessed as incapable of many functions, including getting married, having children and securing employment.

Often this group function outside of their original assessments. We would urge the productivity commission to use caution if choosing to analyse the way that initial compensation assessments are conducted with a view to using any aspect in the costing of an NDIS as often the model is proved inadequate.

7) A quality approach for service delivery

The NDIS Draft Report does not mention the need to implement and monitor minimum service standards or KPIs.

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 initial and ongoing training and assessment. We believe the NDIS should also consider establishing personal care worker training and assessment programs, or work in partnership with existing training and assessment programs. Personal care workers should also be encouraged to undertake tertiary education in disability awareness and service delivery.

People with disability who opt for individualised funding packages should be provided with 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 individual funding packages, to undertake disability awareness and personal care training.

8) Retention of Common Law rights

The Productivity Commission advocates for the removal of common law rights over the short and medium term. We do not believe that this is desirable or necessary to achieve the stated policy objectives.

Any proposal must ensure that a person be able to participate in the NDIS and, if appropriate, bring an action of negligence against a party who has caused the injury. This is important for a number of reasons:

It provides injured people with a right of recourse and access to justice against individuals or corporations who act negligently.

It provides incentives to limit risky behaviour in our community at large. Without the availability of the common law, the risks of injury will be greater with costs borne both by individuals and the community.

No fault statutory schemes by their very nature provide limits on eligibility, the amount of care and unit price, thus restricting choice.

A common law settlement allows individuals the right to determine their own future. Whilst a Scheme can provide a 'safety net' level of care, common law damages supports a person with the aim of living a truly independent life.

Spinal Cord Injuries Australia believes that the NDIS should be created as a hybrid scheme where the right to pursue restitution for physical injury and lifetime care costs should exist alongside a right to access temporary support through a common no fault scheme.

Procedures can be established to ensure that when a person receives a common law settlement, and has previously obtained care costs through a no fault scheme, the amount can be repaid. The person will then transition towards self funding their care for a period into the future until the allowance is extinguished. This hybrid approach has the benefit of greatly reducing the burden of costs to the NDIS whilst preserving the individuals right to seek restitution.

9) The NDIS should work in partnership with other government departments, such as Health and Ageing and Human Services, to obtain the benefits from a whole of government approach to disability.

If and when the NDIS is accepted and implemented by the Federal Government, it is extremely important for a 'whole of government' approach for the interaction between the NDIS and all other government departments and services including Centrelink, education, employment and health etc.

With the proposal for the NDIS to provide aids and equipment, this should address the current and ongoing problems associated with the state and territory government aids and equipment programs that have always been chronically underfunded with people waiting for 2+ years. Although access to these essential programs is meant to be assessed and provided in relation to a person's needs, with an income test in place used to determine the appropriate co-payment, priority has always been given to Disability Support Pension (DSP) Concession Card holders.

Government funded aids and equipment programs aim to support people with disability to live in the community and be active citizens contributing to society, including undertaking education and employment. However, if people with disability achieve this aim and undertake employment of 30+ hours per week (or 15+ hours per week for DSP applicants after 2006) they are ineligible for the DSP and the DSP Concession Card. This aids and equipment eligibility

criteria have always been one of the major disincentives for people with disability to seek employment.

Due to the lack of nursing and support staff in rural and regional areas, and on various occasions in Sydney, people with severe disability often require their personal-care support workers to assist them while they are in hospital to provide personal-care support and other assistance. We would strongly support the Productivity Commission entering into dialogue with the health and medical systems, particularly in rural, regional and remote areas, to enable carers to provide personal-care support in the hospital system if required or requested by the person with disability. This will give peace of mind to the person with disability (particularly if they have complex personal care needs) and free up the workload on hospital staff who historically are under-resourced and overworked. This will also provide some job security for the care workers whose income is based on the number of hours they are providing care for people disability, particularly if they are working many hours for the person who is hospitalised.

In a time when it can be difficult to recruit and maintain personal-care support workers, if people with disability are hospitalised (particularly for a long period of time) it can result in the personal-care support workers leaving the industry. This is a major issue for people who are ventilator dependent and who have a 'support team' rostered 24/7 so they can live in the community but are under a major threat of losing that team if they are hospitalised for a long time. Allowing the 'support team' to assist in hospital not only provides job security for care workers but also peace of mind for the person who is ventilator dependent who otherwise might be required to recruit another 'support team' once they are discharged from hospital.

Although the NDIS aims to provide appropriate support to people with disability, there will always be people with disability that need or require support from family members to enable them to live in the community. Unfortunately, the Centrelink eligibility criteria can have an ongoing negative financial impact on a family member who becomes a carer, but who may be ineligible for the Carer Payment (pension) as it is means tested against the carer's spouse or partner's income.

We would strongly suggest that the Productivity Commission enter into dialogue with Centrelink to address this issue with a 'whole of government' approach with the aim of ensuring people with disability are able to be supported at home in the community with family without the added financial pressure of being ineligible for any Centrelink support, particularly if the family member has given up paid employment to care for the person with a disability.

10) Self assessment and gaining a greater self control over personal needs and service requirements.
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As the NDIS is aiming to provide appropriate levels of support services to meet the individual needs of 360,000+ people with new and pre-existing disability, their family and carers, we would like to recommend to the Productivity Commission that the NDIS assessment system include a 'self-

assessment' procedure for people with pre-existing long-term disability who already understand their individual support needs, and whether they are currently being met. The self-assessment process would speed up the assessment process, with the potential to reduce the assessment costs as it is expected to reduce the number of NDIS assessors.

Furthermore, although the NDIS would undertake the assessment to understand the individual needs of NDIS applicants, there is a number of service assessment matrix that are used by personal-care support services that could be used for the NDIS assessment to match the minimum/maximum level of support services and hours required depending on the level of persons disability.

The use of an assessment matrix supports the Productivity Commission Draft recommendation 5.7; which includes:

"The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (attendant care, aids and equipment, home modifications)".

11) There is the need for agreed common person centred outcome standards

The quality of the assessment process and of the individual assessors will likely have a large bearing on the quality and frequency of services provided to an individual. 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. The goals and outcomes of an individual are likely to change over time. The 'tools' used for this process must be calibrated to reflect this. Having some form of person centred outcome standards might assist this. Given that, in the early stages of adoption of the NDIS, most people are going to take the 'choice of package' option over 'self-directed funding' as stated in the summary, service providers will need to adequately meet the needs and desires of the person using the services.

12) Opposed to concept of a co-payment

In NSW, people with disability receiving personal care support through the Attendant Care Program and the Lifetime Care Scheme are not required to make a co-payment regardless of what their income and assets are. People with disability receiving personal care and other support services through NSW Home Care are generally requested to make a monthly co-payment; however, service recipients can request this be waived on financial hardship grounds. Although not able to quote specific data, SCIA strongly believes the majority of service users would be reliant on the DSP, and any new costs and/or charges would just exacerbate the financial hardship already faced by many service users.

Also, people with disability have the unavoidable extra cost of disability that the general community doesn't have and/or doesn't understand. Extra costs are directly related to the need for continence management and supplies,

personal care support, extra health/medical and medication costs, higher consumption of electricity and gas (particularly for people with a neurological deficit such as spinal cord injury, multiple sclerosis or multi-limb amputees) due to requiring heating/cooling systems operating for longer periods of the day for more months of the year), as well as extra water usage due to the extra time it takes a carer to assist in the shower. For people that are totally reliant on the wheelchair accessible taxi service as their only option of accessible transport, it is extremely expensive (even with a government subsidised fare for eligible participants) particularly for people living in rural and regional areas that are required to travel vast distances.

13) The need for general funding to be maintained for opt in opt out services such as peer support and advocacy.

In chapter 8 of the summary we note the possibility of 'block' funding being retained for certain services. The viability of some services is likely to be jeopardised by the introduction of a NDIS. So what might be the way forward for services such as peer support and advocacy? Having the option to retain some form of block funding would address this. There is still going to be a need for these services when the NDIS is up and running and people with disabilities will want to have access to them. If block funding is not an option, an advocacy service would have to look at alternative streams of revenue such as fundraising. Problems with funding would also lead to cost-cutting measures such as reducing wages and services. This would lead to poorer service quality to the consumer. 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.

Service quality will ultimately decide the fate of such services in a consumer choice market, but how would this be assessed, given the episodic nature of such service providers?

14) Does the disability service sector have the capacity to meet both the recognised and unrecognised need for support in the community?

Currently, the disability sector struggles to meet the demand in the community for services for those that have recognised need. With the establishment of a well funded and managed NDIS, the numbers will increase and service provision will need to be expanded to meet demand. There is recognition of unmet need which will be addressed, but what about unrecognised unmet need? Some people simply do not seek out help such as Aboriginal Australians and people from rural and regional areas.

Existing state based data on exactly who requires services can often be flawed and we would recommend is not used as a reliable source for planning future uptake of an NDIS. Often unmet need and under-met need slips through current funding gaps. This situation was highlighted during the recent NSW upper house inquiry into Ageing Disability and Home Care where an audit of all national disability related data and state based disability data, to identify gaps and real unmet need, made recommendation 1.

There is a shortage of workers in specialist disability services and carers across the range of community services, aging and disability and depressed wages in this area is certainly a factor. How this is addressed as the NDIS is rolled out will be a critical factor in its' early success. As the adoption of self-directed funding increases this will help alleviate the problem through the use of mainstream services and hiring of people from elsewhere.

The success of new services starting up will depend on how well new workers can be recruited into the disability sector. This would depend on the success of such initiatives as Care Careers, funded by the Ageing, Disability and Home Care (ADHC) Department of Human Services (NSW) and run by National Disability Services. The nature and marketing of carer jobs across Australia will need to be well thought out as people in this area have often felt marginalised and under-valued.

15) Aids and equipment have a pivotal role to play in supporting community living.
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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. It is incredible the amount of aids and equipment that breaks down on Friday afternoons and on public holidays.

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.

Close

In closing we would like to express our congratulations at the positive manner in which the rather difficult project of designing a national scheme to support all Australians with a disability has been handled.

We recognise the complexities of what some have called the 'Third pillar of social support' in Australia.

Thank you for the opportunity to provide feedback. Should you have further questions we are more than happy to assist.

Kind regards

Spinal Cord Injuries Australia
21/04/11