Spinal Injuries
ASSOCIATION
Empowering people for 50 years

A submission to the Productivity Commission Inquiry on long-term disability care and support

"A quality NDIS will transform the lives of people with a disability, their families and carers."

For further information:

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About the Spinal Injuries Association

In 2010, the Spinal Injuries Association commemorates 50 years of service to the community, a significant milestone for our not-for-profit, membership-based organisation that is committed to empowering people to lead their chosen lifestyles in inclusive communities.

Our organisation has around 2,000 members and clients throughout the state with nearly 100 staff working in offices in Brisbane and Townsville, along with 700 staff assisting our members in their homes and around 100 volunteers who donate valuable time and energy in a range of key areas.

At the Spinal Injuries Association, we promote people to be as independent as possible. We advocate for equity and inclusiveness in the community and access for everyone.

We provide services and supports that assist people on the long journey from injury to independence. Whether it’s healthcare and lifestyle advice, encouragement and inspiration from someone who has lived through the experience of sustaining a spinal cord injury or personal support assistance in the home, employment opportunities or equipment, our Association is dedicated to empowering people to rebuild their lives and regain their independence.

We are inspired each day by members and clients who are living life to the fullest, just differently than they used to. They have husbands and wives and families. They have exciting jobs and careers, play sport, travel overseas and contribute to their local communities in all sorts of ways. However this is only possible if people have appropriate supports. Unfortunately in Australia the “system” does not support everyone equally and adequately.

The Association’s mission is to enhance the lives of people with a spinal cord injury. We are passionate in our commitment to rebuilding lives, promoting and celebrating independence, and preventing injuries.

About our feedback

The Spinal Injuries Association is proud to provide the following feedback to the Productivity Commission on a national entitlement scheme that it regards as fundamentally important and enormously essential to people with a disability in Australia, as well as significant to the entire population as disability does, and can, affect such a large proportion of the population.

The introduction and spirit of the scheme as we see it reflects our values of putting the person with the disability front and centre – able to make their own choices, be independent and live life in an inclusive, integrated and accessible community.

In order to provide this feedback, we have consulted a number of people including, most importantly, our members. As Queensland’s peak body for people with a spinal cord injury, we have around 2,000 members and clients.

We also have consulted our staff who work closely with our members and clients on a daily basis. They include allied health professionals and people who have worked in the disability sector for 20+ years.

We were overwhelmed with the positive response to such a scheme by people with spinal cord injury and our staff. The Spinal Injuries Association wholeheartedly endorses the introduction of an NDIS as soon as practicable.

We are delighted to respond to your key questions.

Who should be in the new scheme and how could they be practically and reliably identified?

The scheme should be an entitlement-based scheme for people with disabilities and should be underpinned by the United Nations Convention on the Rights of People with Disabilities.

It should therefore include all people with a permanent disability eg. physical, intellectual, mental health, including genetic and acquired disability. The scheme should cover people for their entire life regardless of when they acquired their disability and should be fully portable.

The identification of people to access this scheme should be done through a number of strategies including people registered or receiving services through public and private hospitals; disability services; Centrelink; and all health services and community service providers. Education, promotion and marketing of the scheme should also be undertaken to ensure people currently not identified can self-refer.

It is important to ensure that people have access to temporary support and services as soon as they are identified as having a disability and before full assessment is undertaken. This would prevent people going into crisis or their circumstances being adversely affected or exacerbated.

Which groups are currently in need of additional support and help?

Currently all people with disabilities throughout Australia are disadvantaged by an inequitable, dysfunctional system; in some states and regions moreso than others. The assessment and supports available must be consistent across the nation. There should be no set formula for who requires additional support, as all assessments and allocation should be done on an individual's identified need.

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

The assessment tools and allocation of supports to individuals must be underpinned by the philosophy that people are provided the supports that they require to fully achieve the lifestyle that they seek. This needs to include all aspects of the individual's life, have a focus on the person's strengths and not be based on the deficit or charity model of disability.

The assessment tool needs to be a national, standardised tools taking into account not only people's physical and intellectual capabilities but also the environmental, social, educational and economic context that impacts on them. While measuring these impacts will not be straightforward, the variables outside of the individual's control can quite often have a greater impact on their life than their disability (*The Shut Out Report*, National Disability Strategy Consultation Report. Prepared by the National People with Disabilities and Carer Council 2009).

The assessment of needs should be carried out by specialised disability assessment teams who are across all of the relevant issues that impact on people's lives, in consultation with the person with the disability, the carer, the family and/or other relevant parties, if required.

How could people with disabilities or their carers have more power to make their own decisions and how could they appeal against decisions made by others that they think are wrong?

There needs to be different options for people in regard to their support packages. The option of self-managed/self-directed packages where the individual is given the funding and allowed to manage their package within set guidelines needs to be available for all people. Education and support for the person and carer should also be provided, where requested.

There also needs to be options for people to broker to service providers as many people may not wish to manage their own packages. There would need to be transparent guidelines that service providers follow in this instance to ensure that the person's direction and choice is still at the core of service provision. It may mean that independent key workers or the like are available for people to access to support them to achieve the most with their packages.

If people with disabilities want to access a service provider, they need to be provided with appropriate information about available service providers. The decision will need to be theirs alone with no pressure from funding bodies, service providers or government. Offices may be set up throughout the country like Centrelink offices where people can access independent support and information.

An appropriate appeals mechanism must be developed that is independent from government and service providers, and this needs to be accessible, transparent to all and free of charge. Safeguards must be put in place to ultimately protect the person with the disability from abuse, neglect and exploitation.

How should the amount of financial support and service entitlements of people be decided and by whom?

This should be done through the establishment of an independent expert panel to make these decisions. (A similar model to the Multiple and Complex Needs Panel in Victoria could be considered). The panel should include representation from people with disabilities, the medical sector, allied health professionals and specialist disability service providers. These specialist disability service providers may come from a range of professions or experienced individuals including case managers or advocates.

The support and entitlements that people receive need to be fully funded to meet the individual's needs.

What kind of services particularly need to be increased or created?

The highest priority areas that need to be addressed are the basic supports that allow people to live healthy lives. This is personal support, aids and equipment and access to appropriately trained staff in hospital and community health facilities. The supports that are provided need to ensure the full participation of people with a disability in all aspects of society, including employment, education, social, recreation and economic. Currently only some of these supports are provided. However the supports need to be looked at in a holistic manner and not in segments of the person's life. To ensure health is also maintained, ongoing rehabilitation and health maintenance needs to be addressed particularly for people as they age to ensure maximum independence.

Services should be focused around the individual however there are many variables in society that impact on people's life experiences. There needs to be targeted community development campaigns and programs to ensure that a shift in society's attitude results in community inclusion for all.

There is also a need for 'culture' change at the systems level to ensure that services are not only related to a person's needs but their strengths and aspirations. These programs and campaigns should include, but not be limited to, raising awareness of disability and its impact on people's lives, social inclusion, access and community capacity building.

How could the ways in which services are delivered including their coordination, costs, timeliness and innovation – be improved?

Innovation can come from individuals and groups, both small and large, and a sharing of people's experiences. Partnerships between providers should be encouraged and formalised to assist the coordination of service delivery and optimise resources, thereby enhancing the outcomes for people with disabilities.

Self-directed approaches to funding and management of support, should be further explored and implemented, where requested.

To ensure that people are getting access to the appropriate information and supports they require, a system of "community navigators" should be set up in all areas. These supports can be utilised when people first access the scheme and during different life stages or as their situations change. While these community navigators will be beneficial in the community, it is also recommended that Liaison Officers are introduced in all hospitals to support people with disabilities when they are again experiencing change and are at their most vulnerable.

There should be a review of current approaches to intake and prioritisation of need to improve flexibility and responsiveness to eligibility and requests for service.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

When people first acquire their disability, the facilitation, support or case management for individuals and the family may need to be detailed and intensive to assist people to manage the impact of dealing with their disability.

These supports can usually be reduced as individuals and families become more independent and resilient.

To ensure that adequate supports are provided, there should be a schedule of automatic reviews for people to ensure that issues are identified early or changes to their supports can be identified and acted upon when the need arises. To support these reviews, a streamlined and flexible system and a pool of funds needs to be established and available to ensure easy access for people whose circumstances change suddenly or unexpectedly.

All aspects of this system are based around empowerment of people with disabilities and ensuring that they are in control of their lives and destinies.

Providing people with access to appropriate health and lifestyle education and information will assist individuals to manage or take greater responsibility of their own health and lifestyle choices. This information should be free and available in all formats for people to access. This could perhaps be achieved through information hubs throughout the country.

How could a new scheme encourage the full participation by PWD and their carers in the community and work?

If the scheme takes a holistic and strengths-based approach, and addresses all aspects of people's lives, this will make participation in the community more accessible than it has ever been.

It will mean that people will have personal support to get out of bed, equipment to access the community, access to training and education that will assist them with finding employment, and provide financial security. Concurrent with this, must be investment in community development and disability awareness programs and an investment in attitudinal changes in the community.

How can a new system ensure any good aspects of current approaches are preserved?

A thorough review (literature and practice) of current systems in Australia, with the full involvement of people with disabilities and their representatives identifying best practice, needs to be undertaken and documented.

The scheme should also have a research, review and policy department supporting the ongoing development of models/frameworks of service delivery and community inclusion. This department can commence undertaking research into overseas approaches while the Australian system is under construction.

What should be done in rural and remote areas where it is harder to get services?

The scheme could explore the development and use of technology (eg video linking, real time web conferencing) to provide services and education in remote areas.

Further, the capacity to develop one electronic record for individuals receiving services should be considered.

Commonwealth Respite and Carelink Centres could be expanded to rural and remote areas to provide information, education and resources to people with disability under the scheme.

The scheme needs to consider and include the extra costs involved in staff recruitment, training, salaries, travel and other infrastructure for remote and rural areas. Remuneration and other incentives to attract and retain qualified workers in rural and remote areas need to be considered.

In addition, appropriate training and support for a rural and remote workforce to prevent isolation and enhance quality of performance is essential.

People with disability require flexible support options with reduced bureaucratic practices. The development of formalised partnerships with a range of services to more effectively coordinate resources and provide improved support to people with disability should be encouraged.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the run around) and duplications in the system?

To ensure that there is no overlapping of assessments and that associated paperwork is not duplicated, there needs to be a single point of entry into the national system with assessments and all other systems administered in the states that people live. An appropriate national assessment tool needs to be utilised and all forms need to be standardised.

Partnerships with services to better coordinate assessment and service delivery needs to be encouraged and formalised.

A national database needs to be developed to store all relevant assessment and registration documentation that can be accessed by relevant accredited parties.

How should a new scheme be funded?

The Spinal Injuries Association fully supports the implementation of a nationally funded disability support scheme however we believe that it is the federal government's responsibility to analyse how this scheme will be funded.

However, we do not support an identified levy labelled a 'Disability Levy' as this will only create greater resistance and negativity in the general community about people with disabilities.

While we fully support a national disability insurance scheme, we also believe that people should have access to common law claims. In the instance that a person also has a common law claim, they will not be able to be compensated for supports that are provided through a national scheme to ensure that 'double dipping' does not occur.

However, people should still be able to be compensated for pain and suffering, loss of income and other aspects of their disability that cannot be met by the scheme.

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

All monies put into the disability sector should be seen as an investment in people with disabilities and not as a burden on the community. Measureable outcomes from this investment will include reduction in expenditure on health, the criminal justice system and income support pensions. There will also be greater contribution to the economy through greater purchasing power and the payment of increased taxes as people with disabilities secure employment due to the greater supports in their lives.

What are your views about the "nitty gritty" aspects of the scheme that will make it work practically?

There needs to be a national assessment process, with standardised tools and a national database for information and records.

The scheme should be underpinned by the principles of the UN Convention of the Rights of People with Disability. It must be rights-based, with a focus on an individual's strengths; it must be easily accessible to people with disability; and it must promote empowerment and self-directed support.

The scheme will require robust evaluation, dispute resolution and an appeals process.

How long would be needed to start a new scheme, and what should happen in the interim?

A National Disability Insurance Scheme needs to be established as soon as practical and phased in commencing within a 12-18 month period. In the interim, perhaps the current compensation and insurance systems in each state could pool funds nationally as Phase 1 of the roll-out of the scheme.

Media Release **August 2010**

The power of support – why a national disability support system is crucial

Sixteen years ago, having support made a lifetime of difference to Vicki Field.

Graham Streets, however, never had support.

Today, both Vicki and Graham are passionate advocates for a proposed National Disability Insurance Scheme (NDIS) that the Productivity Commission is currently investigating, with the outcome to be decided in 2011.

Vicki and Graham met in dreadful circumstances – in the Spinal Injuries Unit at Brisbane's Princess Alexandra Hospital in 1994 following horrific road accidents.

Vicki was 18 at the time and studying science at University of Queensland, while Graham was a 26-year-old successful small business owner, running his own electrical contracting company.

Both were outgoing, active, goal-oriented young people with plenty of plans for the future.

Following Vicki's single vehicle car accident where she sustained C6 quadriplegia and internal injuries, and Graham's motorcycle accident on the Gateway Arterial, which not only caused C4 quadriplegia, but the top half of his fingers on his left hand were burnt to the bone from the bike's exhaust, both spent many months (14 for Vicki and 11 for Graham) recovering and rehabilitating in hospital.

In 1995 when both were physically able to leave the Unit, post-hospital support and assistance was minimal. However, at the time there was a pilot project operating called the Continuum of Care program. Four people were randomly chosen (two from the Spinal Injuries Unit and two people with acquired brain injuries).

Like all lotteries, someone has to win and someone has to lose. In this instance, Vicki won and received funding that allowed her to move into temporary housing, before she moved to on-campus accommodation at UQ. The funding also allowed her to receive personal care, equipment and a case manager, who helped her navigate the confusing and bureaucratic minefield of working out what disability and support agencies were available, and what she was entitled to.
"There's no way I would have been able to go back to university if I didn't receive that Continuum of Care funding. I think going back to uni and surrounding myself with people was a really important way forward for me so I could focus on the future," Vicki said.

Graduating with a Bachelor of Economics, Vicki eventually moved into her own unit at West End, where she still lives. Working as an Acting Senior Program Officer for the Department of Communities (where she has been employed for five years), Vicki said she was forever grateful that she did not have to rely on, or be put in the situation, where she had to ask her family to care for her when she left hospital.

“It’s just not a workable relationship – your parents should not have to look after you,” Vicki said.

“Not only was I able to pursue my own opportunities after leaving the Unit because of that funding, but my whole family could continue to live their lives. For example, my mum went back to uni and studied law. How could she have done that if I’d been forced to move back home and become reliant on my family?”

Graham had no such choices. With “grossly inadequate” assistance available, Graham was forced to move back in with his parents at their property at Narangba, north of Brisbane.

“That was a huge mistake, but there was no other option. Being at Narangba was very isolating. There were no footpaths or anything like that. And at that time, personal care nurses didn’t cover the area every day of the week. I couldn’t get people in to assist me, so mum had to do it all herself. And god bless her she did it all, but at her age I’m supposed to be looking after her, not the other way around.”

When Graham moved back home, his parents were in their mid-60s and about to retire. Those plans quickly changed and Graham’s mother became his full-time carer.

“The eight years I spent at home meant by the time I finally got into my own house, I was already eight years behind,” Graham said.

“If I’d had enough funding to get personal care support from the beginning, it would have made the world of difference.

“The day I knew I had to move out no matter what was when I came into the living room to ask mum something and found her crying with her head in her hands.

“She said nothing was wrong but it hit me like a sledgehammer. The reason she was crying was because of me.

“You’re supposed to be looking after your parents in their twilight years, not have them dress you, feed you, clean you up after a bowel accident or be reluctant to go out fearing leaving you home alone. It can be quite humiliating and something no family member should be burdened with.”

Desperate to live independently and relieve his parents, Graham moved into a temporary respite centre, which he refused to leave until housing was found for him.

“I ended up being at the centre for six months. All together I had been waiting eight years for accessible housing.”

Because Graham only received enough funding when leaving hospital to get a powerchair and for the family home to be made accessible, his long-planned dream of studying electrical engineering at university was quashed.

“If there had been that support and assistance available for me to go back to uni, then I could have studied and gone back into the workforce. But I didn’t have the choice,” Graham said.

“I wish I had found employment before I left hospital. I wished a lot of things that I just wasn’t able to do because there was no support available.”

While Vicki enjoys an active life with few health problems, Graham has lost almost 25 kilograms in the past four years and his doctors still cannot find the reason why.

At the moment his funding via Disability Services enables him to 38.5 hours of personal care a week (from 8.30am-11.30am and 9.30pm-midnight each day). However, over the past three months Graham has been experiencing ongoing pressure sores and has spent most of that time in bed.

“I’ve had to call one of my Personal Care Assistants (PCAs) at four o’clock in the morning almost every two weeks of late because I’ll wake up in the middle of the night and be freezing or boiling hot unable to adjust my covers. People with spinal cord injuries can’t regulate their own body temperature, and as I have very limited hand function, I often have to just lay there until my PCA turns up in the morning at 8.30,” Graham said.

“I need more funding now basically so I don’t cook my kidneys because my doona’s too warm. I need that extra bit of assistance overnight so I can actually get a full night’s sleep and not feel as though I’ve been hit by a truck each day.”

While Vicki and Graham have had vastly different experiences over the past 16 years, both agree a NDIS is vital for Australians who have, or sustain, a permanent injury or disability.

“What if it was your son, or wife, or mother, or grandfather who had a spinal cord injury or any type of disability?” Graham said.

“Are you going to drop your job and go and care for them for the rest of their life?

“Just wait until you need ongoing support to be able to live in an accessible home in an accessible community and you want to go back to work and maintain some semblance of your former life. Then you’ll realise that not only is a National Disability Insurance Scheme an investment for the one in five Australians who have some form of disability, but also for the people who care for them.”

A NDIS would be a no-fault insurance scheme funded by all taxpayers through general revenue or an extension of the Medicare insurance levy.

As someone who received adequate support to allow her to return to live as independently as possible following her injury, Vicki knows the value of a no-fault program that provides funding for essential personal care, therapy, aids, equipment, home modifications and access to the community, education and training.

“Wouldn’t you like to know if you were in a situation where you needed personal care support that you wouldn’t have to wait three or four or 10 years before you could get on with your life.

“Why not reduce that long period for individuals who are waiting to get their own house by giving people what they need when they need it.”

Spinal Injuries Association CEO Mark Henley has been working tirelessly with other state and national disability organisations to get the sector’s message out to politicians and the general community that a NDIS is essential.

“For people who sustain permanent disabilities, there is no uniform, instant support to meet their needs,” Mr Henley said.

“A national insurance initiative would not only be highly effective and humane, but fair for every person who requires support.”

Mr Henley said for a NDIS to meet the requirements of all Australians with a disability, both now and in the future, it needed to be fully retrospective and include people who acquired a permanent disability from birth, or at any stage during their life.
“The situation in the disability sector is becoming increasingly dire. Without a funding plan for Australians with a disability, our nation will continue to experience immense turmoil as a generation of ageing carers pass away and people face that difficult choice – to return home to live with ageing carers, be forced to live in institutions with other people with disabilities, or fight their entire lives to receive any kind of financial support, no matter how miniscule, like in Graham’s case.

“Vicki’s living proof that having support from the outset positively impacts on the rest of your life. Vicki had plenty of choices and she’s made the most of them. Graham never had a choice and the results have affected his entire life, and his family’s.

“It’s not too late to give other people choices by financially supporting and empowering them to lead fulfilling, independent lives in the community.”

This year the Spinal Injuries Association celebrates its 50th anniversary of supporting 2,000 Queenslanders who have spinal cord injuries.

For more information, please visit www.spinal.com.au or www.ndis.org.au.

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Version 1

The Spinal Injuries Association supports a National Disability Insurance Scheme

Join us in advocating for a fully retrospective NDIS that supports people who acquire a permanent disability from birth or at any stage during their life.




A NDIS will transform the lives of people with a disability, their families and carers.

What is a NDIS?

A National Disability Insurance Scheme is a national, no-fault insurance scheme that provides funding for people with a disability for personal support, therapy, aids and equipment, home modifications, and employment training.

Most importantly, a NDIS would assist everyone with a permanent disability, no matter how, or when, their disability is acquired. Currently, 700,000 Australians need daily personal support. Only a small percentage of people are receving the support they require.

Not only would a NDIS be welcomed by Australians with disabilities, but also by the people who support them – family and friends.

Frequently Asked Questions

Q: Who would be eligible to receive support from a NDIS?

A: *People born with a disability, or who sustain a disability through accident, injury or as a result of a medical condition, and require assistance with daily living tasks. People with permanent disabilities acquired before age 65 would be eligible for life, without reference to cause and treated equally based on needs.*

Q: What if someone sustained a permanent disability because they, for example, had a car accident. Would they still be eligible?

A: *A NDIS would be a no-fault scheme. The provision of support for people with disabilities would be separate to legal action for negligence/culpable behaviour.*

Q: How would a NDIS be funded?

A: *By taxpayers through general revenue or through a Medicare-style levy.*

Q: When will we know if a NDIS is to be implemented?

A: *The findings from the Productivity Commission's current enquiry into a NDIS will be released as a report on 31 July 2011.*

Why the Spinal Injuries Association supports a NDIS

Sustaining a permanent disability is something nobody prepares for. Generally, disabilities are acquired in an instant, with no forewarning.

Around 90 Queenslanders a year sustain spinal cord injuries. For these people, they not only have to recover physically from the immense trauma sustained, but they will have to, among other things:

- work out if it’s possible to return to their home and what will need to be modified to make it accessible for a wheelchair;
- organise and find personal support if the level of their injury is so high they require daily care;
- see if they can return to their previous job, if they are able to re-train to seek other employment, or if they have to go on a disability pension;
- learn how to access their community and the built environment in their manual or electric wheelchair; and
- deal with ongoing health and lifestyle issues, and equipment purchase.

“Wouldn’t you like to know if you were in a situation where you needed personal care support that you wouldn’t have to wait three or four or 10 years before you could get on with your life,”

– Spinal Injuries Association member.

Want to take action? Here's how….

Implementing a NDIS means enormous social reform. To make sure our politicians know a NDIS is something the community wants and urgently needs, we need your support.

There are four major ways you can influence the findings of the Productivity Commission's report into a proposed NDIS:

1. Email your MP to express your support

2. Visit your MP and tell them face-to-face how important a NDIS is

3. Participate in the inquiry process

4. Spread the word

Visit www.ndis.org.au/takeaction.html for more information on how to be involved.

The Spinal Injuries Association is the peak body for people with a spinal cord injury in Queensland.

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