

Submission to the
Federal Government's
Productivity Commission Inquiry into a National Disability Long-term Care and
Support Scheme

From

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1) Introduction

Spinal Cord Injuries Australia (SCIA) is Australia's leading community organisation supporting people catastrophically injured with a spinal cord injury (SCI) and similar conditions. SCIA was established as the Australian Quadriplegic Association in Sydney in 1967 by a group of young men who had survived SCI resulting in quadriplegia and wanted to advocate for appropriate support services as none existed at that time. SCIA has a long history of developing and providing services to people with SCI, their family, friends and carers and being a voice for their concerns, both socially and to government.

As one of the organisations that assisted the New South Wales Government in the development of the Lifetime Care Scheme (LTCS)—a 'no fault' scheme aimed at providing 'whole of life' support to individuals that have either acquired a brain injury or a SCI as the result of a motor vehicle accident—SCIA has the history and foresight to provide appropriate feedback and comments to the Productivity Commission.

With the development of a shared responsibility approach to funding disability services, the concept of a 'no fault' national disability insurance scheme has always been of interest to SCIA as it is enthusiastic to see the benefits that will come to all people living with a disability through increased financial autonomy propagated by the option of individual and self directed funding. The benefits to individuals should also have a direct affect on addressing much of the financial waste that exists within the disability support system often due to the lack of flexibility and inability to address individual needs.

SCIA supports the work of the Productivity Commission and the assigned members of the panel in putting forward the best case for a shared responsibility scheme.

2) Scope of the Review

The Productivity Commission is requested to undertake an inquiry into a National Disability Long-term Care and Support Scheme. The inquiry should assess the costs, cost effectiveness, benefits, and feasibility of an approach which:

- provides long-term essential care and support for eligible people with a severe or profound disability on an entitlement basis and taking in to account the desired outcomes for each person over a lifetime;
- is intended to cover people with disability not acquired as part of the natural process of ageing;
- calculates and manages the costs of long-term care and support for people with severe and profound disability;
- replaces the existing system of funding for the eligible population;
- ensures a range of support options are available, including individualised approaches;
- includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime;
- assists the person with a disability to make decisions about their support; and
- provides support for people to undertake employment where possible.

In undertaking the inquiry, the Commission is to:

1. Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability.

The Commission is to include an examination of a social insurance model on a 'no fault' basis, reflecting the shared risk of disability across the population. The Commission should also examine other options that provide incentives to focus investment on early intervention as an adjunct to, or substitute for, an insurance model.

2. The Commission is to consider the following specific design issues of any proposed scheme:

- eligibility criteria for the scheme, including appropriate age limits, assessment and review processes;
- coverage and entitlements (benefits);
- the choice of care providers including providers from the public, private and not-for-profit sectors;
- contribution of, and impact on, informal care;
- the implications for the health and aged care systems;
- the interaction with, or inclusion of, employment services and income support; and

- where appropriate, the interaction with:
 - national and state based traumatic injury schemes with particular consideration of the implications for existing compensation arrangements; and
 - medical indemnity insurance schemes.
3. Consider governance and administrative arrangements for any proposed scheme including:
- the governance model for overseeing a scheme and prudential arrangements;
 - administrative arrangements, including consideration of national, state and/or regional administrative models;
 - implications for Commonwealth and state and territory responsibilities;
 - the legislative basis for a scheme including consideration of head of power; and
 - appeal and review processes for scheme claimants and participants.
4. Consider costs and financing of any proposed scheme, including:
- the costs both in the transition phase and when fully operational, considering the likely demand for, and utilisation under, different demographic and economic assumptions;
 - the likely offsets and/or cost pressures on government expenditure in other systems as a result of a scheme, including income support, health, aged care, disability support system, judicial and crisis accommodation systems;
 - models for financing including general revenue, hypothecated levy on personal taxation, a future fund approach with investment guidelines to generate income;
 - contributions of Commonwealth and state and territory governments; and
 - options for private contributions including co-payments, fees or contributions to enhance services.
5. Consider implementation issues of any proposed scheme, including:
- changes that would be required to existing service systems;
 - workforce capacity; and
 - lead times, implementation phasing and transition arrangements to introduce a scheme with consideration to service and workforce issues, fiscal outlook, and state and territory transitions.

3) **Submission**

In providing a submission to the Productivity Commission's inquiry into a National Disability Long-term Care and Support Scheme (SCHEME) SCIA would like to present its submission as ten principles. These ten principles need to be considered as key directions that SCIA believes should be incorporated into any support scheme. The principles outline SCIA's recommendations for the aims and objectives of the scheme and reflect our concerns regarding its possible misdirection.

Ten Principles for a National Disability Long-Term Care and Support Scheme

Scheme Requirements

- 1. A person who acquires a disability through a 'fault based' accident and has historically received a compensation payout should still be able to pursue compensation outside of the treatment under the SCHEME.***

Treatment under the SCHEME deals with the disability whereas compensation pursuit is concerned with rights and recompense. SCIA understands this is endorsed by the NSW Lifetime Care Scheme Authority (LTCSA).

Under common law principles, people acquiring an injury resulting in permanent disability are able to seek compensation for 'pain and suffering' and general loss of earnings. These claims for damages are outside of claims made to secure ongoing rehabilitation and lifelong support for the medical, rehabilitation and support costs. A SCHEME should not impinge on the existing rights of an individual to seek compensation under present legislation in any jurisdiction. Any efforts to reduce or limit existing rights would be contrary to the intent of the SCHEME.

SCIA supports the direction and recognition of the right to claim compensation as implemented by the LTCSA.

- 2. Under the SCHEME there should be an emphasis on service improvement through the creation of minimum service standards.***

One of the recognised negative implications of the SCHEME is that it may force the cost of service provision down and compromise service quality.

This is one of the key concerns voiced by many of SCIA's members. It is also a concern of many organisations providing services to people with a disability. It is a misnomer to believe that organisations providing services to people with a disability are heavily funded. Organisations reliant on government funding often have to survive on inadequate budgets, trying to attract high quality staff whilst offering minimum wages and aiming to provide high quality services.

The SCHEME could force the costs of service provision down through a process of renegotiation of all contracts. This would naturally occur when the SCHEME authority became the contract holder as opposed to the state and territory governments that have traditionally negotiated for the funding for service provision.

As a way of protecting the quality of service provision there should be a set of minimum service standards developed through consultation with consumers and their representative organisations, maintaining quality of services to meet the individual consumer's needs, and with service providers who know what is currently deliverable.

A set of service standards are important as they define the quality that a person can expect in terms of receiving services, but they can also help to define what service funding, development and training may be needed at the provider level.

- 3. *The SCHEME should provide the option for direct individual funding. Service users should be able to purchase services that they require with support mechanisms, such as access to accredited service managers and training if and/or when needed, to provide assistance in managing these funds. Should a service user choose not to manage their funds, then an accredited agency can do so and report to the individual.***

Direct individual funding gives flexibility to the person with a disability. It allows them to purchase services and provides autonomy for those who are able to manage the accountability requirements.

There are many benefits of this funding approach. It creates a market force to tackle, or preferably prevent, poor quality service provision—the emphasis is on service providers to raise their game to retain clients. If the service provider is unable to meet a service user's needs then it may create a situation whereby the provider needs to work with a service user to understand what needs to change and perhaps lobby for funding etc.

Reactive service providers should produce greater dividends to service users as a person's lifestyle choices take precedence over their services.

Direct individual funding should also bring greater benefits to the budget of the SCHEME in ensuring that allocated care hours and provision of services are only delivered as required. This would reduce the waste created by fear of losing care hours and other services. Direct individual funding and responsibility is not suitable for all people with a disability but SCIA supports the principle.

Depending on the number of people that choose the direct individual funding option, it may be a requirement for existing or new service providers to support and train individuals to manage all aspects of individual funding, including bookkeeping, rosters and timesheets, paying wages and superannuation, advertising and recruitment, as well as training personal care staff.

It would be good to see flexible levels of participation provided by service providers, resulting in the service users being as involved as they are comfortable with. At all times, when working in this arrangement, it should be reinforced that the service users are essentially in charge and regular formal reporting needs to occur.

- 4. *The SCHEME funding levels for services should be tiered to ensure that people will receive an appropriate assessed level of funding to meet their individual growth needs. There should also be adequate flexibility built into the system to cater for needs that change over time (short-term or long-term) and appropriate mechanisms in place to cater for these changes.***

The SCHEME should rationalise funding and provide it to service users who need it based upon recognised life/growth requirements. Tiering should be based upon standard definitions of disability type and levels of impairment. There should be recognition of the needs that different disability groups have and appropriate funding planned for these individuals.

This funding needs to have an element of flexibility built into it to support the service user in making life choices, engage with education, training and employment etc. All of which come at varying costs.

There has been much work done to create the basis for this approach within the LTCS's guidelines for levels of attendant care for people with a SCI. Almost all usual activities have been defined by working parties, involving health professionals, insurers, disability organisations and individuals with a disability.

Although currently limited to the chosen activities' impact on care hours it could easily be expanded to look at a whole host of life desires and individual aims including holidays and travel as well as respite.

5. *There should be clear guidelines as to the range and extent of services available under the SCHEME. These guidelines should be outcome based rather than process based.*

Too often support services are pigeon-holed into categories that meet the needs of the funding bodies but may be inadequate or inappropriate in supporting individual service user needs, e.g. the use of service types such as 'community participation'.

SCIA supports the complete rationalisation of existing support services and programs with the aim of ensuring that they are relevant to service users' needs and have a strong focus on being non-intrusive, just complementary.

Historically service development has been patchy with new and innovative services often coming through from grass roots organisations. These organisations have greater contact with their clients than the larger state funding and administrative bodies. Although the state funding and administrative bodies undertake service user and carer consultation, it is SCIA's experience that the feedback provided by service users and their carers is noted but not always acted upon to address the issues and improve the services.

It is SCIA's wish that through the creation of the SCHEME more emphasis should be placed on fostering a positive service development environment in response to real service user needs.

Service users also need to be provided with a clear understanding of the level of financial support that will be provided once it is defined, for example how much can be allocated to home modifications? This is important to ensure that expectations of what the SCHEME can provide are managed but also to provide clarity of exactly what a service user may receive.

By providing information about the types of services and the funding available it is empowering the service user to make informed choices. This stands in marked contrast to the current situation where support services and programs are generally applied by case managers or service providers to an individual through a perceived need.

6. *The SCHEME should be administered by an authority that is directly responsible to both the federal government and to its service users, possibly by a cooperative membership type approach.*

This concept is designed to increase the level of involvement that people with a disability have in their own destinies. Further it provides quality improvement and clear accountability to the community for the support services and programs it funds.

The idea of bringing people with a disability, who receive funding under the SCHEME, into the discussion around service development is certainly a novel one. SCIA believes there is great benefit of service users being involved in the upper level planning process. Perhaps even, as we have suggested, have the SCHEME run as an administrative cooperative or make all service users directors of the SCHEME.

This doesn't need to be as complicated as it may appear. National state-by-state annual general meetings could be a main route for communication and discussion. In addition to this a scheme could be developed for sounding out members to develop new ideas around support service and program development as well as formal critiques of where things are going well or require improvements.

If the SCHEME wants to increase a person's independence with individual funding and an emphasis on participation then many of the core functions of the SCHEME authority should be open to scrutiny through a formal mechanism.

External auditors and review panels should be utilised to make sure that efficiency of operations are maintained and that clients are receiving the services they need. We are aware that in NSW the LTCSA is open to public scrutiny by an annual parliamentary review. This is a great starting point.

- 7. Examples of best practice should be looked upon as drivers for support service and program development across the board. An annual review board involving stakeholders could contribute to ongoing service development. This review board could also be tasked with bringing new innovation from overseas to improve service delivery in Australia. Membership of this board should be reviewed every two years. Further to this approach an annual external service quality audit could be utilised to provide impartial information as to the quality of support services and programs being funded.***

One of the functions of the SCHEME should include a research and consultative body to continually look for 'best practice' in support service and program delivery, as well as innovative ways that have improved the quality of life for people with a disability overseas. Coupled with an ongoing dialogue with service users who know intimately the positive outcomes and failings of any service or program as they live with the impact, this should help the SCHEME develop.

Another of the great concerns that SCIA hears constantly from our members is that they feel excluded from service planning, that they are

mere recipients of services which appear to be designed and created to be as inflexible as possible.

It should be a core task of the SCHEME to work towards a policy of continual self improvement. Advice should be sought to improve areas such as administration, service eligibility criteria, service scope, service coverage (geographic) etc. The feedback required to support this policy should be gathered from both internal means (audits, compliance with national service standards and service reviews) but also external. External feedback can be achieved through regular service user consultations, formal mechanisms, clearly demonstrated excellence in complaint handling with an aim to look for systemic failures of individual complaints and other means.

We support the creation of an independent board to oversee the operations of the SCHEME and for that board to have membership terms of two years. Two years allows sufficient time to obtain a thorough understanding of the program but avoids board members becoming stuck in the 'machine'. It also opens up the board to a regular flow of new people with new ideas.

8. The SCHEME should be funded directly from treasury rather than from a myriad of sources, as is the New Zealand model. Transparency should be achieved by a clean line of funding so that costs can be analysed and appropriate budgets allocated.

There should be a clear and transparent method of funding the SCHEME through treasury with the funding being sourced via a levy, such as a Medicare levy, that could be imposed on all working Australians. In the set up phase of the SCHEME it could also receive funding from existing 'no fault' compensation schemes such as the LTCS and the Victorian Traffic Accident Commission (TAC). Once the SCHEME is fully established we would expect the state based schemes to be fully absorbed into the SCHEME potentially creating either another standard funding route or an argument to cease motor vehicle levy specific funding.

Although the New Zealand 'no fault' disability support program is a great service model its downfall is the diversity of funding sources which has resulted with a great funding shortfall. The New Zealand model uses local council payments, investments and even petrol taxes and a host of other funding sources which is dangerous to a funded service that provides for critical care. It also opens up your revenue sources to a myriad of either competing expenditure requirements or even global market forces.

The LTCS receives a 'clean' funding stream through the NSW Compulsory Third Party (CTP) Green Slip levy, paid for by all NSW motor vehicle registrations, as a base for funding the SCHEME.

Replicating this clear funding through a Medicare levy on a national basis is a logical approach. It provides certainty of funding whilst ensuring that all Australians buy into the SCHEME.

9. *The SCHEME should have a focus on choice of service provider for all service users and not be limited to selecting a few ‘super’ providers. Often the best, adaptive and reactive service comes from smaller service providers.*

With regards to service delivery, it's easy to see that it is far more simplistic for the SCHEME to contract more services from fewer providers but SCIA believes this could drive service standards down and deny innovation. Support services and programs could become compromised as when a smaller number of support services are delivering services to a large number of service users their individual needs can get lost in the need to generalise services.

As part of a service development role smaller disability support services often realise innovative approaches to service delivery that bring benefits to people with a disability.

The innovation of a small organisation that provided support services has led to the Attendant Care Program in NSW—a low cost emergency service—and a host of other programs all conceived by small organisations. It is this ability to be able to address issues and foster the innovation needed to provide sensible solutions that we believe is at the core of smaller organisations.

The smaller organisations are often unencumbered by the bureaucracy that may exist in larger organisations. This can have the benefit of more adaptive, reactive and client focused service delivery. There may even be cost savings in using this approach when comparing similar service delivery costs. They often specialise in working with people who have a specific disability type with knowledge that could become lost in larger organisations. This is an important issue as it can be overlooked when creating a new support service and program from the ground up at a federal level. By supporting and working with smaller specialised organisations it can reduce the generalisation of disability type to a more reasonable level.

SCIA also believes that should the Productivity Commission recommend that individualised funding be incorporated into any national scheme then potentially they will be setting up larger service providers to fail. Smaller, more innovative, organisations will be more adaptive than larger organisations with large numbers of trained service personnel.

10. *The SCHEME should have a strong focus on research. It should be a stated aim of the SCHEME to ensure that all Australians with a disability that have the potential for a cure leading to either recovery or a decrease in the effects of their disability have research undertaken to support them. The SCHEME is an ideal vessel to do this.*

It is a logical channel for a body tasked with all things to do with a disability to also undertake or fund research for 'cures'. This could be through medical, social and physical intervention that all bring benefits to a person with a disability and work to reduce the effects of their disability. Forming close networks with international research bodies and facilities should be a function of the SCHEME.

We recognise that with a limited amount of funding into the SCHEME service provision and direct support are the main priorities but certainly fostering a strong research ethic is a progressive aim.

Specific state based disability research funding could be used to augment national research costs lessening the impact on the insurance SCHEME as states have a clear interest in supporting their residents.

We hope that with research into areas such as Multiple Sclerosis and 'cures' for SCIs moving forwards the SCHEME could support research and bring even greater change to peoples lives then simply empowerment through funding.

4) Summary of Recommendations

- 1. A person who acquires a disability through a 'fault based' accident who has historically received a compensation payout should still be able to pursue compensation outside of the treatment under the SCHEME.**
- 2. Under the SCHEME there should be an emphasis on service improvement through the creation of minimum service standards.**
- 3. The SCHEME should provide the option for direct individual funding. Service users should be able to purchase services that they require with support mechanisms, such as access to accredited service managers and training to provide assistance in managing these funds, available as needed. Should an individual choose not to manage their funds themselves then an accredited agency can do so and report to the individual.**
- 4. The SCHEME funding levels for services should be tiered to ensure that people will receive an appropriate assessed level of funding to meet their individual growth needs. There should also be adequate flexibility built into the system to cater for needs that change (short term or long term) over time and appropriate mechanisms in place to cater for these changes.**
- 5. There should be clear guidelines as to the range and extent of services available under the SCHEME. These guidelines should be outcome based rather than process based.**
- 6. The SCHEME should be administered by an authority that is directly responsible to both the federal government and to its service users. This could be possible by a cooperative 'membership' type approach.**
- 7. Examples of service best practice should be looked upon as drivers for service development across the board. An annual review board involving stake holders could contribute to ongoing service development. This review board could also be tasked with bringing in new innovation from overseas to improve service delivery in Australia. Membership to this board should be reviewed every two years. Further to this approach an annual external service quality audit could be utilised to provide impartial information as to the quality of service provision currently being funded.**
- 8. The SCHEME should be funded directly from treasury rather than from a myriad of sources as is the New Zealand model. Transparency should be achieved by a clean line of funding so that costs can be analysed and appropriate budgets allocated.**

- 9. The SCHEME should have a focus on choice of service provider for all service users and not be limited to selecting a few 'super' providers. Often the best, adaptive and reactive service comes from smaller providers.**
- 11. The SCHEME should have a strong focus on research. It should be a stated aim of the SCHEME to ensure that all Australians with a disability that have the potential for a cure leading to either recovery or a decrease in the effects of their disability have research undertaken to support them. The SCHEME is an ideal vessel to do this.**

Thank you for the opportunity to provide a submission into the Federal Governments Productivity Commission Inquiry into a National Disability Long-term Care and Support Scheme.