Submission No 13

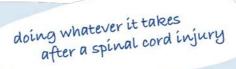
FIFTH REVIEW OF THE EXERCISE OF THE FUNCTIONS OF THE LIFETIME CARE AND SUPPORT AUTHORITY

Organisation: Spinal Cord Injuries Australia

Date received: 26/03/2014

The Exercise of the Functions of the Lifetime Care and Support Authority (5th Review) Submission by Spinal Cord Injuries Australia March 2014









The Exercise of the Lifetime Care and Support Authority (5th **Review) Submission - March 2014**

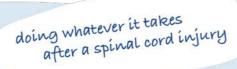
Terms of Reference

That, in accordance with section 11 of the Safety, Return to Work and Support Board Act 2012, the Standing Committee on Law and Justice be designated as the Legislative Council committee to supervise the exercise of the functions of the following authorities:

- (a) Lifetime Care and Support Authority under the Motor Accidents (Lifetime Care and Support) Act 2006,
- (b) Motor Accidents Authority under the Motor Accidents Compensation Act 1999 and the Motor Accidents Act 1988,
- (c) WorkCover Authority under the Workplace Injury Management and Workers Compensation Act 1998, and
- (d) Workers' Compensation (Dust Diseases) Board under the Workers Compensation (Dust Diseases) Act 1942.
- 2. That the terms of reference of the committee in relation to these functions be:
 - (a) to monitor and review the exercise by the authorities of their functions,
 - (b) to monitor and review the exercise by any advisory committees, established under section 10 of the Safety, Return to Work and Support Board Act 2012, of their functions,
 - (c) to report to the House, with such comments as it thinks fit, on any matter appertaining to the authorities, and the advisory committees, or connected with the exercise of their functions to which, in the opinion of the committee, the attention of the House should be directed,
- (d) to examine each annual or other report of the authorities and report to the House on any matter appearing in, or arising out of, any such report, and LEGISLATIVE COUNCIL

STANDING COMMITTEE ON LAW AND JUSTICE

- (e) to examine trends and changes in compensation governed by the authorities, and report to the House any changes that the committee thinks desirable to the functions and procedures of the authorities, or advisory committees.
- 3. That the committee report to the House in relation to the exercise of its functions under this resolution at least once every two years in relation to each authority.
- 4. That nothing in this resolution authorises the committee to investigate a particular compensation claim under the legislation referred to in paragraph 1.







Spinal Cord Injuries Australia Background:

Spinal Cord Injuries Australia (SCIA) was formed in 1967 by a group of young men who acquired a spinal cord injury resulting in quadriplegia, and who wanted to live in the community and contribute to society, but there were no government provided services to support their needs. This group of young men created SCIA, which was originally named Australian Quadriplegic Association (AQA), which changed its name to SCIA in 2003.

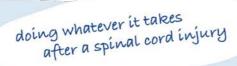
SCIA's Mission "Life without Barriers" is focused to get people with a spinal cord injury (resulting in paraplegia or quadriplegia) 'back on track' by finding the solutions to address barriers that may arise and to provide support to ensure people with a spinal cord injury and similar conditions remain actively involved in personal, social and vocational activities.

SCIA has a proud history of successfully advocating for the development, implementation, review and improvement of the various types of disability, health, community, transport and general support services and programs.

Submission:

Introduction:

SCIA would like to thank the NSW Law and Justice Committee for enabling it to have the opportunity to make this submission. This submission does not address all of this review's terms of reference but it provides comments and suggestions with the aim of raising awareness of the issues in conjunction with options for the Law and Justice Committee to consider when making its recommendations. SCIA anticipates this submission will be given serious consideration and SCIA is able to clarify and/or provide further information about the submission if required.







Employment of Family Members as Attendant Care Workers

Further to the comments made in the NCOSS submission on this issue, notwithstanding the NCOSS support for people with disability employing family members as attendant care workers in specific circumstances, SCIA understands that all families are unique and have different dynamics, and the implications for a person with disability employing a family member as an attendant care worker creates a scenario of "employer" and "employee", which certainly changes the family dynamics.

As people with disability can be very vulnerable, there can be awkward scenarios where a domestic argument occurs between the person with disability and that employed family member, which may not be resolved prior to the next time the person with disability requires the support by the employed family member. And the person with disability may not receive the care and support from the family member as expected, or "person centred".

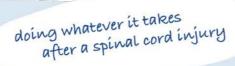
Also, on a different matter, the ability to employ a family member as an attendant care worker provides that family member with an opportunity to earn an income and also receive superannuation, which is not possible to receive superannuation if the family member is eligible for, and receiving, the Carer Payment through CentreLink.

Quality and Selection of Attendant Care Workers

Further to the comments made in the NCOSS submission, which included praise for the LTCSA for enabling LTCS participants to choose their own attending care workers and coordinators, SCIA would like to know if LTCS participants being provided with the option of "direct funding packages" that would provide LTCS participants with the opportunity to directly employee and manage their attendant care workers and other related support services? This option would also contribute to LTCS participants accessing services that are "person centred".

Sargood Centre and Carer Support

Further to the comments made in the NCOSS submission on this issue, SCIA is aware that the Sargood Centre, which is being developed by the LTCSA, is due to start development or operation in 2015, and SCIA believes the Sargood Centre should aim to be a centre of excellence in rehabilitation, transition to education, training and employment as well as providing a large range of assistive technology that will enhance the Sargood Centres' resident's independence, not only while staying at the Sargood Centre but more importantly when transitioning to home.







Assistive technology, such as environmental control units (ECU), can provide the ability for people with significant physical disability to operate a variety of lights and appliances including TVs, audio systems, fans, radios, electric beds, electric blinds and curtain tracks, air-conditioning, electric door operators and telephones etc. The provision of appropriate ECUs can increase a person's independence, autonomy, spontaneity as well as self-esteem and can also give family members peace of mind knowing that the person with a significant disability can have some control over their home environment negating the need for family members to be with a participant at the home.

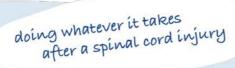
Although attendant care workers will always be required to provide physical assistance for LTCS participants with high needs, including personal care and transferring LTCS participants between bed and mobility aid (if required), dressing, showering, food preparation and feeding etc, an ECU can be cost-effective by not requiring an employed attendant care worker for as many hours during the day.

More Effective Processes and Person Centred Focus

Although the NCOSS submission stated that there was concerns made by some prescribers of assistive technology about the extra reporting required, and that delays in supply of prescribed assistive technology, SCIA supports the need for appropriate assessment and prescription to be made to ensure people with disability receive assistive technology that meets the LTCS participants needs to ensure they obtain the best outcomes, meet their goals and are not abandoning the assistive technology, which can result in a waste of valuable resources.

However, SCIA has reservations about the cost effectiveness of assessment and prescriptions for relatively low-cost "standard" assistive technology that costs less than the assessment and prescription process. Although SCIA is unaware of the assessment and prescription costs (which would vary depending on the complexity of the assistive technology), one example is in regard to the provision of the Kensington Expert Mouse (computer mouse) used by people with limited and functional dexterity, which costs approximately \$100 retail.

SCIA would like to suggest a pilot program, or trial, that would apply a "person centred approach" to service delivery and provide LTCS participants with an ex gratia tax-free allowance of between \$2,000-\$10,000 to research and purchase various types of ECU, computer peripherals as well as software, and home appliances to assist with activities of daily living etc.







Also, as the provision of assistive technology such as power wheelchairs, manual wheelchairs, electric high-low beds, lifting hoists and slings, wheelchair cushions as well as ECUs etc have historically been referred to as being relatively expensive, however, it may be more cost-effective, where appropriate, to refurbish and reissue any unrequired assistive technology. This assistive technology "refurbishment" policy and practice is implemented effectively by EnableNSW's Program of Appliances for Disabled People (PADP) in NSW and other Australian State Government funded equipment programs.

In February 2013, a similar proposal was made to the National Disability Insurance Authority (NDIA) in regard to the NDIS, about the "refurbishment" of assistive technology, as under the NDIS the participants become the owners of the assistive technology. Without the introduction of an assistive technology refurbish and re issuing policy and procedure, there is a strong possibility that any unrequired assistive technology could be sold or given away by the participant or the participant's family or Guardian, who may be eligible to retain the money made from the sale.

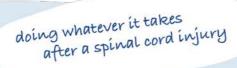
Furthermore, the refurbishing, storing and reissuing of appropriate types of assistive technology could be facilitated by Australian Disability Enterprises (ADE) that would also provide extra work and skills development opportunities and options for people with disability. The assistive technology refurbishing contracts could be offered under tender for specific areas throughout NSW (and nationally under the NDIS). So there are financial benefits for the LTCSA, employment opportunities for people with disability working at ADEs and LTCS participants could receive the assistive technology quicker. Also, if LTCS participants were provided with direct funding to purchase assistive technology, they might choose to purchase refurbished equipment to save money and time.

And finally, any unrequired assistive technology could either be, retrieved from the participant and/or sold by the NDIS before or after it has been refurbished, from which the revenue would be directed back into the NDIS.

People with Disability as Participants on the LTCSA Council

Further to the comments made in the NCOSS submission, which is supporting the immediate recruitment of LTCS participants onto the State Council, which was recommended in the 2nd review and supported in the 3rd review, could the LTCSA Parliamentary Review Committee please clarify if the notice contained in the LTCSA Newsletter (February 17, 2014) available at:

<u>www.lifetimecare.nsw.gov.au/ENews.aspx</u> that states that the Shine newsletter is recruiting 2 LTCS participants to join a Reference Group is one of the same?







Early Intervention Programs for LTCS Participants

Vocational Training

The LTCSA has been funding the InVoc program at the Sydney Spinal Injury Unit rehabilitation services to assist LTCS participants to undertake vocational training, education and seek employment opportunities. As the withdrawal of the InVoc funding by the LTCSA will result in InVoc ceasing to operate in late 2014, could the committee please clarify if there is going to be an alternative service introduced, and if not, what is the LTCSA planning to do to assist LTCS participants in seeking vocational training, education and employment if it is part of the participant's goals?

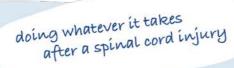
Goal Setting

The LTCSA Newsletter (dated February 17, 2014) available at: www.lifetimecare.nsw.gov.au/ENews.aspx includes a notice that the LTCSA is running a number of on "goal workshops" aimed at a mix of insurers, funder staff and service providers to assist LTCS participants with goal setting. Although this training has merit to enable appropriate staff to better assist LTCS participants in goal setting, SCIA would like to suggest that if LTCS participants have the capacity to undertake their own "decision-making" it would be strongly recommended that LTCS participants be offered the opportunity to have their costs covered by the LTCSA to attend relevant goal setting workshops, as this would be considered "person centred" and provide the LTCS participants with the relevant skills to set their own achievable goals.

Summary:

SCIA strongly supports the concept of the no-fault scheme providing care for life, in conjunction with the provision of reasonable and necessary resources to enable LTCS participants to obtain and maintain their goals. SCIA also strongly supports the need for LTCS participants to be actively involved in the policies and procedures of the LTCS which would enable the LTCS services to grow and meet the changing needs of LTCS participants throughout their life stages.

SCIA believes that LTCS participants be provided with the option of individualised funding packages to have choice, flexibility and control over their services, particularly personal care support, social support and flexible respite services. LTCS participants with direct control over their supports can provide the opportunity for support workers to be engaged in a timely manner rather than waiting for the case manager's approval. In conjunction with this, SCIA is also aware of the potential







problems that may arise when LTCS participants employee family members as attendant care workers, although this may be a preferred and perfectly suitable option for some LTCS participants.

SCIA believes the appropriate types of assistive technology be provided in a timely manner that would enable LTCS participants to be as independent as possible. This would also incorporate the provision, training and ongoing maintenance of environmental control units (ECU) that can enable LTCS participants to have full control of home appliances and equipment. Although some LTCS participants will always require support from attendant care workers, an ECU can negate the need for LTCS participants to ask attendant care workers, or family and friends, to do various activities of daily living. The ECUs can not only provide LTCS participants with greater independence, autonomy and spontaneity resulting in improved self-esteem, it can provide family members with peace of mind knowing that the person with disability can also be on their own for longer periods of time if they want or need to be.

SCIA also supports the need for LTCS participants to be provided with the options for education and training to help with vocational development, including seeking and maintaining employment options. SCIA would like to suggest that LTCSA continue to fund the InVoc program (or equivalent), which was introduced into the Sydney Spinal Units a couple of years ago but the InVoc program will cease in late 2014.

Furthermore, to support LTCS participants to identify and pursue vocational, employment and lifestyle choices, SCIA would like to suggest that LTCS participants be provided with the option, and the funding, to participate in a "goal setting" workshop or equivalent training during rehabilitation or soon after being discharged from hospital, or at any stage their life if required.

Again, SCIA would like to thank the Law and Justice Committee for providing the opportunity to provide this written submission. SCIA anticipates that the content will be taken seriously with the appropriate recommendations made to the LTCSA to ensure the ongoing policies and procedures continue to meet the changing needs of the LTCS participants throughout their life stages.

Yours sincerely,

Greg Killeen Senior Policy and Advocacy Officer