FIRST REVIEW OF THE EXERCISE OF THE FUNCTIONS OF THE LIFETIME CARE AND SUPPORT AUTHORITY AND THE LIFETIME CARE AND SUPPORT ADVISORY COUNCIL

Organisation:

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This submission addresses both the Ninth Review of the MAA and MAC and the First Review of the LTCSA and LTCSAC. A duplicate submission has been processed as received by the MAA/MAC Review and is available for download from the inquiry web page.



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Mr Simon Johnston The Director Standing Committee on Law and Justice Parliament House Macquarie St Sydney. NSW. 2000

Ninth review of the exercise of the functions of the Motor Accidents Authority (MAA) and Motor Accidents Council (MAC) and the first review of the exercise of the functions of the Lifetime Care and Support Authority (LTCSA) and the Lifetime Care and Support Advisory Council (LTCSAC)

Dear Mr Johnston

People with Disability Australia (PWD) submit the following comments with regard to the concurrent reviews currently being undertake by the Standing Committee on Law and Justice with regard to its ninth review of the MAA and MAC and its first review LTCS and LTCSAC.

For the purposes of this submission we have combined our response to these two Inquiries.

About People with Disability Australia

PWD is a national disability rights and advocacy organisation. Our membership is primarily made up of people with disability and organisations mainly constituted by people with disability. PWD also has a large associate membership of other individuals and organisations committed to the disability rights movement.

PWD was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own. We have a cross-

disability focus - we represent the interests of people with all kinds of disability. PWD is a non-profit, non-government organisation.

We have a vision of a socially just, accessible, and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are respected and celebrated.

We believe that people with disability, irrespective of our age, gender, cultural or linguistic background, geographic location, sexuality, or the nature, origin, or degree of our disability:

- have a right to life, and to bodily integrity;
- are entitled to a decent standard of living, an adequate income, and to lead active and satisfying lives;
- are people first, with human, legal, and service user rights that must be recognised and respected;
- are entitled to the full enjoyment of our citizenship rights and responsibilities;
- are entitled to live free from prejudice, discrimination and vilification;
- are entitled to social support and adjustments as a right, and not as the result of pity, charity or the exercise of social control;
- contribute substantially to the intellectual, cultural, economic and social diversity and well-being of our community;
- possess many skills and abilities, and have enormous potential for life-long growth and development;
- are entitled to live in, and be a part of, the diversity of the community;
- have the right to participate in the formulation of those policies and programs that affect our lives:
- should be empowered to exercise our rights and responsibilities, without fear of retribution.

Comments regarding the Lifetime Care and Support Scheme

PWD would firstly like to congratulate the NSW Government on the establishment of a scheme for the lifetime care and support of persons who have been catastrophically injured as a result of motor accidents in NSW. The provision of such supports and services is essential to ensuring people with disability are supported to continue to lead active and meaningful lives following such an event.

The principles that underpin this Scheme, its assessment processes, provision of treatment, rehabilitation and attendant care supports have been well formulated. PWD fully supports the principles as reflected in the Scheme's vision and its Participant Planning Principles which state that it is essential that recipients of this Scheme:

- are treated with respect and dignity and have maximum possible choices, opportunities and quality of life;
- remain central and active in the decision making and planning of their care; and

 receive treatment, rehabilitation and care services which promote the their ongoing independence and participation in life roles.

With regard to the future administration of this Scheme, PWD would like to emphasise the following points:

- A human rights based framework must be reflected in the administration and provision of the LTCS Scheme. As the Australian Government draws closer to its ratification of the UN Convention on the Rights of Persons with Disabilities it is essential that Australia's State, Territory and Commonwealth Agencies, as well as the broader community, take practical steps to comply with the Convention and implements its obligations. In practice this means that the LTCS Scheme must recognise and comply with all elements of the Convention including the recognition that people with disabilities are entitled to enjoy all human rights on an equal basis with others and are enabled to participate fully in society.
- It is essential that the provision of services and supports remain flexible and responsive to a person's ever changing life changes and choices. This is particularly critical given that seventy per cent of participants in this Scheme will be less than 30 years of age at the time of their injury.
- The services and supports provided to an individual must be based on the least restrictive alternative principle. That is, a person has the right to be treated and cared for as far as possible in the community, and afforded the right to treatment and support suitable to their individual needs, preferences, culture and so on. At the same time, adequate resources must be provided to ensure effective care and support within the community.
- It is well understood that the majority of people who will become recipients of this Scheme will acquire their disability suddenly. As a result, they may have little experience of services and supports available to people with disability, or understanding of how to combat the effects of discrimination which are common to people with disability. For these reasons access to independently funded advocacy support is critical to ensuring LTCS recipients are able to navigate their treatment, rehabilitation and future care services.

Comments regarding the Motor Accidents Authority

PWD wishes to raise its strongest concerns and criticism of MAA's decision to provide \$5 million capital, through its Injury Management Grants Program toward the redevelopment of ParaQuad's accommodation facility know as Ferguson Lodge.

PWD calls for the immediate review of this decision as we are concerned that the provision of this capital funding is in direct contradiction with MAA's current Injury Management Sponsorship Guidelines (available on the MAA

website) for the following reasons:

- Sponsorship Policy states that 'service development projects' are not eligible for sponsorship funding. PWD questions how the redevelopment of a Ferguson Lodge meets this policy guideline?
- 2. The Guidelines also state that the MAA aims to promote 'best practice through evidence based treatment, rehabilitation and attendant care services for people injured in motor vehicle accidents'. PWD's concerns in this regard are two fold. Firstly, it is our view that the Ferguson Lodge redevelopment does not reflect best practice or evidence based research on appropriate models of care for people with disability. Ample evidence exists in both Australia and internationally to support the benefits of individualised, community based accommodation support options for people with all forms of disability, as opposed to congregate, institutional models of care.

Congregate care settings, including cluster style accommodation, such as that proposed in the Ferguson Lodge redevelopment have long been associated with the isolation and segregation of people with disability. People with disability in these setting are known to experience cultures of abuse and neglect, loss of individuality, privacy and dignity. Such models also promote a 'whole of life' type approach to service delivery which typically limits a persons choices and control they have over their lives. The overall result is a poorer quality of life and a denial of a person's right to enjoy all their human rights on an equal basis to their able bodied peers.

Our second concern is that the MAA's Injury Management Sponsorship Guidelines refer to the provisions of 'attendant care services' for people injured in motor vehicle accidents. The accommodation support services that will be available through the redevelopment of Ferguson Lodge however, do not fit the attendant care model which refers to support services which enable the individual to live independently, typically in their own homes, and to undertake the full range of everyday tasks that able-bodied people normally do for themselves.

3. Finally PWD wishes to highlight the urgent need to review the apparent inconsistencies between the overall aims and principles of the MAA and the LTCSA. Given these Authorities appear to have responsibilities for, and a commitment to, both injury management and response for those injured as a result of motor accidents, it is essential that the principles guiding these Authorities, and the services/program they fund are consistent.

Furthermore the aims and principles of these Authorities must be based in a human rights framework which ensures that people with disabilities are entitled to enjoy all human rights on an equal basis with others and are enabled to participate fully in society.

Thank you for the opportunity to provide our feedback on the MSS and LTCS Scheme. If you have any questions regarding this submission, please contact Sonya Price-Kelly on 9370 3100 or via email sonyapk@pwd.org.au

Yours sincerely

Matthew Bowden

Acting Co-Chief Executive Officer