MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Community Affairs Reference Committee inquiry into residential care for young people with disability

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Multiple Sclerosis Australia
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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and Awareness
- Communication and Information
- Services provided by our member organisations
- International Collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with the disease, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **‘A world without MS’**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
  Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
  Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with this disease.
- **Communication and Information:**
  Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
  As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
  Representing the MS cause and promoting collaboration with our domestic and international partners.

MS Australia Position:

All people who require supported accommodation options or residential care, should have access to age appropriate accommodation.

Introduction

MS Australia is pleased to provide a submission to the Community Affairs Reference Committee inquiry into residential care for young people with disability.

The focus of the comments, suggestions and recommendations provided in this submission is on key areas that will impact on people affected by MS.

MSA has had a long-established Position Statement on Young People in Residential Care for some years and has advocated for some time in this area.

At the MSA National Advocates Conference in Canberra in October this year, our volunteer National Advocates identified the issue of "Young people in residential care" as a priority for Advocacy in 2015, so we have commenced the process of preparing some more up-to-date material and specifically identifying what we will be advocating for in 2015. Not all of this extra material is ready for inclusion in this current submission, but we wanted to take this opportunity to foreshadow that we will be advocating strongly regarding this issue throughout 2015.

Background

Multiple Sclerosis (MS) is a disease of the central nervous system. There are currently more than 23,000 people living with MS across the country with an additional 1000 diagnoses every year. It is the most common chronic degenerative neurological condition diagnosed in young adults. The average age of diagnosis is between 20 and 40, and 75% of people diagnosed are women.

MS can be a particularly debilitating disease with an unpredictable disease course that affects people in different ways. Symptoms can include severe pain, walking difficulties, debilitating fatigue, partial blindness or thinking and memory problems. For some people MS is a disease of differing severity with periods of unpredictable relapse and remission. For others it is a progressive decline over time resulting in significant levels of disability. For all, it is life changing.

Confirming an MS diagnosis can be difficult. There is no laboratory test, symptom, or physical finding which, when present or positive, always means a person has MS. In addition, some of the symptoms of MS could also be caused by other diseases, therefore a diagnosis of MS must be made through a careful process which usually commences with a visit to a GP, followed by a detailed examination by a neurologist, and other health professionals, and diagnostic tests such as MRI. Whilst there are now several disease modifying therapies available there is no known cure.

An Economic Impact study of MS conducted by A. Palmer in 2011 stated that, "*the typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after approximately 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation. Many of these people with MS develop other chronic conditions in the course of the disease."1*

Discussion

Over six thousand young Australians with a disability now live in residential aged care.

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[1] Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study, September 2011*, page 7.

Table 1: Estimated numbers of young people in residential aged care in Australia, 2005-2010[2]

YEAR	20-29	30-39	40-49	50-59	60-64	UNDER 65
2010	28	105	561	2601	3161	6456
2008	35	149	648	2696	3065	6594
2007	42	164	723	2715	2917	6565
2006	46	173	766	2763	2771	6538
2005	44	176	775	2740	2712	6449

The National Disability Insurance Scheme (NDIS) Act – Section 4 (14) states that people with disability also need supports outside the NDIS, and these supports need to be coordinated with those provided under the NDIS.

The study "A Needs Analysis of Australians With MS" (a detailed study to assess the needs of people with MS prepared by Deakin University in collaboration with MS Research Australia (MSRA), November 2012) found that "a common theme among both the clients and staff participants was the need for specialised and supported accommodation for the more severely disabled individuals' who often have complex care needs.

Both the staff and clients often expressed their concern over the housing of severely disabled young people with MS in nursing homes. For example, one participant stated

"A young person is at the prime of their life, they don't want to be living with older people". (Staff)"[3]

The study also considered the respite needs of people with MS and fifty percent of participants who require respite agreed that respite accommodation is not age appropriate. This outcome is shown in the table below, extracted from a much larger table of outcomes regarding other respite issues.

Needs Analysis Report Table 24. (extract) The percentage level of agreement with various respite statements for participants who require respite.[4]

	Disagree	*Agree a little*	*Strongly agree*	*Don't know*
Respite accommodation isn't age appropriate	17	18	32	33

The report of the study did not make any specific recommendations regarding young people in residential care, but, under the heading Psychosocial Needs, the report recommended the need for a broader variety of peer support groups to meet the needs of people affected by MS, for example age appropriate groups, the need for more locations of peer support, a wider variety of peer support meeting times and an increase in the mode of communication for peer support.[5]

Each of these identified peer support needs will need to be applied to the residential needs of young people with MS, especially those living in aged care facilities.

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[2] *Young People in Nursing Homes National Alliance website: http://www.ypinh.org.au/statistics*

[3] McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 17

[4] McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 43

[5] McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 122

Recommendations

Young people with progressive neurological diseases, such as multiple sclerosis, need an integrated housing and support model that is tailored to their needs and offers access to support and health services, while keeping them connected to the community. The NDIS will offer “individual support packages” to people who live in residential care or community based accommodation options, but there is a critical shortage of age appropriate places. Failure to address the existing shortfall and future demands will put at risk a fundamental rationale for the NDIS.

We need to:

- create articulated pathways of care to delay young people from entering residential care prematurely;
- where appropriate move young people currently residing in nursing homes into age-appropriate accommodation;
- provide support to young people who remain in aged care settings to facilitate enhanced recreational, social and community participation.

This will require the development of key linkages between the supports provided under NDIS and those provided through related health, rehabilitation and aged care systems.

We also need to:

- Monitor the capacity of providers to offer age appropriate community accommodation, with integrated support services, to young people.

This will initially occur in the launch sites and will require that providers develop a viable business and financial model to establish and operate these facilities with a view to current and future demand. Evaluation of the efficacy of this model will need to include stakeholder consultation.

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