People with Multiple Sclerosis – Victoria Incorporated

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Inquiry into Disability Care and Support
Productivity Commission
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Nigel Caswell
Secretary PwMS (Vic)

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Dear Commission

PwMS Vic congratulates you on the draft report you have produced we sincerely hope the recommendations you make will be taken up by Australian Governments. Thank you for the invitation to make a further submission we are pleased to make the following comments.

Employment of people with disabilities

In chapter 4 you make the suggestion that Government should provide incentives for people to work (even if only for a few hours per week)

The fact is that many people with a disability have valuable skills and are ready, willing, able and keen to work – but they are either unable to access the support they need or are unable to persuade any employer to take them on.

People with a disability want to make a contribution to the economic and social life of the nation. However, the Australian economy is missing out on valuable workforce skills, knowledge and experience because thousands of people with a disability are missing out on the chance to work, earn income, become independent and enjoy the social connections we all gain through our working lives.

The NDIS will help increase employment opportunities by ensuring people have the support and equipment they need to work. However, this will only be effective if real effort is applied to encouraging employers to take on people with disabilities and to reward people for getting into work. More support should be provided to employers to help them get the best out of their disabled employees, and the taxation and financial support arrangements must be structured so as to ensure that even a small amount of employment results in a financial benefit to the employed person.

Early intervention

The benefits of adequate early intervention and support during the early years of childhood and during the early stages of many disabling conditions are well known. Yet vital learning opportunities are lost and disabilities can worsen unnecessarily because too few hours of therapy and support are available.

Delivered at the right time services such as speech and physical therapy and specialised equipment such as communication aides can dramatically improve learning potential and social outcomes for children/people with a disability. In some specific diseases such as MS early diagnosis, treatment and support may even mean that the recipients never become severely disabled. The NDIS should ensure that:

1. Australia invests in children by ensuring they receive targeted support and adequate early intervention tailored to their unique needs;
2. early intervention is emphasized for degenerative diseases where the benefits are proven and
3. early intervention is emphasized in communities where disability is over represented (such as indigenous communities).

Aids and Equipment

It is imperative that the number of Aids & Equipment programs is reduced. Funds available for aids and equipment programs are limited and the numerous programs have incomprehensibly different criteria. Consequently many people with a disability are unable to enjoy the benefits of living at home for lengthy periods of time because of inability to speedily access home modifications or for vital mobility aids or other equipment. Some clients may even lose access to vital equipment because they are required by circumstances beyond their control to change form one program to another.

Having the right support and the right equipment makes a dramatic difference to the quality of life of everyone in the family, yet many people and families wait too long for vital equipment – and as a result some people's conditions worsen or their families are forced to go to extraordinary lengths to purchase the equipment.

Assessment and control

The point made in the draft report that the assessment process should be seen as valuable in its self is particularly important. The assessor(s) must have the confidence of their clients; the primary purpose should be to ascertain how best to meet the client's needs. The assessment should not be seen as "a gate-keeping process" designed to control access to support. One of the most important aspects of the NDIS proposals is the intention to allow people to make choices about the kinds of things that will best meet their particular needs.

Electricity costs

The Commission has asked for feedback on the issue of the higher electricity costs which are unavoidably incurred by some people with disabilities.

Heat intolerance is a significant medical problem affecting people with a range of conditions such as Parkinson’s Disease, post-polio syndrome and MS. People with MS are particularly susceptible; as little as 0.5C increase in core body temperature can significantly increase MS symptoms, and in many instances the increase in symptoms may be so severe as to warrant hospitalisation. Most people with MS become unemployed within 10 years of diagnosis. This means that most people with MS have very low incomes whilst facing significant disease related out of pocket costs

These out-of-pocket costs, combined with rising electricity prices; and the increasing number of hot days and nights due to climate change, mean it is more and more difficult for people with MS (and other heat intolerant conditions) on low incomes to keep cool on hot days and nights.

While most of us have a choice about whether or not we turn on the air conditioner, people with MS do not. The need to turn on the air conditioner has a direct relationship to the degree of disability suffered by many people with MS so turning on the air conditioner can be compared to early intervention it has real beneficial effect and increases the ability of people with MS to function effectively in the short and long term.

Most States now have subsidy schemes to alleviate these costs for people for whom thermal sensitivity is disabling. However, two aspects remain critically in need of attention: [1] Many many houses are still very poorly insulated and unfortunately the Government’s scheme to address this collapsed because of fraud and incompetence within the insulation industry; and [2] a large proportion of air-conditioners are old and inefficient . For people with conditions such as MS to get real benefit from cooling subsidies it is highly desirable that these schemes also offer access to assistance with improving the thermal efficiency of their homes and of their cooling systems.

[For further information on the keeping cool problem for people with multiple sclerosis contact Dr Michael Summers, Senior Policy Advisor, (03) 9845 2730 or email at msummers@mssociety.com.au].

Conclusion

People with a disability, their families and carers want the same things in life as everyone else a chance to live a fulfilling life. There is often too little support for people with a disability, their families and carers – and what little support is available can be difficult to access and is rarely able to be adapted to individual needs. When the formal support system fails, people with disabilities go without or their families are forced to fill the gaps. As a result there are high rates of physical, emotional and financial distress amongst many families and Australia is missing out on the potential inherent in many people with disabilities.

Thank you once again for the opportunity to make a submission we hope that your recommendations will be widely accepted

Yours sincerely

Nigel Caswell