

Productivity Commission Inquiry into Long Term Disability Care and
Support Scheme

Submission

PEOPLE WITH MULTIPLE SCLEROSIS, Vic (Inc)

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INTRODUCTION

People with Multiple Sclerosis, Vic (Inc), [PwMS] represents people in Victoria living with the costs and impediments of Multiple Sclerosis, a large proportion of which (more than 1700) are members of PwMS.

PwMS Vic (Inc) welcomes the Productivity Commission Inquiry into disability services and the way they are funded. We support the submission of the Chronic Illness Alliance and support the view that the definition of disability needs to embrace the changing parameters of health, illness and disability.

BACKGROUND

Many of the people PwMS Vic represent have moderate to severe impairments as a result of their conditions. Most involve deterioration and increasing impairment as people age. However MS is commonly episodic as well, meaning that there are periods of time when people are acutely ill, while there are other periods of time when people's health is relatively stable. These episodes typically exist within a framework of steady deterioration.

PwMS Vic agrees that the delivery of disability services and the way they are funded is outmoded and still reflects nineteenth century attitudes towards people with disabilities. However what also needs to be addressed is the fact that both public and clinical views of chronic illness are also outmoded in the way they are represented in public policy. In the nineteenth century and indeed up to the present, chronic illnesses were not included in any disability programs because people were not expected to live. In the early 20th century most people with MS were cared for on the basis that they would not live long. There is still an artificial distinction between chronic illnesses and disabilities which has developed and endured, meaning that some chronic illnesses qualify as disabilities and others do not. Many chronic illnesses 'fall through the gaps' where people do not qualify for disability services.

Since the 1950s there has been a steady improvement in survival rates for multiple sclerosis. Even more recently there is increasing recognition that the human body has a remarkable capacity to compensate for injuries it has suffered. The picture is growing that illness, injury and disability is a far more flexible state than was thought in past decades. This now needs to be reflected in policies and services for people with chronic illnesses, disabilities and injuries, so that services enhance people's own abilities to make improvements.

However, the present state of matters is that these improved survival rates mean that many people with such illnesses live with a level of impairment, and with increasing costs of care and treatment. There is an assumption that the costs of such care for people with chronic illnesses are met through the health and medical system. But this is not entirely the case. Often people with chronic illnesses find they cannot access the services they need which are related to living in the community rather than to their health needs. They are not eligible for some disability services and the services they need are not available from medical services. An example of this is that some people with chronic illnesses do not fit the criteria of eligibility for aids and equipment from state-based services.

These distinctions between disability and chronic illnesses are largely historical and over time some chronic illnesses have been recognised in terms of their impairments while others have not. There is little appreciation by the public and in policy for instance of the debilitating effects and associated chronic costs of living with a condition such as MS; which typically renders its sufferers unemployed and disabled but having an almost normal life span. We would urge any review of disability services

to ensure that these attitudes towards chronic illnesses and the impairments related to them be included in that review with a view of doing away with such false distinctions.

PwMS Vic is aware that many people under 65 who have chronic illnesses end up accessing their superannuation funds in order to pay for services because they have no other means to do so. Consequently they have fewer funds for their retirement and rely more heavily on Government funded pensions.

PRINCIPLES OF THE SCHEME

PwMS supports suggestions that to meet the changing needs of people with chronic illnesses the following principles required are:

a) Based on need

The scheme should be based on need so that those with the greatest need would be ensured of having a liveable income and access to the services they needed. The Alliance agrees that such needs should be judged across physical, intellectual and social impairment. Services would be coordinated rather than case managed and the emphasis would be on optimising people's well-being regardless of how that impairment was contracted.

b) Timely intervention promotes wellness and ability

While those with the greatest impairment should be the greatest beneficiaries of such a scheme it should not mean that those with lesser impairments are left out. All people with needs should receive support proportional to their impairment. Thus those with greatest impairment are the greatest beneficiaries, but those with lesser impairment receive benefits according to their impairment which should minimise the transition from lower impairment to higher impairment where a condition is progressive and/or limit increased impairment due to a lack of intervention. There is strong evidence that people with chronic illness have significantly higher risk of depression, anxiety and other mental illnesses. Timely intervention by services as early as possible will mean that in some cases such as depression and other mental illnesses, many years of dependency can be averted.

Timely intervention includes access to aids and equipment based on needs and the evaluation of how that equipment will enhance the person's life. Aids and equipment programs need to take into account that people with impairments move between states and state-based programs are often inflexible and not equally funded.

c) Encouraging community participation, education and employment

Many people with chronic illnesses find themselves unemployed following a diagnosis. Research shows that many people with MS, epilepsy and diabetes will lose their jobs within a matter of a few years after their diagnosis, even though they could continue with support and flexible arrangements. Younger people with chronic illnesses may also fail to complete their education. Far more support is needed in the community, schools and employment to ensure that both younger people with chronic illnesses and skilled workers with chronic illnesses are able to participate as long as possible in the lives of their communities at a productive level.

d) An infrastructure program

Over recent years the trend has been to de-institutionalisation for most disability clients including mental health clients requiring the community to deal with the ramifications. Infrastructure in the community has been acquired on a piecemeal basis so that a variety of programs has been developed on a case basis but without a structured approach. Consequently there is public confusion as to what services are available, where to obtain them and what are the costs involved.

While older persons with chronic illnesses can follow a "natural" path, with support provided, through the hostel to nursing home stage with clearly identifiable infrastructure, this is not the case for younger people with disabilities. To our knowledge there have been no purpose-built facilities developed to take care of younger persons with disabilities that cannot be managed in the community such as serious Acquired Brain Injuries. Accordingly they are often placed in nursing homes which may be inappropriate to their physical and psychological needs.

There does not appear to be a structured approach to half-way houses within this process of care of younger persons with serious disabilities.

We recommend the inclusion of a budgeted capital works program providing expenditure to permit the development of purpose-built facilities.

All people with disabilities and chronic illnesses are severely disadvantaged by the lack of suitable transport, leading to enforced isolation and inability to work or complete education. Experience suggests there is little reason to believe that any infrastructure program will fix this in the near future so that the Inquiry should consider other means to assist this group of people to a better level of mobility, such as improved half price taxi schemes and mobility cards. Patient travel assistance schemes to assist rural and regional people with disabilities and chronic illnesses need to reflect the current costs of travel to regional and metropolitan centres.

e) People first, funding models second

PWMS Vic is concerned that funding models will reflect the current trend to privatise services as was done with employment services, some years ago. Private providers are concerned with profits rather than providing high quality labour intensive services. Any model should take into account that many not-for profit organisations have been providing services for a very long time, often with charitable money and often in straitened circumstances. Where those services are already good or where funding would assist to improve them, those not for profits should be supported to continue rather than having to compete with private providers.

A national disability insurance scheme would assist people with chronic illnesses in providing a more flexible funding model which took into account episodic illness and in turn created greater opportunities for people impaired by their illnesses to access aids and equipment so they could continue working or continue to participate in the lives of their communities.

However, PwMS Vic does not fully support a no-faults insurance scheme. Some illnesses and other injuries are related to environmental issues and these issues need to be paid for and resolved by those who are responsible for their creation. Currently, legal processes are the most efficient means of achieving this. We do however argue that funding models that ensure equitable and timely access to services will mean that over time the costs to

Government through both health and disability services will be reduced as people with either disabilities or chronic illnesses will be able to improve their quality of life, their health and well-being. This in turn will be reflected in their level of community participation.

f) A complaints mechanism and quality framework

An easily accessible complaints mechanism which is separate to those providing services is required. Such a mechanism should have the power to investigate and address complaints immediately for the individual. However, a complaints mechanism should exist within a quality framework to ensure that systemic problems are continually rectified.

A Consumers and Carers Steering Group should exist within this quality framework as well as consumers and carers being represented on any advisory group for the overall work of the new scheme.

g) Concluding comments:

All of the more than 1700 members of PwMS Vic (Inc) live with the costs and impediments of Multiple Sclerosis many of them face substantial costs and difficulties because of the impairments imposed on them by their MS. Whilst the cause of MS is as yet unknown, it is clear that MS is not caused by any deliberate, accidental or negligent act of the people with MS.

PwMS Vic (Inc) welcomes the Productivity Commission Inquiry into disability services and the way they are funded. We submit that it is high time that support and services for people with disabilities were structured so as to not disadvantage those in the community who through no fault of their own suffer long term costs and impediments arising from such illness and disability.

Submitted for and on behalf of People with Multiple Sclerosis, Vic (Inc)

Nigel Caswell,
Secretary PwMS Vic (Inc)