

2nd February 2010

Hon Tariana Turia
Minister for Disability Issues
Parliament Office
Private Bag 18888
Parliament Buildings
Wellington 6160

Dear Mrs Turia

Disability issues impacting on the lives of people with neuromuscular conditions

The purpose of this letter is to bring to your attention an accumulation of issues that have been brought to my attention by Muscular Dystrophy Association (MDA) members over the last several months, and to suggest how they might be collectively addressed.

The MDA represents people living with a variety of neuromuscular conditions, including muscular dystrophy. These conditions typically cause disabling loss of muscle strength, affecting the ability to undertake basic activities of daily living, mobility, speech, breathing and heart function. The disability is always progressive, life expectancy can be significantly shortened, and there are no cures. It is estimated that there are about 4000 New Zealanders who have such a condition, and there are many more family members who, by virtue of the support that they provide to their disabled relative, live with the condition continuously, often at the expense of a quality of life that most of the rest of us take for granted.

Despite New Zealand being a signatory to the UN Convention on the Rights of Persons with Disabilities there remains a plethora of issues which collectively indicate that those living with disabilities continue to be marginalised from opportunities to fully participate in society in ways that are enjoyed by the majority of their fellow New Zealanders. I have been in my role as Managing Director of the MDA from April 2009. The issues that have been brought to my attention by the MDA's membership in the short time since my appointment have accumulated to the point where it appears that they are so systemically related to the underlying attitudes and beliefs of New Zealand's policy implementers, that attempting to address them issue by issue is likely to yield excruciatingly slow and incremental improvements at best.

The concerns, in no particular order, are as follows:

Funding cuts to schools with special needs units for children with physical disabilities.

As you will be aware, it was the government's intention to do away with the transitional therapy provision (TTP) fund, which is available to twenty three schools throughout the country for the provision of physiotherapy and

occupational therapy to students. Some of these students will have neuromuscular conditions. In the wake of the public response to this issue the government decided that rather than cut funding to existing students, it would not be made available to new students. The MDA believes that all students, irrespective of how they are funded, and whether or not they go to a school with a special needs facility, should have equality of access to the physiotherapy and occupational therapy services they need to ensure that they have the same opportunity as any other student to participate in the education curriculum.

Inequitable levels of support available to those whose disability has resulted from illness compared to those who have been disabled from an accident

This is a longstanding and continuing concern for MDA members, and the MDA is a formal member of the Equity for Illness (EFI) campaign.

In 1967 the Woodhouse Report, the founding document of ACC, recommended that people be given equal entitlements irrespective of the cause of their disability. The then government in 1974 promised that they would do this within the next two years. That promise was effectively broken, and continues to remain broken through to the present day.

In 2001 another government introduced the New Zealand Disability Strategy which includes the objective to “encourage equity of funding and service provision for people with similar needs, regardless of the cause of their impairment”. As far as we can see neither the government of the day, nor any subsequent government, nor any of their agencies, have done anything to promote the realisation of this objective.

Respite care

Many MDA members are complaining about the inadequate availability of respite services for families with young children. This results in families either going without the breaks from the role of full time caring that they need and are entitled to, or their children risk being placed in totally unsuitable facilities which cater primarily for the needs of older people. We are currently surveying MDA members to get a better understanding of the issues and possible solutions, with preliminary information suggesting that the availability of good quality appropriate respite care is geographically patchy, and that Canterbury is particularly underserved in this area.

Mobile school dental clinics

We understand that the Ministry of Health has obtained a legal opinion justifying their decision not to require mobile school dental clinics to be accessible to children with disabilities. MDA members were dismayed to learn this as the decision represents the perpetuation of yet another barrier to their having the same rights as every other citizen to access what they are entitled to, in this case basic health services.

Complex equipment and housing modification delays

Many MDA members are becoming alarmed at the both the historical and current inability of the equipment and housing modifications budget to keep up with demand. This has now reached the point where specialised assessors for both Enable New Zealand and accessible are being required to prioritise applications. This in turn is resulting in MDA members experiencing delays in receiving the complex equipment and housing modifications they need, with non-urgent applications being consigned to a waiting list.

The uncertainty that this situation creates adds to the existing stresses that are already an everyday part of living with neuromuscular conditions. Members are not only starting to feel that they need to fight to have their needs met, but are also worrying about when and whether they or their family member will receive the support they require, and how they will cope during the waiting period.

Paid family carers

The MDA is very disappointed that the government has decided to appeal the Human Rights Tribunal declaration that that the Ministry of Health's policy of not funding the employment of family members to provide support services to their disabled family members discriminates on the grounds of family status.

The MDA believes that it would have been better had the government accepted the declaration and established a process for developing a solutions based response. We have copied you in to the separate letter that we have written to the Minister of Health about this issue.

Representation on the National Health Board

MDA members have noted that that there is no specific voice for representing disability issues on the new National Health Board, despite Disability Support Services and the rest of the Health and Disability Services Directorate now being part of the National Health Board Business Unit.

Much was made of the composition of the NHB comprising a preponderance of doctors and nurses, and how this represented a commitment to the injection of more clinical leadership into the running of New Zealand's health services. This is all very well, but the disability sector is also overdue for an injection of good leadership, which it does not appear to be about to receive any time soon.

MDA members are concerned that disability services will continue to languish under the NHB umbrella even more than they did when they were a Ministry of Health directorate. We believe that our members, along with the wider New Zealand disability community, are entitled to have their services governed by a National Disability Board comprising leaders who actually understand and have a vision for what delivery of disability services should look like.

The above paragraph notwithstanding, the MDA believes that the disability sector should be specifically represented on the NHB to assist in ensuring that that the health system has the capacity and flexibility to respond appropriately to the particular requirements of people with disabilities. For the MDA there are currently two issues that are outstanding in this respect – the provision of cough assist machines and the development of managed clinical networks, detailed as follows:

- Cough assist machines: Several MDA members have neuromuscular conditions which affect their ability to cough, which in turn can result in lung infections or pneumonia. People in this situation typically need weeks and sometimes months of in-patient hospital care before they have sufficiently recovered to allow them to return home.

This can usually be prevented if they have access to a cough assist machine. This equipment simulates the cough reflex and both significantly reduces the risk of acquiring lung infections and accelerates the convalescence process after an infection is acquired. It therefore has a huge positive impact on the quality of life of both those who use it and their families.

Furthermore, each cough assist machine costs about \$7000 to purchase, and should be seen by DHBs as representing an excellent investment from a cost benefit point of view. While some DHBs have purchased these machines, many have not, and many of our members are therefore subject to the risk of an impaired quality of life simply because of where they happen to live.

- Managed clinical networks: A continuing problem for some people with neuromuscular conditions is how to ensure the right clinical care is provided in the face of boundary issues between District Health Boards, and between paediatric and adult services. People do not always live in the area where the clinical expertise is, and many people may need ongoing coordinated specialist care in paediatric services, even when they become adults. The result for many people is that they feel that they have entered a complex maze with no sign posts, and they simply give up trying to access the specialist services that they need. The MDA believes that this situation could be improved with the development and introduction of managed clinical networks, and it is our hope that the new National Health Board will address this as a matter of priority.

The MDA believes that if the needs of people with disabilities are not represented by strong leadership within the NHB then issues such as those above face significant risk of not being prioritised in the face of competing demands from other more powerful interests within the health sector.

Solutions

The MDA understands that there will be resource implications as the needs of people with disabilities become prioritised and addressed. We also understand that it will be difficult for any government to commit to increased resources in a time of economic recession. However, the anticipated economic recovery is now occurring, thereby creating an opportunity for the government to review its spending priorities. We believe that one indicator of the extent to which a country can consider itself to be “civilised” is the degree to which it supports its less able citizens to have the same opportunities to achieve their full potential that the rest of us take for granted. We believe that people with disabilities, including MDA members, are subject to systemic unfairness, and we want a real commitment of will and resources to see this addressed.

The MDA believes that the overall disability policy framework (which includes the New Zealand Disability Strategy and the government’s ratification of the UN Convention on the Rights of Persons with Disabilities) is a good one. The difficulty is that there is little that obliges any of the government’s agencies, or indeed the government itself, to prioritise and implement the policy. The Office for Disability Issues appears to have little influence, and the Health and Disability Commissioner’s office is limited to responding to complaints rather than having the power to proactively respond to systemic issues as it becomes aware of them.

The MDA believes that the establishment of an independent disability commissioner which reports directly to parliament and which has the power to direct government and other agencies to act in accordance with the government’s disability policy would be a good first step in creating a fairer society.

We will be very happy to collaborate with you in the pursuit of these and any other solutions that will assist people with disabilities to achieve equity of opportunity.

Yours sincerely

Chris Higgins
Managing Director

cc Hon Tony Ryall, Minister of Health