

2nd February 2010

Hon Tony Ryall
Minister of Health
Parliament Office
Private Bag 18888
Parliament Buildings
Wellington 6160

Dear Mr Ryall

Paid family caregivers

I am writing to convey the Muscular Dystrophy Association's (MDA) support of the Human Rights Review Tribunal (HRRT) declaration 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. I am also writing to express the MDA's dismay that the government has decided to appeal the declaration.

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. 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 (to be the subject of a separate letter to the Minister for Disability 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.

The HRRT declaration created an opportunity for the government to signal that it takes its commitment to the UN Convention, and indeed its own disability strategy, seriously. MDA members expected that the government would have set up a working group to find a solutions based response to the Tribunal's declaration. They are dismayed and disappointed to learn that, instead, the government's preference is to appeal, thereby putting the issue into the "too hard" basket with the hope that it will be obliged to do nothing.

Family members who provide support to their disabled relatives often forgo paid employment to do so, to the detriment of their quality of life. This occurs

not only as a result of living on a reduced household income, but also as a result of the need to be continuously available for the disabled relative, frequently with little or no respite. If they were to choose a more “normal” life for themselves, then the Ministry of Health would be obliged to provide paid support for their disabled relative. It is unfair that family members who are providing support that would otherwise have to be paid for by the Ministry can not be paid merely because they are family members. Furthermore, the MDA believes that family members will usually provide a higher quality of service than externally engaged paid support workers. The government’s decision to appeal the HRRT declaration signals its willingness to condone arrangements which disincentivise this way of providing high quality care.

As a footnote, we understand that the Crown Law Office had thirty days in which to decide whether or not to lodge an appeal. It was our intention to write to you within this window of opportunity, urging the government not to go ahead with the appeal. We feel that the decision to lodge the appeal well before the thirty days had elapsed was somewhat cynical, and we are left disappointed that the opportunity to influence has been reduced to that of mere protest after the fact.

Yours sincerely

Chris Higgins
Managing Director

cc Minister for Disability Issues
NZ Carers Alliance