Submission No 22

INQUIRY INTO TRANSITION SUPPORT FOR STUDENTS WITH ADDITIONAL OR COMPLEX NEEDS AND THEIR FAMILIES

Organisation: Muscular Dystrophy NSW

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MUSCULAR DYSTROPHY NEW SOUTH WALES

Response to the inquiry into transition support for students with additional and/or complex needs and their families

1 Background

Muscular Dystrophy NSW supports people with approximately 60 variations of Neuromuscular Diseases (NMDs), all of which have the progressive and irreversible wasting of muscle tissue.

From 1st July 2010 to 30th June 2011, MDNSW rolled out case management services to 120 people, as part of a 12 month sector development project funded by Ageing, Disability and Home Care, Department of Human Services NSW.

The most common diagnosis amongst the 120 people who were provided a service was Duchenne Muscular Dystrophy (DMD, 29 people, 23%). DMD is a genetic degenerative disease primarily affecting males. Onset occurs between 2-6 years and boys can expect to be wheelchair bound by about 14 years. DMD eventually affects all voluntary muscles, the heart and breathing muscles. Survival is rare beyond the early thirties, however does occur. Touch and sensation remains intact, and as the disease progresses, swallowing and breathing becomes difficult, and the feet and hands develop contractures.

The second most common diagnosis was Myotonic Muscular Dystrophy (MMD, 19 people, 16%). Also known as Steinert Disease, Dystrophia Myotonica, Myotonic Muscular Dystrophy is a genetic degenerative disease. Congenital form appears at birth and more common forms may begin in early teen or adult years. People with MMD experience generalised weakness and muscle wasting first affecting the face, lower legs, forearms, hands and neck, with delayed relaxation of muscles after contraction is common. Other symptoms involve the gastrointestinal system, vision, heart or respiration. Learning disabilities occur in some cases. Congenital MMD is the more severe form. Progression is slow, sometimes spanning 50 to 60 years.

2 Transition issues

MDNSW has supports families during significant transition periods. During all of the four transition periods (into early childhood education for the first time; early childhood education into primary school; primary to secondary school; and post secondary school), representation, education and training is required. MDNSW regularly attends meetings with school staff, providing specific information about the needs of a person with a neuromuscular disease. Training includes ensuring that teachers' aides understand both the limitations as well as abilities of affected individuals, ensuring that appropriate equipment and assistive technology are available, and that modified toilet facilities are available and accessible.

The case management project identified a significant and growing need to provide emotional and psychological support to people with a NMD, particularly during transition periods.

3 The need for generic functional assessments recognized across government agencies

MDNSW has found that access to programs through Centrelink and TAFE NSW requires medical documentation to establish eligibility for disability related aspects to programs. For individuals not currently receiving medical support, this can be difficult to obtain, especially during transition between paediatric to adult units and where no treating physician has been appointed, or when individuals are not linked in with clinicians for other reasons. Generic functional assessments which are recognised across agencies, and that can be administered by an allied health worker would allow smoother access into programs. The ease and accessibility of generic functional assessments could be updated as needed in response to disability progression. MDNSW supports government proposals to implement generic functional assessments.

4 The need for understanding

MDNSW has found that the most significant issue for individuals and families during all of the transition periods is that the people involved have an understanding, or willingness to understand the emotional impact that transitions have. Transitions often bring reminders of the raw emotions of grief and loss issues associated with having a NMD. Families will often fight to keep their disabled children in the mainstream school system for as long as possible. It is often at points of transition that the realities of the disabling condition are brought to attention, and families are forced to accept that their child will become part of the disability community. This can be extremely confronting for families who up until these points have deferred dealing with these issues. Unless disability is accepted in the wider community and

understood within educational environments, these transitions and acceptance are made more difficult, and impact families in a more significant way.

5 Strengths based approach

MDNSW has found that the best way to support people with a neuromuscular disease is through an approach which focuses on empowering the individual by identifying and developing his or her strengths. MDNSW has found that a “one size fits all” approach to disability degrades and marginalizes this group. The people who MDNSW support have various levels of complexity and individuals require support which is appropriate to their level of functionality. As many of the people we support have full cognitive capacity, educational programs and special needs classes need to be appropriate and suitable to meet the developmental level of the individual.

6 Case examples (names have been changed to protect identities)

6.1 Peter

MDNSW has been working with Peter, an 11 year old boy, and his mother. Peter (whose name has been changed to protect the individual) will be transitioning into high school next year. He will not be enrolled in the local public high school where the majority of his friends will be going, as it is not appropriate for the full time use of a wheelchair. Instead, he will attend another public high school that has been determined as more appropriate for his condition, although it is further away from his home and friends. Peter has needed assistance with understanding this process of change on an emotional and social level, and will require representation when entering the new school. Representation will involve training staff to ensure that they understand his condition and needs, including giving him permission to leave class when he needs to, and other exceptions to normal rules.

6.2 Brendan

MDNSW has been working with Brendan for the last six months. He recently turned 18, and faces significant transitional issues. He has Duchenne Muscular Dystrophy and motivating him to consider vocational options after school is difficult due to end of life and deterioration issues. He is currently doing his High School Certificate through Pathways, however it has been decided that he will discontinue this at the end of the year. MDNSW is currently working with him to consider employment, TAFE or further education, or other post-school options. Brendan is fully dependent on all aspects of personal care. Brendan gets around in his electric wheelchair with only minimal use of his fingers. He has full intellectual capacity, and his insight into his deteriorating condition often leaves him feeling hopeless about a future with little sense of reason to invest in vocational activities, yet he also recognises that spending the last years of his life bored in a wheelchair with no stimulation is no quality of life either.

MDNSW has been assisting Brendan in looking at employment opportunities that would allow him to:

- Work shifts of a maximum of three hours at a time
- Not require functional movement above the use of fingers
- Be based in a wheelchair accessible environment
- Provide assistive technology as required

MDNSW has also been looking at further study options that would factor in all aspects of his disability.