Submission
No 274

INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

Organisation: Muscular Dystrophy Association NSW

Name: Mr David Jack

Position: Chief Executive

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Submission

To the Inquiry into the provision of education to students with a disability or special needs

Name: David Jack

Designation: Chief Executive Officer

Authority to lodge submission: Board of Muscular Dystrophy Association NSW

Submission

Muscular dystrophy is a neuromuscular, genetic disorder which results in the progressive deterioration of muscle strength and function. MDNSW represents the interests of persons with muscular dystrophy and their families and carers. Our clients cover a broad range of ages and severity of disability but they share the same goal and that is to be treated in a dignified, supportive and compassionate way. Our client's are often severely impacted by their condition on a physical level but not at all or only marginally on an intellectual level. Education is in some ways even more important to our clients because they are unable to participate in many other activities. In Australia education is a basic human right and for people with a disability it is of paramount importance to ensure that right is equally accessible. The provision of a fairer and more equitable education system will ensure that people with a disability have an improved quality of life including: increased independence; enhanced self esteem; improved decision making; sense of achievement and a more positive outlook.

For the purposes of this inquiry MDNSW undertook a survey of its 400 members in order to gain a better understanding of their individual experiences and thoughts around the provision of education in NSW. Of those 400 members approached, 73 people responded in writing.

The survey results identify the clear and consistent theme that the provision of education to persons with a disability is inequitable, sporadically available, inadequately funded and difficult to obtain and negotiate.

The survey included responses from a large group of people with a neuromuscular condition (47% of respondents) and carers (32% of respondents) of all ages, including school aged children. A summary of key statistics:

Question	Yes	No
5. Do you believe the funding for the education of Primary aged children with a disability is adequate?	14%	72%
6. Do you believe the funding for the education of Secondary children with a disability is adequate?	12%	65%
7. Do you believe there is an adequate number of special education places for Primary aged children within the education system?	9%	70%
8. Do you believe there is an adequate number of special education places for Secondary aged children within the education system?	4%	73%
9. Do you believe there is a suitable curriculum for intellectually disabled and conduct disordered Primary school students?	10%	53%
10. Do you believe there is a suitable curriculum for intellectually disabled and conduct disordered Secondary school students?	10%	50%
11. Do Primary aged students and their families have access to professional support and services, such as speech therapy, occupational therapy, physiotherapy and school counsellors?	51%	29%
12. Do Secondary aged students and their families have access to professional support and services, such as speech therapy, occupational therapy, physiotherapy and school counsellors?	38%	21%
13. In your opinion do Primary school teachers receive adequate teaching training in terms of pre-service and ongoing professional training?	14%	63%
14. In your opinion do Secondary school teachers receive adequate teaching training in terms of pre-service and ongoing professional training?	11%	61%

Key themes emerged from the results supported by many individual stories and comments highlighting the participant's recurrent experiences and frustrations. These themes and quotes from members are included below:

Code – Q = Question, C = Comment

Theme 1 - Availability of services is poor

- "Impossible to get into any of the above [services]" (Q11 C6)
- "I know there is a staff counsellor at school, who deals with the kids with disabilities, she is only part-time so things usually take a while to happen. As for speech, physiotherapy and occupational therapy and other services I haven't been told about them. Maybe they think we are told by other people like the hospital clinic etc" (Q11 C8)
- "extremely limited" (Q11 C9)
- "limited" (Q11 C10)
- "From personal experience the services are so limited that in most cases they have no therapeutic effect." (Q11 C12)

Theme 2 - Availability of information to families is at times limited

- "I am not sure how much is given to the school and how it is used for my son. We are not told anything. Yes, I know he gets some, but as I said to be used for what I don't know." (Q5 C5)
- "I'm sure they have "access" but may be unaware of these services or they may not be geographically accessible i.e. not enough services and also may not be able to afford the services" (Q11 C11)

Theme 3 - Services worsen as child gets older

- "Children up to and including 7years have more help than over 7" (Q11 C 3)

Theme 4 - Meeting criteria, strong advocacy and 'where you live' determine service levels

- "I think it is adequate if you are fortunate enough to meet a variety of criteria and know how to access the system. If not, it can be very inadequate" (Q5 C2)

- "the level of service depends on where you live, the services in your area, and your ability to advocate for the needs of your child" (Q11 C1)
- "Sometimes depending on where you live" (Q11 C5)

Theme 5 - School advocacy and attitude at times inappropriate

- "as long as the school is successful in attaining applications lodged for necessary improvements" (Q5 C3)
- "as long as the school is successful in attaining applications lodged for necessary improvements" (Q6 C3)
- "This very much relies on how much the principal cares about children with disabilities" (Q13 C6)
- "No because they are too busy teaching and doing admin work" (Q13 C3)
- "A lot of teachers assume that people in wheelchairs are stupid and its very unfair" (Q14 C3)
- "teachers and schools are, on the whole, no better equipped to handle physically disabled children than they were thirty years ago" (Q15 C3)
- "In Year 5, my teacher clearly did not understand muscular dystrophy and would accuse me of being lazy but in reality it was because my arm would get sore from the school work. She obviously did not know or want to know that muscular dystrophy affected my arms as well. So, those sorts of things made me not enjoy primary school a great deal. I also feel that some of that may have impacted on my educational development." (MB)
- "Last year he entered Year 7. Even though we explained Henry's condition to the teachers only two made allowances for him. We waited months for a laptop. He was constantly in trouble for not completing work and most of the teachers didn't want to go to the trouble of putting things onto the laptop even though he has a thumb drive with him at all times." (Email)

Theme 6 – Lack of equitable provision of education and support services

- "I think there should be equal opportunity to everyone and currently there isn't." (Q5 C4)
- "Where it exists it is often generous but it doesn't always exist where it should - or in the form in which it should exist." (Q5 C7)

- "I think there should be equal opportunity to everyone and currently there isn't" (Q6 C4)

Theme 7 – Long waiting lists

- "there is a way too long waiting list for these services." (Q11 C2)
- "we have utilised outside services & waiting lists are long" (Q11 C13)
- "Yes but many current wait lists are so long it is like having no service at all" (Q11 C15)
- "too long waiting list." (Q12 C3)
- "waiting lists are very very long" (Q12 C12)
- "Yes but many current wait lists are so long it is like having no service at all" (Q12 C14)

Theme 8 - Families sometimes just give up

- "There can always be more - but people often put up with what they can get." (Q11 C14)

MDNSW believes that the quality of life of our client members is being compromised by the inadequacies in the provision of education to persons with a disability. The lack of a consistent provision of an education resulting in individuals being marginalised at best and ignored or discriminated against at worst is irresponsible and inappropriate in Australia.

Our members are encouraged that this inquiry is being held and that their voices are able to be heard.

David Jack

Chief Executive Officer