Submission
No 283

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

Organisation:	Makaton Support Group
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The Chair of the General Purpose Standing Committee No.2

Ms Robyn Parker MLC,

Parliament House,

Macquarie Street,

Sydney NSW 2000

Re: The Provision of Education to Students with a Disability or Special Needs

"Interacting with the education system can be a frustrating and confusing experience for parents of a child with a disability or special needs, as they attempt to ensure that their child gets adequate support to reach their full potential". This is certainly our experience.

I am writing this on behalf of a group of about 10 parents who have school aged children with disabilities. The group was established by the Speech Pathologist from the School Therapy Team in the central network of South East Sydney Illawarra Area Health Service as a Makaton/signing support group for parents of children with disabilities or special needs, and is now parent led and run.

Our experiences of getting a placement in the Education system are varied but unfortunately no-one in our group have had a good experience.

I will try to address the terms of reference that are relevant to the members of our group, giving examples where appropriate. In writing the submission our hope is that the system can improve and that other parents will not have to experience the frustration, stress, anguish and at times utter despair when all we want is the opportunity for our children to receive the education that best suits their needs, which will ultimately allow them to live full lives and contribute to society rather than be dependent on society.

Best practice approaches in determining the allocation of funding to children with a disability, particularly whether allocation should be focused on a student's functioning capacity rather than their disability

Within the current system in N.S.W. it seems that children are categorised by their disability. Placement is made on the basis of the child's most significant disability as perceived by the Department of Education. Children with multiple or complex disabilities are not placed in the school or class which best suits their needs but rather in the school which the panel feels corresponds to most significant disability. The panel does not appear to look at the total child but rather tries to make the child fit their category.

E.G.:

"Our daughter started school in January 1999 and turned 6 in February 1999. She missed the vast majority of Kindergarten due to relapsing with Leukaemia in the beginning of the school year (March 1999), followed by a large number of hospital appointments and admittances throughout the year and a subsequent bone marrow transplant in the September, leaving hospital December 9th and returning to school for the last week and a half! Due to the fact she was already aged 6 repeating Kindergarten wasn't an option. Going back to school the following year she was obviously behind her peers and the headmaster tried to secure some additional help for her. By second term her teacher was voicing a lot of concern. The education department sent out a person to assess "E" in the classroom in order for her to receive some funding for a teacher's aide. She agreed that help was needed, however the letter back to the school said that there was no funding available at that time and that none would be forthcoming. The headmaster felt he had tried all avenues open to him and that his hands were tied. Unfortunately in June 2000 she suffered a rather large seizure and missed most of term 3. Her MRI showed that some of the treatment had done some damage to the back left part of E's brain during transplant and had been further aggravated by the seizure.

In July 2000 I went along to the Children's Cancer Institute annual update. It was opened by Junior Minister for Health. Later in the day the Minister for Education spoke about the importance of early intervention for our children and how this can make all the difference and how we as parents should be looking into accessing this!. I was very excited to hear this so I put my hand up to ask a question. Her response was very vague and something along the lines of there were proper channels that schools have to go through

I then decided to go to see our local member. He was fantastic. Anyway to cut a long story short, he finally managed to secure us some funding through the education department. A wonderful person who restored some of my faith in politicians. The funding continued through to year 6.

Why did I have to go to such lengths though? All reports show she clearly was in need. The application forms from the education department, that needed to be filled out each year lent towards children with language difficulties or physical disabilities. It was *extremely difficult each year to fit "E" into the categories to secure the funding each year. Her disability seemed unrecognised*

The level and adequacy of current special education places within the education system

- Many children are travelling to IO and IM classes. Whilst establishing these classes is involved and costly, paying for taxi transport for 13 years is equally expensive.
- In the current system children will not necessarily be allocated to the class closest to their home.
- Some children have to travel excessive distances to school.
- E.G.:
- *It was suggested my son "L" should go to a physical disability unit .I was disappointed "L" could not get any funding to attend the private school his siblings attend. After long discussions we determined that it was near impossible that "L" would be at school a forty-five minute drive from home in case of an emergency and the other children were fifteen minutes in the opposite direction. It was not safe and I wasn't comfortable with having no access to "L" during the day. Situations inevitably arise where you have to get them from school. This scenario was impossible for me to manage. We decided that we had to move out of the house we'd just built so that the older children could walk to school and that Luke could go to the physical disability unit we knew was nearby.*

Student and family access to professional support and services, such as speech therapy, occupational therapy, physiotherapy and school counsellors

- Students with physical disabilities who are assessed as having a mild intellectual disability or above are eligible to receive services from the School therapy team for Students with a Physical Disability, from the central network of the SESIAHS. This service includes Occupational therapy, Physiotherapy and Speech Pathology. Children with intellectual disabilities from our area are eligible to receive these services from ADHC; however in our groups experience this service is minimal and difficult to access. Children can wait for years for a service.

- E.G.: *"A" was referred to the school aged team two years ago. He had a needs assessment two years ago, and has had no therapy services. He has a severe language delay and because ADHC cannot provide him with the service he has to have the support of a private speech pathologist.*
- *"A" cannot walk long distances and needs a manual wheelchair. To apply for one through Enable NSW he needs an occupational therapist report and the family need an OT to help prescribe the correct chair. He has been waiting 2 years for this service.*

<u>The provision of adequate teaching training, both in terms of pre-service and ongoing professional training</u>

- Our group originated from our need for signing support so signing and communication is an important issue for us.
- Early intervention for children with disabilities recognises the need for alternative and augmentative communication (AAC). Early intervention programs promote signing especially the use of Makaton for children who cannot speak. The public education system, in this area at least, does not promote, encourage or support the use of signing. One reason would seem to be lack of training in signing.
- Training in all forms of AAC is essential for teachers of children with intellectual disabilities or complex communication disorders.

E.G.:

- *"R" has a severe communication disorder and has been signing since he was very young. At preschool his teachers used Makaton signing and acknowledged that even then R could sign better than them. The issue was raised at his transition to school meetings, but no firm commitment was given. His parents assumed the school would see how well he signed and support would be given. They knew the area had itinerant hearing support teachers who could sign and R had started to use Auslan. When R (who is in foster care) started school his DOCS (community services) caseworker contacted the areas disability support consultant and was assured the school would be able to provide support for signing. No one at the school could understand "R" The parents offered to pay for the teacher to do a one or two day signing course (cost $200-400), the schools reply was you will have to pay $300 per day for a* *casual teacher too. The teacher never took up the offer. The Department of Education refused to allow any assessment from an itinerant hearing teacher who signed Auslan, despite this being the easiest way to assess his capabilities. Even to an untrained person it would have to have been obvious he was doing something when he moved his hands in every effort to express himself and to answer questions, and when all else failed he would "dramatise" what he meant'*

Any other related matters.

Meeting a child's individual needs

- This has been one of the major issues for the parents in our group.
- Where a child has different needs and additional support is required, that support is not supplied.
- Not all children fit neatly into a category. The current system does not allow for parent input into the process, the members of the committee deciding what a child needs have never met the child. If a "label" is given to a child parents cannot get their knowledge of the child's needs taken into consideration. In our group alone, the parents include teachers, doctors, nurses and therapists working with children with disabilities so they do have knowledge as well as parental insight.
- E.G.:
- *In year 6 we found out that "E" was given an assessment label of a child in the IO range. Though we were well aware of her learning difficulties and knew that she was way behind, we were unaware of her IO status until we started sourcing high schools for her and we tried to get her into an IM class at our local high school. I spoke to a lady at the local office about "E"s placement and she was the person who told us of her grading. I know what the IO classes are and knew that it was not the right place for Emma. When speaking to the person dealing with "E"'s placement I tried to explain "E" to her. I asked if she had ever met "E" or spoke to anyone who had dealings with her. She said "No". All placements are done by the papers, reports and the information in front of her. I asked if there was any way we could get "E"'s label changed from IO to IM. She answered and I quote. "Absolutely,*

categorically, NO". She would not entertain the idea that meeting "E" or talking to her teachers would give her a better picture of her needs. That day would have to be one of the lowest points of my life. I felt completely helpless against the system and useless in being able to secure "E" the learning environment, both socially and educationally, that would suit her needs. In the mean time we went to visit our local school to see their IM and IO classes. The teacher showed us into the IO class where the children were learning to introduce themselves to people. Only 1 child managed this. Our daughter is able to introduce herself and hold down a reasonable conversation with people, familiar and strangers, without prompting or practice.

- *"C" had been receiving cancer treatment from birth and suffered multiple disabilities because of the treatment. His parents wanted him to start school when he was 6 years and 4 months old because of his lengthy hospitalisations..... I know we had to fight too hard to get him an exemption. We were given reasons like he'll be the oldest in his year in year 12 and all his friends will be younger than him and we can't guarantee that the class won't be full next year. We had to fight to prove he was disabled enough to get into the class although he was too disabled for main stream. We basically were a piece of paper to the department and that's what they go on, not on people's individual circumstances. It's what the child looks like on paper as to where they are placed which is wrong.*

- *"M" is deaf with an intellectual disability she communicates by Auslan. Her parents have found a school that meets her needs, the school were happy to accept her. The Department of Education said she could not go there because it was not their region but they know there are some students have accessed the school from out of school area*

- *"R' uses Auslan signing. DET staff refused to support R signing they stated "expressive communication is not important for education" they considered as long as R could hear what teachers were saying it did not matter that they could not understand R. Told us "R" should not be able to sign Auslan because he was assessed as having a moderate intellectual disability. Asked that R be allowed to have a trial at our local school in the support unit for students with physical disabilities which had 3 vacancies and where both teachers on the class were enrolled in TAFE level courses in Auslan and were using it in the class for a deaf student, request was denied. R also has a physical disability. The request was refused.*

- *He was then assessed by school counsellor, results were viewed by private psychologist who said showed "R" has mild intellectual disability and severe* *communication disorder which impacts on assessment. School counsellor requested a meeting with us, concerned that during assessment teacher could not understand "R's" answers but he appeared to be answering in sign. Following meeting school counsellor and district guidance officer wrote submission to DET recommending parent education of school staff in signing/ access to itinerant hearing teacher who signs to support school staff/ a teacher's aide who signs, again this was refused. We removed "R" and he is now enrolled in our local school in a mainstream class where they reverse integrate him into the class where the teachers sign. Now we have a happy child. Why did we have to through a year of fighting to get what our child needs and deserves. It was only the sensible, insightful local school principal who helped us.*

- *This is"M"'s second year at school but her teacher and aids don't used sign to communicate with her. We have been asking principal to have someone can sign all the time in her class to teach and communicate with her. "M" is deaf and has a disability and can functionally communicate using Auslan the principal has not changed anything. She is totally isolated in her class.*

Treatment of Parents by DET Staff

There are many examples of parents being treated poorly by the DET staff allocating places, in our area:

E.G.:

- *told me that"L" belonged in a school for special purposes, refused my pleas to let him show them what he could do, flatly stated over and over that they believed that "L" was unintelligent (in front of him), which he reacted to and started getting distressed, they snickered at my descriptions of his abilities as though I was a child making things up and insisted I sign the document stating that I agreed with their choice of school.*
- *I asked if the letter would be attached to the document, to which they replied a flat, no. When I asked to take the form away with me they said that it had to be back in their hands by the following Tuesday as time was running out!*

- *She would not entertain the idea that meeting "E" or talking to her teachers which would give her a better picture of "E's" needs.*
- *We felt like she was trying to pull the wool over our eyes and fob us off or trick us into something, that we might agree on the off chance that it might be o.k.*
- *We contacted our local Catholic school. We are not Catholic, but just desperate parents trying to find the right place for our daughter. We gave them all of "E"'s reports and results of testing to look at. They welcomed us, showed us around their 'special ed' department and explained everything they had to offer. We could not believe it. After the interview we were advised that they would accept "E"and make provisions for her including a teacher's aide for the vast majority of classes.*
- *Our child "C" was a piece of paper to the dept and that's what they go on, not on peoples individual circumstances*
- *No-one would listen to our concerns, they told us it did not matter that no-one could understand "R" because he understood the teachers. They made suggestions like "have you tried speech pathology" and "why did you choose to teach him to sign" which are very condescending remarks and show a lack of understanding of communication. I referred to the DET's own policy on communication for children with special needs, the Disability Standards for Education which support R's right and need to communicate and to the DET's stage 1 English curriculum which has a whole section on outcomes based on expressive language but they just kept going back to their argument that it didn't matter if no-one understood him. Can you imagine what it feels like to be communicating and no-one understands you? To make matters worse I witnessed him being disciplined for signing and told to use his words but he doesn't have any! What choice did we have but to remove him from that school?*

Ann Midgley

On behalf of the Makaton Support Group, a parent led and organised local support group for carers of children with disabilities who use Makaton and Auslan