

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

Organisation: Down Syndrome NSW
Name: Mr Stephen Clarke
Position: Chief Executive Officer
Date received: 19/02/2010



Down Syndrome NSW

Submission to the General Purpose Standing Committee No. 2:

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

For Legislative Council of NSW

Submitted 19th February 2010

Stephen Clarke, Chief Executive Officer

Down Syndrome NSW

Ph. 9841 4408

executiveofficer@dsansw.org.au



Down Syndrome NSW
80 Weston Street
PO Box 9117
Harris Park NSW 2150
P. 9841 4444
F. 9841 4400
E. admin@dsansw.org.au
W. www.dsansw.org.au



Submission prepared by **Kathi Beck**

Information Officer (Library)
Down Syndrome NSW

on behalf of the Board and members of Down Syndrome NSW

February 2010



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Introduction

Down Syndrome NSW is a family support organization, established in 1980. The majority of founding members were parents of very young children with Down syndrome, the first modern generation of parents to raise their children with Down syndrome in their own biological families as a matter of course.

Down Syndrome NSW has supported two generations of families throughout their sons and daughter's education, providing access to the latest research, resources and practice experiences throughout the world. We receive approximately 5000 inquiries each year, a significant proportion of them about various issues concerning schooling.

Our library collection is well stocked with relevant resources, and we still find ourselves very frequently referring both teachers and families to the NSW Department of Education and Training's own Jill Sherlock Memorial Learning Assistance Library – one of the least well known, but highest quality specialist resources available to NSW families and schools.

Down Syndrome NSW has responded to demand from families and from schools to provide face-to-face training for teachers and other school personnel, mainly through a program of seminars offered around the State, that is well attended. Approximately 2000 teachers and other school personnel have attended these events since 2004.

Individual inquiries from school personnel are dealt with individually by Down Syndrome NSW Information Services staff, by phone and email, and occasionally in person.



Additionally we offer regular information sessions to families of children preparing to enrol in school and in high school for the first time, in response to the demand for support through these potentially difficult transitions.

Down Syndrome NSW concentrates its resources and work only on supporting people with Down syndrome, of all ages, and their families. No-one has a more vested interest in the wellbeing of people with Down syndrome than their families, and the organisation has developed considerable expertise and a reputation as a highly regarded source of evidence-based information over 30 years, amongst families and the professionals supporting them.



1. Nature, level and adequacy of funding for the education of children with a disability.

From the feedback of our members, it is our view that the funding is not adequate. Many children with Down syndrome, based on standard psychometric testing are assessed as having a mild intellectual disability, which does not qualify them to even apply for individual funding support. However, these tests only target some aspects and not all characteristics of Down syndrome are taken into account. (These are also the areas often improved by Early Intervention Programs prompting one member to write "the MORE successful the Early Intervention program has been with a child the LESS support they are given to capitalise on that achievement and become successfully integrated individuals in our society. ") Children with Down syndrome require more support in schools than students with mild intellectual disabilities alone, because of the specific range of impacts that Down syndrome has on a student's capacity to function within the learning environment. Down Syndrome Education International and others have researched and documented the particular accommodations needed in the school environment for students with Down syndrome. They include:

- supporting the universal short term auditory memory and processing impairments, by accessing relative strength for visual learning and memory through the routine use of visual tools
- supporting students to be safe in the playground, when "wandering" is an issue
- supporting communication development, because of severe speech delay, affecting significant development in other areas, such as social interaction
- providing adapted and augmented communication strategies
- regular support to initiate and stay on task
- positive behaviour support to promote inclusion in the classroom and playground



- accommodating toileting needs and the need for toilet training
- supporting the development of play skills
- adapting for visual processing impairment, even when visual acuity is within normal limits or corrected
- making appropriate curriculum adaptations in all key learning areas
- adaptations to accommodate health problems that occur more commonly in children with Down syndrome, including obstructive sleep apnoea, middle ear effusion, upper respiratory tract infection, hypothyroidism

Another concern raised by our members is that their freedom to choose the type of education they think is best for their child is restricted by differing levels of funding. Members choosing Montessori, Christian and other non-government schools have all commented along the lines of one member that "although we are happy to pay the cost of this choice like any other parent, we would like to know that we are not penalised with a lack of financial support for special needs relative to children in other schools." There is the added anguish that if they want their child to attend the same school as their siblings, they may be denying their child with Down syndrome the support he needs. The funding should be attached to the student and follow the student wherever he goes.

2. Best practice 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.

Our member families indicate that they find it challenging to have to continually prove that their child needs funding. A child born with Down syndrome will always have Down



syndrome and its related need for support. The need for continual assessment is time-consuming and expensive. Parents often need to take time off work to take their child to the assessments. Schools and teachers must submit applications that take up their time and can take months to complete and need to be repeated every year. In the end, these requests for additional support are usually granted but in the meantime, the supports are not in place and the safety of the student is at risk.

Best practice would be to include students with Down syndrome in the defined DET disability criteria as are students diagnosed with Autism. This would allow funding to be used to support students with Down syndrome to reach their potential rather than be used to assess their needs again and again.

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

A big area of concern for our members whose children go into special education settings is that there are limited places and they do not have a choice of school. They do not have the option to send their child to their local school or even their closest school with a support class. They must apply to the district and may be placed anywhere within that district and accept the stress for the student of long rides in a taxi or bus (or the parents must juggle making sure their other children get to their local school with transporting their child with Down syndrome to their school and their own work commitments) as part of their day.

Many have commented on the lack of openness of special education teachers and facilities. Members relate attending an information night for Year 7 parents at a school where 10% of the students are enrolled in learning support units. There was no mention of these students at all at the presentation and when the Year 7 parents were



encouraged to explore the school where the classrooms were all open and teachers available, our parents found the special education unit locked and empty. After enquiring, the unit was reluctantly opened up and despite this being in the middle of the school year, the parents found the walls empty—no visual aids nor even student work displayed.

There is the impression that this lack of openness is because the special education teachers believe they have all the answers and do not want any information from parents despite the fact that most parents are very well informed about their child's disability and needs and can access information and resources more readily than teachers. Another parent commented that when her daughter went from a mainstream class into a support unit she felt as though she had "handed (her daughter) over to the system and my opinion was no longer of any value. Parents need to be seen as a source of information not irritation."

4. The adequacy of integrated support services for children with a disability in mainstream settings, such as school classrooms.

Down Syndrome Education International research stresses the importance of whole school inclusion. Research has found the most important predictor of successful inclusion is staff attitude. All staff need training on the benefits to all children including children with and without disabilities. Research also shows that there must be adequate resources to support students and teachers. Teachers must be trained (addressed in 7 below).

Currently these things are not universally happening. Whilst some members report skilled teachers doing their best with minimal support, others report strong opposition to meeting the needs of their children because they don't have the time or resources.



Even when support is given, there is always the threat that it might be taken away. One member reports that her child had been given minimal support, which she supplements with volunteer help but that funding support was withdrawn since her child was "doing well with the aide" and now she needed to learn to function without any help. This is akin to taking a wheelchair away from a physically disabled student so that he/she would learn to function without it.

We also feel there is a significant need to address social skills as part of children's education. Schools do not feel that this is part of their role despite policy directions in the Special Education Handbook for Schools that social skills and communication need to be part of their education. "Social skills are important for school success and long term adjustment." It mentions instruction in formal or less formal situations and specifically mentions "in the playground." (Section 2.3, p. 6)

One member writes, "Socially supporting a child with a disability in the playground would extend enormous benefit in the classroom setting as well. Often children with disabilities find themselves at a loss in the playground with poor communications skills, unable to initiate games or even with the skills to participate in playground games. Left to wander some even find themselves spending time outside the Principal's office on a regular basis having got themselves into trouble or acting out through frustration or boredom. These children find themselves being punished for inappropriate behaviour when with support they could be included in playground activities, have better self esteem and reduce the inappropriate behaviours that bring them to the Principal's attention."

There is some concern about the use of support aides. Many teachers rely heavily on the sometimes untrained aide to solely work with the student with Down syndrome



and many parents comment that there is a lot of "babysitting" of students with disabilities. Often the teacher isolates the child with Down syndrome together with the aide so that they do not disturb others in the class. The child may become reliant on the aide and does not interact with their class peers. This hampers inclusion and other students view this student as separate from them.

5. The provision of a suitable curriculum for intellectually disabled and conduct disordered students.

There are many resources that specify ways to modify the curriculum and teaching materials for people with Down syndrome. Currently it is up to individual teachers to make modifications but not all feel confident or trained to do this. Many simply reduce the amount of work required or use lower year textbooks rather than addressing the need to make it visually accessible amongst other recommended accommodations.

Many leave it up to untrained aides to teach the student and decide what accommodations to make. It would be useful if the DET developed recommendations on modifying curriculum using research from Down Syndrome Education International that could be used by teachers.

Members also brought up the lack of appropriate curriculum in special education. One member wrote, "I also want it made compulsory that all schools be it mainstream or support stick to the curriculum. Some high schools are only babysitting children – there are no IEPs and no life skills curriculum." Another said, "Expectations are levelled at the lowest abilities."



6. Student/Family access to professional support and services, such as speech therapy, occupational therapy, physiotherapy and school counsellors.

For the most part access to these services during Early intervention is good. Therapy after that is still vital but difficult to access. It is not provided in school unless organised independently by families. Many families are on the waiting list for years particularly for speech therapy that would help their education as well as their lives. Provision of therapy services within schools is scant, patchy and rarely sufficient to benefit the child significantly. Many therapy provisions are implemented as group activities, and do not address individual needs.

7. The provision of adequate teacher training, both in terms of pre-service and ongoing professional training.

We find that training is needed both for pre-service and ongoing training. Many teachers particularly special education teachers have out of date knowledge and are not encouraged to learn what the current best practice is for students with Down syndrome. Professional learning on Down syndrome could be provided online as is planned for Autism Spectrum Disorder in the School Learning Support Program. Down Syndrome NSW regularly holds seminars on various aspects of Down syndrome including educational needs that are open to members and non-members. One parent writes that her school is reluctant to send teachers to attend workshops because of the cost involved not only for the workshop but also for relief teachers. There is an excellent DVD from Down Syndrome Education International that could be used to set up a training course or at the very least be provided to every school with a student with Down syndrome. Access to libraries such as the NSW DET's Jill Sherlock Library should be promoted and encouraged. Down Syndrome NSW also has a team of Young Educators, a group of adults with Down syndrome who go into medical schools and



universities to help educate students about Down syndrome and to dispel any misconceptions particularly among those who will be working with people with Down syndrome but who previously have never even met any. This program could be extended to pre-service teachers.

An additional concern is training of teacher aides. Parents report that the aides are relied upon to teach the student with Down syndrome however, as one parent writes, "I have great concerns with this as very often the Aides have no training at all as teachers, let alone special education teachers, so our children are given even less qualified staff than the rest of the class."

Resources

Down Syndrome Education International research and publications <http://www.down-syndrome.org/information/>

Inclusion in Practice: educating children with Down syndrome at primary school DVD, Portsmouth UK: Down Syndrome Educational Trust, 2007.

Above resources useful for training teachers on learning styles of children with Down syndrome, useful for curriculum modification and methods of instruction.

Learners with Down syndrome: A handbook for teaching professionals, Down Syndrome Victoria, 2009.

Available from Down Syndrome Victoria (RRP \$9.90) Ph. 1300 658 873 or info@dsav.asn.au

Example of a NSW DET school that provides a high standard of education for students with special needs: **Finley High School** in the rural far south of NSW. We believe the inquiry should observe and talk to Merrill Carroll, teacher in charge of special education and her colleagues, students, parents and Principal to see what is best practice in NSW.

