

**Submission
No 291**

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

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The Provision of Education to Students with a Disability.
2010 NSW Parliament Inquiry.

Submission

I write to you as a mother of a child with a disability and as a qualitative researcher in the field of autism and education. My submission is prompted by concerns that the already limited choices available to parents of a child with a disability are further contracting at this moment in NSW.

Recently I made the decision to remove my 8 year-old-son from his autism-specific satellite class (provided by Autism Spectrum Australia) in Sydney. Ewan has been attending an autism-specific placement since the beginning of his school career. While the support given to his learning difficulties has been terrific, Ewan has fared less well emotionally because there are three children with very challenging behaviours in his classroom. As there are only six children in the classroom altogether, the school day can be quite harrowing with outbursts of swearing, doors being kicked and other 'explosions' occurring on a regular basis.

My son is very gentle and is often upset by his surroundings. However, he still requires a lot of assistance with learning. In this sense, the ratio of one teacher and a teacher's aide to six children, provided by Autism Spectrum Australia, is ideal. Let me give you a concrete example of the kind of difference this high ratio of teachers to students can make. Two years ago, I was told my son would probably never be able to read. With intensive input from me and from his classroom, he is now reading quite well. This will make a tremendous difference to his opportunities in, and enjoyment of, life.

My decision to move my son is based on a complex series of weighing up the pros of high teacher-student ratios and autism-specific teacher knowledge and training against the cons of continued exposure to other children's challenging behaviours.

Ewan is classified as having a borderline intellectual disability. He is, therefore, ineligible for most support class placements. My only option is to send him to a regular classroom in a regular school. Many teachers advised me that he would be better off in the nurturing and friendly environment of a small school.

I therefore contacted (earlier this week) a school nearby that has an enrolment of fewer than 200 pupils. The Principal was initially sympathetic to our predicament. I had arranged to meet her, with my son, the following day. That afternoon, she phoned me back to say that she had been talking to various people in the Department of Education who had all advised her to say 'no' to me without even meeting my son. The basis of her refusal was that proposed changes in the funding for disability in NSW schools mean that funding will no longer be attached to the child but will be based on a variety of factors, including prevalence data. As she already has a number of children with autism and Aspergers in her school, she explained she could not take my son, as she would receive no additional funding for him.

My only 'choice' has been to enrol my son in my local government school, which has a much larger student population. I fear that the substantial gap between a classroom of six pupils with constant aide support and a classroom of approximately 30 pupils with minimal extra support may prove too difficult for my son.

In the course of doctoral research I am currently conducting, I have interviewed 22 mothers in Sydney whose children, diagnosed with autism, are transitioning to primary school in 2010. While I have not yet had the opportunity to fully analyse that data (and the research is a longitudinal study over 3 years), I can tell this Inquiry that mothers frequently told me appalling stories of informal exclusionary tactics adopted by NSW government school personnel in relation to children with autism. One mother, in particular, provides a memorable example of this. Living around the corner from her local school, she approached the school about enrolling her son in Kindergarten. She was told they would not process her enrolment because they did not 'do' children with disabilities. The reason for this, she was told, was because it would poorly affect their NAPLAN results and other competitive test scores. She was advised to try another school in the area with a 'less academic' reputation. I am pleased to say that she persisted and her son is now enrolled at the local school. But the fact that some educationalists seem either entirely unaware of or undeterred by anti-discrimination legislation is remarkable, hurtful and unacceptable.

Put succinctly:

- a) While most parents continue to support a continuum of educational provision for students with a disability, the market is currently very restricted with no 'in-between' options and continued difficulties in supporting students with challenging behaviours with disabilities and students with disabilities with no challenging behaviours in the same setting;
- b) Educational 'choices' for parents of a child with a disability are currently narrowing due to the twin demands of greater stress on school 'scores' and a fear that changes to the funding model for disabilities will result in fewer resources being available to schools.

I also attach a brief article, published in the popular press in 2009, that addresses issues of school choice and autism.

Rozanna Lilley
19 February 2010

Searching for the Right School: A Sydney Dilemma

Rozanna Lilley

Deciding on the right primary school is always difficult. While some parents opt for their local school, others search far and wide, comparing private and public offerings, looking for the elusive perfect combination of good after-school care, enrichment activities and academic excellence. In 2006 I was searching for the right primary school for my son, Ewan.

In the course of this search I rang or visited a number of the government schools in my area, two Steiner schools, a Montessori school, and two nearby Infant Schools. I also considered some 'special education' environments. My most recurring education fantasy involved moving to the South Coast, altering our identities and not attending school at all! Ewan is diagnosed with Autistic Disorder and Mild Intellectual Disability. He is a typical autistic child in that he has a very irregular pattern of cognitive strengths and deficits, chronic anxiety problems, disordered language skills and immense difficulty adapting to change. Finding the right place for any child is hard. Finding the right place for a child with a disability is an especially daunting task.

As part of this search, my partner and I visited an Infant School in the Inner West. As we took our seats for the Information Evening, a live jazz trio entertained us. There was wine and snacks, and a buzz of excitement in the air. We heard about how the kids loved school, the fostering of their creativity, the need to listen to and respect them. An electronic whiteboard was positioned at the front of the room. One word was scrawled across it—*passion*.

The next day we visited an Autism Support Class at another Inner West school. There were no Kindergarten children in the class. An atmosphere of diligent calm pervaded the room. Signs on the wall offered useful suggestions, such as 'What can I do at lunchtime? I can play my Nintendo'. The teacher told me that she was 'running a boot camp for autism'. I chatted with her about my son. She advised me that I should try to get him reclassified as having a Moderate Intellectual Disability so that I could send him to a Support Class where they would expect to deal with toileting difficulties. I cried for a while in the playground.

Welcome to Disability Land. It's a topsy-turvy world. Instead of people saying nice things about your kid, you listen amazed as the child you love is described as a list of deficits. Often these deficits are scaled and the scales have potential resources attached to them. People advise you to keep your kid up the night before a disability assessment, so that they will do badly and you will get more help or funding. You no longer have a 'sensitive' child; you have a child with 'poor emotional regulation'. You no longer have a child with talents; you have a child with 'splinter skills'. You no longer have babysitters; you have respite workers. Your child is no longer enjoyed; they are managed. You are not a mother; you are a carer. In the process, the fragile vivacity of childhood is sometimes threatened by the very mechanisms of classification and surveillance established to protect and help kids with disabilities.

If we listen to the parents of kids with disabilities, we hear this story again and again. Recently I have been assisting an Early Intervention centre, Pathways, to produce a

booklet documenting parent experiences of schooling for kids with disabilities. Experiences vary widely, depending on both the individual child and the capacity and willingness of the school to include them. Some of the kids have Down syndrome; many are classified as being on the autistic spectrum. The common thread that connects these stories is the difficulty of making a decision, a difficulty borne out of both pragmatic and philosophical considerations, and the experience that genuine educational 'choice' is more of a rhetoric than a reality.

Over the last few decades there have been vast changes in attitudes towards, and service provisions for, people with disability in the wider community. Before the 1960s, institutionalisation of the developmentally disabled in psychiatric hospitals and other facilities was standard practice. Nowadays these institutions have been closed and the predominant philosophy of care for people with intellectual or other disabilities is known as 'normalisation'. The education sector has been part of this change. In Australia all of the major education providers are philosophically committed to inclusion. Put simply, this means that students with 'special learning needs' can and should be educated in the same settings as their normally developing peers, rather than being placed in segregated settings such as support classes or special schools.

Educational inclusion has, at times, been an intensely controversial topic. On the one hand, those advocating for full educational inclusion largely reject the need for specialised teaching methods, arguing that what needs to change are oppressive attitudes towards disabled kids and discriminatory social practices, which have deep historical roots. On the other hand, there are those who argue that education can remediate the effects of disability and that a range of special education programs are designed to do just that. There are thus significant tensions between parents who have enrolled their children in segregated settings and those who have not. This debate is especially intense in regard to autism, as numerous studies suggest that many kids on the spectrum may not cope well with the hurly burly of classroom life and do better in highly structured and predictable environments.

Certainly parents of kids with disabilities report a range of experiences. They are all worried that their child might be bullied or lonely at school. Often that worry is justified. One mother, who enrolled her son in their local school, told me that his Grade One teacher put the class on one side of the room and her child on the other side of the room, at a separate table facing the wall. This may be inclusion but it is not inclusive. Eventually the child moved to a special school.

Some kids with disabilities have what are known as 'challenging behaviours'. Many of these students are diagnosed with autism. While no-one underestimates the difficulty of including these kids, it remains the case that the education system often serves these children poorly. Anecdotally, strategies such as suspension and exclusion are common. Truancy and school refusal are also frequently reported. Parents, especially mothers, bear the brunt of these systemic failures to provide a workable education for these students.

When inclusion does work, it can be inspiring. Parents cite the adaptability of the teacher and their willingness to respond to parental suggestions as crucial to the success of inclusive education. The importance of the Principal's attitude in shaping the whole school culture is also frequently mentioned. Rather than seeing children with disabilities as a burden, Principals who embrace inclusion stress the advantages of having kids with

disabilities in the school, generally in terms of encouraging a genuine understanding of diversity.

Parents who send their kid with a disability to their local school are usually primarily motivated by social factors. As one mother, speaking about her 11-year-old daughter with Down syndrome, expressed it: 'The social stuff was the most important for us; for her to be in the community with mainstream peers'. Another mother echoed this sentiment, recounting the pleasure of other children greeting her son as they walked to the local library. They are also often motivated by social justice considerations.

Parents need to feel included too. They do not want to be excluded from community life, from knowing other parents in their street, from helping out at the school canteen, from attending sports carnivals with other parents—from the myriad of seemingly mundane activities that allow them to widen their circle of friends and, simply, to be acknowledged as a mother or father. For it is in these actions that we all grow as adults, supporting one another in the immense task of parenthood. Sadly, some parents of kids with disabilities find that they are not welcome by all at their local school. Sometimes both they and their child are excluded—from birthday parties, from offers of friendship, from the daily round of school engagement. Already struggling with their loss of entry into a world of parental pride based on a regular progression of childhood achievements and a competitiveness borne of the certainties of 'fitting in', they find their difficulties amplified through ostracism. Given this, it is little wonder that some parents make strenuous efforts to hide the knowledge of their child's disability from other parents in their school community.

Recently the Australian Government committed \$190 million to the Helping Children with Autism package. Initiatives include extra funding for early intervention services and workshops aimed at educating both teachers and parents of school-aged children. Generally the case for these sorts of packages rests on a characterising social policy spending as an investment. Every dollar spent now, the public is told, will save money later, as more individuals with autism will be able to eventually live independently if offered the right sort of interventions and the right sort of education early on.

Phrased this way, the provision of quality education for children with disabilities makes good economic sense. However, schools are under multiple pressures to perform in a competitive marketplace. In this environment, having an inclusive school culture may actually be counterproductive to attracting the 'right' students and their families. The increasing move to judge schools according to their academic outcomes, combined with the existence of a well-established special education sector in New South Wales, creates an environment that is often not conducive to the adoption of inclusive practices.

Put more directly, parents, and their children, continue to struggle with discriminatory community and school attitudes towards disability. While the economic or business case for improving services to individuals with disability is welcome both for its optimistic stance and for the practical changes wrought, it cannot directly address this discrimination. Only a commitment to social justice can.

Earlier this year I was thinking about moving my son from his autism-specific school setting. He has done well there but I had a strong sense that it might be time for him to take his place amongst his peers. I was intimidated by the large size of my local school and had been advised by numerous education professionals over the years that a

small school would be a more promising setting for my son. Looking for a nurturing environment, I phoned a very small Inner West primary school, and outlined our situation. The administrator talked to the Deputy Principal and then returned to the phone and gave me a 'message'. The message ran like this: 'The only reason our school would take a child like yours is if your local school refused him'. This repeated, albeit more bluntly, my experiences a few years earlier with two other schools in the Inner West. Many of these schools are operating close to capacity. They have few reasons to take out-of-area enrolments and even fewer to accept kids with disabilities who are not in their catchment.

Some schools, however, are really making an effort. Recently I attended another information evening. This one was at my local primary school. It is a large school with a diverse student body. I came away deeply impressed with the school and, in particular, with the Principal. A proactive approach to inclusion was part of a broader school culture, which emphasised the need to respond to students as individuals, to build on their strengths and to develop an ethical framework to live by. Innovative programs were in place, including the introduction of philosophy in the early school years, and the Principal was directly involved, on a weekly basis, in planning for the needs of students who require extra support.

All parents make difficult choices about schooling. For families who have a kid with a disability, this is a complicated, and often a heart wrenching, process. All parents do what seems best for their child at any given time, in the light of their available choices. For parents of kids with a disability, those choices are fewer and harder. I may never make the decision to send Ewan to our local school. But I am very glad it is there.

Sydney's Child October 2009: 23-25. Special Series, Shades of Sydney. Also nationally syndicated in Adelaide's Child, Brisbane's Child, Canberra's Child, Perth's Child and Melbourne's Child.