



Do Special Needs Require Special Schools?

Rozanna Lilley writes about the complexities of finding the right school for a child with a disability – including her own.



Illustrations by Gregory Baldwin

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

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.

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 born out of both pragmatic and philosophical considerations, and the experience that genuine educational ‘choice’ is more rhetoric than reality.

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

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education’ environments. My most recurring education fantasy involved moving to the South Coast, altering our identities and not attending school at all!

Ewan has been 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 were snacks and wine, and a buzz of excitement in the air. We heard about how the kids loved school, the fostering of their creativity, and 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.

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

Over the past few decades there have been vast changes in attitudes towards, and service provisions for, people with disabilities in the wider community. Prior to the 1960s, institutionalisation of people with developmental disabilities 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 full educational inclusion largely reject the need for specialised teaching methods, arguing that what needs to change are oppressive attitudes towards kids with disabilities and

and would 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 1 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.

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When inclusion does work, it can be inspiring. Parents cite the adaptability of the teachers 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 child 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 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 welcomed 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 born 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-age children. Generally, the case for these sorts of packages rests on 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 children continue to struggle with discriminatory community and school attitudes towards disability. While the economic or business case for improving services to individuals with disabilities 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 among his peers. I was intimidated by the large size of my local

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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 reasons to accept kids with disabilities who are not in their catchment area.

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,



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in particular, with the principal. A proactive approach to inclusion was part of a broader school culture that 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 required extra support.

All parents make difficult choices about schooling. For families who have a kid with a disability, this is a complicated and often heart-rending 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. ■

Rozanna Lilley is a social anthropologist based at the Children and Families Research Centre at Macquarie University.

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Ongoing Assessments

The educational choices that parents of children with disabilities make for their children do not have to remain static, writes school principal Jo Karaolis.



Illustrations by Gregory Baldwin

As parents around the country focus their minds on their choice of school for their child next year, I am reminded of the strain that that question can pose for parents of children with disabilities. The risk of getting it wrong weighs heavily when your child has many difficulties to face in life and you know that the right intervention at the right time can achieve miracles. As principal of a school for children with special needs, I am often asked to advise parents who have a child with a disability on the difficult choice

between mainstream schooling and special schooling. I always answer that there are benefits in both and disadvantages with both, and that parents have to choose the benefits that are most important to them and the disadvantages that they can best compensate for.

There are obvious benefits to a special school: small classes, specialised teaching, staff and parents who understand disability and don't pass judgement, an appropriate curriculum, the opportunity to take part on an equal footing in every school activity,

the chance to be school leaders. There are hidden benefits too. Your child gets invited to all the birthday parties and sleepovers and finds out what it is like to have friends with whom they have lots in common. The big disadvantage for many parents is that their child is not in a 'normal' environment, with

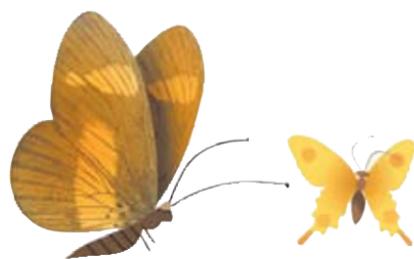
normal role models. There are undoubted advantages to a child with disabilities being in a mainstream school. There is more to aspire to, there are more-challenging ideas and your child hears and learns from the more-complex conversations of children in the mainstream. But I have become

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convinced that the lure of 'the normal' has to be challenged. I believe it to be a false lure that springs from the denial that stems from grief.

It is terribly hard to learn that there is something wrong with your child and to accept that it cannot be 'fixed'. Some parents are told the news when their child is born. For others, it may take until their child is three or four years of age before their secret fears are confirmed by a psychological assessment that labels their child 'developmentally delayed'. I admire the parents who can embrace this without any sense of loss and get on with making the best life they can available to their child. My heart goes out to the parents – the majority of parents of a child with special needs – who deep down in their psyche fight against the idea that their child can't be like everyone else. Our desire for normalcy for our child is perhaps part of evolutionary survival; it is such a strong instinct.

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The second step was when I realised that all their limitations were limitations that each one of us shares; that their anxieties and fears are our own; that their 'differences' are differences embedded in all us 'normals', but writ large. The difference is that we 'normals' have learned to hide all the parts of ourselves that don't fit into current notions of what is socially acceptable; to keep our hands still when we are excited, to shut our lips firmly on our inappropriate comments, to absorb our anger inside ourselves instead of letting it fly out, to fill our minds with thoughts of the past and the future rather than living in the moment. The third step that made me abandon the concept of 'normal' as synonymous with 'desirable', was the day I realised how happy the children at this school are compared to the rest of us.

I think it is important for us to uncover the deep prejudice that underlies our notion

that 'normal is good'. The greatest artists, thinkers and leaders have not been normal. As children, most of them were misfits, the butt of jokes or worse.

Twenty or more years ago, the philosophy of inclusion became the creed of all who cared about children with special needs. They called it 'normalisation'. Every child with disabilities should be able to go to their local school, like every other child. At the same time, special schools were being set up for those who wanted to make a career in sport, or in the performing arts, or in agriculture. But for children who needed more-specialised teaching, more-individualised programs, greater consideration of their need for space, for time out and for specialised learning materials, normalisation in the local school became the universal cry.

The inclusion movement has some great victories to its credit. No school can now legally refuse to accept a child, no

matter how great their difficulties. Many schools have learned to provide richly and lovingly for children with extraordinarily high needs for physical and sensory adjustments. Thousands of parents will attest to the benefits their child has gained from being included in their local 'normal' school.

Inclusion has not worked for every child or for every school. It is fundamental that parents have the right to choose the setting they want for their child with special needs. That choice is not always an easy one to make. Like many tough decisions, it is a choice between two 'goods'.

A mainstream setting offers good role models: 'normal' children with good verbal language, good play skills and a benchmark of performance to aspire to. Parents can feel very comfortable when they drop off their child with special needs

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continued from page 27

in the morning into this group of happy, able children. They can't help but feel that their child will grow more like these others as each day passes.

A special-school setting offers a different kind of 'good', equally valuable. Here there are small classes, specially trained teachers, and classroom language and activities of a pace and kind that allow the child to understand and participate. Here every parent understands what it is like to have a child who cannot speak very well, who isn't toilet-trained yet, who has emotional meltdowns and behavioural outbursts over getting wet or having to share a toy. Here everyone gets invited to parties and picnics and no-one is left out, because these children love everyone without distinction.

When their child is first starting school, my advice to parents is to choose whichever setting they are most comfortable with for their child; to try it and see. Follow your heart, or your gut. I do, however, have a strong view about the later years of primary school. I worry that at this important stage, when high school looms, parents are sometimes not making a choice at all. Their child is in a mainstream school. This has gone really well in the past, but by about Year 3 or Year 4 it starts to get more difficult for some children. The pace of the class has picked up. The teacher has to get creditable results in the national assessments. The children have become more discriminating in their friendships and less willing to include the child with special needs, who can be a drag on their time and attention. In the best of schools, there may be some isolated but malicious targeting of children who are less able to defend themselves. I have seen children of this age who have become skilled 'bluffers'. They spend their day at school hiding their difficulties by being quick to write answers on their page – any answer, as long as they are writing like the others and finishing when the others finish. I have seen children who cannot read deflect

unwanted scorn by being the funniest child in the class, the one most often in trouble with the teacher, the 'clown'. I have seen children who are always first to have their hand up to answer the teacher's question, but the teacher doesn't ask them because they are always wrong. It's having your hand up that matters.

The road ahead for these children is not promising. Their self-esteem plummets. Their defence mechanisms become ingrained. High school is likely to present six years of mandatory discomfort, if not downright pain.

This is the time for parents to make a renewed commitment to doing their best for their child with special needs. As puberty approaches, new potential for learning emerges, with a greater working memory and increasing specialisation of the brain. Intensive literacy and numeracy teaching at this age can turn non-readers into readers, and help children who are not numerate to become numerate. Best of all, the right teaching in the right environment can restore self-esteem and enable a child to develop a positive image of themselves, ready for their adult years.

At our school, we encourage all students who can to have a go at mainstream schooling after doing our school-beginners program. Then, after two or three years, if things are no longer going so well at the mainstream school, they come back and we help to prepare them for high school.

Having one or two years in a special class is not for everyone. Some children who are very socially aware will find it too hard and, for them, I recommend that parents pull out all the stops and invest in intensive speech therapy or private tutoring again. But please don't do what your child is doing and hide from the problem. It is at this point that your child needs you to be a parent, to identify the difficulties and to believe that solutions exist – and then to find them. ■

Jo Karaolis is principal of St Lucy's School.