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

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

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 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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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
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, 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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