

family

A D V O C A C Y

## A parent's perspective An inclusive education as part of an inclusive life

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I am living proof that you can negotiate an inclusive education for your son or daughter with schools over a 13 year period and survive the process! Any extra grey hairs are easily coloured over and the outcomes for my son have been overwhelmingly positive ones. My son, Alex, recently finished his school life, graduating from Year 12 in 2008. He spent every day from kindergarten to Year 12 a member of ordinary classrooms. I would like to share some reflections on his and our family's experience during these school years. I want to share what I see as the enormous benefits of an inclusive education for him. However, I also want to bring a 'bigger picture' view to our consideration of schooling and place it into a whole of life perspective.

When we use the word *education* to mean *formalised education or schooling* we need to remind ourselves we're dealing with a fairly artificial construct. We go through 13 or so years of school, then may go on to university or TAFE and we call that our education. But we all know that education in its broader sense is a much, much bigger thing and that we have innumerable opportunities to go on learning throughout our lives. Those of us who have managed to become as ancient as I have will no doubt have a perspective on schooling as one very small, albeit very significant, part of their lifelong learning experience. Before I discuss further what we've learned through Alex's schooling, I want to reflect a little on where school fits into most of our lives.

Personally, I have a fairly dim recollection of things that were important to me at school. I certainly don't remember what I was being taught in Year 5 English, though I might put some of it into practice in daily life. I *do* remember some of the friends I made and the games we played at lunch time. I remember teachers I connected with and teachers I loathed. I remember some had the power to inspire me and make me feel good about myself and others had the capacity to make me feel very small. I remember plenty of angst, times when I may have suffered embarrassment or felt awkward in a range of contexts and I also remember times of joy, laughing with friends or feeling proud of my achievements. Each of us will have our own collection of memories that make up our school experience.

My guess is that only a small part of what comes back to us most vividly will relate to the actual stated business of schools - the overt curriculum. I think of school education as being a little like an iceberg. The visible tip is what we commonly think about when we use the word *education*. It's the stated curriculum, the KLAs, English, Maths, Science and so on. It's about the novels, chemical reactions, volcanoes, Egyptian pyramids, essays, basketball rules...a vast and impressive array of subject matter with which we'll come into contact over 13 years. In any discussion about inclusive education, there is likely to be some emphasis, quite rightly, on how students with disabilities might access this curriculum in personally meaningful and effective ways. That is very important, undoubtedly.

However, when we do reflect on our own school years, there's so much more than the 'subject matter' that assumes an important place in how we remember our education.

There is so much learning that is less prescribed, less pre-determined and more incidental.

I'm not even talking specifically about an inclusive education here yet, but one like most of us experienced in ordinary schools and classrooms. Typically, school is where we start to get a sense of who we are in relation to the world, a sense of how we relate to others. We form friendships. These come and go over the 13 or so years. Some people acquire enduring friendships; others find real reward in a string of friendships that change as they change and grow. We also work with a succession of acquaintances with whom we may not even have much in common; some we may not like much. We acquire skills intentionally but also incidentally. We learn about interpersonal communication. We learn about appropriate behaviours in different contexts - the classroom, the formal assembly, the informality of the playground, the public gaze of the field trip. We learn to cope with conflicts, learn to compromise, learn to stand up for things we think important. We learn from our very low points, of failure, isolation or embarrassment; we experience high points of success, companionship and belonging. The incidental curriculum offers us all so much. In effect, we experience a vast array of opportunities for practice - practice in communication, in relationships, in community, in citizenship, in ideas, in ethics, values and in a sense of self.

That's all of us. All of this is also fundamentally true for individuals who have a disability.

As parents of children with a disability, we are offered choices regarding their education that other parents aren't offered. The choice they will not be offered, but we will, is to send a child to a separate system, away from where most typical kids will grow and learn. When a child is offered a segregated school environment, there will still be an intentional curriculum, but we remove the incidental curriculum of a diverse, busy, stimulating typical school community. I believe we really rob them of something enormously significant.

Somewhere very early in our sons' and daughters' lives we may get drawn into a mythology surrounding disability that says only specially trained personnel can meet the needs of people with disabilities in specialist, disability-specific settings. We get convinced all kinds of 'programs' are necessary. With the best of intentions we may channel our kids off into a separate, specialist world, thinking they're going to benefit from that. I would assert, however, that people who spend their time in this 'disability-land', first as kids at school, then as adults in disability-specific day programs and services, can become invisible to the wider society. Speaking both historically and currently, they are not highly valued by the society. They may be assigned a label or a group identity but few typical people may ever come to truly know them as individuals. Segregation in schooling can set up a life of marginalisation, of invisibility. It is not the logical pathway to a life as a known, valued individual included in a community.

Even educationally, it never made much sense to me when we had to choose a school for Alex.

A young person who may have problems communicating surely needs more, not fewer, opportunities to practice their communication with others.

Surely, we thought, Alex would need lots of communication partners and different models to help him practice and understand the 'unwritten rules' of interactions.

Wouldn't a young person whose developmental pattern is different from the typical need more, not fewer opportunities to be immersed in the world of kids the same age who can model the unwritten rules of being 6, or 10, or 16?

A young person who may have limitations in mobility or comprehension would surely need more, not fewer opportunities to explore a range of experiences to find those things that really interest them?

The most concerted efforts of a specialist teacher or dedicated teachers' aide cannot, I believe, replicate the richness of the typical hidden or incidental curriculum.

When we talk about an inclusive education we really elevate the importance of that incidental curriculum. An important element of an inclusive classroom is that a real, deliberate emphasis will be placed on creating a mutually supportive community of learners that is explicitly taught to value one another and to appreciate difference. Young people in inclusive classrooms can access a very rich and varied assortment of incidental learning opportunities. In an inclusive classroom, teachers raise these to a position of much greater importance and consciousness.

During his years at school, Alex's disability, his personality, his interests, his way of communicating, his vulnerabilities, his sense of humour and the wider societal issues that will affect his life have all been opened up to learners in his class to find out about. Students have often worked in small groups with him. They have been explicitly given the information they need to know how they can help him and how he can contribute. They took very quickly and easily to the idea that everyone doesn't have to do things in the same way. They understood that though Alex may not have the capacity to do all of a task, he could do something and it was often their job to work out just what his contribution could be.

In his primary school classes every single member of the class will have worked with Alex either in a pair or a small group. Thus, they all had opportunities to get to know him. The photographs we sent in from home gave them a glimpse of his life beyond school. They were excited about providing him with support. We had to laugh when one child commented that he was a 'celebrity' and that his life was 'exotic'.

In the best of his classes, one child's talent for drawing, another's Mum's fabulous Turkish food or another's religion have all been seen as opportunities to embrace the diversity within every class. In the best of Alex's classes, he hasn't been an 'add-on' but one of the many people in a diverse class population with some learning and reward to offer others.

As part of really embracing this diversity, a sense of community is consciously and continuously fostered in an inclusive classroom. Relationships are carefully nurtured. The incidental curriculum, to an extent, becomes intentional as opportunities to 'learn inclusiveness' are embraced.

So supporting one another is a deliberately built ethos in an inclusive classroom. Students are taught to see helping one another as a natural consequence of being in a learning community together. The most striking thing about Alex's schooling is the amount of natural support within his classes from students working with him in small groups, that didn't rely on funding or on teachers' aides or other 'add-on' strategies. Teachers' aides were very often able to help students understand more about Alex's communication, or whatever, then fade out and leave it to the kids while supporting the whole class as needed.

A person with disability will come to be known individually in a valuing and supportive environment. When an inclusive community is built, an important consequence is that people come to know each other as school/class mates, as friends, as team members, as valued individuals with names and real identities, personalities, senses of humour, skills, and vulnerabilities. They learn to be comfortable and conversant with diversity. I've seen kids who have been through classes with Alex cringe when someone outside that community has used language they know to be insensitive.

I've seen teachers who haven't been a part of Alex's life respond with amazement when one of his friends casually takes a tissue and wipes saliva off his chin.

As a result of 13 years spent largely in such classrooms, Alex has become quite widely known in our local community, not only by the actual students with whom he shared classes, but their siblings, their parents, their aunties, their neighbours, the school staff, teaching and ancillary, the bus driver and so on. When he's met down town, he's greeted by people, who know him by name. I've never clapped eyes on many of them before. We're now very much focused on using that direct knowledge of him and wider benevolent interest in his life acquired through school to build his links with his broader community. I would not want to be attempting to do that in post-school years without the impact of his years of inclusion.

The reason we chose the regular class and worked towards an inclusive education for Alex was because we had firmly established a vision of what we wanted for his life as a whole. We didn't want a life of invisibility to others. We wanted him known and cared about by others. We didn't want his life to be constrained by groupings and programs; we wanted him free to develop skills and pursue interests. If we wanted to see him developing a real life, embedded in his community, then the choice of an inclusive education was the only possible path to choose. The choice we make for our sons' and daughters' education can have far-reaching ramifications when it comes to achieving a particular kind of life for them.

As parents, negotiating our kids' education, we need to keep our focus on the 'bigger picture' of education and how that fits into our vision of the kind of life we ultimately want for our sons and daughters. Most of us will share certain fundamentals in that vision. We'll share most of the fundamentals with parents of all kids. Most of us will want our kids to be happy, confident, to have friends, to have interests and skills and opportunities to develop these. We should formulate that vision and keep it in mind. A good life for people with disabilities will not just happen. It will be the result of the choices you make, based on the vision you have. Without the active pursuit of inclusiveness, our sons' and daughters' lives are likely to become isolated and impoverished.

When young people with disabilities have the benefit of an inclusive education, they can be seen as individuals. They are known by name. They are valued. Alex has been a class mate, a group member, a friend. People have had the opportunity to and were encouraged to take the time to find out more about their friend or classmate. They became very skilled in the kinds of support he might need at any given time. They've enjoyed his love of rhythm and singing and have enthusiastically sought ways to engage him.

Think of the average size of a secondary school. Some parents of children with disabilities shy away from larger school size as a scary thing, a negative. However, literally hundreds of people have had the opportunity to know and support Alex in an inclusive school community.

Alex's example demonstrates that this can be a reality even for people with very high support needs and complex learning issues. In fact, when a person has very high support needs, it is even more imperative that they have more opportunities to be known on an individual basis and not seen in terms of a label or what a label might communicate about who a person is. Alex and other people with very high support needs are even more vulnerable than most, to spending their lives being invisible to the rest of the community.

We, as a society, can ignore, neglect and disregard those who are invisible to us as people. We, as individuals, respond very differently to people we've come to know and value personally. Transforming our schools and classrooms into truly inclusive places has enormous long term potential in how the wider community comes to regard diversity in general and people with disabilities specifically.

Now that we've entered into the next stage of Alex's life, with that vision of a good life still in mind, I want to share a few reflections about what his school years have given him.

As I said, Alex completed year 12 in 2008.

He's graduated with his class, went down the 'red carpet' with his friend, both gorgeously dressed. We once received, along with all other parents, a 'school readiness' checklist at Alex's preschool. The reality is that Alex would still be unable to perform most of the tasks listed that were meant to signify that children were ready to start kindy, but he *does* now have his HSC and got the biggest round of applause at the graduation ceremony.

He thoroughly enjoyed Woodwork, Metalwork, Art and Sport & Leisure. We have no way of knowing what else Alex has learned of the actual curriculum in the context of those ordinary lessons. His communication difficulties mean we don't always know what he understands. He is able to recite the periodic table from hydrogen down to iron, for whatever that's worth! We know he's at least had an opportunity to be immersed in those lessons. He worked on goals that were personally relevant to him within the context of the broader curriculum and received a statement of attainment which detailed which "Life Skills" outcomes he had achieved in each subject area. Being in the same classrooms has never meant the same work, the same outcomes. That would be silly.

The students with whom he has graduated may or may not have continuing contact with him. However they take with them into their lives and communities the benefit of that learning about inclusiveness.

When Alex gets his hair cut in town, it will be his lifelong friend who will cut it.

The mechanic he chooses, the shop assistants who serve him, his chemist and so forth are likely to be people he knows. One school mate has inquired about becoming one of his support workers and he now goes swimming with Alex each week. When Alex's friend becomes a child care worker, she will have no problem facilitating natural supports around children with a disability. She's already commented that she doesn't really 'get' why her TAFE courses make such a song and dance about including kids with disabilities, when, to her, you just do it because it comes naturally, of course. Others Alex knew at school may experience the benefit of an inclusive education in ways we will never know about.

Relationships are most definitely key to ensuring a person is embedded in their community. Through school, we certainly worked very hard to foster friendships and I certainly encourage others to do so as well. Look not only to what school offers, but local sporting teams, clubs and so forth. Begin as early as you can to widen and deepen the acquaintanceship of people in your community with your son or daughter.

We had huge birthday parties every year for Alex.

Eventually we just invited everyone from his class because we didn't want anyone left out. They provided an ice breaker and an opportunity to meet more people who might potentially have an impact on Alex's life. I'd do it all again, of course, but I also now have a bit of perspective to offer on these friendships that I may not have had back then. As parents, we often get worried about maintaining friendships and it can be upsetting for us when friends might 'move on' from our sons and daughters as some of Alex's friends have undoubtedly done. Some have also moved away from town, are travelling, studying elsewhere and so on. I now realise there's something quite natural about the coming and going of friends. I know I don't see any of my own school friends now; I haven't for many, many years. Some people may have some school friendships that endure throughout life but an equally common experience is that some old friendships wane and new friendships are formed in new work/leisure contexts.

We try to work towards maintaining Alex's friendships, but it's not necessarily that big a problem if some turn out not to last. An inclusive education has afforded Alex something really important in this area, beyond the friendships that may, or may not last. He understands friendship. He's been a friend and has had friends. He appreciates what friendship gives him. He knows the feeling of connectedness. I see him now using that knowledge in his own way. He is

making new friends in his new life. He knows in his own way that it's something he needs to put effort into.

The important thing is that people continue to have the *opportunities* to make friends and acquaintances through real activities in typical settings amongst a variety of people. This can certainly be problematic once the universal entitlement of education is over. In the adult world, quite frequently, membership needs to be negotiated more concertedly. It can be less automatic. But whatever avenues are open to a person, such as TAFE, work, club membership or whatever, if people are pursuing their interests and developing their skills alongside others who share those interests, through real involvement in typical activities in typical places, the opportunities are there.

Alex goes to listen to music at our local Irish pub often on a Sunday afternoon. There's a group of regulars, who greet him by name, as do the bar and restaurant staff. It's our belief and this is reinforced often by the feedback we get, that people generally *want* to see young people with disability out and about doing the stuff everyone else does and want the opportunity to know them. One man at the pub commented upon how rarely he sees young people with significant disabilities out in places like the pub.

Why he may not see this often has a great deal to do with the way supports for people with disability are arranged around the person's perceived need for programs and services, often defined in a rigid 9-3 model, and not around a person, their interests and friends. Alex has a range of support workers, many around his age. That support is individualised and directed by us, in a family-governed model. This choice, like the earlier choice about school, was based on our vision for Alex's life. It allows us to try to build on Alex's inclusive education and to keep the focus on Alex's inclusion in his local community. It allows him, if we think he will enjoy it and will have the opportunity to meet people, to go to the pub on a Sunday afternoon, or to a party on a Saturday night, or whatever. We think that is immeasurably more valuable than the 'adult day program' which becomes the default choice for so many young people with significant disability.

We're often taught to fear our wider communities, to see them as a potential source of harm or negative attitudes to our sons and daughters. Sometimes people choose separate services thinking of them as being more protective than the world at large. On the contrary I would argue there is enormous latent goodwill in our wider communities. Recently we have had an indication of this. Not long ago, we decided to contact our local free newspaper. They have a feature in it called "*Getting to know you...*" and each week it introduces a community member who answers a list of questions about themselves. It's a simple little 'filler' in the paper, but it has quite a wide readership. We asked whether it would be possible for Alex to be featured in this way and we sent in the information. Well! The feedback from that article has been



unbelievable! Many people who don't know Alex or us have said hello to him in public places and commented that they saw the article in the paper. Invariably, they then go on to say how lovely it was to see a young person with a significant disability included in that feature and then, often to ask us about Alex's life. The Irish pub had the article taped to the wall near the bar for weeks. People in our community *want* to see young people with disabilities leading a real life; they *want* to register their support for this and that simple article, it seems, has given people a vehicle for doing so.

Alex is now an artist. Well, that's a role we've worked hard to establish for him, though he needs a great deal of support with it. He began to learn about spray painting and stamping in Art at school. His teacher had been quite determined to find ways Alex could engage with and enjoy art and came up with these methods that worked for him.

Now, Alex sells cards made from collages of his stamped art work in various outlets in town and he sells paintings at local markets. He's sold 10 paintings so far, in two markets. His cards sell well and he now has a contract to produce 1000 Xmas cards for a business. With support, he's in regular contact with people in the shops that stock his cards and also sees people he knows at the markets.

Interestingly, when I was trying to find out what all his fellow Year 12s were now doing (with an eye to finding out which chemist, mechanic etc for Alex to go to...) we were fascinated to find "Artist" written in next to Alex's name on the list the Careers teacher gave us. This was feedback to us that the role is establishing itself in people's expectations about Alex.

He is also starting to take up more aspects of the role, little by little. We see the evidence that Alex continues to put what he learned at school into application in his life. On a regular visit to one of the outlets that sells his cards, Alex was thanked by the staff and his response was to promptly say, "You're welcome". This was an amazing achievement for him. I think there is a subtlety and depth in the interpersonal learning he's acquired through an inclusive education that is invaluable and continually surfaces when you least expect it.

So we will continue to work hard on achieving a vision of a valued, included life for Alex. I would strongly encourage parents to remain firmly focused on their own vision for their sons' or daughters' lives that stretches way beyond these present school years. What will that adult life look like for your son and daughter, ideally? Who and what will it need in it? What choices can you make now that will facilitate that vision?

Gather support around you to help keep the focus on your sons' or daughters' lives.

School can seem all-consuming while you're working to try to make the experience as beneficial as possible for your family member. It's easy not to think about what happens at the end of it all. It can be quite easy to get so caught up in the nitty-gritty of who is and isn't doing what you think they should be at school that you can forget the big picture of life beyond. I've seen people become quite burnt out 'taking on' schools over issues I might have seen as relatively minor in the scheme of things. Some teachers will not transform their classrooms, others will. The process of doing so may seem to you agonisingly slow at times and your efforts may feel futile. I would be lying if I said Alex's school life was truly inclusive in all ways at all times. At times, it has been really ordinary. Schools are very imperfect places, very often, no matter how much effort you put in. There are highs and lows, good and poor teaching. Alex's schools did a better than average job, with plenty of sustained input from us and other parents. But it's worth assessing which battles need to be taken on when put into a lifelong perspective, and which might be better let go.

Above all, maintaining a vision of a valued life is crucial. Making choices that further that vision is crucial. School is not the be-all and end-all of your child's life, but it does present a wonderful opportunity to develop more capacity for your vision to be realised. Hopefully, beyond the 13 or so years of school, our sons and daughters may enjoy a span of life that may stretch another 50, 60, 70 or whatever years. An inclusive education can go a long way towards starting that life out on a pathway of connectedness in an inclusive community.