

Down's Syndrome

and

A School for Dominic by Mum Bronach Gumbrell

Having just scraped the mud from the kitchen floor for the second time today, returned an array of football boots, swimming trunks and Lego men to their rightful places, and scooped something gooey but otherwise unknown into a tin, I am reminded of the joys of being mother to three boys. Even with the mess, like any parent, I am immensely proud of my children. They make the best mess, of course. Dominic (who has Down's syndrome and autism), Tom and Joe, are unique, bright, rewarding and demanding in their own way. Parenting them has been, and will continue to be, a rollercoaster ride but this is not of their making, it is just how life is. However, no rollercoaster can be as scary as having the responsibility of making decisions that could colour the rest of a child's life, like choosing a school.

How does any parent go about making a decision about schools for a child with special needs? It's unlikely that they will have many of their own experiences on which to draw. They may know some people who have similar children but probably not many to call on for advice. Professionals provide a nudge here and there, but if our experience is commonplace, then parents are pretty much on their own.

At the time of writing, Dominic is twelve years old. He has already made his way through one special needs playgroup, 4 nurseries, a mainstream school, a school for children with severe learning disabilities, had a split placement, been home tutored, and now attends a specialist school for children with autism with a strong ABA approach. And we're not done yet. Even though his current school is excellent in so many ways, it isn't the right fit for Dominic.

To write the history of Dominic's education so far, with its twists, turns, battles, standoffs, rages and tears, would fill this entire magazine and, I suspect, many of you with a child with dual diagnosis could write a similar story. So rather than recount the details of our journey, I have drawn out the issues that are prominent in my mind when I recall our experiences.

There are good guys and let's not forget them

We were very fortunate to receive excellent support and specialist input in the early years of Dominic's life. The special needs playgroup and local education nursery he attended stand out particularly for the combination of their expertise and their absolute focus on the children. The early development groups that Dominic attended at the Downs Educational Trust in Portsmouth helped to highlight the differences between Dominic and other children with Down's syndrome, sensitively raising for the first time the possibility of autism. The consultant and psychologist who made the formal diagnosis of autism when Dominic was seven were caring, professional and supportive. There have been a number of individual teaching assistants, teachers and our current education authority caseworker who have all given us hope because they were willing to put Dominic before the system.

There are the not so good guys

The list here could be lengthy. Of note is one LEA manager who threatened to withdraw his approval for Dominic to attend mainstream if we continued to ask for one to one support; the educational psychologist who sat in a formal review meeting, saying nothing, and when asked for his views said he didn't know why he was there; the taxi driver and escort who abandoned Dominic at school one afternoon without any other plan in place to get him home, and so on. The top of the list has to go to the local education 'panel/committee' that have made so many decisions about Dominic without ever meeting him or us! To them, Dominic is just an expensive name on a list. I have learned to my cost that in every battle with a bad guy, it is essential to keep detailed notes of dates, times and direct quotes. These details are your ammunition. Fight from the word go. You won't gain anything through patience and polite behaviour!



Autism

Decisions that you make early on can come back to bite you!

When a child is four or five, it's difficult to think beyond their first school year but it is essential to have a view to the long term. We learnt the hard way that the placement you choose first can block changes at a later date. Had we known that Dominic had autism when he was 5, we would not have taken the mainstream route, not because it was the wrong placement but because there were no placements left in the specialist schools when he was 8 and needed to move on. This is particularly the case in schools for children with autism where heavy demand means that spaces are filled in the reception year and few become available thereafter. Similarly, if you start out at a special school, it's extremely difficult to get a child into mainstream (or other schools) if this doesn't work out. Having an early diagnosis can mean all the difference to decision making.

The people who run and work in a school are more important than the type of school.

Dominic thrived in his mainstream school until a new head teacher arrived who made it very clear that she did not want Dominic there and made his life very difficult. Within two terms, he was thrown out with only a days notice. If a school is the right place for your son or daughter, those responsible will make the environment work for your child through; the support given, modifications made to the environment, the activities available and the external expertise they bring into the school. This means doing it, not just talking about it.



You don't know what goes on in school until you see it for yourself.

Take the time to observe. Go unannounced. Don't take the word of the teachers that all is hunky dory. When I visited Dominic in the special school we had to accept because there were no other options available, I was horrified at how he had regressed and the low expectations they had of him. I was more horrified that these expectations did not change over time despite numerous attempts to explain what he had already achieved. How wonderful too, to see when a child is doing things you had no idea were in his repertoire.

Don't accept your child's limitations – look for more

I have a strong belief that we underestimate the potential of many children with Down's syndrome and autism. To me, autism is like a barrier that encases the child, stopping them understanding what's happening around them and allowing them to escape underneath it when it all gets too much. For the observer, it's very easy to assume that the barrier is the child and that there's little going on beneath it. I am in the fortunate position of knowing what Dominic is capable of achieving because I have seen it, beyond the barrier. Through a personal contact, we came across a fabulous tutor who worked with Dominic for two days a week for two years. With her, he was a transformed child. The chemistry between them was pure magic and the difficult behaviour disappeared leaving a motivated, happy child who was in the right state of mind to learn. The autism didn't go but we could work with it rather than fight it. At this time, Dominic was in a split placement and acting like a wild child at school. It took video recordings of him working with the tutor to get the staff at school and the educational psychologist to believe that he was in the wrong place – jaws dropped.

Down's syndrome and autism makes for something different

Children with this dual diagnosis are as varied as any other group of children although I have a sneaking suspicion that

they differ from those with autism in being more interested in other people. Dominic certainly is. He craves attention and has refined skills in winding others up, all done in a totally knowing way! For him the fun is the reaction, not what he obtains through it. He thinks about my reaction in a way I do not see in other autistic non-Down's syndrome children. This is the main reason why his current ABA school does not work for him. The rewards of disrupting the class and seeing the reactions of other children and adults far outweigh any other reward that can be given. His behaviour is telling us that he wants to interact with us, not learn drills, however worthwhile they may be. Until research moves on from counting the heads of those with a dual diagnosis to studies of the differences between the autistic and dual diagnosis populations, and the implications this has for education, we will just have to guess at what suits our children best.



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Hey, what's wrong with a little creativity?

There are ways of meeting the needs of children who do not fit into the existing menu of schools but to do so requires creativity, working outside the current system and some deep thinking. I know, there's not much of this around when it comes to education. For instance, why not see virtual schools in the form of small groups of children with similar needs taught by a teacher and assistants. Each 'class' can be located where it's most convenient for the children (a room in a primary school, a church hall, the home of a willing parent etc) and supported from a central hub of experts who can be called upon when needed. The class would exist for as long as the cohort of children required

education. This is already done in other countries so why not here? If Dominic could be taught with a small group of other children with Down's syndrome and autism, not only would he have a tailored education but we would all gain in knowledge about which strategies work best with this population. This is what is meant by 'action research' – so let's have a little action, please.

It's easy to see only the behaviour and not the human being

I started my career as a clinical psychologist working with children with special needs. Recently I undertook a voluntary placement back in the health service working with adults with learning disabilities. This was a rude awakening to how little has changed in twenty years. Services are still poor, those with behaviour problems (even minor ones) are not tolerated well, and wider society has changed little in terms of accepting those who are different. However, the most frightening aspect of adult care is how easily professionals and carers forget to see the person behind the condition or the behaviour. They don't ask how would I feel in this situation? What would I do? What matters to this human being? Who do they miss/mourn? This is particularly true in the autistic community where sometimes it's simpler to assume the child or adult doesn't feel. We must see difficult behaviour as communication and look beyond it to the whole person, to see people like us. We must appreciate their need to belong, to be respected, their need for love and for achievement, and it must start in school.

I know that unless we get a grip on Dominic's behaviour problems now, the future for him when he leaves education will be bleak. That's why we are about to embark on a battle to get Dominic educated at home by the tutor who worked with him so well, hoping that the difficult behaviours will fade over time. We will need funding for this and, as it will be bucking the system, I suspect our proposal will receive a frosty reception even though it will be a cheaper option than his current school. But wouldn't it be refreshing if this time, just for once, common sense prevailed and the decisions makers thought about my beautiful son and not just his brown file of notes.

