

# I Knew Very Little

Annette Caelli

As a child, I don't think I considered disability. I think I just saw people's differences simply as diversity, as you would different flowers, animals, etc. There was no issue of good/bad, included/not included. What I knew of disability was through interaction with people in the normal course of life. Unfortunately, though my parents did not discourage interaction, we had very few close contacts with disabilities outside of age-related ones.

When I went to school, suddenly those with the more challenging disabilities were 'cleansed' from my world. I'm not sure if I questioned why this was so at the time, but for the first time being different seemed to be threatening. 'Spastic' was an insult, a description of one to be segregated from the group. Once again, any education I got was through interaction outside school with the disabled and their families. I vividly remember being entranced at the sight of a teenage dwarf, climbing on the back of a motorcycle behind her boyfriend, long blonde hair flowing from the helmet as she rode.

In mid-Primary, I visited on occasion another school with a Special Ed unit. Oh, so that is where all those people go. They must be REALLY different to not be included in the main stream. Perhaps they were dangerous, scary, in need of SPECIAL treatment; I did not know the 'special' techniques. so I could not interact. They had their part of the school; 'we' had ours. At my own school I was considered academically talented, so the teachers put me to work helping classmates who had difficulty reading. I would take them outside on the steps of the building, segregated from the others, to help them. I have mixed feelings about this now. In a way it labelled them clearly as the 'slow' ones, but at the same time they had at least one peer who accepted them and that relationship continued through school. I was also fortunate that my brother had a friend who had had meningitis as a child, whose mother ignored the opinion of the time and did everything in her power to get him into mainstream. He started out with a severe speech impediment, etc., but in the end graduated with his peers and had normal friendships. I thank his mother for now being one of my greatest inspirations.

In high school, we were once again in segregated classes and even though there was no physical separation at lunch time, etc., there was social isolation. I remember still having a desire to communicate at times, but feeling out of my depth and unsure if my doing so would in some way be damaging or undesirable within the system. Those who had disabilities that did not prevent them from being in the main stream, e.g. epilepsy, were the people I learnt most about in school. Fortunately, I caught public transport to and from high school. On my bus was a young lady with Down syndrome. She often sat immediately in front of us and had a very social nature. She brightened many a day for my friend and I, and we were drawn to communicate despite any apprehension we might initially have had. I learnt more from her than many.

In University those with intellectual disability had mostly disappeared. Inclusion was largely in the form of wheel chair ramps and disabled toilets. In the old lecture theatres, still those in wheel chairs would be limited due to the stairs to sitting in the more easily accessed front rows.

Outside of uni I taught ballroom dancing. I was lucky to be asked to teach a 'special needs' class. I was never informed specifically of each person's diagnosis (although the person with Down syndrome was more obvious) and I must admit I was apprehensive when the parents and carers left the room to allow the students to experience the lesson with their peers. In the end it was a wonderful experience. I learnt that even within a category of disability there was in fact a whole range of ability. I learnt that speech was not the only form of communication. I learnt that even people with severe disability responded to contact. I learnt that sometimes it took weeks of developing trust before they would demonstrate their knowledge or skill. I was dismayed that such wonderful people had been largely removed from my educational, working and social world for so long; it put us at such a disadvantage to start with. I thought I then understood what it was to deal with disability as a parent (I was wrong.)

I entered the workplace and finally I was starting to see more people with severe disability being 'included' in my world - trolley boys etc. Whilst a positive sign, sadly the years of segregation made things more awkward than they otherwise might have been. I loved these people for their work ethic and their sincerity. I was embarrassed when people took advantage of this; I was delighted when the barriers were overcome, especially to see them being included socially.

Now I am a mum of a child with a disability. The day before the diagnosis I KNEW VERY LITTLE. If I had relied on the experience of my formal education, I would have known next to nothing; I would have been extremely under-prepared for what we were to face. I thank God that there were brave parents out there, who resisted the pressure to hide their children away from a harsh society, who ignored the stares and the ignorance, who pushed rightfully for inclusion. These people and their families (many of them strangers and faces without names) were my informal educators and, unbeknown to me at the time, they would become my hope and greatest inspiration when I needed it most.

Only now do I begin to understand what it must have been like for them, the challenges they would face every day. I have experienced guilt for not having done more previously. I have moved on from guilt about the past to effort toward the future. Each time I have to jump a hurdle, I can feel better for knowing it may be one less hurdle for the person behind me.

