

Dreaming for different futures

I would like to introduce two brothers to you. Both are in their early 20s.

<p>The first brother:</p> <ul style="list-style-type: none">• is fairly loud and outspoken• is extremely good natured and almost always happy• has an absurd sense of humour• doesn't have a huge number of friends because he likes to form strong relationships with only a few people• really loves the beach, swimming and bushwalking• is unemployable• loves to go driving• enjoys listening to jazzy music• adores sport, especially AFL and Rugby League• when he goes out, he enjoys going to places where there are fewer people• would really love a dog.	<p>The second brother:</p> <ul style="list-style-type: none">• is severely intellectually disabled• has autistic tendencies• hyperventilates• has scoliosis• does not speak or use sign language• has few fine motor skills• regurgitates his food and bites his hand.
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Both of these brothers are actually the same person and I used these descriptions because it really helped me to think about Matt's life and what might constitute different futures for him.

The first brother has many interests that could lead to numerous jobs or career paths - for example, National Parks and Wildlife Service, landscaping, courier, Surf Life Saving, working at a swimming pool, beach management.

The second brother doesn't have very many options at all, because the way he is defined and categorised makes him unemployable. It also takes his humanity from him.

In talking about what I have gained from being Matt's sister, I think about him in terms of the first description. I'm really glad to be Matt's sister. He has shaped my outlook on life and many of the values I now hold. These values are really important because they are what makes me, me. He has made me strong and really clear about the things I believe in. For example, in many of the struggles my family has had with professionals and caregivers in Matt's life, I am always really clear about how I value him and what I would like to see happen for him. He has helped to make me a reasonably articulate and passionate person.

Matt has also often led me to think seriously about some of my actions and words. For example, it has always really upset me that when new friends come to visit my family, I always tell them about Matt - like some kind of warning. But I do not warn my friends about my other brother even though he can be a pain in the butt at times too. I let people decide for themselves about him. So I have decided to do the same with Matt, and now I introduce him as normal.

I have also become conscious about my actions and words regarding people with disabilities in general. Matt has given me a wider perspective about people with disabilities. They do exist, they are extremely vulnerable and they are excluded from most valued arenas of our society.

I am also glad to be Matt's sister because I feel that I have given him a lot of things that will hopefully push him further towards an alternative and preferable future. I am a young person and therefore I surround Matt with language that is appropriate to his age. And what's more, he understands this language. This is of enormous benefit to him, especially when he is with other young people. But more than this, the language allows Matt to be his age. He is not an innocent child and he is not moulded to the desires of older people.

I am also an appropriate role model for Matt. This works in a similar way to language. Matt always has access to the behaviour of other young people. It surrounds him also, and he learns from it and picks a lot of it up. This is particularly important for people with disabilities, because image constitutes a lot in our society. I am also important for Matt, because I can say "Hey Mum, skivvies and tracksuits with zippers up the sides aren't in fashion anymore!!!" (even though my Mum would never dress Matt like that anyway). This acts as a kind of safeguard, to make sure Matt portrays an image appropriate to his age.

Parents are often over protective and there have been times when I have told them to loosen up. I take risks and Matt has to too. This is how we learn about ourselves and our limitations.

I guess I am really saying 2 things here. I am not saying that all parents of kids with disabilities should rush out and have numerous other children!! But I am saying that young people with disabilities need to be surrounded by other young people (without disabilities) as much as possible. It means they have to be part of their community, their street and broader neighbourhood - to be where the action is, to be where the kids are. They have to experience what growing up is like (the ups and downs, everything) and they cannot do it in isolation, segregated from what the world is really like.

Secondly, I do not feel that Matt is a burden and I never have thought this. I am not, and never have been jealous of any extra attention given to him because I have always realised that any extra attention was necessary. A lot of professionals and 'experts' say that brothers and sisters of people with disabilities are often neglected or miss out on vital care and attention. They turn everything into a problem and I think, often make parents worry more about their parenting skills and whether they are doing it all right. There have been times when extra attention and care has been given to Matt, but I have turned out alright in the end. I am a fairly ordinary 20 year old.

This is not to say that life is a breeze. I have grown up knowing that life is tough and often a battle. But it is also difficult for Matt and he is ultimately the one who will face this difficulty for the rest of his life - not me or the other members of my family.