INCLUSION

Daniel Shields stands in front of the kitchen notice board where the pictorial program for his recreation group hangs. "How many more sleeps before I go out with my group?" he asks, for the third time today. Because of his severe intellectual disability he has no literacy or numeracy, so he is not really asking how long it will be. He is confirming that I have not forgotten about it, because he needs me to get him ready and to take him to meet the group. He is also saying that he is looking forward to it impatiently - in fact, it won't come fast enough.

Daniel has lived at home with us for all of his thirty-three years and I have observed him on a daily basis. I call him my longitudinal case study and I am wondering when I will graduate. We have included him in almost everything we have done over all these years yet it is the people who have a disability similar to his own whom he counts as his friends. Lonely and isolated at home with boring, ageing parents, he asks repeatedly that his friends come over to visit. There are three brothers and any number of extended family members who are involved with Daniel, but these are not the ones he asks for. His supported employment workplace is another social outlet and contrary to what most of us would think, Daniel believes that workdays are better than holidays. The respite cottage, where he also meets his friends, is, according to him, better than home.

Over many years, I have discussed my "research findings" from my longitudinal study with my fellow caring parents, who have almost uniformly said to me "my son (or daughter) is just like that". Anecdotal evidence seems to support my findings: people with an intellectual disability find their primary sense of community from within the group of people with a similar disability. Parents like me have witnessed the delight that our sons and daughters share in each others' company. Those parents have similarly included their children in every aspect of their daily lives, yet they know that their highly social sons and daughters gravitate to the group of like people for their deep sense of connection, belonging and identity.

We would agree that for most of us, the three cornerstones of our lives are our families, our careers and our friends. When I consider Daniel's life, I realize that he will never have a family of his own and although he has work, it is not a rewarding and fulfilling career. Therefore, the third pillar, the social network, assumes a far greater importance in his life than in the lives of the non-disabled. Now we must consider how these highly social beings access their social network. In many cases, there is not the ability to use a phone, drive a car, write a letter or work a computer. People like Daniel need to be physically present to relate to their friends and to gain pleasure from those relationships.

A generation ago, an awareness of the sub-human conditions that existed in some institutions brought about a move to close all congregate care facilities for the disabled across the developed world. The residue from this movement still causes any suggestion of togetherness of people with a disability to be labelled "congregate" and "non-inclusive." Whether in their living arrangements, their work or their play, people with a disability are socially valued by some only if they can be cheek by jowl with their non-disabled peers. They need to be as much like us as possible and they need to be in small numbers - preferably solo.

The push for inclusion has come from within the disability sector, led by well-intentioned activists who are often people with a physical disability. These are people who, without cognitive impairment, can manage their own lives with some physical assistance and who can relate to their peer group through various media. They are a different cohort from the one I am discussing and yet they believe they may speak for

this group. Parents like me, who do not agree with them, are regarded as old fashioned, holding back the tide of progress, over-protective and "afraid to let go".

One of these well-intentioned but misguided activists acted for my family as an advocate for a short time. This person met Daniel and agreed that his heart's desire was to be with his disabled friends. However, it was pronounced that he is "the exception to the rule". This statement would have gone unrefuted some years ago as I would have been able to quote only a few local families in support of my argument. However, since the advent of the internet all this has changed. Families are connected now as never before and I hear every day from all over the country that my views are echoed by parents, carers and service providers who deal with people with intellectual disabilities.

The inclusion issue is highly contentious and it is time to examine where these tightly held beliefs are coming from.

Can a person with a disability be valued only if he or she behaves as much like us as possible? Is social acceptance dependent on the ability to fit in and conform? Is it not easier for the aspects of a person's disability that label him or her as "different" to be more easily overlooked or minimized if he or she is tucked away in a group of non-disabled people? Is it not confronting for us to see a large group of obviously "different" people all of whom have an intellectual disability? How much of the movement towards inclusion may be a reflection of our lack of acceptance of who our people really are: people who have intrinsic differences that must be valued in a pluralistic society, people who have a guileless human-ness, and people who, like ourselves, make relationships with like people?

The implementation of community inclusion has had some poor accommodation outcomes for many people with intellectual disability. Some live alone in isolated "inclusion" with minimum drop-in support, the television the main companion. Some live in group homes with people who are not of their choosing and with care-givers who are not supervised. Often they are located far from their families. The small cluster or village community that exists in other countries has been outlawed here, a result of the inclusion movement, or possibly the result of our rejection of who our people truly are.

 I am hoping with the dawn of the age of person-centred planning, there will be more effort to stand in the shoes of the person with intellectual disability and a greater attempt to discover what it is that the person really desires in life. I am hoping, too, that parents and other close family members, those who best know the person with a disability and who have invested decades of care in that person, will be allowed the right to speak on his or her behalf. The natural authority of families, so often undermined and misrepresented, must be given full rein. Currently, families have little representation in the affairs that directly impact on the lives of their family members. Daniel has very simple language and cannot articulate well what he wants. I am his voice because I know him best.

Six years ago, a group of local like-minded parents formed RASAID (Ryde Area Supported Accommodation for Intellectually Disabled)*. We are committed to making a clustered residential setting for our twenty sons and daughters in our local area. Daniel has grown up with this group of people - they are his community and he is part of theirs. Our state government has agreed, after much debate and contrary to formerly held views, that our model of accommodation is an approved one, although they are yet to build it for us. We see this project as the natural progression of our ideas about inclusion. Our sons and daughters will be living in a house like yours and mine, in a street like any other. They will have access to the wider community but more importantly, they will have access to their own community, the community of people like themselves.

At Daniel's supported employment workplace, there is a new lunchroom being built. It will be shared between the workers who have a disability and their non-disabled support staff. There are those who say that all people with a disability must work in open employment and that this workplace is congregate. There are others who accept that not everyone can work in an unsupported situation but that the workplace can be as inclusive as possible. The lunchroom is a paradigm of inclusion in practice. Inclusion is not about an address. It is a mindset around acceptance of difference.

RASAID: Ryde Area Supported Accommodation for Intellectually Disabled.   www.rasaid.org.au