

Some Thoughts on Leadership

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The history of people with a disability is indeed very bleak. In fact, the most common societal response to people with a disability has been outright killing or social exileⁱ. Aristotle stated that “Let there be a law that no disabled child shall live” and Sparta had a policy of leaving children with a disability out in the weather to die. In the middle ages many mothers who had a child with a disability were accused of sleeping with the devil and executed. The people themselves were always on the margins of society and warehoused in ‘cities of the damned’ along with prostitutes, epileptics, paupers and others abandoned by society. These evolved into the huge institutions of the 18th and 19th century, with many continuing on until late last century and some even exist today. In the early part of the 20th century with the advent of Darwin’s theory of ‘survival of the fittest’, the theory of eugenics was developed by Galton, a nephew of Charles Darwin. This had a huge impact across the western world with citizens joining eugenics societies and competitions held for ‘the best-bred baby’. People with disability were seen as a moral and genetic threat to society with strong moves across the western world to segregate and sterilise them – particularly people with an intellectual disability. Leaders such as Churchill, Keynes, Huxley and many others spoke on the dangers of ‘idiots, imbeciles and morons’ as they were called, and the intelligence test was used to find them and separate them out. Families were encouraged to send their child to the institution for the good of the country. The eugenics idea was taken up by Hitler with the result that over 250,000 people with disability were murdered. The gas chambers were actually designed by doctors for the killing of people with disability and upscaled for the mass killings of other groups.

We now have a situation where the majority of institutions have been closed in Western Society; the law has been changed to allow all students with a disability to access mainstream schools; we have a national disability support scheme; every education department policy extols the virtues of inclusion; we have a member of parliament with cerebral palsy; the United Nations Committee on the Rights of People with a Disability (CRPD) has set out the rights of people with a disability very clearly and over 170 countries have ratified them – including Australia. It is very easy to become depressed about the need to continue to fight for rights that others take for granted, and we all know that this fight will go on for a long time yet. However, it is good to look back every now and then and see what has been achieved – to go from mass killing of people with a disability which was ‘understood’ by other countriesⁱⁱ to a situation where children with a disability can share classrooms with their peers and many adults are now living fulfilling community lives and in real jobs. I can think of no other area of social change that has happened so quickly. Mental health is only just emerging. Women have been fighting for equality for well over a century and still have not achieved it.

So, in those dark times when it all seems just so impossible and nothing seems to change, realise that we have come a very long way. It might help!

The critical questions to guide us in the future are “How did all this progress occur?” “Who was behind it all?” Was it all just a natural evolution? Of course it was not.

Following the second World War and the revelation of the horrific treatment of outcast groups by the Nazis, western society recoiled and became much more sensitive to the end result of societal rejection. It was during the 1950's that an amazing event occurred. Families stood up against a society that was telling them to put their children away 'for the good of the country' and instead set up their own alternative. This was the start of the voluntary agencies that still exist in every Western country. They quite often had names that reflected the underlying assumptions of the society at that time (Slow Learning Children's group; Spastic Welfare Association; Mentally incurable Children's Association etc.) but all were driven by an intense desire to provide a better life for their children.

It is worth reflecting on the bravery of those families. They stood up against their neighbours, often their own families, the law and the society overall and said: "We are going to do this". When we look to advocate for people with a disability today, we need to acknowledge that we are standing on the shoulders of giants. I don't think we really acknowledge these people well enough as sometimes the services that they founded have become 'part of the problem', but in their time they were powerful leaders who were incredibly brave visionaries.

In the field of education, if a person had an IQ below 50 they were deemed 'ineducable' and with an IQ below 30, 'untrainable'. If you had an IQ between 50 and 70, you were only capable of the most basic 'life skills' education, and couldn't possibly fit into the local school and classroom. It should be noted that the previous definition of intellectual disability was an IQ of about 85, but with a simple redefinition, a large number of people with an intellectual disability suddenly became normal. Such was the arbitrary nature of the definitions. Children with an intellectual disability living in the country were transported to the major centres and stayed in hostels so they could attend the special segregated school, but for many, there was no educational option available. Again, parents came to the fore and established 'activity therapy centres' so their children could receive some form of education. Similarly many parents, particularly those in regional and remote areas prevailed on their local principal to attend the local school, which occurred 'under the radar' of the education departments.

Most important, parent groups started to advocate for universal access to education. In WA it was a group called 'Watchdog' who campaigned tirelessly for changes to the law which were achieved in 1979. While they had some support from professionals, teachers and academics, the driving force was the families. Of course, there were some parents who took the lead and did the media interviews and visited politicians, but they would have been powerless without the strong backing of many families who worked in the background in support.

This is an important point: Leadership is not just those who stand in front: those behind who are working their networks, talking to family and friends, helping to write submissions – these are also leaders without whom little would be achieved.

In the field of inclusive education, again it has been family leadership that has been the driving force. In the early 1970s a group of families sued the State of Pennsylvania on the basis that whether a student was placed in a segregated class or mainstream was arbitrary.

This led to the enactment of US Law 94-142 that stipulated education had to be based on the 'least restrictive alternative'. While this still allowed that 'some students could be segregated', it was a major shift to a rights perspective. For those children with very significant disabilities, mainstream education was still barred to them in America (and totally denied in Australia as mentioned previously). Parents joined together to set up TASH, a group focussing on these children. At least one parent went off and did a PhD in Special Education and became a Professor of Special Education to make it harder for the group to be dismissed as 'just a group of parents with unrealistic expectations'. There is a message in this. Family members who also have higher qualifications are particularly powerful: they have the lived experience together with the status and knowledge to be impossible to dismiss. As several parents have found, I tend to push them in that direction, even though I know that they already have extremely busy lives.

In Australia, similar groups were starting to form. I do not know the starting dates of many of these groups but we have had Family Advocacy in NSW, Foundations forum; QPPD; QAI; CRU; Star; Foundation for Social Inclusion; CYDA; CLP in SA; Imagine More; Queensland Collective, The Australian Alliance for Inclusive Education (All Means All), and many others. Some have come and gone but all have left a mark – and all of these are parent run, even if they have paid leadership on a day to day basis. Some have run brilliant campaigns – of course Family Advocacy has and is still doing so; QPPD and CRU produced some fabulous reports and several have run major national and international conferences. Others such as the Down Syndrome Association started being very focussed on segregation but have shifted substantially to a rights-based, inclusive framework.

Again, this was parent leadership. They often had and still have important allies, but it is parent leadership that is the foundation

In my own history, it was a parent who totally changed my direction. After an experience working in a large institution that still traumatises me to this day, I set out to change these sort of places – in fact I even did a PhD on changing institutions. I ran several institutions that service providers from other States would come to visit to see the work that we were doing. I set up an institution school (of course segregated) to show that these 'untrainable' people could be taught to read and do mathematics. Together with the Director General of Education (who had a daughter with a disability) we set up the first school in WA for students with multiple disabilities – I provided the building and support staff and he provided the teacher. I went on to the university and became an Associate Professor of Special Education, preparing teacher trainees to work in Special Schools. In short, my mission was to produce the best possible segregated education and other services.

Out of the blue I received a phone call from a parent whose daughter was attending the local school which two of my children also attended. I was aware of this as my son would come home and talk about it and he was very positive about it all. She reported that her daughter was about to be expelled and asked for my assistance. I went and saw her and her family and the more I heard the more I became concerned. Here was a woman who understood the importance of inclusion intuitively despite the enormous pressure to succumb to the segregated pathway. All of a sudden, I 'got it'. For more than 20 years of close contact with numerous people with a disability and their families I didn't see the

massive discrimination happening – and I was part of it. A person that many of you know, Darrell Wills, called me a ‘recovering segregator’. This is super accurate, and perhaps applies to us all individually and collectively.

As with many families I meet over time, she has become a friend and we have worked on many advocacy projects together. The important point though is that this parent changed my life. I could still be tidying up the deck chairs in the segregated system if this parent hadn’t shown me the truth that was before my unseeing eyes. Be aware that you can have the same effect. Working supportively with a teacher can turn that person from a sceptic to a great advocate who will inspire the staff room . A professional who ‘gets it’ can be a great help in the school meetings where you can feel totally alone.

Of course, this is leadership. By your actions you are making changes and influencing others, even though that might not have been your intention.

Some of these families have had the enormous courage to take the system on in a discrimination case. I have been with several of these families on that journey and I know it had a huge impact on them. They have been imaged as a incompetent parent, an ideologue who put their own interests ahead of their child and had their smallest angry comment in frustration used as an example to support these projections. All of this on top of the huge amount of time in preparation, usually high financial and emotional costs and they run the risk of losing the case with massive costs awarded against them.

Of course, this is amazing leadership that always causes the system to change. But it is not for everyone!

Post school, we have also seen great examples of leadership. Those parents who have stuck it out and kept their child in mainstream classes through to year 12 almost always report that it was worth it, despite the trauma that many experienced. They set a vision and held on to it over many years and as a result they often have a young person who is independent, perhaps moving into their own home, getting a real job etc. Those parents have become leaders and an inspiration to other families, by following that vision.

On independent living we have numerous examples of families forging an ‘ordinary life’ for their offspring. In research conducted for the Australian Research Council involving Curtin, Sydney and Melbourne universities, 130 examples of people with intellectual disability in non-congregated situations were evaluated. 83% of the individuals had been living in these arrangements for more than one year, 43% for more than 5 years and 23% more than 10 years. 42% were living with a partner, community member or host family. In the majority of these situations the leadership to set up these arrangements had been families, often assisted by a service provider willing to look for creative ways to fund and support the arrangement. Many of these people had very significant disabilities. It was inspiring to be involved in the evaluation of some of these arrangements and see people with very significant disabilities living with a community member and experiencing real community relationships.

Similarly, we have been involved in evaluating micro-enterprises. These are arrangements where people with often very significant disabilities set up a business supported by a paid staff to provide a range of different services and products. Who was the key driving force in almost all cases? Families. They are of course the leaders who inspire and encourage others to do the same and shame the segregated service system who work with much less capable people in most cases.

So, in summary, I wanted to share the real story of the massive shift in attitude towards people with a disability since the second world war. Families have been the leading force behind all of the major changes and continue to be so. Professionals and service managers might be in the limelight and interviewed in the press, but the real power comes from the legitimacy of your position. Change always has, and always will, be based on the leadership of families, and increasingly, people with a disability themselves.

It is also very important to see that there are multiple forms of leadership. There are only ever a few who have the ability and personality to stand at the front and be the public face. However, the real power comes from collective action, and that is where everyone can be a leader. Sharing stories with your family and friends; helping to write letters to a parliamentarian; contributing to Facebook and other groups; being willing to stand with another family either directly or via social media; building a good life for your son or daughter.

It has always been an incredible privilege to share the lives of so many families. Thank you for the opportunity.

ⁱ Bradock & Parish (2000). An institutional history of disability. University of Illinois. , and “As short History of Disability <https://www.youtube.com/watch?v=js2ggVhmH88>

ⁱⁱ At the Nuremburg trials after the war, the people involved in the killing of people with a disability were not put on trial. The American prosecutors argued that the policy was ‘understandable’.