

Down Syndrome Association of Queensland Lunch

20 June 2008

Your Excellency, Quentin Bryce AO; DSAQ President, Mrs Sandra Mayberry; Friends of the DSAQ who were responsible for organising this wonderful function; Special Guests, Ladies and Gentlemen.

I must admit to being somewhat nervous about speaking to **this** audience. It's only a few years ago that I was President of the DSAQ.

I've thought about lots of different approaches to speaking here today. I want to talk about a lot of serious topics, but I don't want to bore you to death or have everyone crying in their coffee.

I want to talk about the principles of Normalisation as they are being applied or mis-applied in 21st century Australia and I want to talk about institutionalisation and the fears I have for the future of Inclusive policies in 21st century Australia.

In the end I decided to invite you all to join me on a journey. The journey of the past 24 years of my life and a journey I would like to never end.

The journey starts 24 years ago—24 years and 4 months and 7 days ago, to be precise—because that's when Joanna Suzanne Boyce, my third child, my youngest daughter, was born with Down syndrome.

The journey is only incidentally about Jo's life. It's more about the journey of a woman and a mother; it's about the process that helps to turn a mother into an advocate.

I attended my very first Down Syndrome Association function when Jo was about 3 months old. This was in Melbourne--where I then lived--in 1984.

The topic, I remember, was tongue reduction surgery and, more generally, plastic surgery for people with Down syndrome. I wasn't very fussy about the topic—I just wanted to learn anything I could about Down syndrome.

I remember only a few things from that DSAV function—I was still in a state of shock following Jo's birth.

At the time of that first DSAV meeting, I was still thinking in terms of how to achieve the perfect child. Some of you will know that "perfect parent syndrome"—if **only** I do enough physio, if **only** I use enough flash cards, if **only** I buy enough educational toys, the Down syndrome will go away.

So I was startled by the spirited defence of one mother, obviously a lot further along the journey than myself, who was appalled at the idea of plastic surgery to 'fix' her son.

She said something like: “My son is a well-groomed fashionable young man. He’s very proud of his appearance—he doesn’t want to change it and I don’t want him to change it.”

It was my first lesson in seeing disability as something other than deficit.

Educational inclusion was the hot topic in Victoria in the 80s. The breakthrough there had come in the 70s when the then Victorian Government decreed that children with Down syndrome were “educable”.

This might seem quaint, almost laughable now but it wasn’t then. Can anyone look at the displays here today and around this room and say that people with Down syndrome aren’t educable????

So when you’re wondering how brave you can be in advocating for some radical change for the benefit of your child remember that without a few crazy, brave people in the 60s insisting that people with Down syndrome **could** be educated, we very well might not be having this conversation today.

As I mentioned, educational inclusion was another journey all its own.

A wonderful and wise woman called Tony Macdonald recalled trying to get her son Rohan into special school in the 60s in Victoria.

She was confronted with the old “experts” ambush--which some in the audience will be familiar with.

The experts’ ambush goes like this: you arrive at a meeting believing that you are there to talk about your child’s abilities with allies, and find that an extra three or four people have been invited along to discuss your child’s deficits and these people are not allies, they are opponents.

When Tony arrived for her appointment to demonstrate why Rohan should be allowed to attend even special school there were six people, six experts from the Victorian Department of Education, on the other side of the table ready to argue why he shouldn’t.

It’s testament to Tony’s tenacity that Rohan did attend that special school.

And as Jo got into the education system I began my advocacy journey—firstly by working to make Jo's education experience as good as it could be and then, realising that it was the “system” that needed fixing, I became a member of the committee of the Down Syndrome Association of Victoria.

In the mid 80s, the DSAV succeeded in getting the Victorian Government to fund an advocacy organisation so parents could mount their own experts’ counter-ambush in the education system.

There are, of course, all sorts of versions of the expert’s ambush.

I remember when Jo was very tiny, one young speech pathologist told me that Jo's intellectual ability was obviously very severely impaired.

"How can you tell?" I asked, devastated! "Because", she replied, "she doesn't stop the activity I've given her when I say **No**."

I was relieved enough to laugh out loud and comment that, on that basis, I also had a 7 year old and 5 year old who were severely impaired. And then **she** looked at me as though **I** was the strange one!

But it was another step in my journey—don't always trust the "expert". Many of them are not.

It was only as Jo began her journey through the kindergarten and school system that I slowly began to realise that it wasn't Jo who needed fixing; it wasn't Jo's parents who needed fixing for wanting Jo to have the best life and the best resources she possibly could; it was the system, or rather the systems, that needed fixing.

And in terms of education, it's my personal view that we won't fix education until we abolish special schools. If mainstream schools had no option but to accept children with disabilities, they would concentrate on how to make it work, not how to avoid getting involved.

And if all the human and funding resources currently tied up in special schools were handed over to the mainstream system, it would be so much easier to make it work.

It's a testament to the tenacity of the DSAQ that for the first time this year, the DSAQ has been funded to provide an educational adviser for families with a primary school child.

Success in advocacy is never going to be about BIG BANG change—it's about small incremental change to the values that underpin the systems we need to live with.

It's about being able to look back in 10 or 20 years and say: "What I have done, what we have done, has made a difference."

It was in the 1990s that I came across the term "Normalisation" and started a new part of my journey.

I'm not sure how many people know about the principle of Normalisation—many in this room will know much, much more than me, some won't.

Briefly, the principle of Normalisation was first developed in the 60s in Scandinavia. The chief proponent of Normalisation is a now-elderly American academic, Wolf Wolfensburger.

Normalisation is defined as "making available to all people with disabilities, patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society".

Doesn't sound very radical, does it? But it was and, still in some sectors, is. Normalisation underpins educational inclusion, social inclusion, de-institutionalisation of all kinds!

Normalisation is not about 'normalising' the person; it's about normalising his or her environment.

So in a society where the great majority of people live in homes of their choosing with people of their choosing, undertaking activities and work of their choosing—people with a disability should have the opportunity to do, as closely as possible, the same thing.

Probably the best encapsulation of Normalisation that I've ever read was written in 2002 by a Norwegian disability advocate, John Sandvin.

He wrote:

“When a child goes to a special school, it is **not** because the child has an intellectual impairment, but because the community school does not welcome children with an intellectual impairment.”

“When a man in a wheelchair cannot enter the bus, it is **not** because he uses a wheelchair, but because the **bus** is inaccessible.”

I felt that I'd found a wonderful way of turning my thinking about systems on its head.

The ideas behind Normalisation were revelatory to me. I hadn't had the long, hard struggle of the generation before me to close down the institutions--those dark, sometimes abusive, places where no-one lived with people of their choosing or undertook activities of their choosing when they chose.

But the need to say: "Yes, we have come a long way, but we're not there yet! We still have a long way to go," set me off on another journey.

About this time Jo was a few years off moving out of high school and, quite frankly, high school had been less inclusive than primary school and--post-secondary, well, post-secondary the inclusion options started to run out.

Normalisation gave me another way to see our journey from here—to a life where I supported Jo to genuinely make her own choices. And some of these have not been and will not be what I would have chosen.

Jo doesn't want to analyse it too much. She just wants to get on and have her version of a normal life and enjoy every minute of it.

But as a parent I see it as my duty to go on trying to change the systems and make the systems that support Jo's life and Jo's genuine choices better.

And that's led me to the most recent part of my journey—as a politician, a senator for Queensland.

Now we are kidding ourselves if we believe that it's just politicians and governments that make the systems that order our lives—the social, educational, financial and work and belief

systems. We are all complicit in some way in organising and accepting and functioning within those systems.

But politicians, as policy makers and policy implementers, have a bigger say than most.

And one thing I really enjoy is that people **listen** more. I'm a member of the Senate Community Affairs committee and at one of my first hearings, I commented to Centrelink that some parents of children with a disability in Townsville thought their local Centrelink was like a remand centre.

Now as Sue Boyce from the DSAV or from the DSAQ or from QPPD (Queensland Parents for People with a Disability), I'd said something like this dozens of times.

But this time, the reaction was amazing. Offers to visit Townsville Centrelink, bring the parents with me; inspect Centrelink's customer service training and auditing.

Invitations I accepted. In practical terms, all that's come out of that is that a group of parents now have a system of speaking regularly to their local managers at Centrelink—but it's a start.

And now I'm trying to take the senators of Australia on this journey with me. I've spoken about ability, not disability; I've spoken about respite, not just as relief from the terrible "burden" of caring, but as part of those normal breaks that members of all families have from each other. Dad's Saturday golf is a form of respite—and probably not just for Dad

I've started a conversation about how we treat the most vulnerable people in our community. Our system currently forces individuals and families to impoverish themselves before offering government assistance, and that assistance rarely leads to a dignified, sufficient life.

Obviously, as taxpayers, we don't want to support people who have the resources to support themselves, but nor should we require people in our society to become beggars before we help.

We're certainly better than we were at helping disadvantaged people than we were, and as a society, Australia is among the best, but there's still a radical change in the way that we deliver "welfare" to be made. I don't know what the answer is, but I've started talking about it.

And I've raised my very real fears about attempts to reintroduce institutions—albeit mini-institutions—as an acceptable part of the Australian system.

In my view, this is one area where we all need to keep saying: "We got rid of institutions—well, most of them—because institutions allow the conditions that lead to violence, bullying, perversion and corruption to flourish."

"We can do our damndest to have better institutions, but history tells us they always end up causing harm and pain."

I think the most wonderful part of my ongoing journey has been the advice, the wisdom of other parents--and absolutely, most importantly, the shared humour, sometimes very black. And almost always directed at the systems that we see as not understanding, not accommodating, not being empathetic to our children.

Something wonderful happens when a group of parents, who may have absolutely nothing else in common except loving their child with Down syndrome, get together. No matter how much family, friends, health professionals and others may empathise, it's these parents who truly understand, who don't need a 10-minute backgrounder before they appreciate you and your child and whatever your current DS topic or problem is.

We must celebrate that and we must celebrate how many more people are prepared to come on the journey with us in 2008, than 10 years ago or 50 years ago.

But we must also sometimes say and do the crazy, brave things that will make life better for our children.

Jo is 24 now and well and truly on her own journey. I'm looking forward to the rest of our journey and to keeping on asking "Why not change it? We, as a society, **can** do better".