

Lifelong Learning

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In 2005 I had the privilege of having dinner with two young adults with Down syndrome. My colleagues and I had worked with these two people from the time they were about six weeks of age. Both, as adults, were now active members of the community; both had jobs and both seemed happy. Seeing them there sure made me happy as both had been participants in early intervention services in which I was involved. However, these two fine young people were more the product of ongoing education than simply early education. As important as early education can be, the fact is that what is most important is ensuring ongoing intervention, i.e. the opportunity for lifelong learning.

Education is a lifelong process which neither begins nor ends with schooling. Similarly, it is carried out by many people who are not teachers. Parents are at the heart of this process.

Peter Mittler in a keynote to the 19th National Conference of AASE in 1995 wrote: *"In the field of intellectual disabilities, we need to define education in very broad terms as anything which systematically promotes learning and development. Defined in this way, education is a lifelong process which neither begins nor ends with schooling. Similarly, it is carried out by many people who are not teachers. Parents are at the heart of this process. The years spent at school are clearly of vital importance but they are only one element of the educational process."* (p.5)

I will just make a couple of observations. Firstly, the vital role of parents will become even more important in a social and economic climate characterised by concepts of deregulation, competition, choice, user pays and mutual obligation. I fear my recent experiences with hospitals may apply to educational institutions, i.e. if you want to ensure your loved ones receive an adequate service, then you have to be there, speak up, look after their interests, and as nicely as you can, be 'in the face' of those who provide the service. There is an assumption that all consumers can speak up and look after their own interests – but we know that not everyone has the skills or capacity to do that.

Secondly, every one of us learns from experience and from exposure to challenging and interesting situations, not just from good teachers. As Professor Sue Buckley, an expert on Down syndrome and the mother of a young woman with Down syndrome writes: *"There is no evidence to support the view that children with Down syndrome reach some ceiling in learning by adolescence and do not go*

beyond it. Studies following children over time have disproved this myth. People with Down syndrome continue to develop reading and writing, speech and language, independence and social skills into adult life. Indeed the author's daughter with Down syndrome, Roberta, made quite dramatic progress between the ages of 22 and 31 years thanks to a move to independent supported living and to falling in love."

Similarly, many of us can report, as did a mother to me just a few weeks ago, that their adult children with a disability often 'take off' in their learning, including in their academic learning, after they leave compulsory education. This raises the issue of educational opportunity for adults.

When educational programs are available for school leavers with a disability or those about to leave school, they often focus solely on employment. In today's climate that is not an inappropriate focus, but it is limited, if that is all there is. I believe we need to have precisely the same opportunities for everyone, and in lifelong learning, that does not necessarily mean only the skills to get and keep your first job.

The Disability Standards for Education (Commonwealth of Australia, 2005) give individuals with disabilities and their supporters considerable leverage in getting not just an education but an appropriate education – if they are willing to use the Standards. As we all know, there are personal risks associated with 'taking on' educational institutions and there can be emotional and financial consequences of going to court. However, I think the Standards can be used more cleverly and with greater finesse. Think of it as your 'educating the

education providers about how they can stay out of court’.

Developments in the compulsory education sector will have a major impact on lifelong learning for people with Down syndrome. With a greater proportion of students with a disability attending their local school, mainstream teachers need to change the way they teach. I am heartened by much of what I see around Australia as I undertake research on students with disabilities in the mainstream. Sure there are teachers who find inclusion is too hard for them; sure there is an over reliance on teaching assistants; and yes, teachers are right in saying there are not enough resources, enough professional development and certainly not enough time. However, inclusion is happening and, remembering my earlier point about ‘you don’t just learn from teachers but from opportunities and involvement’, it is clear that the students attending regular schools are going to graduate with a different set of skills and aspirations for their future because of their mainstream experiences. It is encouraging too, that some teachers no longer see their class in terms of disabled and non-disabled, or even in terms of groups of mixed ability, but as individual students with individual needs.

One of the really complex issues in compulsory education at the moment is curriculum. There is a preference in some states to use and adapt the ‘standard’ curriculum and some teachers are making this strategy work for students with disabilities. However, it is a tricky and demanding task to ensure that the general curriculum is relevant, that it responds appropriately to individual needs, and that it links with the child’s Individual Education Plan (IEP).

In an address to the national Australian Society for the Study of Intellectual Disability (ASSID) Conference on ‘Education, Work, Career and Security’ I made the point that *“the subtext in the discussion about contemporary curriculum goals for students with intellectual and developmental disabilities is that school students with disabilities had better learn the skills, find the supports and develop the networks that will assist them to have a good life without extensive government support once they have left school”*.

Much is talked about adaptation – and again – it is a good thing to do and many teachers are skilful and creative at adapting the curriculum. However, as Westwood (2003) observes, adaptation can also mean a watered down

curriculum and in a real sense, discrimination through denial of opportunity. As one student in the Ash et al research on students with disability in further education in England (1997) commented about her adapted curriculum: *“We didn’t learn much (in the special school). We used to do little kiddies’ stuff. We didn’t do hard work but at college we do hard work and then we learn more.”*

In conclusion, the opportunity to participate in lifelong education is regarded as an essential human right. But as we well know, rights are not always honoured. Even in developed countries like Australia we see daily examples of rights being denied or ignored, even at the very time we are applauding ourselves for honouring them. Discussion about rights reminds me of what a research participant with an intellectual disability said to me in answer to one of my questions about rights. She said: *“You can’t eat and wear rights can you Tony?”* I think she was alluding to the fact that you can assert your rights for all you’re worth, but if society and governments don’t honour them, then what’s the point?

There are some competing themes in Australian society today. While we believe we espouse a ‘fair go’, mateship and inclusion, we are also exhorted to fend more for ourselves, to get the best deal in a competitive environment, to pursue our choices and to be ‘aspirational’. We are frequently reminded of our mutual obligations and given assurances that there are some basic safety nets, (subtext for ‘We’ll help if you’re desperate but don’t expect too much from government!') In a society like this it is essential that we use whatever leverage we have to ensure that people with a disability receive the support to access the services they need. In relation to their learning opportunities beyond compulsory schooling we are lucky to have the new Disability Standards for Education. These Standards have the force of law and outlaw discrimination in education on the grounds of disability. Parents and supporters would be well advised to study the Standards and to use them to facilitate a better lifelong learning deal for their sons and daughters with a disability.

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Ed - View the Disability Standards for Education at www.dest.gov.au

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