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### **On Access, Advocacy and Adjustments**

In 2004-2007 I was part of a team that constructed a method for allocating funds to students with disabilities in Queensland schools, which reflected the principles of access and participation outlined in the then draft Disability Discrimination Amendment (Education Standards) Act. This method for identifying and distributing funding, the Education Adjustment Program (EAP), is still in use. I would like to present my observations and comments on how one system, and the members of that system, reacted to and absorbed EAP. We published a paper about the psychometrics behind the Education Adjustment Program (EAP) elsewhere<sup>1</sup>.

#### *On Access*

Many people come into the field of disability from personal experience of an impairment, or from the experience of seeing a loved one negotiate a disability. I came into the disability field from a sciences (statistics and psychology) background, and a wish to establish myself as a psychologist and teacher. I graduated with an implicit belief in the constructs of my profession, and their ability to explain the *personal encounter of difference*, which, I believe, is the central experience of disability.

What changed my perceptions? The Felliniesque experience of seeing a young man with Down's Syndrome cheerfully point to the anatomical characteristics of the disorder in a presentation to student nurses at a hospital in New Zealand; the change in behaviour of a young woman in a school, whose reportedly intractable sexual promiscuity was reduced by giving her the job of sports equipment distributor; my own darling father's experience of dementia before his death – these are a few. In each of these cases, I was struck by the subjective and objective experience of difference, and its role in defining who we are.

Encountering difference is not unique to those of us with an impairment. A psychoanalyst would say that the personal encounter of difference is a fundamental building block of one's personality: the 'gap' between what our needs are, and how they are met is the start of discovering personal boundaries. However, the objective crystallization of that experience of difference, by others, in a socially approved and systemic manner, is, of course, one definition of social prejudice. It is also a component in the process of building a body of knowledge.

Like everyone else who worked in the field of disability, my concept of access morphed from the ideas of 'normalisation' in the 80's to 'mainstreaming' and 'inclusion' in schools to 'access' as it is now. This progression in language reflects our understanding that we are talking about a process that applies to all, and in a range of contexts. As education is all about access – it is essentially the process whereby we

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<sup>1</sup> Development of Education Adjustment Program (EAP) Adjustment Profile Instruments: A report to the Performance Monitoring and Reporting Branch. (2005)

give access to our culture from one generation to the next, this latest linguistic iteration is particularly apt.

How does this affect my personal understanding of access? I now see access as essentially an acknowledgement of common humanity. If some action facilitates that encounter of common humanity, it is access. Access therefore includes the many high tech supports that a physically impaired person needs in daily life. It can also mean that the eye contact you make with someone is as important as the physical lifting you might do.

#### *On Access and Advocacy*

Systemic attempts to describe difference are necessary to a deeper understanding of a condition, but they are also fraught with cultural and linguistic constraints. This is part of the tension between building knowledge about disability, which can be used for advocacy, and true access for those with a disability. Building knowledge is necessary for us to progress from personal experience, with all its problems of bias, to a broader, more valid and reliable shared understanding. However, as scientists, professionals or just citizens of the world, we also need an awareness that formally applying a knowledge set, no matter how sophisticated, can trap us into the beliefs behind that knowledge set. I would like to acknowledge here the steps taken by researchers to empower and include the disabled in asking questions, gathering data and interpreting findings. My point is that this is only a beginning: as practitioners we rely on an historical mindset that can alienate us from those we want to support. EAP was not immune from this.

The development of a knowledge base for advocacy, can remove us, to some extent, from the personal encounter of access. I don't want to intellectualize too much here. An example of what I mean is the tendency in my own professional area to confuse diagnosis (of a condition) and differentiation (e.g. the individual's learning characteristics) with support. I won't easily forget the pain in a parent's voice as she told me, after I had summarized my results of the psychometric review I had completed for her child. "I know he has memory problems. Every assessment he's ever had says that. But what are you going to do about it?"

I could use those results to argue for special consideration for that child, but whether I enhanced that child's – or his mother's – access to the school community is questionable. Multiply this scenario by several thousand, and you have the evolution of a particular kind of chattering class: those whose experience of impairment is filtered by the instruments of measurement, and whose *raison d'être* is to transmit that experience, in an even more filtered form, to systemic managers.

#### *On advocacy and Adjustments*

The EAP team was very aware that advocacy for a student with a disability within the education system often meant balancing the description of a student's educational needs with the risk of reinforcing pathology.

Essentially the key relevant point in the DDAE (Education Standards) legislation for the Department of Education and the Arts (DEA) was:

*(1A) For the avoidance of doubt, disability standards may require a person or body dealing with persons with disabilities to put in place reasonable adjustments to eliminate, as far as possible, discrimination against those persons.<sup>2</sup>*

We reasoned that, if we allocated extra funding for disability on the basis of the adjustments made in school, we were not only transparently matching our funding with legal requirements, we were also shifting the focus in schools from the impairments of the students to what schools needed to do to support these students.

In practice, the reaction of education professionals was mixed. Our pilot research suggested that consumers (parents, students, some teachers) liked the concept, and thought it would make some forms of advocacy easier. For example, some of our Indigenous parents thought that they would have more chance to talk adjustments over with their own community using the EAP process.

Many of our professionals, who were strong advocates for their students with disabilities, did not like EAP. They furiously questioned the validity, reliability and fairness of the process. It is easy to disregard this questioning as fear of accountability, fear of hidden funding cuts, or simple conservatism. However, with the advantage of time and distance, I now think that there were at least two valid concerns: the uncomfortable relationship between the concepts of adjustments and curriculum, and the loss of the detailed consideration of educational need for a student.

Curriculum can be "...the lessons and academic content taught in a school or in a specific course or program"<sup>3</sup>, or more broadly, curriculum can refer to the entire program provided by a classroom, school, district, state, or country<sup>4</sup>. Basically, the DDAE (Education Standards) sidestepped the issue of curriculum definition:

It is unlawful for an education provider to discriminate against a person on the ground of the person's disability or a disability of any of the person's associates:

(a) by developing curricula or training courses having a content that will either exclude the person from participation, or subject the person to any other detriment; or

(b) by accrediting curricula or training courses having such a content.<sup>5</sup>

In the light of this statement, the difficulty of reconciling the educational needs of some very disabled students with, say, advanced maths courses led to some linguistic gymnastics. This is a trivial example, but teachers of students in special schools, where 'the curriculum' as outlined in education documents is only loosely related to what students may need on a daily basis, had enormous difficulty with the idea of adjustments. I believe that a key part of this difficulty is that the word 'adjustments' trivialises what must be done to support some students. In the drive to ensure access to 'curriculum' the fundamental experience of some students almost disappears.

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<sup>2</sup> Disability Discrimination Amendment (Education Standards) Act 2005

<sup>3</sup> The Glossary of Education Reform (<http://edglossary.org/curriculum>)

<sup>4</sup> Wikipedia (<http://en.wikipedia.org/wiki/Curriculum>)

<sup>5</sup> Disability Discrimination Amendment (Education Standards) Act 2005.

Language again serves to ‘disappear’ part of the experience of disability that we find inconvenient.

EAP in its original form acknowledged the importance of careful consideration of a student’s learning needs, but it did not state that this consideration of needs formed part of the funding cycle (as had been the case in earlier funding processes). It was the intervention that was funded, rather than the formulation of need. I believe now that de-emphasizing needs assessment, for all our intention of reducing ‘labeling’, reduced the richness of the discussion that has to be had around our students with disabilities. By adding the language of adjustments, we enriched this conversation. By avoiding some of the diagnostic/ differentiating terms, we risked losing our connections with important bodies of knowledge. I am pleased that much of the formulation process has been retained in the current process.

So how does a system promote access?

I think EAP has improved how schools consider access for students. But language must always lag behind lived experience, so a good process is always going to be superseded or modified. A system that promotes flexibility and renewal is a start. One that maximizes decision-making close to the student is important. Finally, a robust view of where we have come from helps us move to where we want to go.