Submission
No 685

INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

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Inquiry into the education of students with a disability or special needs.

Submission
by

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Contents

Our Story.

Over the past 20 years both my children have attended school in NSW. We are a single parent family living in a regional centre.

As well as raising my son I have paid work experience in the private school system, and as a tutor of teenagers with Autism Spectrum Disorder as well as in research and adult education. In 2009 I presented a paper at the inaugural Asia & Pacific Autism Conference in Sydney entitled 'Blasting the Pity Principle'.

My son has severe Autism, and severe communication disorder. He is non – verbal and has severe hyperacusis. He completed year 12 last year and has now moved on to a day service programme.

He completed his entire schooling in the state school system in support units attached to mainstream schools.

My son's primary school education was a journey through hell. It was improved in his last two years by the involvement of the then Human Rights Commission, the eventual transfer of his teacher and reforms to the operation and practices of the support unit. Most of my son's education and skill development took place at high school.

The difficulties we experienced, however, were not due to the education delivery structure of a support unit attached to a mainstream school but to the manner in which the then Principal and class teacher were able to manipulate that structure and block or circumvent every formal channel of complaint or investigation.

High School was a different story and my son enjoyed most of his time there – again in a support unit but in a more Autism aware environment where, with one glaring exception, his teachers accepted the challenges he faced as being part and parcel of his disabilities and successfully accommodated them into his programme.

My daughter was educated in both the private and public systems.

Introduction

The comments in this paper are based upon approximately 20 years experience with the NSW education system both public and private and my experiences in parenting a child with severe disabilities. Most therefore relate to students with severe disabilities.

The title of this inquiry refers to disability in the singular it is important to note that most disabilities do not come alone. Invariably they occur with other disabilities and complex medical and therapeutic issues, especially when students are young. A recognition and acknowledgement of this is crucial to any system of special education.

I. Categorising Autism

Five years ago the NSW Department of Education stood alone in Australia in categorising Autism as a behaviour disorder rather than a disability. I am not sure whether this is still the case.

Any system of special education needs to include Autism as a neurologically based, lifelong, incurable disability in just the same way as cerebral palsy and epilepsy are disabilities over aspects of which the student has little or no control.

Autism must be recognised as primarily a disorder of communication, which is so much more than talking, and the role of speech and other therapists is crucial at all points of a students school life.

Categorising Autism as a behaviour disorder insinuates that it is curable and that behaviours associated with it are under the control of the child. It diminishes the experience of those living with the disability and gives systemic encouragement to those like the former Principal of my son's primary school who publicly referred to Autism as 'naughty boy syndrome'.

It encourages a 'siege' 'them & us' mentality among inexperienced staff working with students with Autism. There is so little Autism specific training that it has become wrongly equated with violence when it should be equated with ineffective communication systems and anxiety.

It focuses attention only on what is immediately visible and not on what really needs to be dealt with -

- we don't categorise Cerebral Palsy as a 'wheelchair disorder'
in the same way
- Autism is not a 'behaviour disorder'.

Recommendation 1.
That Autism be recognised and categorised by the Department of Education as a neurologically based, life long disability and programmes and practises amended accordingly.

Recommendation 2
That any student with Autism in a special education placement whether mainstream of in a support unit have weekly direct access to a speech therapist who has specialised experience with autism and that the supports arising from these therapy sessions be accommodated within the student's programme.
(this may only be necessary in regional areas which do not at present have access to specialist autism speech therapy services)

Mild - moderate intellectual disability

The NSW Education Department current practice of compulsory mainstream placement of students considered to have a mild intellectual disability with minimal support is highly questionable.

The ability of these students to gain the literacy and numeracy skills needed as a basis for independent life has been severely compromised by this policy. It places them at a higher risk of homelessness, unemployment and poverty and increases their potential to be mixed up in criminal activity.

These students could function under an integrated model of both mainstream and support unit placement at present they slip through all the safety nets and support services.

Only a matter of years ago they were compulsorily transferred into full mainstream enrolment with minimal support eg 1 part time teacher to 25 students of differing ages and in a variety of classes. This, I believe, was a grave error of judgement.

Terms of Reference

1. The nature, level and adequacy of funding for the education of children with a disability.

Funding is not an area in which I have expertise however a more detailed tailoring of assistance according to the needs of each student would appear to be the most economic way to proceed.

It's like buying school shoes – accept that it's expensive and if you're going to spend the money you want the best support and fit possible for that child.
Tailoring the fit of the shoe to your child's foot is the key to success.
But there will always be children who simply cannot wear a regulation school shoe however it is fitted or modified (and they will usual be children with autism!).

Whatever the system is it must be flexible enough to let them wear slippers or rain boots or runners etc because the important thing is that they are there and happy and learning.

Flexibility of assessment is the key to best assessing the individual needs of students. In practise aiding in mainstream classes appears to allocated after year 2 on the basis of physical need eg toileting rather than learning needs.

The fewer 'tick box', 'one size fits all' questionnaires the better.

Consideration must also be given to the amount of stress placed on already highly stressed families caused by annual funding reviews. Families already under often severe financial and emotional stress should not feel they are responsible for ensuring their child's level of funding, master complex and lengthy forms and then have race around getting reports from therapists and doctors.

Neither should it be presented as an act of charity or special treatment often accompanied by an expectation of gratitude. Careful revision of the language used would be worthwhile.

This funding is the right of the child it is not a special favour.

My experience with both my son and daughter leads me to favour the education delivery structure which combines a support unit with a mainstream school at infant, primary and secondary level for students with disabilities but especially for those with intellectual disability. (See section 3.)

Recommendation 3.
Whatever system of funding is adopted for special education in NSW it should adequately tailored to meet all the learning needs of each student as an individual and include places in mainstream classroom settings and places in special education support units attached to mainstream schools.

Recommendation 4.
That in considering the funding for special education the Department use long range demographics of the population of younger children with disabilities.

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2. Best practice approaches in determining the allocation of funding to children with a disability, particularly whether allocation should be focused on their functioning capacity rather than their disability.

The use of the word capacity in this context is troubling as it seems to contain a measure of finality – ability would be a better choice of language as it allows for changes over time.

Any assessment of students with a disability must combine a consideration of **both** their ability to function in a variety of environments **and** their particular disabilities as well as how these impact upon their learning.

One contentious issue in my son's primary school experience was that both the class teacher and principal insisted that they were obliged only to cater for his perceived intellectual disability not his Autism. I insisted that any programme must take his Autism into account because even then it was clear that there were major cognitive processing differences between children with Autism and children without Autism.

For example his literal interpretation of the world meant that symbolic- diagrammatic, visual communication systems were completely ineffective the programme also presumed that he understood what communication was.

Issues such as the education implications around the theory of mind in Autism were not even considered for discussion.

Sensory dysfunction was regarded as 'non – compliant behaviour' and requests/ suggestions to modify the environment, from therapists or myself, or programme to accommodate it disregarded.

Not all non – verbal students with severe Autism have a low IQ or can be presumed not to understand what is said around them. I would refer the Committee to the excellent autobiography of Lucy Blackman a young Australian woman with Autism. (Lucy's *Story by Lucy Blackman 1999, Book In Hand, Brisbane ISBN 0646374087).*

The job of discovering and unlocking the skills and ability levels of these students is a major challenge facing the teaching profession we should be aiming for best practice. These kids are lifelong learners we need to give them the best start possible. We are among the most wealthy nations on earth we could do amazing things.

Recommendation 5.
That an individual student's ability to function in a variety of different environments combined with their particular disabilities and the issues for their learning caused by their particular disabilities be the basis for determining their areas of need and consequent funding support.

Recommendation 6.
That schools and parents in regional areas be provided with access to Autism specific services.
(these are currently only available to Sydney and surrounding areas.)

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3. The level and adequacy of current special education places within the education system.

There are not enough places in special education and not enough adequately trained and motivated teachers and aides.

Demographic issues and future planning.
The current system does not appear to take adequate account of long term demographics and is more focused on a 'bums on sits' approach to resource allocation.

It has come to my attention that at least one support unit is threatened with closure due to falling enrolments for this year. There was only one child aged appropriately for entry to year 7 and next year there may well be none but the year after that there may well be at least four students likely to take up support unit placement and more in the following years. This is basically a demographic problem made worse by the Department policy to compulsorily give mainstream enrolment to students previously in support unit IM classes. (see section 4 also)

A revision of allocation process taking into account the demographic peaks and troughs that inevitably will occur ands applying them in forward planning is essential for an equitable allocation of special education places.

Integration of support unit places and mainstream class placements.

Most children with disabilities attend school for exactly the same reason that other children attend - viz: to gain whatever level of academic understanding and skills they can master.

Social connection is important but secondary to the acquiring of skills especially literacy and numeracy and an engagement with the practice of learning.

Flexibility of provision is the key to best addressing the individual needs of students. For example the system of provision at Sandon Public School in Armidale NSW is very effective. It provides a small class number for students with disabilities to do their academic and skills based learning and also access to the student's age appropriate class where they can engage, with support if required, in other activities such as craft or sport or music.

When my son began school he could not have survived in a mainstream setting given his hyperacusis and the level of his Autism combined with largely unimpaired mobility. Regardless of how many aiding hours could have been made available he could not withstand the environment of a primary or infants classroom.

Attending a support unit was our only feasible option. I moved my daughter to the same school and they were able to share a life outside home together independent of their parents as ordinary siblings do. This was really beneficial to my daughter and assisted in developing their now very close bond.

As teenagers they attended different schools.

For my son, being in a support unit in high school allowed him to build friendships with other students in similar situations and with whom he was later able transfer to his Day Service programme.

When students without disabilities leave school they often continue contact with the friends they have made during school and these connections make the move to university or work much easier. Children with severe disability, especially those who are non verbal, do not make friends in the same way.

They connect as we all do with the people who have had similar experiences and interests and while interests may be shared as part of school life once HSC study leave hits in October that commonality usually ends. They cannot go to the pub at night; they cannot play sport at the level of their age peers, etc.

My son like most of us does not like to be in situations where he stands out like a 'sore toe' and it is extremely challenging finding activities which can be enjoyed by both him and his non – disabled age peer group where he maintains dignity and meaningful connection. He has an active social life but through family connections.

As the first generation of students with severe disabilities in mainstream placements will not reach year 12 for a few years there is yet time to address the problems of social peer isolation in young adult life

If the statements of principle appearing in section 4 of the Education Act 1990(see section 8) are to be upheld parents and families of children with disabilities must be given a choice of the type of enrolment which best suits their child.

Recommendation 7.
That special education places be provided in both mainstream classes and special education support units within mainstream schools.

Recommendation 8.
That support units not be closed as has currently been forecast but rather they be increased so that at all levels parents are able to choose the best learning environment for their child.

Recommendation 9.
That prior to any support unit being closed a five to ten year demographic assessment of need take place.

Recommendation 10.
That integrated support unit/mainstream enrolment places be opened up again to student with moderate to mild intellectual disability.

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4. The adequacy of integrated support services for children with a disability in mainstream settings, such as school classrooms.

Here it is crucial to distinguish between 'integration' and 'inclusion'.
The Committee will undoubtedly have read the McRae Report (1996) so I will not revisit this. (see section 8)

There is a lot of hype around about 'inclusion' which is often mistakenly believed to mean the mainstream placement of students with disabilities. What we have currently is a poor cousin of proper integration.

Caught as we are in many areas of disability (eg: supported accommodation, therapy services provision etc) between adopting the American model, with its relatively ferocious accountability infrastructure, and the English model of complete government responsibility – we have ended up with something that is neither fish nor fowl.

> Inclusion is not just letting a kid with a disability be in the classroom it is all about a meaningful, multi dimensional education for that student – **being there is not enough!**

My son had just begun school in 1996 and I was privileged and very excited to hear David McRae speak publicly to his report. We thought great things were about to happen almost immediately.

Sadly the mass of Education Department Staff were not ready to make the journey (only three years earlier in around 192 – 93 teaching staff at our local high school had gone on strike in an attempt to prevent a support unit being attached to the school).

The strike was unsuccessful and the unit functioned extremely well though not as an integrated part of the school. It is now faced with closure on the basis that parents are choosing mainstream enrolment (1 did this year). There are possibly no children with disabilities of an age to enter year 7 next year but in two or three years there may be around half a dozen but there will be no support unit for them and they will be FORCED into a mainstream enrolment which is worse than being forced into an integrated support unit.

I remain unconvinced that mainstream teaching staff feel ready or favourably inclined towards something as challenging as completely integrated classes.

Things like the Purvis decision; the placing of students with severe disability in mainstream classes with inadequate preparation and support of the teachers; and minimal funding combined with changes in the curriculum and reporting procedures and an ever increasing load of paperwork and record keeping has made even the most dedicated and creative of teachers feel overwhelmed.

How do you teach maths to an 8 year old who hides under a desk with his hands over his ears because the noise of the other 30 children colouring in and talking quietly is too much to bear?

How many members of the Committee would choose a room with maybe 35 people in it doing a variety of activities at any one time as the place to begin to learn a new language, or calculus, or how to read hieroglyphs?

Mainstream classrooms are particularly fraught for children with Autism for whom face blindness and lack of theory of mind can mean that they the learn social skills, which other children seem to absorb by osmosis, by rote. But this is rarely recognised as a funding need.

This problem is exacerbated for girls with Autism who tend to internalise stressors and anxiety and withdraw, while boys tend to act out and misbehave and thereby gain some level of attention albeit often not addressing the crucial question.

It mitigates in favour of bullying and intimidation of students with Autism spectrum disorders, particularly Aspergers Syndrome, by emphasising their difficulties in social understanding and not providing at least a balancing adequate emphasis on their areas of strength.

Inclusion is possible but if honestly implemented would require a massive reduction in class sizes, which, ironically, would probably gain the immediate support of most mainstream parents who are not always in favour of having 'that kid' in the class. As well as many other changes most of them expensive and challenging.

It would be morally wrong to enact half measures which gave an appearance of inclusion but essentially guaranteed its failure and probably lead to someone in the Department 10 or 12 years from now coming up with the idea of 'special schools' - the nemesis of integration and inclusion.

Integration on the other hand is possible and is happening as we speak in schools such as Sandon Primary School Armidale. (see section 3)

Some children and young people can cope with a mainstream class especially those with only mobility problems and no intellectual disability.

Others cannot but all are deserving of the best education possible. It is not a one size fits all situations – flexibility and tailoring is the key.

Recommendation 11

That if the system of including students with special needs is adopted it be combined with a system that also offers special education support units and where a student is included in a mainstream class the class size be immediately reduced to a maximum of 18 students with a minimum of 1 teacher and 1 teachers' aide.

5. The provision of a suitable curriculum for intellectually disabled and conduct disordered students.

The combination of these two 'categories' of student is offensive and puzzling. It presumes that 'intellectual disability' and 'conduct disorder' always go together and can be dealt with in the same way.

It has been my experience that the worst behaved students do not have an intellectual disability.

The educational needs of these two groups of students could not be more different.

If I had 10 cents for every school report brought home by my son where each tick box category said "striving to achieve goal" I would be a wealthy woman. I did not want him to learn a second language when he was non verbal in English – yet he went to primary school French classes;
I did not care that he did not understand or join in team sports; or that he was as his kindergarten report described 'a loner' and would not join games in the playground; I still do not see that the history of WW1 and Gallipoli etc was in any way relevant to him.

The Department in its insistence that everyone do the same thing in the current curriculum has made that fundamental error of the innate discriminator of
- treating everyone the same rather than equally fairly.-

Sending my son a letter with his confidential pin number to access his HSC results on line is a good example of this. Neither he nor I needed that 'gentle reminder' of the loss his disability has caused.

Merit awards

The current focus on excellence and achievement has lead us all away from commending effort and persistence as perhaps even more valuable signifiers of success. – keep a tally at your child's school each assembly for who and what receives recognition certificates and medallions.

Remember these 'merit systems' can also be used as weapons against parents who are problems. My son's primary school teacher once gave him a certificate of achievement for 'good toilet use' and insisted he walk out before the whole school assembly to collect it and shake the Principal's hand but that was in the bad old days ! Wasn't it?

If I had my time over again I would like to see the special education curriculum have its own 'Key Learning Areas' of literacy, numeracy, and life skill, creativity and music, with non competitive sport and dance for physical activity. There should also be a requirement that all therapists recommendations be embodied in the students programme within a fortnight of receipt.

Recommendation 12
That special Education for students with an intellectual disability have its own KLA's of literacy, numeracy, life skills, creativity and music. That it include non competitive sport and dance as physical activity and that it be flexible enough to allow teachers to design an individual curriculum which plays to the strengths and supports the weaknesses in the child's learning.

Recommendation 13
That recommendations from a student's therapists be embodied in the student's programme within two weeks of receipt.

6. Student and family access to professional support and services, such as speech therapy occupational therapy, physiotherapy and school counsellors.

When my son first began school in 1996 the then DOCS now DADHC speech therapist and occupational therapist who had worked with him in early intervention made weekly visits to school and conducted sessions in the support unit with him and the other children. The then Principal and teachers did not allow parents to attend these sessions (at early intervention parents had been encouraged to be present) and all information had to passed from the therapists to the teacher and then on to the parents. If parents had questions for the therapists they also had to be placed through the class teacher. It was years before I learned that this did not happen at other schools.

Parents were allowed to invite therapists to their child's IEP meetings each six months but this was sadly inadequate.

This *'therapy by Chinese whispers'* made it extremely difficult to maintain effective home programmes and life became extremely difficult. As a parent I was caught in the middle of a strange sort of power struggle where the teacher believed that the therapists should be subject to her direction and decisions.

I had no way of knowing whether the speech therapy exercises and OT programme were being implemented at school. As it turned out they largely weren't.

The teacher claimed, fairly, that she was not a speech therapist or an OT but still would not agree to me attending the sessions with the therapists.

In effect my son's therapy was reduced to less than a quarter of what it had been before he began at school but his need was increasing every day.

When my son was in his middle primary years the then school Principal banned the DADHC therapists from the school and they did not return for nearly a year.

I and other parents accessed DADHC therapy services outside school premises but by this time staffing shortages for therapists had begun to hit regional areas significantly and hours were reduced further.

The Committee should note that if a child is a DADHC client I have been informed that they cannot access Community Health Therapy Services without relinquishing their client status and in regional areas there are few therapists with experience with Autism or significant disability to be found other than those employed by DADHC.

From around the age of year 10 until he left school my son did not receive any direct therapy services at school.

In High School support Unit (other than in year 9) the implementation of recommendations I received from speech therapists and his clinical psychologist have been welcomed by my son's teachers and they and the head of the unit have been very supportive.

Sadly though, it is still the case that the personal disinclination of an individual teacher has more weight than the recommendations of his therapists or psychologists.

Recommendation 14.
That a student's with disabilities therapy assessments and monitoring be primarily the province of their parent/carer and that any recommendations and applications of those assessment and monitoring be immediately embodied into the student's individual education programme.
(see also recommendation

Recommendation 15
That speech, occupational and physio therapies be provided at school as part of the student's programme at the parent's request at no cost to the parents.

7. The provision of adequate teacher training, both in terms of pre-service and ongoing professional training.

Autism can be one of the most challenging and confronting disabilities facing teachers in any setting. Given the increase in the number of diagnoses it is reasonable that most teachers in NSW schools will at some point have at least one student in their care that has an Autistic Spectrum Disorder.

As well in relative terms Autism is a new disability and while research is happening now it is enough to indicate that there are large cognitive differences between student with an Autism spectrum disorder and those without. Issues such as memory functioning in autism, sensory dysfunction and cognitive distraction are essential knowledge for any teacher with a student with autism.

A great deal of pain and anguish has been experienced by all concerned but mostly students with Autism when a special education system underpinned by educational practise based upon students with Downs Syndrome which is in may ways the polar opposite of Autism.

Take for example the idea of ' time out' or 'naughty chairs' for a child with Down Syndrome these are forceful punishments but for a child with Autism who lacks the social understanding that he is part of a group and longs to be on his own where he isn't bothered by others these are heaven sent opportunities.

Pre – professional teacher training for special educators needs to include and be underpinned by a philosophy that as teachers they do not have all the answers and to meet the complex needs of their student s they must learn to cooperate with parents and other professionals to achieve the successful outcomes they desire.

If they ever get a 'problem parent' give them a job rather than make their classroom a parent free zone – trust needs to be earned.

Recommendation 15.
That a study of the latest research into the various cognition issues in Autism be a compulsory part of all teacher training in NSW. Also that it be a mandatory professional development component for existing teachers.

Recommendation 16.
That life experience (i.e.: a lived experience as a sibling or parent) of disability be one of the desirable criteria for the appointment of special education teachers

Recommendation 17.
That all future training of new teachers include at least one mandatory forum style question and answer session with a panel of parents of children with disabilities, including at least one parent of a severely disabled child.

No.8 Any other matters.

i. Accountability and protection for the most vulnerable.

Parents realise that their child's teachers are generally well intentioned and skilled at what they do but must manage somehow under an enormous mountain of policies, procedures and regulations which have little to do with the imparting of knowledge or skills to their students.

These policies procedures and regulations did nothing to get a workable communication system for my son in accordance with his speech therapist's and paediatricians recommendations. I obtained a private advocate and lodged a claim with the then Human Rights Commission.

Only after I did this did people from the Sydney Office of Department of Education became involved and without demur instituted a pcs visual communication system suitable for autistic children – in wide use in Sydney schools – for a number of years and a number of other reforms completely restructuring the support unit and its programmes.

They also put paid to the practice of placing all and only the non – verbal students in one class and verbal children in another.

Being able to speak was regarded as an indicator of higher IQ by the then teacher and students were transferred out of the class, sometimes within a matter of hours, once they began to speak. This same teacher flatly refused to use the pcs visual communication system.

From the Sydney Office intervention onwards my son and his non verbal friends were in an age appropriate grouping with their verbal friends with other disabilities, he no longer had to watch television as part of his programme, and he slowly began to acquire skills and knowledge – five years after he began school.

I tried every avenue I knew to solve this problem over a lengthy period of years. My son could not tell anyone what was going on and I was patronisingly dismissed as a neurotic parent. This combined with the ultimate power of the School Principal who, at one point banned all therapists from entering the school for nearly a year and shortly after refused entry to the then Autism Association behaviour specialist on a prearranged trip from Sydney regarding my son.

The stress and emotional distress this whole experience caused to my son and our little family cannot be adequately described. Worst of all my son lost the opportunity of five years of learning at a most crucial time in his life.

The situation could easily occur again and a system of external review especially in regional areas is the only effective method of circumventing a repetition.

Recommendation 18.
That a system of external inspection of all special education placements be instituted, particularly in Regional areas, where parents and therapists can be involved and where the reviewer is completely unknown to the teacher and school principal.

ii. Poverty and disability

Raising a child with a disability is a free ticket to poverty.

Invariably one or both parents' working lives and consequently income is curtailed and the family is required to meet medical and therapeutic expenses with the consequent costs of travel and accommodation which most families never dream of. There is also the sad fact that the rate of family breakdown under the consequent stress is enormous resulting in most being single parent families.

Mine is one of those families and I can assure the Committee it is an extremely hard life. A life made worse by the insensitivity of many teachers and staff but enhanced by the empathy and support of others.

One does not easily recover from the damage done by the thousands of little cuts caused by a sad combination of insensitivity, fear, lack of knowledge and a bureaucratic power structure. An aspect of this is the consciousness of individual teachers and teachers' aides where a motivator I have termed 'The Pity Principle' is often present. I presented a paper on this topic to the Asia Pacific Autism Conference in Sydney last August (2009) and recommend it to the Committee.

As well, the Australian Institute of Family Studies Research Report No. 16, 2008 *The Nature and Impact of Caring for a family member with a Disability in Australia.* will, I believe assist the Committee in its deliberations.

It would also be beneficial if the Committee could examine the recent Federal Government report on the Inquiry into the Better Support for Carers in Australia.

Recommendation 19.
That any system of special education recognises that financial restriction and poverty are part of the lives of many families with a child with a disability, that this places extra stress on an already stressed family.

iii. Discipline policy and its impact on family relationships & family poverty.

The current discipline and suspension policy is especially punitive and purposeless for students such as my son and places a burden upon already stressed families much more onerous than on those with student without a disability.

Suspension from school as a deterrent to misbehaviour in a child with severe disability is fruitless as students with severe disability do not associate not going to school with their particular misdemeanour.

These students cannot be left at home on their own as a high school child without a disability might be. So a parent/carer must remain with them when they would otherwise be working, as is the case now in most families.

Just holding down a job is an achievement for a parent with a child with a disability. You never know when you are going to have to take time off to be with your child in hospital or to care for them at home.

The current system places a far more onerous burden on the parents and families of students with disabilities than it imposes upon the parents of students without disability.

Recommendation 20.

That completely different and separate discipline and suspension policies and practices be applied in consultation with Parents where a student has a disability severe enough to require constant supervision. That these policies and practices NOT include suspension from school attendance as this a punishment which is ineffective and more onerous on the student's family than on those of a student without a disability who can remain at home unsupervised.

v. *Inclusion – being there is not enough!*

true inclusion means making the careful distinction between treating students equally fairly and treating all students the same.

Over the past ten years or so a quasi American practice of inclusion has been pasted over the top of a system which does not contain the infrastructure physically or philosophically to support it.

It is crucial to remember that in the American system legislation creates and guarantees the right of every child to an education and there is an independent infrastructure to deal with the infringement of this right.

In NSW the situation is not the same. Section 4 of the Education Act (NSW) 1990 makes a bold statement but there is no infrastructure to ensure that **any** child's right to an education is guaranteed.

As well, section 4 may well contain the seed of its own destruction. How can a right be granted as could be construed from subsection (a) and yet also be the responsibility of individuals as stated in subsection (b)

"Principles on which this Act is based

> *In enacting this Act, Parliament has had regard to the following principles:*
> *(a) every child has the right to receive an education,*
> *(b) the education of a child is primarily the responsibility of the child's parents,*
> *(c) it is the duty of the State to ensure that every child receives an education of the highest quality,*
> *(d) the principal responsibility of the State in the education of children is the provision of public education."*
> *(Education Act NSW 1990 Section 4)*

To have a true system of meaningful inclusion for students with disabilities there first needs to be a full and unequivocal statement of the right to education of all students. This then needs to be accompanied by the establishment of an independent infrastructure which will ensure that right.

The alacrity with which the High Court decision in the matter of Purvis v NSW Department of education and Training.(HCA 2003) as supporting the rights of schools to deny this presumed right of education to students with Autism is more revealing of the true philosophy underpinning the NSW Education system.

A former principal of my son's High School used the Purvis decision as justification for his year 9 teacher to go back through his school records and list every potential misbehaviour for 3 years (there were about a dozen most had never been reported to me and had been deemed insignificant at the time) as a justification for suspending him from school. The Principal argued that his suspension was 'respite for the teacher' and she was supported in this stand by the decision in Purvis as advised to her by the Department's legal section.

A long discussion ensued, my son was not suspended, the High Court's decision was not revisited and the matter was never raised again.

vi. Siblings.

The Education of students with disabilities is only one aspect of the lives of these families and to be effective it must recognise the student and their family in a holistic way. This must include the formal acknowledgement, recognition and support for the siblings of the student - often students themselves and dealing with issues on a multidimensional level usually beyond the ken of their teachers and fellow students.

Recommendation 21.
That any system of special education at all levels recognise, acknowledge and support the siblings of students with disabilities in tangible and positive ways.

vii Taxi Transport Scheme

As a single parent who cannot afford to run a car the Taxi transport subsidy scheme has been a life saver. It has allowed my son to become known in his community in a positive way and as an individual I cannot praise it highly enough.

It is however difficult to access and making this process a little easier would help many families. It would be wonderful if it was extended to cover attendance at day service programmes but I recognise that this is not within the parameters of this Inquiry.

Recommendation 22.
That the Taxi Transport Subsidy Scheme be continued and access to it be made easier.

Viii Transition into the outside world.

Much more could be done around this issue. Last year my son's teachers went above and beyond the call of duty and he received 4 weeks of 1 - 2 half days supported transition to his day service programme. This required me to locate support workers on the days his teacher was unable to attend as there were little or no funding to replace my son's teacher while he did this other staff generously 'mucked in'.

Looking back the entire process would have been much better if it had begun when my son was in year 10. It had long been clear that he would be applying for Community Participation Programmes and a day service programme at a centre was what I felt was in his best interests both short and long term.

There is an enormous amount of information about the variety of programmes and different types of funding available for each and which service providers provide what and when. Although not strictly the province of the Department of Education the opportunity to really get to know about what the options really are would be good from a parent's perspective.

My son, as with most Autistic students, finds changes to routine and new places and people extremely distressing and a system which allowed him to familiarise with the place and people over a long period of time would have been very beneficial and reduced the enormous stress he and our family were under.

viv Inter-departmental cooperation

I realise that any such programme would require a strong liaison with Dadhc and adult service providers (there are not many in Regional NSW) but I believe it is possible.

Another aspect of the year 12 experience which I could well have done without was the questionnaire associated with the assessment process.

It is intolerable that my son, at 18 years old, just beginning his life in the world of adults should be assessed in terms of a tick box questionnaire so similar to the one I completed to determine my father's needs when entering a nursing home in his late 70's.

This questionnaire included ridiculous questions such as 'does the client engage in risky behaviours eg smoking in bed?' but nothing and no space to explain the needs caused by my son's Autism. It was done by a member of staff from regional education department office who had met my son perhaps half a dozen times and though well intentioned was given an hour to interview me, his teachers and complete the form.

I realise that this issue resides in that 'pea soup fog area' which exists between government Departments and in which so many gentle souls get
lost and wander away forever but there is definite room for improvement in the role played by the Department of Education.

Recommendation 23.

That the process of assessment and information to Parents about Community Participation Programmes begin in Year 10 and that this be a collaborative process with service providers and other Departments and Parents.

Recommendation 24.

That transition programmes to Community Participation Programmes begin when the student is in Year 11 in the same way as work experience programmes and that these be adequately funded with experienced staff who know the student.

Recommendation 25.

That it be formally recognised that students and people with disabilities are life – long learners just like the rest of us.

Recommendation 26.

That potential Community Participation funding recipients be identified in Year 10 at each high school that parents of each child be connected with each other and active steps taken to encourage communication between them. That parents then be introduced to <u>all</u> the service providers operating in the area. In year 11 each school arrange information meetings with DADHC and other funding bodies to introduce the process and problems they may encounter.

Recommendation 27.

That transition to community participation programmes be run in a similar way to transition to work programmes.
Thereby allowing students with severe or profound disability the same two year transition currently available to less disabled students.

Recommendation 28.

That students with disabilities be allowed to continue attending school until the last day of school in the year they are in year 12.

Recommendation 29.

That completely different and separate discipline and suspension policies and practices be applied in consultation with Parents where a student has a disability severe enough to require constant supervision. That these policies and practices NOT include suspension from school attendance as this a punishment which is ineffective and more onerous on the student's family than on those of a student without a disability who can remain at home unsupervised.

Conclusion.

Students with disabilities are, like the rest of us, life long learners. We live in one of the wealthiest countries in the world - we can afford to give them the best start in life possible. Lets do it!

I am more than happy to address the Committee should they desire it.

Appendix 1.
List of recommendations.

Recommendation 1.

That Autism be recognised and categorised by the Department of Education as a neurologically based, life long disability and programmes and practises amended accordingly.

Recommendation 2

That any student with Autism in a special education placement whether mainstream of in a support unit have weekly direct access to a speech therapist who has specialised experience with autism and that the supports arising from these therapy sessions be accommodated within the student's programme.

(this may only be necessary in regional areas which do not at present have access to specialist autism speech therapy services)

Recommendation 3.

Whatever system of funding is adopted for special education in NSW it should be adequately tailored to meet all the learning needs of each student as an individual and include places in mainstream classroom settings and places in special education support units attached to mainstream schools.

Recommendation 4.

That in considering the funding for special education the Department use long range demographics of the population of younger children with disabilities.

Recommendation 5.

That an individual student's ability to function in a variety of different environments combined with their particular disabilities and the issues for their learning caused by their particular disabilities be the basis for determining their areas of need and consequent funding support.

Recommendation 6.

That schools and parents in regional areas be provided with access to Autism specific services.

(these are currently only available to Sydney and surrounding areas.)

Recommendation 7.
That special education places be provided in both mainstream classes and special education support units within mainstream schools.

Recommendation 8.
That support units not be closed as has currently been forecast but rather they be increased so that at all levels parents are able to choose the best learning environment for their child.

Recommendation 9.
That prior to any support unit being closed a five to ten year demographic assessment of need take place.

Recommendation 10.
That integrated support unit/mainstream enrolment places be opened up again to student with moderate to mild intellectual disability.

Recommendation 11
That if the system of including students with special needs is adopted it be combined with a system that also offers special education support units and where a student is included in a mainstream class the class size be immediately reduced to a maximum of 18 students with a minimum of 1 teacher and 1 teachers' aide.

Recommendation 12
That special Education for students with an intellectual disability have its own KLA's of literacy, numeracy, life skills, creativity and music. That it include non competitive sport and dance as physical activity and that it be flexible enough to allow teachers to design an individual curriculum which plays to the strengths and supports the weaknesses in the child's learning.

Recommendation 13
That recommendations from a student's therapists be embodied in the student's programme within two weeks of receipt.

Recommendation 14.
That a student's with disabilities therapy assessments and monitoring be primarily the province of their parent/carer and that any recommendations and applications of those assessment and monitoring be immediately embodied into the student's individual education programme.
(see also recommendation

Recommendation 15

That speech, occupational and physio therapies be provided at school as part of the student's programme at the parent's request at no cost to the parents.

Recommendation 16.

That a study of the latest research into the various cognition issues in Autism be a compulsory part of all teacher training in NSW. Also that it be a mandatory professional development component for existing teachers.

Recommendation 17.

That life experience (i.e.: a lived experience as a sibling or parent) of a person with a disability be one of the desirable criteria for the appointment of special education teachers

Recommendation 18.

That all future training of new teachers include at least one mandatory forum style question and answer session with a panel of parents of children with disabilities, including at least one parent of a severely disabled child.

Recommendation 19.

That a system of external inspection of all special education placements be instituted, particularly in Regional areas, where parents and therapists can be involved and where the reviewer is completely unknown to the teacher and school principal.

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Recommendation 21.

That any system of special education at all levels recognise, acknowledge and support the siblings of students with disabilities in tangible and positive ways.

Recommendation 22.

That the Taxi Transport Subsidy Scheme be continued and access to it be made easier.

Recommendation 23.

That the process of assessment and information to Parents about Community Participation Programmes begin in Year 10 and that this be a collaborative process with service providers and other Departments and Parents.

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Appendix 2.

Blasting the Pity Principle!

Turning parent: professional relationships on their head - aspects of life with a child with Autism in regional NSW.

By
Kate Thomas

Paper presented to the inaugural Australia & Pacific
Autism Conference.
Sydney
August 2009

For Edward (2001)

My son's mirror neurones misfire.
They say that's why he can't read what I'm thinking.

His Broca's broke.

Overwhelmed, afraid and confused by
The verbal density of life;
The lights, whirl and 'busyness' of places;
The randomness of people and their
movements;

In kinaesthetic and sensory overload-

He screams and 'goes to ground'
And Strangers Stare

Transfixed by difference.

When the terror, innate to mud and frogspawn, subsides

He sees
The magic in sunlit motes of dust;
The visions in cathedral windows;
The beauty and purity of form in
a bubble.

He hears
Dogwhistles;

Distant hums;

The clack - clack of butterfly wings.

On the edge of the world he remains in the now.
He looks from the corners of his eyes..............

and knows.

Blasting the Pity Principle!

Turning parent: professional relationships on their head – aspects of life with a child with Autism in regional NSW.

Introduction

The purpose of this paper is to provoke and promote discussion rather than provide any hard and fast answers and I apologise in advance for any toes I may tread on in doing so - there are sure to be some.

'The Pity Principle' is deeply ingrained as a mindset, and mode of interaction, in the structures and people with which we and our children with Autism must deal. In analysing it we must question ourselves, as well as others, and this is always challenging.

The 'Pity Principle' applies to all areas of life, when you live with Autism, but I will illustrate it in this paper mainly in relation to school education as this has been the main area of our experience.

The 'Pity Principle' applies to all areas of disability but I believe that because Autism challenges a socio – linguistic society at its base point the 'Pity Principle' asserts its presence more strongly.

This paper is written from a parental perspective. I do not suggest that I understand the experience of people with Autism even my treasured son, Edward, who often mystifies and amazes me.

So what is the Pity Principle?

It has been difficult to find the right words to adequately describe the mindset of and the impact upon both sides of an interaction that is the 'Pity Principle'.

It is founded upon the concept of 'special treatment of' rather than the 'acceptance and accommodation of' **DIFFERENCE**. - But this is too simplistic.

It begins when we say to ourselves *"Oh that poor disabled child"* and we look at their carer with the jaundiced eye that admires what it does not understand and supposes we could not cope with.

It is underpinned by fear.

Fear of difference felt by all of us in the general population, fear of retribution against us or our child and fear of being, or perceived as being, professionally inadequate or ill equipped to cope with a person who we perceive as different to the norm.

The 'Pity Principle' is that which allows a teacher, teacher's aide, or any worker in the field to believe that the work they do with a child with autism, or in fact any disability, is somehow more special than the work done by their counterparts working with a child without a diagnosed disability.

That their work and dedication is somehow more special and more worthy of recognition by virtue of the difference of their 'client' from the norm and the more different that child is, the more exceptional are they and their work.

The 'Pity Principle' is fed by statements from peers such as
"I don't know how you deal with those kids I just cant get my head around intellectual disability and to have a kid rock like that all day would drive me crazy."

If it is stated often enough that somehow these workers are a breed apart and this is combined with the close relationship which may develop and often contains a higher percentage of 1:1 teaching than with other children the 'Pity Principle' can become ingrained .

It is supported by the systemic 'siloing of expertise' within the school education community and the structure of the early intervention and school education which systemically separates the parents of children of different ages.

Teachers and other workers receive constant reminders from their peers and the press about how special they are to be dealing with "*that sort of child*" and can fall, often unconsciously, into the mindset that the specialness of the child /adult has somehow rubbed off on them and they too are special.

This mindset leads to a need for their 'specialness' to be acknowledged not just by their peers but by the parents and others working with the child and when the acknowledgement is lacking or inadequate it is all too often taken as personal criticism.

The power structure between school and parents also needs to be re examined. We have undoubtedly all been there the lid of the drink bottle is left loose the drink leaks out through the school bag, you write in the communication book that you would like this not to occur again, no reply, but there are no further leaks. Then at Friday School Assembly your child stands before his peers and school community and receives a merit award for '*good behaviour using the toilet*'. This is not creating a valued life or individual in that community but it strengthens the operation of the 'Pity Principle'.

Years ago someone asked me what was the most difficult thing about parenting Edward, who at the time had a few challenging behaviours, they were astounded when I said
" *Always having to be grateful for every little thing* " .

At that time I was too busy and burdened to do much self analysis but later I realised how easily being grateful for things done for Edward came to me. If, by comparison, Emily's teacher had done the same I would have felt no special gratitude just appreciation that she had done a good job, for which she was well paid and been professional in her approach.

But I knew how challenging Edward could be and was afraid that if I didn't behave in the expected way there would be repercussions for him as well as me and he, unlike his sister, could not tell me what happened each day. Edward and his class mates were chosen on the basis that they did not have expressive language and the consequent assumption of very low IQ.

I now know that my gratitude actually fed the operation of the 'Pity Principle' but worse than that the 'Pity Principle' in this situation disguised the teacher's inability to cope and allowed the unusual educational and administrative practices at the school to remain undiscovered until some years later when

HREOC[1] and the Sydney office of the Education Department were called in and major changes resulted.

The expectation of gratitude is difficult to deal with in the parent : teacher power play that operates in our system of school education. It sustains and enhances the 'Pity Principle' and renders potentially good, but appallingly funded, inclusion measures a mere token.

The Early Days

Edward was born in Armidale in 1990 my daughter Emily was three years old. In 1993, Edward scored 41 on a CARS assessment and our adventure into autism and disability began but my introduction to the operation of the 'Pity Principle' had begun earlier.

At 14 months Edward said his last word "Odette" (he name of a little girl his age with whom he often played) Over the next year and a half I doggedly pursued my intuition that something was very wrong with my little boy. He didn't speak or cry or shout he rarely made any sound at all. He played cutely, but very oddly, with ordinary toys, he became dominantly left handed, he became very clingy but didn't like to be touched or held -- list goes on and would be familiar to most parents here.

My difficulty was getting people to believe that something was wrong. I experienced first hand the overwhelming powerlessness one feels when faced with the perception, favoured by my partner (Emily and Edward's father) that Edward appeared to be a healthy little boy with some quite excentric behaviours – undoubtedly caused by his mother's neurotic insistence the something was wrong with him.

What you see is not always what you get!!!!!!!!!

Finally, in one of those flashes of fate which bless us now and again I met a woman on the Early Intervention Team, an Occupational Therapist who had studied with Lorna Wing and who, I believe, knew immediately what was up with the little boy so fascinated by her colleague's second skin (her stockings).

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[1] Human Rights and Equal Opportunities Commission. Now the Australian Human Rights Commission.

She treated me with enormous kindness and support but in a way which acknowledged my intelligence and grief. We headed off to the Prince Of Wales Hospital where after a battery of tests Edward received his PDDNOS[2] badge.

We returned to Armidale and the next morning that same OT,having been contacted by the Social Worker at Tumbatin[3], was on my doorstep at 9.00 am with tickets to the Tony Attwood workshop happening that day in Armidale.

Dr Attwood's workshop was a revelation. The autistic child he described could have been Edward I began to have an inkling of what I was dealing with and that it might just be possible to cope after all. We headed straight for the Autistic Association and a CARS Assessment.

And so began our lives in the fishbowl of early intervention.

There were regular visits to and from therapists; our wonderful occupational therapist coached me in various 'at home' strategies to deal with Edward's sensory dysfunction, as well as working with Edward himself; his speech therapist introduced me to concepts like 'environmental sabotage', and amongst other things, taught Edward to sit in a chair at a table I was grateful but there was no expectation that I should be.
Together, we developed a selection of ways of helping Edward cope with what to him was a terrifying and unpredictable world which often caused him physical pain.

The Early Intervention Teachers ran a playgroup for children in the programme where everyone was known only by their first names (for confidentiality reasons).
The Autistic mums soon spotted our children lining the cars up and with a few others began to meet and talk together away from the playgroup. This was the beginnings of our Autism Support Group. The therapists didn't mind but the Teachers did.

When the organisers of a programme don't like participants talking to each other outside the programme – its time to get a new programme!

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[2] Pervasive Developmental Delay Not Otherwise Specified.
[3] Childhood Developmental Clinic at Prince of Wales Hospital Sydney.

The Early Intervention Teachers also conducted the dreaded 'home visits' where they *"just checking up on how you are coping dear."* And so I immediately hid the dirty dishes in the oven, got out of my pyjamas and wore my hair in a turban scarf to disguise the fact that I'd not been able to have a shower for two days because Edward wasn't sleeping and I really wasn't

coping. Because I knew that when DOCS, as it was then, checks up on how you're coping you're one step away from losing your kids.

None of these teachers mentioned that I could have had respite or home care assistance if I wasn't coping - that was another parent nearly a year later.

The teachers as a matter of course and without reference to the families made themselves Case Managers for the children receiving therapy services from DOCS. They argued that this made it easier to organise and convene therapy team meetings and a holistic service for and about each child. The role of Case Manager was then automatically handed on to the class teacher when the child began at school.

I wrote to DOCS formally advising them that under the then Disability Services Act I would be Edward's Case Manager would convene meetings when necessary and manage his therapy programme. The Therapists didn't mind this but the teachers did.

Years later I discovered that our first Early Intervention Teacher had recommended against any housework assistance for me as she considered after inspecting my home that I was coping well. She didn't ask me if I wanted assistance because she didn't want to place added pressure upon us while the family was coming to terms with Edward's disability.

This was not an act of malevolence or vindictiveness but the mindset which suggested to her that she had the power to make such a decision without reference to anyone else is the 'Pity Principle' in action.

It also reveals the perception assumptions which allow the 'Pity Principle' to flourish. Anyone who lives with Autism knows that what you think you see happening is never the whole picture - and may well not be what you think you see at all.[4]

The school years

Our school experience did not begin well.

The story is long and heartrending, so I will attempt to extract instances and incidents which illustrate how the 'Pity Principle' influences the actions of individual school staff and how it has been embedded into the school education system in NSW.

More than in any other area it is in school education that '*the expert knows better than the grieving if not witless parent*' aspect of the 'Pity Principle' operates most strongly.

Edward was enrolled in an Early Intervention Class of three children deemed to have high support needs.

The E.I Teacher, in an exquisite example of siloing, did not have to work in tandem with the Montessori preschool Edward attended and insisted that it would be detrimental for him to attend both, the therapists could only provide service to state schools and preschools and so Edward left Montessori to attend Early Intervention Class.

Once this had been done he refused to recognise or act upon the medical or therapy reports about Edward's sensory problems, in particular his sound sensitivity, he approached the class and his teaching solely from the point of view of intellectual disability. He told us he was *"... in awe of how parents in our position coped but that our children were a special gift he was honoured to share with us"*

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[4] There is a marvellous article entitled 'The Eye of the Beholder: the Stereotype of Women Convicts 1788 - 1852 ' by historian Michael Sturma in *Labour History* 34 May 1978 . In it he deals poignantly with the issue and benefits of multiple perspectives.

He insisted that the children respond to the ringing of a small hand held bell every 20 minutes "to get them used to change in the environment at school" where bells signalled a change of lesson..

Edward went to ground and screamed every time the little hand bell was tinkled and was deemed to be non compliant. (And as we all know compliance is what you most need when you are beginning kindergarten.)

When his mother complained, the teacher wrote a five page report and attached it to Edward's Department of Education School Counselling file – it's probably still there today but probably has company I can only guess as

parents are denied access to these files. They are accessible only to school counsellors and teachers who may need to comment upon a child's behaviour.

These 'School Counselling Files' ,and we all have them, are a systemic support of the 'Pity Principle' where 'special treatment' from people with 'special knowledge' must be bureaucratically defended and not open to scrutiny.

In Primary school, 1995 - 2003 Edward covered his ears, went to ground and screamed when the PA system was used at outside morning assemblies (which were held even when it was snowing) His distress was variously admonished for being non compliance, ridiculed for being attention seeking or ignored. It was never accepted as a part of his Autism and something which required sympathetic and positive assistance.

Therapy services previously available weekly or fortnightly from DADHC[5], as it was now called, were now provided monthly and on a consultative basis at school, during school hours and only to teachers who would then, <u>if they deemed it necessary,</u> advise parents of what the therapists had said.

Therapists did not meet separately with parents – but I insisted that as Edward's Case Manager they had to meet with me. The therapists were happy with this but the teacher and Principal were not.

None of the children in Edward's class of 6 had expressive language. Parents of children in Edward's class had only the word of the teacher herself for what

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[5] Department of Aging Disability and Home Care NSW

was done. One child who regained expressive language was moved to the moderately disabled class within 48 hours.

Edward's teacher 's stated belief was that there were some children who were not ready to be taught and that this was indicated by the need to use photographs as a means of communication rather than 'compic' (the only visual communication system she would, as a professional , agree to use) I argued that the 'compic' programme was too symbolic and required an understanding of communication process that Edward did not have. His speech therapist argued this as well but in the context of school education therapists and other outsiders could only make recommendations and it was up to the class teacher and the Principal to choose whether to adopt them.

I was variously deemed a trouble maker, grieving, attention seeking, and using complaints about Edward's education as displacement for not having yet come to terms with my son's disability.

At length, I withdrew Edward from school and sought help from the Human Rights and Equal Opportunity Commission and Disability Advocates to have his educational programme include and address the needs created by his Autism.

At around this time the School Principal banned visits from the DADHC therapy staff. Parents were never told why but it took nearly a year for their return to be negotiated between the two departments.

My attempt was successful but it did not win me any friends among the teachers, mainstream parents and other staff at the school who, encouraged by the Principal, saw me as a wicked discontent and troublemaker making life difficult for those poor teachers who looked after 'those poor disabled kids so well.'

In his last two years of primary school, following the intervention of HREOC and Advocacy Northwest Edward was allowed to go inside at morning assembly time. He was placed in his age appropriate special ed class rather than with younger children who also had no expressive language.

In a regional town like Armidale there was no other school for Edward to attend . Likewise there is only one high school which he could attend. All the teachers know one another. Today I often see staff from Edward's school while doing the groceries, at the movies etc and our paths cross in various community groups. This has been difficult at times but largely positive as it has allowed us to see each other as people rather than simply the roles we play around Edward's Education.

There are no therapy services at High School and there hadn't been an occupational therapist in Armidale for some years. In fact the position remained vacant on the DADHC therapy team until the beginning of last year. One OT worked for Community Health but you cannot access services there if you are considered a DADHC client. – it's considered double dipping!

In 2004 when Edward began High School and went to ground screaming on his first day when the PA system was used his new teacher (new to Armidale

but not to autism), rang me and asked whether I minded if Edward didn't go to morning school assembly as he seemed sensitive to the noise of the PA system.

Did I mind?! Not at all. Such a small thing really but the teacher's behaviour made me think that maybe I no longer needed to fight for everything and when I thanked him he replied cheerily *"Just doing my job"*.

Things went reasonably well until a new teacher began in year 9.

Edward's year 9 teacher, a close friend of those at his primary school, decided that the classroom needed to be restructured. She obtained desks with half metre noticeboards attached to the front –so that the kids would not be distracted by things in front of them- she covered the boards with bright orange glossy paper and placed Edward's desk next to an uncurtained window.

Edward's light sensitivity and his aversion to orange and yellow had been well documented on his file as was his need for photos and a literal visual communications, but she knew best. Edward's behaviour at school went down the tubes .

The Teacher then went back over the previous three years and compiled a dossier of occasions where Edward had gone to ground or exhibited some other non compliant or challenging behaviour. These had been meticulously if erroneously recorded and kept in a file but never notified to me. She then went to the Headmistress who promptly wrote to me threatening to suspend Edward for persistently breaking school rules.

And there I was at another meeting only to be told by the head that his suspension should be regarded as 'respite for the teachers' and that since the 'Purvis'[6] decision they were completely within their rights.

This was too much I explained that the facts and decision in Purvis did not apply here and if they wanted to test it they could go ahead. Edward and I would be accompanied by the press the next time they saw us and I would be overjoyed to be instrumental in having a travesty like Purvis overturned in the High Court. They could also expect an invoice from me for my lost wages if they suspended Edward as unlike other year 9 students he could not remain at home alone while I went to work .

The impact of this High Court decision on the relationship between schools and the parents is worthy of detailed investigation, there's possibly a PhD there, but at Armidale High School[7] in 2006 it was interpreted as 'cart blanche' for teachers.

In regard to the 'Pity Principle' the High Court decision in Purvis appears to have placed the specialness of special education staff above that of their students with Autism so that the teachers' needs rank more highly than the child's right to an education.

I left the Principal's office, with my astounded support person, feeling nauseous and dizzy. I went home and smashed a few plates (we have a special collection for smashing purposes) and decided to tell them what I thought.

I wrote a 5,000 word paper (with appendices) responding to their charges against Edward, designed a new reporting system, behaviour assessment forms and communication strategies to be used in the support unit. The Head Teacher was amenable to adopting almost everything and made them part of Edward's Education plan but although generally applicable they have not been extended to other children in the unit.

Edward was not suspended and a new teacher began in year 10 (teacher number 23)

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[6] Purvis v New South Wales [2003] HCA62;217CLR92;202ALR133;78ALJR1(11 November 2003)

[7] It is interesting to note that in 1992 when the Special Education Support Unit was being established at Armidale High School the mainstream teachers went on strike in an attempt to prevent the unit being created.

Edward has had this quiet and creative man as his teacher for three years now. He has learned to love going to school and has made enormous educational gains, achieving skills which I had thought were beyond him. My sorrow is that Edward must leave at the end of the year when he could potentially achieve so much more.

Where we stand now.

At the time of writing (June 2009) Edward, Emily and I stand on the precipice of his life as an adult in the outside world. And it is terrifying.

I have written to all the Post School Service Providers I could locate asking what they can offer Edward in 2010 but have received not one reply.

One Service Provider has a purpose built Centre, to which the Armidale Community contributed a great deal, but has in the last few years moved away from disability service provision to that of aged care and they now extend through out the Hunter Valley and up the mid - north coast of NSW. The Community Participation programme is now a very small focus of a continually diversifying and expanding organisation and sadly the services provided, especially to young people who have left school in the post atlas years, reveal the change of emphasis. I am awaiting confirmation but it appears that this service provider charges around $40.00 an hour for 1:1 support in activities.

They employ mostly young casual workers, usually university students financing their studies.

Another service provider who last year received Federal Funding to provide a centre based programme in Armidale has verbally informed me that they do not have enough clients to make it worthwhile. They are restructuring and will let me know what they intend to do afterwards. When I asked what had happened to the funding for a centre based programme they explained they were not accountable to families on issues of funding and referred me to their website. Again I am awaiting confirmation but this service provider appears to charge around $25.00 per hour for 1:1 support in activities.

They employ a smaller number of permanent staff who are trained and have a history of work with people with disabilities.

Appendix 1 outlines the process for assessment and funding of post school options in 2009 in NSW. There have been many changes in recent years in particular the provision for families to design and manage their child's programme.

This has been heralded as a great step forward for accountability and 'client power' but for my money the jury is still out.

It could be argued that the whole scheme is a mechanism for getting already weary and aging parents to design and run their child's post school life

options because there isn't enough money in it to make it attractive to the organisations who should be doing the job anyway and small organisations cant get a foot in the door because of the funding requirements- but that would be cynical.

The content of programmes is theoretically devised through meetings with the family members and client but there is no assurance that anything in the plan will be actually done and there is no accountability back to the parents or client if it is not. (just the same as school Individual Education Plans)

Not many of you will come up with having coffee at the 'magic doughnut' each week with people paid to be there with you as an act of participation in your community -- and yet this is a significant plank of the 'community *participation*' programmes I have so far discovered.

If you have a moderate to severe disability and you do not get a large enough allocation to enable you to have the amount of 1:1 assistance the Service Provider feels you need then you must remain at home for the left over hours which can be as much as two to three days. In doing so these kids and their families become invisible and become *'those poor young people stuck at home with nothing to do…'*

Ironically, this is happening even at a time when the government is pouring money into locating the "Hidden Carers" in our communities to ensure that they are receiving enough services.[8]

The Howard Federal Government's petty economic rationalist insistence that a work provider must demonstrate financial sustainability prior to and in order to receive any Federal Government Assistance has resulted in the provision of employment services for only the most able and behaviourally compliant young people.

As well, it has resulted in many supported workplaces being closed and their workers placed into already overcrowded 'Community Participation' leaving even fewer paces for the young people leaving school. It is deeply troubling that the Community Participation programme is growing from both ends in this way.

Most of us gain our sense of belonging through the work that we do and our various voluntary commitments. If you are on a Community Participation scheme the funding agreement for your programme prevents you from working and limits other areas such as voluntary work. This forces CP participants to be seen as poor dependent disabled people ripe for a bit of special treatment guided by the tenets of the 'Pity Principal'. Give these people agency over their lives and the picture changes quite markedly. This is what we have to achieve.

It would not be surprising if in five years the families of these kids in Armidale got together and set up a parent run organisation to provide activities and social interaction for their kids. This is exactly how the first Service Provider I mentioned came into being about 25 years ago.

A socially useful and connected life

My vision for Edward in five or six years is to see a young man tall with a neat beard smiling and with his head held confidently as he walks along. He is happy and healthy and goes each day to a place where he contributes in a useful way to his community. His community knows and accepts him as a person. He is still learning and each day is presented with academic and creative tasks and

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[8] NSW Health Department Hidden Carers Projects. Grant Applications for projects to discover and assist Hidden Carers in the Community in NSW close at the end of June 2009.

activities which challenge but don't overwhelm him. He is happily living at home and transitioning into accommodation with his friends in a supported housing situation. This transition focuses on him and the needs created by his autism for routine, predicability and familiarity.

Many people have told me with disarming honesty that meeting Edward has changed their lives. He has opened their perspective to one that is broader and their life to a richer understanding of what difference really is and that there is nothing to fear.

But this has been an experiential learning acquired through time and interaction with Edward on an individual basis.

To broaden the scope of this experience we must consciously socially engineer situations where these interactions can occur.

To do this we must create socially useful, valued and visible life in the community for our young people with sever to moderate disability.

To do this requires several measures being taken simultaneously here are four to be going on with

- challenge and prevent the siloing of expertise and knowledge we need to mix the field of science and music and arts and agriculture and law etc taking the best from each and forming a new whole of operational knowledge;
- replace the economic sustainability clauses in disability funding agreements with clauses which require the demonstration of socially useful and valued connection building activities with the community .
- Debunk the mindset that says "but we've always done it this way it's the only way we know" eg: stop using revamped aged care questionnaires to determine the futures of 18year olds;
- Connect the parents and families of differently aged children/adults to combat isolation and share experience and knowledge

Conclusion

The "Pity Principle" lies, often 'dogo', deep inside the interactions between the parents of people with Autism and the teachers and other workers, paid or voluntary. who work with them. It is an easy and comfortable position in many ways and requires considerable courage to recognise and address in ourselves.

It penalises the good and dedicated people who do work with our kids because they like them as humans and can empathise with their situation.

It rewards those who feel sorry for them in their disabled state and wish to help these poor souls achieve a better life. This is rescuing and my son does not need to be rescued from his Autism.

It is a part of who he is. It does bring with it a variety of sensory issues which can make his life and the lives of those closest to him very difficult. Simultaneously, it gives him a phenomenal memory, a dry sense of humour, a truly Zen approach to life and a guileless way of being in the world that endears him to those he meets.

Edward needs to be accepted for the person he is with the challenges he faces and gain the sense of belonging and identity from his role in his community that we all take for granted.

Recognising and challenging the operation of the 'Pity Principle' in ourselves and others is the first step, and possibly the most difficult, to be taken in order to build connections today and inspire a brighter tomorrow for us all.

Kate Thomas June 2009.

APPENDIX 1: THE POST SCHOOL ASSESSMENT AND FUNDING PROCESS IN NSW 2009.

In NSW post school funding is firstly separated into two streams[9]
The choices:-
1. Transition to Work – this is reserved for the more intellectually able and behaviourally compliant young people. These kids are trained in and placed in supported work. NOT usually the general workforce

2. Community Participation [10]– In Community Participation you do not work . As well the present system makes it difficult not to remain in the 'done unto' category.

The process
A tick box questionnaire is completed in the last year of high school to assess the needs of all students who may be eligible for this funding to determine which of these two streams the child is to be placed into. Edward and I and his teacher and the visiting professional did this in May 2009.

The regional office of education allocated ½ an hour its completion. On the one hand this is a cursory time in which to determine a child's future options but on the other it is so distressing that the hour that it actually took was just about as much as I could manage.

It must be stated here that the questionnaire I answered about Edward bore a remarkable resemblance to the Aged Care Assessment Tool used to determine my father's needs a couple of years before. One question about dangerous behaviours asked whether Edward was in the habit of smoking in bed – an option not usually given to us as parents of kids with Autism.

Later in the year you are advised of the steam into which you have been plunged. If you find yourself floating down the Community Participation stream, which is likely for us, there are different pieces of leaves, twigs or lily pads onto which you can grab but be warned -- you are likely to still get wet and cold whichever you choose.

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[9] Department of Aging, Disability and Home Care Post School Programs Community Participation and Transition to work. 2008 2009 also avail able on the DADHC website www.dadhc.nsw.gov.au
[10] Department of Aging, Disability and Home Care NSW 'Community Participation Program Guidelines' October 2006.

More choices

As a parent you can now select the manner in which you want your child's (now a client) service to be provided. There are three alternatives

1. **Centre based programme with Community Access**: where the 'client' does various activities in the community but is based in a centre with a peer group;

2. **Individual Community Based Options** where the service provider acts as a coordinator and helps the 'client' to develop a programme of activities in the community with 1:1 support at times ; and

3. **Self Managed Packages;** where the 'client' and their family develop their own programme within the DADHC guidelines and a service provider manages the legal, financial and administrative arrangements.