A4 UPDATE
Autism Aspergers Advocacy Australia

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SPECIAL DISABILITY TRUST OFFERS OPPORUNITIES FOR AUSTRALIAN FAMILIES

The Federal Government is helping families self-fund the care and accommodation needs for their members who are affected by a severe disability, through the introduction of the Special Disability Trust introduced on 20 September 2006. Federal Member Margaret May and the Department of Families, Community Services and Indigenous Services has recently released the "Special Disability Trusts – Getting Things Sorted" booklet, which explains the benefits and requirements of the Trusts.

Gold Coast disability and estate planning solicitor, Katrina E. Brown of Attwood Marshall Lawyers, advocates the use of the Trusts as an excellent measure for assisting families to succession plan for the benefit of family members affected by disability. Ms. Brown, a single mother of two children on the Autism Spectrum Disorder, is implementing Trusts for both of her children.

"The obvious benefit of the Trusts", as explained by Ms. Brown, "is that the Trusts can fund those special care needs that are unique to the disability of the trust beneficiary."

Ms. Brown, her mother and extended family currently fund the children's home schooling fees, therapies and medical expenses which exceed $30,000 per year for Kyle, 11 and Collin, 5. By shifting resources through the Trust, Ms. Brown will be able to establish investments for Kyle's and Collin's benefit, which will earn income to assist in paying their disability

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specific costs, whilst achieving preferential tax treatment. When the children reach majority, their trust will not be counted as an asset if they need to apply for the disability pension.

One of the most important benefits of the Trust is the ability of aging parents of children with severe disabilities to plan for retirement and the aged pension. In order to qualify for the aged pension, the parent must comply with asset and income tests through Centrelink. Similarly, for the child to qualify for the disability pension, they too must satisfy asset and income tests. This Trust will allow aging parents to gift up to $500,000 per year to their child to establish a Trust to fund the child's disability related expenses – and that $500,000 will not be considered an "asset" for the child's own disability pension calculations. The Trust income will similarly not be included in the child's income calculations for Centrelink.

For many adults affected by disability, retaining the pension entitlement is their only way of accessing sheltered work environments, which allow the adults to interact with their peers in a supportive environment. Retaining the pension for these adults has little to do with money – but is vitally important for their continued ability to participate in their community.

Expenses, such as family vacations or costs associated with "normal" day to day living, such as rent on the family home, cannot be paid from the Trust. Only those expenses specifically related to the care and accommodation of disability related costs can be paid.

Any person can contribute to a Trust. Those contributing have the ability to direct that remaining capital contributions existing on the death of the beneficiary be refunded, paid to other persons or dealt with in their own Estates. However, during the lifetime of the beneficiary, the use of the capital and income is at the discretion of the Trustee (either an independent person, or two or more persons serving together).

The Trust must comply with specific investment regulations – all of which serve the purpose of protecting the beneficiary from abuse. Failure to comply will result in severe ramifications, such as the loss of disability and age pension. Specialist financial and legal advice must be acquired to determine whether the Trust is appropriate.

Convenor's message

Dear A4 member

I am very pleased to report A4 has an energetic steering committee vigorously discussing an array of issues and activity. Hopefully, some of the key discussions will reach fruition and be reported soon.

Another of our long-serving steering committee members has resigned from the committee. I thank Karen Mackie for her many valuable contributions to A4. I am sure A4's membership appreciates her efforts and wishes her well.

Please also welcome two new members who joined the Steering Committee.

I am writing this between preparing for a couple of coming appearances at Parliament House: to meet with a FaCSIA (Dept of Families, Community Services and Indigenous Affairs) advisor and to appear before the Senate Committee that is inquiring into the Commonwealth State and Territory Disability Agreement. They want to ask me about my submission and the A4 submission to their Inquiry. Thanks to the A4 members who also sent submissions. Hopefully, together we are making a strong impression.

On 11 September, Dr Lawrence spoke to Parliament …

> to draw attention to the needs of people with disabilities, particularly those with a developmental disability, and their families and carers. My observations suggest that these groups, people with a disability and their carers, are not benefiting as they should from our prosperity. There is a growing unmet need for services.
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> > http://parlinfoweb.aph.gov.au/piweb/Repository/Chamber/Hansardr/Linked/4959-3.PDF, pp 61-64).

Dr Lawrence announced that she and other politicians have formed “a cross-party friendship group, the Parliamentary Friends of People with Disabilities”. In the coming months A4 needs to consider contacting this parliamentary friendship group.

Back in March this year, A4 sent a submission (see http://a4.org.au/documents/AdvocacyReviewFinal.doc) to the review of the National Disability Advocacy Program (I apologise for not mentioning this in a previous Update).

The consultant’s review is available from the FaCSIA website (see http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/representation-ndap.htm). The report offers 27 recommendations about disability advocacy in general. The report talks a lot about “rights”. For example, Recommendation 3 says …

> **That as a principle advocacy should be provided to those people with disabilities who cannot advocate for themselves, in order that their human rights are upheld.**

Based on existing policy/practice, governments will restrict advocacy services (despite Recommendation 11) to the chronologically advantaged and people with an intellectual disability. People with ASD would be denied funded advocacy.

“Human rights” means the rights of all, such as freedom of speech for people who are non-verbal, the right to worship a deity of their choice (as long as they don’t put Jedi on their census form), etc. In Australia there is no provision of rights to receive essential services, support, an effective education, or treatment for their disability. We have a country with no explicit rights and governments with a history and policy of ignoring rights due to international law such as the UN Convention on the Rights of the Child or the rights of people with a disability. Authorities in Victoria can impose arbitrary “restrictive interventions” (which means some form of incarceration) on people with an intellectual disability under Victoria’s new Disability Services Act without even the basic protection processes available for alleged terrorists.

Recommendation 8 in the review says …

> **That the Australian Government in collaboration with States and Territories instigate a public awareness campaign targeted at people with disabilities, their family carers and their service providers, on all advocacy options available to them (whether funded through the NDAP or not) to uphold their rights.**

My observation is that families who are aware of advocacy services do not use those services because their observation or experience is that generic advocacy services cannot help people with ASD. They find the cost in terms of the family effort to access an advocacy service is not worth the benefit.

Advocacy services are not effective at helping individuals to access other services if the other service does not exist or is chronically overstretched. Discussing human rights and awareness does not address the issue.

Regards
Bob Buckley

9/10/2006

UK Parliamentary Committee reports on Special Education

Bob Buckley

Below are some paragraphs from the House of Commons Education and Skills Committee, **Special Educational Needs: Third Report of Session 2005–06, *Volume I,*** *Report together with formal minutes*, Ordered by The House of Commons to be printed 21 June 2006 (see http://www.publications.parliament.uk/pa/cm200506/cmselect/cmeduski/478/478i.pdf)

The report discusses education outcomes for students with special education needs (SEN) in the UK; and highlights some especially poor outcomes for students with autism. While systems in the UK are not identical to those in various Australian states and territories, there are similarities. Forces in both Australia and the UK have worked, and continue in their efforts, to eliminate special education and replace special schools with inclusive education.

The evidence presented strongly indicates that inclusive education, as practiced in the UK, has failed many children with autism spectrum disorders. This information is unpopular is some circles because it challenges a popular education paradigm that has spread through other aspects of disability ideology.

The report's Conclusions and Recommendations (pp104–118) say …

> **4.** The Warnock SEN framework is struggling to remain fit for purpose, and where significant cracks are developing in the system—most starkly demonstrated by the failure of the system to cope with the rising number of children with autism and social, emotional or behavioural difficulties (SEBD)—this is causing high levels of frustration to parents, children, teachers and local authorities. (Paragraph 17)
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> …
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> **9.** Special educational needs exist across the whole spectrum of social classes and abilities. It is important to recognise that some conditions which give rise to SEN, in particular along the autism spectrum and specifically Asperger's Syndrome, can defy an easy correlation between those conditions and social deprivation—as well as the children often being above-average intelligence. It is important therefore that social deprivation is not seen as the only and automatic benchmark for addressing SEN issues. (Paragraph 36)
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> **10.** There is, however, a strong correlation between social deprivation and SEN that deserves careful consideration by the Government. SEN policy should explicitly address these overlapping sets of needs where they occur. (Paragraph 37)
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> …
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> **12.** Children with Autism Spectrum Disorder (ASD), and social, emotional or behavioural difficulties (SEBD) provide an excellent example of where the old Warnock framework is out of date and where significant cracks exist in the system to the detriment of those who fall between them. Far more important, however, is the frustration and upset caused to parents and families by the failure of the system to meet the needs of these children. This needs most urgent resolution. (Paragraph 43)
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> …
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> **The cost of failing children with SEN**
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> **14**. The continuing correlation between children with SEN and exclusions, low attainment, not being in education, employment or training (NEET), and even youth crime, means that there are significant

long term economic and social costs involved in failing children with SEN. The personal cost to families of children with SEN should also be considered. (Paragraph 49)

15. There are considerable costs involved in failing to meet the needs of large numbers of children with SEN. Moreover, the Government has a responsibility to provide high quality education for all children to enable them to reach their potential. (Paragraph 54)

…

24. It is widely recognised that there is a strong correlation between exclusions and children with SEN—particularly those with social, emotional and behavioural difficulties and autistic behaviour. The Committee finds it unacceptable that such a well known problem continues to occur. The Government should enhance existing, and improve alternative, forms of provision, training and resources rather than using an increasingly punitive approach for these children and families involved. (Paragraph 95)

25. Schools need better guidance and staff training in dealing with disruptive behaviour by children with Autistic Spectrum Disorder, particularly Asperger's Syndrome, and social, emotional, and behavioural difficulties. Schools should give careful consideration to these children in their behaviour strategies and make appropriate adjustments in disciplinary responses especially when considering exclusion. This needs to be backed up by closer DfES guidance and local authority monitoring, details of which could be collated by either Ofsted or the Schools Commissioner, with a view to urgent and substantial reduction in the numbers of exclusions. (Paragraph 96)

…

68. We support the recommendation made by the National Autistic Society that "local authorities should ensure that every child with autism has local access to this diverse range of mainstream and specialist educational provision, and report publicly on the range of provision that is provided" and would extend the requirement to all children with SEN and disabilities. (Paragraph 262)

69. We believe early diagnosis of children with autism and particularly Asperger's Syndrome is likely to be a preferential route, as witnesses have suggested, rather than statementing. We urge that local authorities be given a statutory responsibility to consult and work with autism groups, both locally and nationally to forward this objective. (Paragraph 263)

The "Warnock framework" referred to above means Inclusion in education.

The report shows education for students ASD is an unmet challenge, a challenge that defies existing approaches. Governments and their education bureaucracies have failed children with ASD. They will continue to fail students with ASD while they persist with regarding ASD as part of some other disability group or as a socio-economic problem.

This report shows that the growing numbers of students with ASD have distinct needs that governments and their education services have yet to meet.

The Second report describes the evidence given to the committee. It mentions "autism" or "autistic" 361 time, and "Asperger" 44 times. The evidence is rather damning of education for students with ASD in the UK. For example it says …

> 2.6 In a recent Office for National Statistics reports[5], 27% of children with autism in the sample had been excluded and the vast majority of these on more than one occasion. Exclusions also start young:
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> > *"My son was permanently excluded from nursery and from two schools by time he was seven years old. He has now been out of school for 15 months."*
> >
> > Parent of an autistic pupil, ringing helpline organisation

The UK Special Education Needs report presents a challenge for governments in Australia to show they do better in educating student with autism. It should demand that state education systems show they clearly recognise and address the distinct needs of students with ASD.

Simply, when it comes to ASD, Australian bureaucrats do not know what they are talking about. They have not measured outcomes or even considered the available evidence. They prefer to operate on the basis of unsupported and false assumptions. The direct result of their ignorance and prejudice is that they fail their governments, their communities and their professional standards. These are key features of bad government.

We must reject suggestions that the systemic failures are unintended or unexpected consequences of inclusion policies, as was suggested in relation to deinstitutionalization of mental illness. These are the policies of the moral vacuum called economic rationalism: they are treasury-led swindles promulgated in the full knowledge that funding for essential monitoring of outcomes is not available and there is no safety net or "provider of last resort" in place.

The next challenge for the ASD community is to avoid a knee-jerk reaction, either from the community or from government that push away from integration and inclusion. In my view, we should not reject inclusion. Instead, we should insist inclusion is a goal for people with ASD rather than a method for teaching and service operation. For many students with ASD inclusion is not an effective teaching method but it remains an essential goal.

We need to insist that the resources required to ensure a student with ASD develops skills needed to learn in a mainstream classroom are an essential part of the individual's education program. Without all the resources needed across all elements of the student's placement, the student is denied an effective education.

Many students with ASD can benefit significantly from integration with specialist support as part of their education. I have personally observed students learn, and subsequently maintain, social and learning skills in such settings. But progress to effective inclusion only succeeds once the student has all the skills needed to benefit from the educational opportunities available through inclusion. Educators have to appreciate that so-called inclusive setting and/or practices cannot ensure a student with ASD catches up with classmates, no matter how much unbridled optimism and self-delusion they unleash.

The promise of better outcomes for students with ASD will only be realised when governments actually fund and monitor the services they claim to provide to ensure their expected outcomes are achieved.

The federal government should start by reporting the inclusion rates for students with various types of special needs in the national benchmark testing. We need to know whether education is actually inclusive and equitable.

I urge parents to insist schools include students with ASD in national benchmark testing. All exclusions must be formally reported to both the state and federal bureaucracies … who should report annually. We need to know whether 27% of students with special needs are excluded from Australian schools. We need to know whether education systems in Australia are any better than those in the UK.

Autism numbers in SA

Bob Buckley

Increased referrals in SA recently made the news (see http://www.news.com.au/adelaidenow/story/0,22606,20514382-2682,00.html). According to Autism SA's Annual Report (see http://www.autismsa.org.au/pdf/AR%2006.pdf) most of those diagnosed under 6 years of age have "autism" while over 2/3 of those diagnosed at school age have Asperger's syndrome/disorder.

The diagnosis rate for the under 6 years age range is similar or a little higher compared to elsewhere in Australia.

Comparing diagnosis rates for Asperger's in SA with WA gives a very different picture. According to the WA Register, very few people are diagnosed with Asperger's in WA. In SA, diagnosis is close to 50/50 between autism and Asperger's. This suggests chronic under-diagnosis of Asperger's syndrome/disorder in WA, and a high level of awareness in SA. The feeling is that diagnoses are given in SA to help people access the services they need.

Autism SA's latest Annual Report says …

> A notable increase in referral sources this year were those coming from the correctional services system – both for adults currently in a correctional setting and those awaiting trial. The diagnostic service is investigating the expertise and resources needed to best meet the needs of this population

This development suggests that failure to diagnose and provide appropriate support and possibly early intervention for people with Asperger's syndrome is expensive for the community, both financially and socially.

There is no mention of PDD-NOS in SA (generally, DSM-IV terminology is used in SA). This may be due to SA Government discrimination[1]: the SA Government does not fund diagnosis of PDD-NOS or services for people with a PDD-NOS diagnosis.

NSW — state of persecution

Bob Buckley

I wrote previously about DADHC in NSW and how in regional NSW its officers decided a mother, who has been diagnosed with autism, is somehow making her sons autistic. Soon after the mother's GP retired, DADHC got together with her new GP and called a meeting of various agencies. The meeting shared private information about the mother and her sons without her permission. Initially, the NSW government agencies denied there were any minutes of this meeting. Later, it turned out there are minutes (but there are differing reports as to the accuracy of various versions of the minutes).

An apparent purpose of the meeting was developing a plan to require new assessments of her two boys with autism from selected local service providers. DADHC staff in the region wanted to control the content of the sons' assessments. The apparent goal is to get the mother diagnosed with Munchausen's syndrome by proxy, and her sons to be seen as her victims.

The mother is deeply suspicious. She has reports from staff in a number of service providers that she says simply ignore or misinterpret her sons' symptoms and behaviour. The psychiatrist who visits the area has said he does not believe in autism. DADHC rejects recent reports from a paediatrician (who the mother feels has the best understanding of autism in the region), from a private speech pathologist (who sees the boys regularly) and from specialists in Sydney.

DADHC involved Education Department staff, DOCS staff and Mental Health staff in their meeting. The mother fears, with reasonable justification, that DADHC staff have acted to discredit her and prejudice local agencies and service providers against her.

Since March, I have been trying to help this mother get assistance and support. Her first priority is to move away from the region and its DADHC staff.

Clearly, she cannot get any support or assistance from DADHC in her region. Since their appalling actions are the source of this persecution, the mother feels (reasonably in my view) she cannot have anything to do with them.

She is extremely reluctant to talk to any service providers in her region, especially the agencies whose staff participated in DADHC's meeting described above.

And she feels that whenever she talks to anyone who is not sympathetic to her autism, she just gets in trouble. She no longer has faith in her ability to communicate. She asked me to

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[1] This discrimination is probably lawful under the Cth *Disability Discrimination Act* 1992.

help her. I cannot afford to do much advocacy in individual cases, but this case seemed so extreme and as no other assistance is available I felt I had to do what I could.

I contacted DADHC head office hoping I could get a case manager to help her relocate. They told me they only provide case managers for people with intellectual disability. Since she does not have an intellectual disability they would not help.

This DADHC policy and practice of denying case management for people with ASD who do not have an intellectual disability clearly discriminates against people with ASD. In this case, it leaves a severely disabled mother and her sons without essential support.

Discussions with staff in the NSW Ombudsman, NSW Disability Discrimination Legal Service and HREOC confirm my believe that Section 45 of the Cth *Disability Discrimination Act 1992* supports this DADHC policy and practice as lawful discrimination.

I contacted Aspect Inc., who did not call me back.

I contacted the local state MP, who called me back and told me everything was organised. We heard nothing further from him or his office.

I asked a local (federally funded) advocacy service whether they would support this mother. From what I hear, their contribution has been minimal … though I don't have their side of the story because they are never available to talk to me and they won't call me back. One of the first tasks the mother needed help with was to complete an application form for housing in another area. After six months when the form had not been completed, surely a simple task that an advocate could easily assist with, the advocate said the mother should get DADHC to complete the form. The advocate's suggestion was insensitive and extremely distressing for the mother. People with a disability do not need advocates who cannot complete relatively simple tasks and who inflame situations such as this.

This mother is in deep distress. She gets no support for her autism. The drugs she was given were not effective. Her son with the highest support needs was out of school for an extended period. In her situation, she has no access to respite.

Mental Health Services in NSW are regional in nature. This matter involves some very serious mental health issues. In my experience, NSW Mental Health Services processes are too rigid to be as effective as they should be, especially for people with an autism spectrum disorder. In this case, their staff do not recognize the mother's concerns about their collaboration with DADHC's nefarious activity in the region. And they do not have services suitable for a person with autism who is experiencing mental health issues. Nor do they see support for a person with autism and escalating mental health problems as something that they should act on.

Someone suggested NSW DOCS might help. I contacted DOCS. DOCS insist on contact through its call centre … another process that is profoundly inflexible and utterly unhelpful. The DOCS call centre staff were especially rude and clearly had no interest beyond the possibility of separating children from their parents. They could not give me any credible reassurance that their staff knew anything about children or families with members diagnosed with autism. In the circumstances, I advised the mother against involving DOCS. She agreed.

The mother is extremely wary of Education staff since they appear to be involved with DADHC in the conspiracy to reassess her sons. She has raised numerous serious issues about her sons' education and treatment at school that have not been addressed … but she is unwilling to meet education representatives because she has lost faith in both their intentions and her ability to communicate, and she does not have a case manager or an effective advocate locally to support her. She feels people don't listen to her (based on my observations, I agree with her).

People in regional education in NSW seem to have a pretty poor understanding of the special needs of children with autism. They have even less understanding of a parent with autism who has a different approach to social conduct and communication. Their approach to administering special education is not inclusive of parents with autism.

NSW public Housing … is the one shining light

The person in NSW public Housing who has been involved is the one shining light in this matter. She has acted quickly and decisively when given the information she needed. It is a relief to me that there is at least one good person in the NSW public service willing to help a family in crisis.

Overall, this saga shows NSW DADHC and the NSW Government learned nothing from its past disasters relating to autism. Services and support for people with autism in NSW are in an extremely poor condition. The federal government should be deeply embarrassed that its CSTDA funding support this debacle in NSW.

Hopefully, the timely federal Inquiry into the Commonwealth State and Territory Disability Agreement will result in some improvement to services and support for people with an autism spectrum disorder.

Grievance Debate

Disability Services

Dr LAWRENCE (Fremantle) (4.20 p.m.)—Today I want to draw attention to the needs of people with disabilities, particularly those with a developmental disability, and their families and carers. My observations suggest that these groups, people with a disability and their carers, are not benefiting as they should from our prosperity. There is a growing unmet need for services. It is now possible to reduce this unmet need, but left much longer it will become insurmountable and then will become an excuse for inaction.

Such unmet need undermines the dignity and quality of life for a great many Australians. They are an often forgotten group, and many endure enormous strain silently and without complaint. To draw attention to this unmet need and to tell the stories of people with disabilities, I suggested to my parliamentary colleagues that we form a cross-party friendship group, the Parliamentary Friends of People with Disabilities, and it has been formed, I am pleased to say. It is particularly important because between now and mid-2007 the new CSTDA—that is, the Commonwealth State/Territory Disability Agreement—will be negotiated. Unfortunately, previous agreements have been the cause of acrimonious division, buck passing and blame shifting. I believe that collectively we owe people with a disability a far better result than this.

The parliamentary friendship group has over 50 members and senators signed up. The co-convenors are Senator Rachel Siewert, Mr Kym Richardson, the member for Kingston, and me. We are very pleased that, without being invited, the Prime Minister and the Leader of the Opposition requested that they be co-patrons. We will make sure that as co-patrons they hear the stories of people with disabilities and their families.

The group endorsed the broad aim of raising awareness and support for people with disabilities, their families and carers, but we need to do more than that. To put us in the picture, a few statistics are in order. The ABS estimates there are about 687,700 Australians below 65 with a profound or severe core limitation on some of their functioning—mobility, intellectual functioning and sensory functioning. About one in 10 Australians provide care and support for a person with a disability. ABS surveys have shown that nearly 40 per cent of primary carers spend at least 40 hours a week meeting their caring responsibilities—more than the average working week. It is important to note that a significant proportion of these people are over 65, a time when most of us can imagine retiring.

The Developmental Disability Council in Western Australia, an admirable and very active group, surveyed people in Western Australia who are caring for people with a disability and found that more than half the respondents care for a person needing constant care—24 hours, seven days a week. I believe it is important in this parliament that we restate the principle that we all have a responsibility to ensure people who have a disability are provided with the help they need, when they need it. It is not just up to their families.

The members of the parliamentary friendship group and I share the vision of advocates in the sector that we need to develop and implement policies which eliminate the need for people to beg to have their basic needs met. They should not have to do that. In my view, how we respond to people who cannot by themselves fully meet their own needs and how well we embrace the core values of equal value, human worth and dignity of all people is a measure of our decency as a society. Conversely, when we fail to meet their needs, we are clearly demonstrating our lack of decency.

We all understand that families will always do their utmost out of love and a sense of responsibility for people with a disability, but they simply cannot and should not be asked to provide all the care. In any case, it is not possible. They cannot provide, for instance, for the specialist services in health, education and transport or for the social needs of all their family members. People with a disability should be able to enjoy the company of others as well. They should be able to integrate into the community and to take part in meaningful employment. These are not things that families and carers can provide. Nor can they provide the facilities that allow access to employment and those normal social experiences that I have talked about.

Importantly, they also need decent respite—not just an hour or two here and there. They need time to lead their own lives, to develop their own relationships and to parent their other children. In my view, the system at the moment is out of balance. It is weighted too heavily on individual and family responsibility and not enough on the rest of us—the community and governments. We are not providing our share. The cost of this imbalance is taking its toll. Anyone who spends time with people with a disability and their families will know that there is a great deal of pressure placed on the individuals with the disability as well as their family.

There is a cost to those with a disability who are denied the possibility of reaching their full potential and taking part in community life. These are very important objectives for every human being. It is taking its toll too on the families and carers who are struggling to meet the needs of their loved ones. They feel their inadequacy—or at least that is the way they often describe it to themselves, when in reality they are being asked to do the impossible.

I listened a couple of weeks ago as a woman in her 40s, perhaps—one of my constituents—with an early adult son who needed a great deal of care, described in some detail what her daily life was like. I would not want to live that life. She was stressed and overwhelmed and she was asking for care. She should not, however, have to beg for that care. What she demonstrated to me is that sometimes the needs of a single family member, with all the love in the world, can actually dominate all aspects of normal family life. She did not have a life of her own to speak of.

I commend to the House the report of the Developmental Disability Council of Western Australia, which we have circulated to a few members, called *When needs go begging*. It not only gives an outline of the lives of people with a disability in Western Australia—it could be anywhere—but also of their families. There is a story in here which is typical, and I have a little time to read it into the *Hansard*. It is about Michael Tilbrook. In some ways Michael is typical of a person with a disability who is being cared for by his family with some support from government services. Michael is 14 years old. He has a condition which results in the progressive deterioration of his physical abilities. His parents say that the biggest pressure for them is the loss of their freedom and lifestyle. They say that their social life is next to zero and a simple weekend away can take months to arrange. Most of the rest of us take something like that for granted.

Also, Michael does not go out as much as he could if they had help, and holidays are especially long and lonely for him. The lack of services means that Michael suffers as well. Since Michael was diagnosed at the age of four, his life has been gradually more affected as his condition has developed—from a young boy who could walk, talk and play to a young teenager who can hardly talk, cannot move without his wheelchair and has lost most of his self-reliance for the most basic needs. Of course, some children are born with disabilities of that kind. The parents say that it has been heartbreaking to watch his gradual decline, and it is not finished yet. They say, 'God only knows how much more he may lose and the future is a big question mark.' They go on to talk about their lives.

There are many such stories in here, including of elderly people trying to provide care for their now middle-aged children with intellectual disabilities and sometimes with multiple disabilities, which means 24 hours, seven days a week care is what is required. They are people who are suffering at the moment from the failure of governments at both state and federal levels to provide adequate respite and accommodation to allow them to plan for the future.

I know the members of the parliamentary friendship group join me in urging the state, territory and Commonwealth governments to properly negotiate the new CSTDA. It is an important agreement because it talks about the responsibilities that various levels of government should undertake. The first agreement was signed in 1991. It was intended to provide a national framework so there was not duplication and so there was streamlining of the administration of specialist disability services. It made some very important steps forward. Unfortunately, as I said, the last one seems to have been beset by vitriol and a lot of debate about who was responsible for what rather than accepting that collectively we all have to ensure a better outcome. So we need another CSTDA but this time those shortcomings that have been identified must be overcome. There must be a genuine commitment from the Commonwealth, state and territory governments to people with disabilities and their families to not fight with one another. There must be an approach to disability that is about people not politics and a commitment from the various governments to work in partnership with one another rather than sparring all the time. In particular, there must be a commitment to resolving unmet needs for support services and a proper plan to accomplish this so that people with disabilities and their families can lead dignified and full lives.

Event Notices in A4 Updates

A4 may publish short event notices, up to one page, that may be of interest to people with ASD, their associates and relevant professionals in our A4 Updates. Please send your information in MS Word (or RTF) format and send your electronic copy directly to the A4 editors (edit@a4.org.au).

It is important that we can cut and paste the material into the Update ... which is prepared in MS Word.

If you need to provide more information, then put a link to information or a flyer on your own web page and ask people to download it.

Publication is subject to editorial discretion. A4's publication process takes some time so please ensure you send your notices in early.

Review of the book Nobody Nowhere

Williams, D. (1992). *Nobody nowhere: The remarkable autobiography of an autistic girl.* *London: Transworld*

Donna Williams was born Australia in 1963, she currently resides in Melbourne. Nobody Nowhere is the first in a series of three books that make up Donna Williams' Autobiography to date, *Somebody Somewhere, Like Colour to the Blind* and *Everyday Heaven*, conclude the series. Donna has also published other books relating to the understanding of Autism, including, *Autism and Sensing: The Unlost Instinct* and *Autism: An Inside-Out Approach*. Donna is a Painter, Sculptor and Composer and has also released two CD's containing her own compositions.

Nobody Nowhere is Donna Williams' own account of growing up in a dysfunctional family in 1960's and 70's Australia. Donna gives us an account of her world, the world of Autism and her struggle coming to terms with the world we live in. Donna likens this to a battle, which began the moment she was born. She recounts her first memories of pursuing the dream like state of her world only to be interrupted by the harsh world around her.

As the narrative unfolds Donna recounts life events such as beginning dancing lessons and school, juxtaposed with the rage in her family and the raging battle inside herself. Donna describes her mother as hard and her father as indifferent. Throughout the book it is revealed that she suffered neglect and systematic abuse at the hands of her mother.

Donna describes the evolution of two characters in her early childhood that were directed at the outside world, Willie and Carol. Willie was oppositional and defiant, and Carol out-going and sociable. Via these characters Donna attempted to stay in touch with the world. These characters were the key to communication.

Carol, Willie and Donna moved through turbulent Primary School years and friendships with varying degrees of success. Donna and her characters continued through to her teenage years which were punctuated by puberty, leaving school, starting work, forming friendships and relationships, again juxtaposed with family breakdown, abuse, total immersion in her own world, self-injurious behavior, and a series of failed or abusive relationships with the opposite sex.

Donna began counseling in her late teens and began to unravel her tumultuous childhood. Aspiring to be like her counselor Donna completed her secondary education and enrolled in university. For Donna, University became a place of discovery and revelation and forming new, healthier relationships. After completing University Donna began working life as a social worker. However, the mystery of why she was like she was still played heavily on her mind and affected her life. Donna decided to travel overseas and it was in London that she sat down and wrote this account of her life. In an attempt to demystify her life experiences she took the manuscript to a child psychiatrist. After reading the manuscript the psychiatrist concluded that Donna's experiences were typical of those of a person with Autism.

In his introduction to the book Dr Lawrence Bartak says this of Donna's story:

Nobody Nowhere does us all a great service. It reminds us all what it means to be human. It is a moving and fascinating story of a life still beginning. It brings a wealth of insights about being disabled and about being courageous. It has an abundance of help for professionals working with children and young adults and will illuminate many of their puzzling experiences of working with autistic children.(p xv)

Nobody Nowhere does indeed remind us of humanity. Humanity, common to all of us, whether we live with or without disabilities. We can identify with Donna's struggle in coming to terms with herself and the world. It is this commonality and essential humanity that should guide us when working with people with disabilities and not our perceivable differences. Through realising common humanity we can recognise that the same things are important to the quality of life of all individuals.

Donna highlights the human need to categorise in the Afterword to the book:

All people like to put things into categories like with my buttons, ribbons and bits of coloured glass. As for people, I had only ever truly felt there were two categories: ‘us’ and ‘them’. Most people see things in these terms, but with different and more value-laden definitions.(p179)

Judging people in value-laden terms leads to the devaluing of people with disabilities. Donna was labeled many things including weird, insane, stupid and crazy. These are all devaluing judgments that detract from and obscure Donna as a person. Giving People with disabilities devaluing labels often denies them opportunities; this was evident in Donna’s early experiences with education.

After one week at primary school I was taken out of my class and, with four other children, placed in a special class called the ‘Country Infant Room’.(p 22)

The title ‘Country Infant Room’ implies that Donna and her classmates had the abilities of infants. As Donna points out this tendency to categorise is common to almost everyone. This is something that needs to be addressed when working with people with disabilities. It is obvious throughout the book that Donna has strengths and abilities however it was common for people to focus on her disability rather than these abilities. In order for us to work successfully with people with disabilities we need to value their strengths and abilities and enhance these instead of isolating and escalating devaluing characteristics.

Donna’s problems with communication prevail throughout the book. It is evident that she struggled to communicate her needs to those around her and also struggled to decipher the communication of others. Communication for Donna is effortful and she speaks of the need for this to be recognised:

When I spoke, it was important that I knew I was being listened to and that the listener understood the seriousness of what I was trying to say or get around to saying, and the amount of courage it took.(p195)

Donna highlights the importance of listening to people with disabilities and the need to recognise the significance of what they communicate.

A lot of the insight Donna has achieved has come from direct experience with the world around her and unrestricted access to the knowledge that comes with being able to make mistakes.

… many of the things I did were dangerous…only the unthreatening nature of privacy and space would inspire the courage to explore the world and get out of my world under glass step by step.(p195)

Privacy, space and dignity of risk taking were as vital to Donna’s development as they are to the development of every human being. The significance of giving people with disabilities the opportunity to develop through their own risk taking is one of the most valuable insights that Donna gives us.

In discovering that she had Autism Donna was able put into perspective the behaviours and inner turmoil that led her and others to believe she was mad. Donna’s powerful ability to reflect and analyse her own situation has provided an insight into living with Autism.

Professor Anthony Clare writes in the foreword to Nobody Nowhere:

Individuals with autism are believed to have an abnormality of brain development which means they cannot process information appropriately. Facial expressions, emotional reactions, conversational tones which most people interpret with scarcely a second thought, are puzzling, mysterious, coded communications to be painstakingly unravelled by the autistic.(p ix)

Donna is able articulate what lies behind the behaviour that results from a person with Autism attempting to relate to the world. In doing so Donna provides an outline of language in her world, which reveals the behaviours as mechanisms for sorting out and regulating the input from the outside world. Donna also gives a series of hints on the best way to approach people with Autism.

The strength, perseverance and tenacity shown in Donna's account of her early life serve as an inspirational tool in inviting us to consider these qualities in other people with disabilities. Although Donna seems extraordinary in what she has achieved her over all achievement is made up of small steps, small battles that were fought and won. People with disabilities are fighting and winning small and not so small battles every day. The qualities that enable them to do so should be celebrated.

Donna wrote the following song which encapsulates her experiences growing up with Autism. It is the title track for her CD *Nobody Nowhere*.

In a room without windows, in the company of shadows,
You know they won't forget you, they'll take you in.
Emotionally shattered, don't ask if it mattered,
Don't let it upset you, just start again.

In a world under glass, you can watch the world pass,
And nobody can touch you, you think you are safe.
But the wind can blow cold, in the depths of your soul,
Where you think nothing can hurt you till it is too late

.

Run till you drop, do you know how to stop?
All the people walk right past you, you wave goodbye.
They all merely smiled, for you looked like a child
Never thought that they'd upset you, they saw you cry

.

So take advice, don't question the experts.
Don't think twice, you just might listen,
Run and hide, to the corners of your mind, alone,
Like a nobody nowhere.

Amalgam

The following article was submitted by someone on the autism spectrum who researches health and autism and has agreed to share his findings and musings on the hazards of amalgam. Amalgam has been indicated as a possible problem for many people.

The basic issue with drilling amalgams is the volume of the drill hole in the amalgam gets turned into an aerosol of very fine amalgam particles exposing a huge surface area to promote mercury vapour and silver leaching and its very hard to keep some of this from being breathed in or swallowed. I have seen research which shows that dentists ingest a surprisingly large amount of this, even with suction. The short term mercury dump from this is horrific and ingested amalgam seems to deliver large amounts of mercury and possibly silver.

Any amalgam particles breathed in, end up in the gut as far as I can see as the mucus developed from the lungs to clean them is swallowed. The newly placed amalgam emits huge amounts of mercury vapour in the first weeks.

Even mercury free dentists get mercury exposure from drilling amalgam out.

End Note:

Many people over the age of 20 (and some under that age) have some amalgam in their mouths; your decision is to have it removed and risk the possible consequences or to leave it in. Some people are more sensitive to it than others and this is a personal decision for all.

Letters /Emails

Please send letters to edit@a4.org.au. Letters sent to the editor may be published unless they are clearly marked “not for publication”. Normally, they will appear with your full name and state unless you mark them clearly “anonymous” or “first name only”.

Dear Editors

I'm outraged about something.

The thing I'm outraged about is the ABC TV program "The IT Crowd". It makes it doubly outrageous that it is the ABC.

The thing that program clearly ridicules and parodies is the set of characteristics that come with having Asperger’s Syndrome. Highlighted are social, verbal and physical clumsiness and also difficulties with social and sexual relationships and things like immunity to fashion.

It wouldn't be unfair to portray those things however I feel it is cruel and nasty and against all the values the ABC claims underpins it to not balance portrayal of the negative with portrayal of the positive. The honesty, the integrity the intelligence, immense ability to focus, logic and mathematical skills, the ability to understand and build and fix complex things. We don't look for every chance to take a long lunch or piss off down to the pub early. We finish the job, and we care whether it’s been done right. The IT Crowd is the sort of one-dimensional one-sided stereotype from the nastiest sort of people, those who think they are superior to everyone else, and think they can vilify and ridicule and belittle everyone else because of that.

It isn’t about not appreciating humor. Things aren't funny if they're not fair. It’s OK to laugh at people's oddities if you show the other side. The IT Crowd doesn't.

Here I am, an adult with Asperger's Syndrome, someone who has worked in the IT industry precisely because that's where people like us "fit", where our strengths are valuable and our weaknesses don't matter, but now find myself out of a job. And I have to try to get one with an organisation like the ABC portraying people like me the way it is. As stupid and incompetent, and having no positives whatsoever.

I've complained to the ABC – I received no response. I think the Autism Spectrum Disorder community should be doing something useful for adult AS sufferers for a change and express its ire to at the ABC.

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Dear Editors

I would like to start by thanking A4 for an informative and very helpful newsletter. Not only does the organization seek support for people with autism it also serves as an outlet for parents' frustrations.

I particularly related to Mrs Semmens letter *Story about my son Jordan, aged 9* (September 2006). I have worked, as an education assistant, with AS students for the past 12 years and have experienced the frustration and battles that parents have to endure just to get some support or help with their AS children. Mrs Semmen's plea: *Does anyone care?* is a common one among parents and yes, there are people out there who care.

In 1995 I was employed by a Perth high school to work with 2 students with AS. They were among the first to be integrated into a main steam high school and as I had just completed a Young Autism Program at a local university, it was thought that I would be qualified to handle the transition. As it was unfamiliar territory for the whole school, I was given the freedom to work with the students using the knowledge gained from the program.

Working one-on-one with the students, every session, every day gave me the opportunity to observe and understand these wonderful, bright people. Although it was a struggle and very hard work with many days of utter frustration for both me and the students, I finally realized that the secret to success was in the understanding of the autistic mind. Imagine how difficult it must be for them, forced into a "normal" thinking world, with limited social skills and a different level of understanding, following instructions as they perceived it only to be told off for doing the wrong thing. Wouldn't you be frustrated? Wouldn't you lose your temper?

I built up a relationship of trust with these students and interpreted all written text for them. I also acted as a go-between whenever they were in trouble because I learned that they had difficulty recalling an incident and as it always ended with the AS students reacting violently, they were the ones being disciplined. It took a while but through that relationship of trust they opened up and enlightened me. They were being teased and because they lacked the social skills to deal with the situation, they became frustrated and reacted the only way they knew how, with violence. When questioned by the principal they would answer questions truthfully with yes/no answers which led to the discipline. As soon as we tried a different approach and actually went back to the beginning and found out step by step what actually happened, then we learned the truth. We also realized that not only were they being picked on, they were also being disciplined for standing up for themselves.

At the end of the first year of high school these students had taken a giant leap forward, academically and behaviour -wise. The parents' joy was short lived when they were told that my EA time would have to be assessed for the following year. With the support of the high school, the parents fought to retain the EA assistance for their children. Thanks to the efforts of those parents, other parents and schools AS high school students have access to EA assistance at high schools in Perth.

By the time these two students successfully graduated year 12, other main stream high schools were enrolling AS students and our school received many calls for information or assistance. The school suggested I write an information booklet or manual to assist other schools with dealing with AS high school students. I was unsuccessful in having this published and promoted by the large companies and resorted to self publishing with little help in promoting it through the media.

So yes Mrs Semmens, there are people who care. I fully understand your frustration and I sympathize with you because I have seen it in parents over the last ten years. But rest assured that with the efforts of organizations such as A4 and with the tremendous support and help of people like Mr Don Randall and others, autism will get a higher profile and maybe it won't be such a struggle for parents anymore.

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A4 is a grassroots organisation. All A4 activity, such as publishing the Updates (newsletters), is done by volunteers. Please understand that A4 volunteers may have no training or qualifications for their various roles. They do the best they can for people with ASD, their families and associates. A4 welcomes assistance and constructive criticism.

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