



The Secretary
Senate Community Affairs Committee
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Parliament House
Canberra ACT 2600

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Dear sir/madam,

Inquiry into Special Disability Trusts

Thank your for inviting (21/5/2008) Autism Aspergers Advocacy Australia (A4) “to provide a written submission addressing any or all of the issues” relating to the Inquiry into Special Disability Trusts.

This invitation took us by surprise because we feel the answers are obvious in relation to people with an autism spectrum disorder and their families. However, we appreciate the opportunity to explain again the situation facing families of people with an autism spectrum disorder.

The Australian Institute of Health and Welfare (AIHW) reports that people with autism report a very high rate of severe and profound disability; higher even than people with Alzheimer’s, intellectual disability, etc. Many people with autism spectrum disorder need 24 hour close supervision.

While the needs of many people with autism can be reduced through effective early intervention, few families can afford it. The Government’s Best Practice Guidelines¹ say for a child with autism “a [early intervention] program needs to be of at least 20 hours per week over an extended period of at least two years”. This equates to 1000 hours of evidence-based intensive autism-specific early intervention per year. The associated report shows that this service is available only from a small number of privately funded service providers. Effective early intervention for a child with autism is difficult to access in Australia and costs in excess of \$40,000 (post tax) per year. This burden falls on the families so few families can afford it; or if they can, they are left with a substantial debt, from which few will recover financially.

Some families are lucky: they are able to access and pay for early intervention that is effective for their child; following early intervention, their child can benefit from the available education and subsequently live independently. They are unlikely to need, and may not qualify for, a Special Disability Trust.

¹ See

[http://www.health.gov.au/internet/wcms/publishing.nsf/content/D9F44B55D7698467CA257280007A98BD/\\$File/autbro.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/content/D9F44B55D7698467CA257280007A98BD/$File/autbro.pdf)

In other cases, especially those who receive little or no early intervention or a later diagnosis, a child with autism reaches school often with severe or profound disability and life-long support needs that are both substantial and will be met mostly by the family in the form of direct care.

Many children with autism are excluded from school for part of the school week² which means that at least one parent is unable to work in an era where most families need two incomes. The burden on the other parent (in the few cases where families remain intact after their child is diagnosed with autism) is usually career limiting.

Most families find there are no suitable post-school options for people with autism. So one parent has to leave work to become a fulltime carer when their child with autism leaves school.

A4 is disappointed that Government is asking in this Inquiry why few families can create a Special Disability Trust for their disabled children when they have explained repeatedly the extremely difficult circumstance in which most families live. We are concerned that the Government does not hear our message; and the voice of numerous other groups, especially carer organisation who frequently raise carers' concerns.

Please, please, please believe A4, other organisations and the individual members of the community when they tell Government that their needs are not being met, that we need significantly more help and support from Governments, and that outcomes for people with a disability and their families are far from equitable.

In relation to the Inquiry Terms of Reference ...

- (a) why more families of dependents with disabilities are not making use of the current provisions to establish Special Disability Trusts;

Few families of people with autism have the financial capacity to contribute to a Special Disability Trust.

Nor are we yet aware of any government proposals that will significantly improve this situation for families of children with autism spectrum disorders. For example, while very welcome the Government's *Helping Children with Autism* initiative may contribute towards early intervention to a maximum of \$8,000 per year³, this just 20% of the cost of an effective program.

When announced, the Government said the *Helping Children with Autism* initiative is just a beginning. We agree: there is still a long way to go. Special Disability Trusts are such a long way down the track for the families of people with autism.

We include two annexes (see below) from people who have specifically considered the value of Special Disability Trusts

² We do not have data for Australia, but there is a large amount of anecdotal evidence ... my own son who is about to turn 17 years old spend two school-age years without a school placement. A UK Inquiry was told 25% of students with autism are excluded from school at any time ... we expect the situation is similar or worse in Australia.

³ It will probably be less than \$8,000 per child when it is rolled out later this year ... providing around 20% of the cost of early intervention, and possibly complicating further the organisational burden on families to manage the complex array of services their child needs.

(b) the effectiveness of Part 3.18A of the *Social Security Act 1991*;

We do not have the capacity to consider this and comment on it.

(c) barriers in the relevant legislation to the establishment of Special Disability Trusts; and

Contrary to the UN Convention on the Rights of the Child, children with autism in Australia do not have a legal right to treatment, rehabilitation and education. Children in Australia do not have Human Rights including protection from discrimination of all forms.

A consequence is that Governments (state and federal) develop services for some people with disabilities but often exclude people with autism from services for treatment and rehabilitation of their condition. There are case-management and respite services for people with intellectual disabilities, that are denied to people with autism. Australian law protects this form of discrimination.

These are major issues ... with the minor consequence that they are barriers to the establishment of Special Disability Trusts for people with autism.

(d) possible amendments to the relevant legislation.

While Australia has ratified numerous international treaties on the rights of children and people with a disability, it has refused to translate these into law (as is required by those treaties).

Children with autism in Australia need their rights under international law protected. This is one of the most basic steps that can be taken.

The next step is to develop a system of services that leave a significant number of families of people with autism spectrum disorders in a position where a Special Disability Trust is even an option.

We would certainly be interested in speaking to the Committee on these issues. I can be contacted on 0418 677 288.

Yours sincerely,

R. Buckley
Convenor

10/6/2008

Annex 1.

In my experience, the senior carers are not seeking intervention. We have not attempted to market to them, but perhaps this is something which should be undertaken.

The families I have been seeing are setting them up in estates, and then sending in their families to do the same (we do this for a heavily discounted price) so that the first to pass establishes the trust and the balance fund into it.

Most of the families cannot afford the capital gains on stocks to transfer in, or cannot afford stamp duty to transfer in property, or simply do not have the assets to fund the trust. If we could have capital gains and stamp duty waived, then this would free up significant opportunities; however, as it is, the families cannot take out mortgages to fund the capital gains tax and/or stamp duty to send the assets over to the special disability trust.

Until these are dealt with, I do not see many families utilizing the trusts. The only families that can afford the trusts are those that can transfer funds from operational trusts, such as family trusts and/or business trusts. By and large, families with assets that can be transferred in are simply not willing to pay the significant tax bill that comes with recognising and transferring the assets. To them, it is better to just keep paying bills for the person after tax because usually the up front costs are in excess of \$10,000 (taxes only).

Annex 2

We had an accounting group look at the SDT set up. There are some major issues for anyone venturing down this path.

Firstly, the income generated by the trust has some very restrictive conditions:

- Can only pay for "reasonable accommodation" what ever that means ... they don't give a definition
- Can only pay for services the disabled person needs, that means if a non disabled person uses or needs it then it doesn't fit the trust payment criteria
- That all the income generated by the trust is assessed for tax purposes as a normal income, that is a working persons income, so that 0 to \$6,000 is tax free and the rest is taxed at the normal rates and if there is income left over in that financial year that has not been used to support the disabled person, this left over portion is taxed at a flat rate of 45%, that is 45 cents for every dollar, that is what a person pays on an income of more than \$150,000 per year.

The (parent) pensioners can earn \$24,867 (single) or \$41,360 (couple) before they start paying tax and the tax is done at an offset \$1 per \$8 earned.

I don't want to even think of the rip off merchants who would happily target desperate parents, take the money a run schemes.

For the young parents, who are paying for intervention services, speech, psych and other support services the governments have them on waiting lists, those who are cashing in the superannuation funds, I'm not sure that they would be cashed up enough to set up a trust that would be of any use, especially the single income families and the sole parent families.

Setting up and hiring an accountant to do the sums, lodge the trust tax returns each year, the keeping of receipts and day-to-day management is a real expensive exercise and time consuming....imagine the elderly parents caring and becoming the bean counters also.

If you hire a relative to come in and help with the day-to-day care, (this is not unusual) the relative cannot be paid by the trust.

Then there is a restriction of having \$500,000 in the trust, if this earns say 7% that is \$46,500 income taxed at the trust rate: tax paid would be roughly \$7,500 leaving \$39,000. so if you hire a carer for 8 hours a day at \$20 per hour, this would cost \$41,600 and your left with 16 hours of no help, and your in the red \$2,600 per year.

So not matter how you look at it, it does not work....

These figures are crunched on what is available and not to be assumed as expert advice.

Hope this helps the Senate figure out why only 22 trusts have been set up across all disabilities since Sept 2006.