Submission to Senate Community Affairs Committee Inquiry into Special Disability Trusts

Submission Closing Date 13 June 2008

This Submission is made by Mr and Mrs Alan and Barbara Raine, from our personal experiences of trying (to date unsuccessfully) to establish a Centrelink approved Special Disability Trust for our adult son, Mr Steven Raine.

This Submission consists of:

- our submission, to be publicly available of 4 pages
- a Confidential attachment of 2 pages, which is not to be publicly available

We will be pleased to attend a Public Hearing in Adelaide of the Senate Community Affairs Committee Inquiry, to provide any further information relating to our submission.

Alan and Barbara Raine
Belair SA 5052

9 June 2008

Submission to Senate Community Affairs Committee Inquiry into Special Disability Trusts

We are making a submission to this Senate Inquiry because we have experienced difficulty in our attempt to set up a Special Disability Trust for our son Steven, who has Asperger's syndrome, a form of Autism.

Steven receives a Disability Support pension. He works now for 8 hours a week on a supported wage, and it is considered that with his disability he will never be able to obtain work in the open market for even a minimum wage. Although we have worked very hard, with the assistance of experts at Autism S.A., to make him as independent as possible, he still requires a considerable amount of help to manage his household affairs.

As we are now in our sixties and moving towards retirement, we have made every effort to set Steven up as best we can for his future. We have purchased a modest house for him within walking distance of our home, and also within walking distance from his three supportive brothers. Every week we as a family assist him by helping him with shopping and finances, supervising essential housework, purchasing frozen meals (he is unable to cook) and overseeing his budget and Centrelink paperwork etc. This care takes one of us, usually myself, his mother, at least 6 hours a week. His brothers will continue to provide this care when we are no longer able.

It seems to us that for Steven a Special Disability Trust (hereafter referred to as SDT) is ideal. We were advised by Centrelink to set up a SDT when we consulted them about the best options for ensuring the security into the future for our disabled son. When we first heard about the SDT we were delighted. It seemed that our situation was exactly that for which SDTs had been designed. It would enable us to give Steven, via a protected trust, the house in which he currently resides, close to family who can provide the care and support he needs. However our attempts to have Steven accepted as eligible for a SDT have met with frustration.

The problems we have encountered have not in any way been with Centrelink staff, who without exception have been understanding, sympathetic, helpful, and thoroughly professional. The problems are with what appears to us to be inappropriate regulations, and the process and paperwork for applying for a SDT.

1. The forms to complete when applying to Centrelink for eligibility for SDT are not appropriate. One must apply on forms designed for requesting a "Carer Payment and/or Carer Allowance". **We are not seeking and never were seeking any payment whatsoever.** Specific forms which truthfully represent the intention only to apply for SDT need to be provided. In every conversation with Centrelink staff and others we have had to correct the misconception that we are applying for payment.

2. In addition to the lack of forms specific to the purpose, the current forms give no scope for describing Steven's actual disability. The forms solicit information mainly about physical disability. Steven has a very real but hidden disability. We believe that although he is continent, able to dress himself, feed himself, walk unaided etc., his life is nevertheless as severely restricted by his disabilities, though in different ways, as a person who is confined to a wheel chair. Steven suffers a permanent medical condition, a pervasive developmental disorder, which has been rigorously assessed and legitimately qualifies him for a Disability Support Pension, but this cannot be demonstrated on the "Carer Payment" application forms which give very little scope to describe psychiatric / psychological impairment. Examples which describe Steven's disabilities more specifically are included in a confidential attachment to this submission, in order to show the difficulty we experienced in reporting Steven's handicaps on the forms provided. His behaviours are typical of Asperger's Syndrome, but where on the "Carer Payment" forms we are obliged to complete can such disabilities be included?

3. This is compounded by the rigid rules stating who is able to complete the Health Professional Assessment. This is listed as "a medical practitioner, registered nurse, occupational therapist, physiotherapist, member of an aged care assessment team or an aboriginal health worker". Steven does not currently receive treatment from any of these professionals. Our local GP only sees Steven for infrequent minor medical problems, and while he knows Steven is genuinely severely disabled by Asperger's syndrome, he also found it hard to adequately demonstrate this on the forms provided. A more detailed, knowledgeable and appropriate assessment could be obtained from a psychologist associated with Autism SA who would have a deeper understanding of the difficulties Steven and other Asperger's adults experience. But this is not permitted under the current regulations.

4. A further objection to the use of the "Carer payment" forms is that to gain the necessary 30 points required Steven would have to be so severely physically disabled that it is hard to know how he could possibly manage to live semi-independently anyway! The needs identified by this form may be relevant to a decision to award a Carer payment to someone providing hours of physical care. But when the aim is to facilitate secure and suitable accommodation for someone in Steven's situation (and when no payment from the public purse is required and in fact the effect is to save the government a great deal of money), why is physical disability given so much emphasis? We believe the point system on the "Carer Payment" forms for estimating the degree of disability is not accurate or relevant to our situation, and indeed to many other people who could benefit from SDT.

5. Every effort has been made by ourselves and others to get Steven into employment. After more than 12 months with disability employment agency Interwork he has finally, recently, been able to obtain 8 hours work

a week helping in a Grain and Fodder store, on a supported wage. It is not at all likely that he will ever be able to achieve more than this. Steven's Interwork coordinator rates his degree of disability on Interwork's scale as grade 4 on a scale of 1-5, grade 5 is totally disabled. Surely the two facts - that he qualifies for a DSP and is genuinely and permanently unable earn a minimum wage - should be enough to make him eligible for SDT?

6. Steven currently lives in supported accommodation, with both the accommodation and the support supplied and paid for by his family. We have done our best for our own, because we wanted to avoid a situation in which Steven would be isolated from family and friends. He is unable to drive and public transport to our suburb is limited. We did not want him to have to live in supported accommodation in a suburb far from family. We know that his autistic behaviours make it difficult for him to share accommodation with others, and he benefits from the stability of having his own place, close to the extended family support which enables him to achieve his best. But because we, his family, provide the accommodation and care he cannot be considered eligible for SDT by the alternative (to qualifying a hypothetical carer for a carer payment) covered in the Social Security Act 1991 Part 3.18A, paragraph 1209N section (b) (ii). He is not ".. living in an institution, hostel or group home … for which funding is provided … under an agreement between the Commonwealth, States and the Territories …". In fact there is hardly any suitable supported government-funded accommodation available for Asperger's adults like Steven.

7. While we have been prudent and made tight but just adequate provision in superannuation for ourselves, we feel we deserve the "safety net" of being eligible for a part pension if world economic events beyond our control reduce our funds by too much. We have had to make many personal sacrifices and in so doing have saved the government a great deal of money. If we had to sell Steven's house to support ourselves, it would be a tragedy for Steven and for us. And of course the costs to Centrelink would then increase. If we are unable to set up a SDT for Steven this is the scenario which may eventuate. Families who do as we have done should be rewarded, not penalised.

8. In the course of providing this accommodation for our son we have already had to pay considerable extra costs to government bodies in the form of stamp duties, land tax etc. There will also be substantial costs involved in arranging via a solicitor to actually set up a SDT. We do not expect ever to be recompensed for these costs, but at least if we were able to set up an SDT for Steven future costs may be minimised. More incentive in the way of decreasing such expenses would encourage more parents to provide for disabled sons and daughters themselves by setting up SDTs. **Encouraging more families to set up SDTs would save government money.**

At this stage Centrelink have refused Steven eligibility for a SDT. We have appealed to the Social Security Tribunal who acknowledge that we have a genuine case and have recommended that Centrelink reconsider our case and accept a report from a psychologist associated with Autism SA. Nobody wins if we are denied a SDT, it could potentially be a disaster for Steven, heartbreak for us, and increased ongoing cost to the public purse. We are hopeful that a better outcome can be achieved. We welcome this opportunity to present a submission to this Senate Committee, in the hope that the situation may become easier for ourselves and other responsible parents as a result of your deliberations.

In summary:

We hope this committee will review and amend legislation regarding Special Disability Trusts so that –

- Specific forms relevant to the intention are supplied for application for SDT.
- Developmental disorders such as Asperger's Syndrome and Autism, and psychiatric/ psychological disability are equally recognised for eligibility for SDT.
- The nonsense requirements of section1209N (b) in the regulations regarding beneficiary requirements for SDT are abandoned. That is, that as well as being in receipt of DSP and being unable to work for even a minimum wage, a hypothetical carer for the beneficiary of a SDT must be able to qualify for a carer payment, or the beneficiary must be living in a Government funded institution.
- Further incentives be considered to encourage parents to provide for their own, because this lifts the burden from government and also, very importantly, results in better than institutionalized care for disabled people.

ALAN and BARBARA RAINE 9th June 2008
on behalf of Steven Raine