The Secretary
Senate Community Affairs Committee
PO Box 6100
Parliament House
Canberra ACT 2600

SENATE COMMUNITY AFFAIRS COMMITTEE

INQUIRY INTO SPECIAL DISABILITY TRUSTS

Terms of Reference

(2) The following matters relating to special disability trusts be referred to the Community Affairs Committee for inquiry and report by 18 September 2008:

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

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

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

(d) possible amendments to the relevant legislation.

I will address myself to the above terms of reference in order, and in so doing document some of our experience in the setting up and then administration of a SDT. I will give some personal thoughts from our experience and information gained in talking with other parents who are caring for disabled children.

Some background of our situation.

My wife and I have been wrestling with the problem of the care and accommodation of our Down Syndrome daughter Debra for a number of years.

We arranged for her to be trained through the Uniting Church "Genesis" program in 1997 in Blackburn Victoria. During that 20 week 'live in' course she learned to live independently of us. She then lived in rented accommodation for 2 years before we decided to buy a house for her. The full story is recorded in a book that we have written, "Letting Go. The Story of Deb." ISBN 0 9756792 0 1, (Book enclosed). Part of the struggle was to have the story published. In the end we published it ourselves through the Broughton Family Trust hoping that our story would help others in a similar situation, and from the feedback we have received, this is the case.

Because of the rules governing Superannuation Funds I could not purchase a private property through the Broughton Superannuation Fund. I had then to transfer some of our superannuation payout into the Broughton Family Trust so that we could purchase a house for our daughter. This process cost us a lot in terms of tax and later in reduced Centrelink benefits as it was counted as a gift for 5 years. That was all part of the additional costs we had to bear, being parents of a disabled person.

Then the Government changed the Centrelink rules to count Trust assets as part of the Appointor's assets. Again we were caught in the overall strategy of the Federal Government to manage Trusts. We can appreciate the need to tighten the rules for Trusts, but found it difficult because our Trust was run mainly to provide housing for our daughter and three of her disabled friends who all live together in our house, under minimal guidance from Genesis.

With the ability to establish a SDT we were able to eventually transfer the house into the Deb Trust for the benefit of our daughter. However we faced a few difficulties concerning the transfer.

In working through the process of setting up this Special Disability Trust for our daughter we were faced with a possible expense of $21,000 which is made up of Capital Gains Tax and Victorian Government Stamp Duty on the transfer of the property from one trust to another. Quite frankly we could not afford that sort of expense. Fortunately we were able to obtain a Private Binding Ruling from the ATO and were granted ex gratia relief from the State Stamp Duty by the State Treasurer. I have communicated the details of these processes to Centrelink in the hope that other carers will be able to benefit from our experience.

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

Perhaps the first thought is the amount of advertising about the SDT.

We had just managed to live on our finances since trusts were considered by Centrelink as the assets of the appointor. I had discussed the problem with many friends and associates and heard that legislation for the establishment of SDT's was imminent. I worked towards establishing a SDT and had the Deb Trust established in December 2006.

I have seen and read, since we established the Deb Trust, several articles in "News for Seniors". Perhaps there should be an article in each issue. However that is a restricted audience.

Many parents I talk too are unaware of the possibility of an SDT for their child. I have tried to encourage them to at least investigate the establishment of a trust. If information about SDT's was sent to every Special School, Special Development School, ATSS and Supported Employment Centre, the information may be communicated to parents in the position to set up a SDT for their disabled dependent.

In discussion with a parent recently it was stated, "It is just too hard, all that legalistic process we have to go through". She had placed it into the hands of a solicitor and they wanted $1500 to set up the trust which she thought too much. I agreed. She was daunted by the process even after I had explained what I had done and how I had achieved the outcome we wanted. Perhaps an educational approach to how people might go about the process of setting up a trust needs to be designed and written in very simple step by step terms. A check list of steps to follow is needed. A flow chart would be useful, with questions to answer and paths to follow to achieve the end result.

The first problem we encountered was the "Care" test when our daughter failed to reach the required points level, the first time around. Fortunately I had written and described our situation, so the SDT Centrelink team in Perth recognised our problem. Thankfully we had very supportive members of that team who advised us to fill in another "new" application and 'think outside the square'. This new application enabled Debra to be re-assessed as needing care, (we reached the required 25 points) and so the trust we had set up could be recognised as a SDT.

This could be a recurring problem for 'high functioning' disabled people like Deb. My impression is that others will need to follow a similar path unless some different criteria test is employed. The difficulty is that having been denied once, they will not persevere. It was a daunting prospect for us as professional people with the ability and tenacity to continue with the arduous process.

It appears to me that a much simpler test needs to be applied in the case of certain disabled people. People with high functioning ability would most certainly be disadvantaged by the present test. (It seems that Centrelink have taken the standard test they use for determining the care level needed for the "Carer Allowance" and used that as a rough instrument to assess the care needed for a person to qualify for consideration for a SDT. Probably the numerical, cut off level, was modified.)

A much simpler approach would be to consider the disability. If it is a genetic disability (e.g. Down syndrome) or birth related, or acquired brain injury there is very little doubt that the person, no matter how high functioning they may appear will always need some level of care to function as a productive member of society. Other criteria for needing care could be their attendance at a Special School or Special Development Facility or attendance at a Day Training Centre. If this could be recognised as evidence that the person 'needs care', then the whole process would be easier for more parents/carers.

Of the 8 young disabled people that have at some time been accommodated in our house, all of them have attended Special Schools, but still function very well in the community and attended a Supported Employment Workshop. They would fail to reach the necessary 25 points on the "Care Scale" administered by Centrelink, therefore they would not qualify for a Special Disability Trust being established for them. Yet they all needed some form of care and support from parents or friends to continue to function adequately in their situation.

Another disincentive for parents to establish a trust for their disabled dependent is the extremely limited range of purchases that can be made from the trust for the 'accommodation and care' of the individual.

At present household appliances are specifically excluded. I can foresee that we will have to replace things, in the near future, (that are at present in the house we established for our disabled daughter) like, refrigerator, stove, chairs and tables to name a few, all capital items. It would be better if a list of household appliances were available that could be purchased by the trust (or some discretionary power given to trustees, who have to account for expenditure anyway) for the continuing care of the beneficiary. Perhaps a more detailed accounting of expenditure could be introduced rather than just the financials from an accountant. The way the trusts are set up, these items must be purchased out of the persons pension which would be a very difficult task given the present amount of the payment and all the expenses it must meet. It appears to us that the definition of what constitutes 'care' is extremely limited.

I have had discussions with a parent not even considering setting up a SDT for his daughter on the grounds of the very limited items for expenditure.

Even an annual holiday is specifically excluded. Our daughter works a 38 hour week for the year with 4 weeks annual leave, the majority of which is at Christmas time. The Deb Trust is denied the opportunity to pay for this trip. However we have been able to pay for the "Care" component of the costs of her trip. But that required a bit of lateral thinking on the part of the trustees and could be a disincentive for many carers/parents.

Some parents, or carers may not have the necessary finance to provide a lump sum to establish a trust and may need to contribute on a weekly, monthly or annual basis to build up the funds in the trust over a number of years. Has this been addressed in any way?

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

On the personal, family and financial level this legislation has been a very effective instrument for us.

Involvement of siblings.

Our three able children have always shown a great interest in the future care of their disabled sister. Over the past 10 years of her 'independence' they have been prepared to help with occasional care when my wife and I were away on holidays. In establishing the SDT, Deb Trust they were involved in the initial discussions of what it would mean for Deb, them personally, and for us as their parents. They were very supportive of what we wanted to achieve for Deb and for them.

They agreed to be joint Trustees with us and were supportive of the provision that three of the Trustees had to sign for expenditure. In signing the trust deed they realised that they became legally responsible for the trust property, income and expenditure. They agreed to take turns in managing the trust accounts. It was a bonding exercise for us all.

Income of trust providing for future care.
The income from the trust should accumulate over the coming years until Deb needs more intensive support from an independent person or organisation. The other trustees (siblings) realized that there would be funds available for the future care of Deb and she need not be a drain on their resources, or that we would expect them to care for her in their own homes.

The fact that the trust income would accumulate and provide for the future care of our disabled daughter also provided us with a real sense of security. Here was a realistic provision for her future care and accommodation.

Our Income level.
The tangible present benefit of the SDT Deb Trust was that we were able to give away a house in our Family Trust to the Deb Trust worth $330,000.00 which had been counted as our asset by Centrelink from 2003. That increased our combined Centrelink Pension from $40 per week to in the order of $400 per week.

Immediately prior to the establishment of the SDT our income from the Family Trust was $182 per week, Centrelink Pension $40 per week and from our Superannuation Fund $321 per week, Total $543 per week.

Presently, Centrelink Pension $436, Superannuation, $327 Total $763 per week. So having given away a house at present worth $330,000 we are $220 better off each week and we know that our disabled daughter will have sufficient funds for her accommodation and care into the foreseeable future.

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

It appears to me in reading the amendment to the act that established SDT's that there is very little that is a barrier to the establishment of a trust. It is the administration of the act where the problems are evident. The criteria and the instrument used by Centrelink to establish the need for 'care' is a difficulty for 'high functioning', intellectually disabled people.

Another administrative barrier might be the need for some people to build up the assets of a SDT over a number of years and have these contributions recognised.

(d) possible amendments to the relevant legislation.

There is nothing in the amendment to the act that determines the level of taxation that will be applied to a SDT. This from bitter experience presents a real disincentive for the trust to make a profit and build up the reserves for future care and accommodation needs.

In establishing the Deb Trust we transferred a house previously held in the Broughton Family Trust into the Deb Trust. Three disabled people live with my daughter in that house and the rent that they pay provides now, and will provide for the future, care of Debra. Thus the Deb Trust is assets rich (but not to the $500,000 limit) but cash poor. It is important that if the Deb Trust is to pay for all the future care of Debra it will need cash reserves, at least to the limit allowed. We can then safely employ carers to provide the necessary level of care.

The whole question of the taxation of these trusts needs to be addressed for the ongoing viability of the trust and in the final analysis for the people or organisations who will benefit when the trust is no longer a SDT.

A major difficulty we have faced in the financial year 06-07 year was the tax levied on the trust. It amounts to 46.5% plus the Medicare Levy. For a normal trust this can be reduced, (even to zero), by disbursing profit to the beneficiaries and they pay any tax, but this process is specifically excluded for Special Disability Trusts.

The Deb Trust made a meagre profit of $1199 for the financial year 2006/7 and had to pay $558 in tax. The trust will again this year have to endure the heavy tax burden unless something is done in the next few months. It appears that here we have a situation where one arm of Government is trying to help disabled people and another is hindering. This situation needs urgent and retrospective amendment.

It would be advantageous if any tax change could be retrospective, as some trustees would be in a similar position to the Deb Trust in losing nearly 50% of the profit for last financial year and that will occur again for the financial year 2007-8.

A much more equitable process would be for the ATO to tax the trust at the marginal rate of the beneficiary. In other words **consider that the profit is paid** to the beneficiary, but retained in the trust, and the beneficiary has to pay the tax, if any. That might be a bit complicated for the Tax Office, but I guess they would be able to cope.

I would be prepared to give evidence before the committee if that would be advantageous and help to clarify the situation.

Yours faithfully

Brian Broughton (Trustee, Deb Trust)