Submission to the Senate Community Affairs Committee inquiry into Special Disability Trusts (SDTs)

From Ray and Wendy Walter, parents of Glen.

June 2008

Overview of where we have been and where we are today

We have written this submission as parents of a 35 year old son who has an intellectual disability. He is employed by a business service provider in Perth and, while he is very capable at work, his hourly rate of pay will only ever be a fraction of that earned by those in the open workforce.

Like many others in his situation he is unable to manage his own affairs and will never, through his personal endeavour, be able to pay for his accommodation, care and other basic needs in life.

It was always our intention to follow the well worn path of others and incorporate a trust structure in our wills as a way of providing for the future care needs of our son in a way that would NOT impact on his ability to receive appropriate Disability Support Pension entitlements.

In mid 2002 while seeking advice on estate planning we were shocked to find that in January of that year the goal posts had been dramatically shifted and all funds held in trust were now Centrelink accountable and would be deemed to be the assets of a trust beneficiary for social security purposes.

As a result of that change the deployment of a trust was rendered virtually useless for families wanting to make either full private provision or at least to provide some additional support to any Government funding their loved one might receive.

We understand that the Government changed the legislation to stop people abusing trusts for personal gain. However, this has had significant unintended consequences for people like our family. In effect, the changes mean that those on a Disability Pension now stand to lose all or part of their pension if a trust was set up to provide for their future care and/or accommodation.

In September 2005 Minister Kay Patterson announced that the Government would create a Special Disability Trust, this was in response to the wishes of families and carers who were trying to find a way to make private provision for their family members with a disability that would not financially penalize them or their family member.

In June 2006, under the guidance of then Minister Mal Brough, legislation was introduced and passed that, providing a person with a disability met certain criteria they would be classified as having a “Severe Disability’’ and thus would be able to qualify to be the beneficiary of a Special Disability Trust.

We had assumed at that time along with many others that it was the end of a four year journey of lobbying that had consumed our lives almost daily.

Unfortunately that was not to be. As is often the case - the devil was in the detail. Having gained a better understanding of the implications of the regulations it soon became clear all was not well. Two more years of pleading for change have culminated in the Senate Community Affairs Committee inquiry that is currently taking place.

Our thanks to Greens Senator Rachel Siewert and her staff and the other members of Parliament that we have approached who listened, and agreed that changes were needed.

Senator Siewert however was prepared to take the next step and initiate the motion to give interested stakeholders in the disability sector the opportunity to speak up and be heard.

Key questions

At this point we ask the following questions of any member of parliament who may be reading our submission:

1. Do you believe it is fair, just and reasonable that some people with disabilities have been singled out to be the only members of our community to pay Capital Gains Tax on the sale of their place of residence?

2. That if families strive to make private provision for their disabled sibling by using an SDT they should be happy and thankful that they face the prospect of paying 46.5% tax on some of the income of that trust?

3. That due to recent changes in the SDT regulations only those who are living in approved accommodation can have their Food and Utilities (Water, electricity, gas etc) paid by a SDT. But if they have an SDT and are *not* living in approved accommodation all those items must be paid from their pension. Is this not discrimination?

Summary

The following outlines the few positive and the overwhelming *negative* points of the SDT legislation as it currently stands and other points of interest.

Positive Points:
1. Property can be held in a STD
2. Centrelink concessions

Negative Points:
1. Eligibility to be a beneficiary of a SDT is too restrictive
2. Capital Gains Tax payable on assets transferred to a SDT
3. Limited use of SDT funds
4. Tax payable at 46.5% on unused SDT income
5. Capital Gains Tax payable if a property held in a SDT is sold
6. Stringent reporting and audit requirements

Other Points of Interest:
1. Difficulty obtaining the First Home Buyers Grant
2. Only small numbers of Special Disability Trusts have been set up
3. Public Trustees have not embraced SDTs
4. Succession planning for carers submissions and consultations 2006
5. Experts and Lawyers say two trusts will be needed
6. Canadian Registered Disability Savings Plan
7. Name change may be beneficial

Positive points

Property can be held in a SDT: In addition to the $500,000 in assets for care and/or accommodation needs, a property (place of residence for the beneficiary) can be held in the SDT the value of which will not count towards the $500,000 limit.

Centrelink concessions: If family members who contribute property or invested assets to a SDT are pension age or 5 years pre pension age they will not be penalized by the Centrelink Gifting Rules for doing so.

Assets held in a SDT to pay for care needs will not be treated by Centrelink as being owned by the beneficiary, therefore they will not be taken into account when assessing the beneficiary's pension entitlement.

Negative Points

Eligibility to be a beneficiary of a SDT is too restrictive
We believe many potential beneficiaries will fail or struggle to qualify for eligibility because they will be unable to meet Subsection 1209M(2)(b).

To understand the point we are making on this eligibility issue we have copied part (2)(b) of 1209M which states:

> *(b) the beneficiary must:*
>
> *(i) have a disability that would, if the person had a sole carer, qualify the carer for carer payment or carer allowance; or*
> *(ii) be living in an institution, hostel or group home in which care is provided for people with disabilities, and for which funding is provided (wholly or partly) under an agreement, between the Commonwealth, the States and the Territories, nominated by the secretary under subsection(3).*

It is a fact that families have already, and many more will be forced in the future, to apply for carers allowance or carer's payment in order to meet this particular beneficiary's requirement. A payment they may have been entitled to receive but not *sought* to receive in the past.

As the majority of disabled people will never receive Government funding for accommodation or care needs, part (ii) of the above is not applicable for most families who may wish to utilize a Special Disability Trust.

This leaves part (i) the Carer Payment or Carer Allowance option as their only chance to qualify to use a SDT to make private provision for their family member.

In instances where the disability is *moderate*, for example Mild Intellectual, Autism or Spasmodic Mental Disorder, it can be very hard for the applicants to score high enough in "hands-on care" category to qualify to receive an allowance. It is not uncommon for applicants in this situation to make numerous visits to their Doctor and Centrelink in order to achieve the required level of points.

For some a rejection of their first application is enough of a deterrent to put them off the idea of reapplying. It must be noted that often times the people making the application are elderly and find the whole process difficult if not distressing.

Qualifying is more difficult if the person with a disability is not living at home, as it must then be shown that at least 20 hours per week is provided in the areas of personal "hands-on" care.

For these people who may not have a physical disability but lack the intellectual capacity for planning and management that prevents them from looking after their own affairs, the current legislation is far too restrictive. In effect, the definition of what constitutes "Severe Disability" has been set too high.

The Hansard record on the day the legislation passed through the Senate (22 June 2006) shows that this very issue was of concern to Senator Patterson when she spoke on the Bill.

Senator Patterson could see that this group for whom the Legislation was intended to embrace may, in fact, struggle to qualify under the regulations proposed.

It was pleasing to see that an assurance was given by the Minister at the time placing on the public record that the issue would be revisited and rectified if necessary.

Families with a son or daughter who has a mild intellectual disability know only too well how hard it is to obtain assistance when the disability is not visible.

- **Recommendation: We would ask that the Senate Committee suggest the adoption of amendments so people like our son <u>*are*</u> able to qualify *as was originally intended.***

Specifically, that in Subsection 1209M(2)(b)(ii) that the wording be changed to embrace anyone who is eligible for any special disability service funded through the CSTDA.

While we understand the perceived problem to this change may stem from the fact that there is no nationally consistent process for determining eligibility for CSTDA funded services, surely any funds allocated under that agreement would be going to people the SDT Legislation had intended to embrace.

If this opening up of the eligibility is a concern selected CSTDA funded services such as Day Services, Supported Employment placements, Alternative to work etc should be added to (2)(b)(ii) as an alternative to the funded accommodation now specified.

For those people who still fail to qualify under subsection 1209M(2)(b)(i) or(ii) even with the suggested broadened guidelines, we believe a third option must be inserted to give these people the opportunity to prove the disability is at a level where the use of a SDT is justified.

The third option could read:
(2)(b)(iii) If the beneficiary is unable to utilize either criteria (i) or (ii) that in order to measure the level of disability a case can be presented on behalf of the beneficiary to an independent panel for assessment.

Capital Gains Tax payable on assets transferred to a SDT
When a property or assets are transferred into a SDT capital gains tax is payable. This is unfair when some of the assets that were to be gifted may have to be sold to pay the CGT.

In regard to property the following problem has occurred when parents or grandparents have, prior to the SDT Legislation, purchased in their own name or family trust, a property for their disabled family member to live in. The current value of that property in many cases is preventing the parents or grandparents from receiving a pension or substantially reducing the level of their pension entitlements because it is treated by Centrelink as *their* asset. They may now wish to transfer the property into a SDT but doing so will trigger a capital gain that in many cases they could not afford to pay.

This all seems very unjust when all they were doing was providing a home for their family member who can never provide for themselves and for whom governments have failed to accommodate.

- **Recommendation: If it can be shown that a property was purchased solely for the purpose of accommodation for a disabled family member and held in a trust or in the name of the purchaser and never used as a rental investment property it should be able to be transferred to a SDT without incurring Capital Gains Tax.**

- **Recommendation: If the property had been used as a rental investment prior to occupation by the person with a disability, Capital Gains Tax *could* be paid on an agreed value increase between the time of purchase and the time the family member took up residence.**

Limited use for SDT funds
Limiting the SDT to covering the cost of providing only for care and accommodation is far too narrow.

Items such as Private Health Cover, Medical Expenses, Dental treatment, Recreation etc are all costs that can not be paid by a SDT unless they are specifically required to meet specific needs which arise from the beneficiary's disability.

For many on a Disability Support Pension with little or no other income the chance of being able to afford Private Health Cover is almost out of the question.

We all know the waiting lists for medical and dental treatments in the public system are unacceptable for anyone. But if the person awaiting treatment has other disabilities the additional suffering they will be forced to endure would be intolerable.

Apart from the quality of life and the well-being of the beneficiary, it must be in the best interests of their carers, government agencies and service providers if immediate treatment is available.

A recent change to the Social Security (SDT) (FaHCSIA) Guidelines 2008 has been the inclusion of Item 19 under the examples of what are reasonable care needs. It reads as follows:

"The daily care fee charged by an approved provider in relation to the principal beneficiary's care and accommodation in a residential care service provided by the approved provider, and

any additional itemized fees which are specifically for the care needs of the principal beneficiary resident in that service".

As a result of this change a SDT beneficiary who has Government funding for care and is residing in accommodation run by an approved provider will have far greater use of a SDT than a non funded SDT beneficiary. This is because, in addition to the accommodation component of the daily care fee the SDT could previously pay, it can now also pay the full cost of food, utility services (water, electricity, gas etc) as well.

In comparison, a SDT beneficiary who is *without* Government Funding and not receiving a service from an approved provider *cannot* have the costs of their food and utility services met by the SDT, except for food and utility services that are specifically related to their disability. (For example, special dietary foods or the electricity needed to charge a battery for an electric wheelchair *could*, in their case, be paid by their SDT, although their pension would have to pay the *balance* of the cost of those items.)

For some this change will bring welcome relief in the administration area and free up additional pension for other quality of life needs.

For the Trust to receive greater acceptance the restrictions on what the funds can be used for must be eased.

- **Recommendation: The scope of the items that can be paid for by the SDT needs to be widened.**

Private health cover, medical and dental procedures etc should be items that can be covered by the Trust without having to justify that the service or treatment was specifically related to the person's disability as currently stated in the Trust guidelines.

In order to maintain a level playing field the recently inserted Item 19 of the Trust Guidelines quoted above must be extended to embrace **all** SDT beneficiaries, not simply those in receipt of a service from an approved provider.

We are constantly reminded of the health benefits that come from regular exercise, and these benefits apply especially to people with intellectual disabilities. Therefore recreational needs, including things like sporting and fitness club memberships and an allowance for holidays should also be covered by the Trust.

It must be noted we are talking about people who may never have the opportunity to partake of gainful employment or accumulate any savings or superannuation to pay for the things that many of us take for granted. Therefore these suggested changes to the legislation are quite critical to ensuring that people with intellectual disabilities like our son have equal opportunity to enjoy quality of life.

Issues related to taxation

The two tax issues outlined below are prominent in the list of concerns within the SDT that have been identified by professional people (Lawyers, Financial Advisors, Accountants etc) prompting them to advise families to proceed with care if contemplating the establishment of a SDT.

1. Tax payable at 46.5% on unused SDT income.

2. Capital Gains Tax payable at 46.5% if a property held in a SDT is sold.

Tax payable at 46.5% on unused SDT income.

The realization that any unused Trust earnings will be taxed at 46.5% has come as a huge shock and is making families step back and reassess their options.

Due to the limits placed on the Trust expenditure (outlined previously) it is going to be very hard for families to assess the level of funds to place in a SDT to cover care and/or accommodation needs *without* having excess earnings that will be hit by tax.

It is well known that the vast majority of people with a disability will not receive Government funding. Moreover, many families have never even bothered to apply after being advised that, while one of them can stand, they will not be seen to be in so called "critical need."

Two possible options for funding for care are Government (Commonwealth and State) or private provision using a SDT.

It is an interesting exercise to look at a comparison of those two forms of funding and how the indexing of future increases in the cost of care is considered.

Government Funding

A $ amount that is granted to a person with a disability for the rest of their life to pay for their care needs. It is provided at no cost to the family and, most critically, ***indexed annually*** - a clear recognition by governments that *the cost of care will increase*.

Special Disability Trust

A $ amount (up to $500,000) that is provided by the disabled person's family, comprising of after-tax dollars and in many cases retirement savings will be used.

Like the Government funded beneficiary, the cost of care for the person being funded by a SDT will also increase, as acknowledged by Government indexing annually the original $500,000 SDT limit that is excluded from social security and veterans' entitlements means test limits for the beneficiary.

However, the impost of tax at 46.5% on the unused Trust income will severely reduce the opportunity for the Trust to grow in value and provide care for the rest of that person's life. That care may be needed for more than forty years.

If, after a number of years, the funds in a SDT have reduced to a point that they are insufficient for a service provider to continue to look after the disabled beneficiary, the question must be asked, what will be the outcome?

Will the person be evicted from their place of care or will the Government have to step in and provide the funding shortfall?

Surely the logical change to make would be to allow unused income to remain in the Trust *untaxed* to give the Trust every opportunity to fund the beneficiary's care needs for life.

- **Recommendation: A fair and simple solution would be to treat the taxing of a SDT in a similar manner to the tax treatment of a Superannuation Pension.**

On the passing of the beneficiary, before any monies are distributed, tax would then be paid at 15% on any unused earnings that have built up in the Trust.

At 46.5% the tax payable on unused SDT income is at the highest rate paid by anyone in this country. No one is going to set up a SDT *unless they are sure all income can be used*.

We must not forget that taxes will be paid on any monies paid out by the Trust. Payments to carers will be subject to income tax in the hands of carers and GST is payable on all expenditure by the Trust.

Capital gains tax payable at 46.5% if a property held in a SDT is sold, even if it is sold for relocation purposes.

As we are aware a property can be held in a SDT, the value of which does not count towards the current $516,500 limit the Trust may hold for care needs.

Placing the property in a SDT will for many be the preferred, and for some the *only*, option as outright ownership for many disabled people may not be possible due to lack of testamentary capacity or security fears.

Any capital gains tax payable on the sale of a property in a SDT is grossly unfair as the following example clearly shows.

If a family had two siblings, one able bodied and the other with a disability the parents may decide to provide funds to both those siblings to purchase their own homes. This may be done in their estate planning or while the parents are still alive.

The able bodied sibling can buy a home in their name and after living in the property for one year or longer sell that property and pay no Capital Gains Tax on any profit made from that sale. They could if they so wished use the full sale price to purchase another property.

For the sibling with a disability, due to circumstances beyond their control, property ownership in their own name may not be possible or desirable and the use of a SDT to purchase and or hold their property (Principal place of residence) would seem to be a good option.

The huge downside is that at any time in the future when their property is sold, because it is held in a SDT, Capital Gains Tax will be levied on any profit from that sale. This may well leave a shortfall for relocation purposes to another property or for any other future care and/or accommodation needs.

Key point: We would like to believe this outcome was unintentional but it would be hard to find a clearer case of DISCRIMINATION.

In the Special Disability Trusts Measure Q & A info put out by the Commonwealth, Items 14 & 15 show clear reference to a property in a SDT being a “primary or principal residence”.

This indicates that the Commonwealth acknowledges a property in a SDT to be the principal place of residence of the beneficiary and therefore should be exempt from Capital Gains Tax like any other owner occupied property.

- **Recommendation: Simply treat a property held in a SDT that is occupied by the beneficiary as we would treat any other owner occupied property. Capital Gains Tax should not be applicable.**

Stringent Reporting & Audit requirements.
The Reporting & Audit Requirements of a SDT exceed the rules applied to other forms of Trusts.

Other Points of Interest.

Difficulty obtaining First Home Buyers Grant
It appears that the Grant is available if the SDT is purchasing a place of residence for someone with a *mental disorder* but not in the case of someone with a *physical disability*.

- **Recommendation: We believe the legislation should be amended so if a person qualifies to be the beneficiary of a SDT, any first property purchased for them should qualify for the Grant.**

Only small number of Special Disability Trusts have been set up
In the 18 Month period to March 2008 only around 22 SDTs were set up Australia wide, even though thousands of calls to Centrelink in regard to SDTs (2,300 calls in the first 9 months to June 2007) have been made.

The low take up is being put down to lack of interest or that SDTs may only be for the wealthy.

This is far from the truth as there is vast interest among carers and organizations in the concept and it is only when the downside details are explained that people are turned away.

Public Trustees have not embraced SDTs
The Public Trustees are extremely reluctant to utilise SDTs and in some states they are not being used at all. We are told this is due to the administration requirements being unworkable. This is hardly an endorsement from the people whom one would expect to be one of the largest users of SDTs.

Succession Planning for Carers submissions and consultations 2006.
In November and December 2006 submissions were called for and consultation meetings were held in all States to find out what were the key issues for families trying to plan for the future.

Ian Spicer AM chaired the consultations and he was to report to the Minister. All participants were told they would receive a summary and that the report from Ian Spicer, once cleared by the Minister, would be made available. The summary has been sent out and is available on the web but the final report which we believe went to Senator Nigel Scullion in 2007 has never been released.

As SDTs were one of the more prominent topics at the consultations and drew many responses via submissions, we ask that the Senate Committee seek out that report as it may contain some extremely relevant information. If possible a meeting with Mr Spicer could prove invaluable.

Experts and Lawyers say Two Trusts will be needed

Carers are being told *two* Trusts will be needed in order to avoid tax on unused SDT income. A SDT set up to earn just enough to pay for what it legally can cover, and a Protective Trust-All Needs Trust for fundamental needs and quality of life expenses. This is a cost and administrative nightmare.

Canadian Registered Disability Savings Plan

In Canada an organization was formed some time ago called PLAN Canada. The aim of this group is to set up lifetime support networks for people with disabilities and to bring about change in the disability sector.

In March 2007 they had a major breakthrough when the Canadian Government announced the creation of a Registered Disability Savings Plan that appears to have many aspects that may enhance our SDT legislation.

We would urge the committee to inquire further into the Canadian Government's model.

Name change may be beneficial

While we understand a Trust Deed would still be required, a change of name from Special Disability Trust to Special Disability *Savings Plan*, or the like, may be worthy of consideration for the following reasons.

When raising the subject of SDT in recent years with individuals or groups attending forums dealing with disability matters, the immediate and sometimes lasting reaction to the word "*trust*" appears to be turning some people off the concept. It brings instant images of wealth and in some situations causes individuals to dismiss the idea of using an SDT – simply because they perceive it to be outside the scope of their capability.

For others who may have already in past years finalized their estate planning it is hard to convince them that the SDT may give their disabled sibling a better deal than the Trust they have already chosen to use.

It is hoped in the near future the SDT will have its own taxation regulations along with Social Security concessions as is the case with Superannuation. Like Superannuation, a stand alone name without using the word *Trust*, would give this vehicle its own identity.

Similarly if present or future Governments, as they currently do with Superannuation, chose to follow the Canadian example and also contribute to a savings arrangement for people with disabilities it may be more palatable if the word Trust is not involved.

Conclusion

Finally can we say that families in our situation are simply asking that legislators form a partnership to work with us and not against us. Working together we believe we can find the best possible solutions to provide a better quality of life for those members of the community with a disability.

The removal of the barriers outlined above we believe can be done at little if any cost to the Commonwealth and would be a huge step forward in making that partnership a reality, bringing hope and providing some peace of mind to families who can see little light at the end of the tunnel unless these changes are made.

We thank you for the opportunity to take part in this enquiry.

Ray & Wendy Walter
Parent/Carers of Glen.