Submission to the Senate Community Affairs Committee
Inquiry into Special Disability Trusts

I am the parent of a 21 year old son whom has an intellectual disability. I have 4 other children ranging in age from 20-31 years. We are a migrant family, so the extent of family support for our son is restricted to three sisters and one brother. As parents we have a duty and responsibility to ourselves, our family member with a disability and our other children to ensure that we are fully informed and that we have a valid and up to date estate plan and will.

I have been advocating for people with disability since his birth, with a long active involvement with the Down Syndrome Association of WA. I was a member of a group facilitated by Barry McKinnon Chair of Disability Services Commission called Removing Barriers Advocacy Group which was wound up when Barry McKinnon resigned from DSC last year. I am currently a member of the Board of Directors of ACTIV in Western Australia. I would like to make it very clear that this submission is from me as a parent and not as a director of Activ.

There are a number of families who are in a position to provide accommodation and support for their family member who has a disability and we are one of these families. We want to be able to provide for our sons full life needs and expenses for living and caring for him long after we are gone.

The introduction of the Special Disability Trust in September 2006 appeared to be the answer to the protection of our family member who has a severe disability as defined by the legislation. However on closer examination the trust itself is of a very restrictive nature. I will provide a list of points that I think are an issue and need to be addressed.

Funds that are donated to the trust should be a deductible tax item for the donor or at least be taxed under the same rules as contributions to superannuation.

In our case my husband has already paid the top rate of tax on his income. There is no strong financial argument for us to quarantine up to $500,000 in cash or assets and also a property in a Special Disability Trust when we could be using that money in an interest bearing investment and leaving that property in a situation where it can be negatively geared, allowing us to accumulate further assets. We may as well just continue to pay for all of his needs now without the administrative nightmare that the Trust in its present form presents. We are not giving our son a gift we are actually providing for all of his care and accommodation needs and wish to continue to do so.

Any income that is generated by the trust and that has not been spent on care and accommodation in any one financial year is subject to tax at a rate of 46.5%

I suggest that this ruling is very short sighted. This high rate of tax is very unfair. We would like to get the Trust to the maximum before retirement and endeavor to keep it to the maximum cash balance for the rest of our lives. The reason for this strategy is that we need the Trust to accumulate enough funds to be able to provide care for our son when we are long gone.

The cost of caring for him will become exponential as he ages. He has Down Syndrome and there is an increased incidence of Alzheimers Syndrome in people with Down Syndrome. If we are bound by the rules of the Special Disability Trust as it stands we cannot accumulate enough money to support him when we retire are no longer here. Also as the gifting rule of the Trust is limited to $500,000 we would need to set up another Trust to accumulate sufficient funds to support him for his life. Why can the Trust not have the same or similar guidelines to superannuation whereby we would be able to accumulate sufficient funds to care for him until his death?

Capital Gains tax is applicable to a property donated to the trust.

The Special Disability Trust rules that property donated to the Trust becomes the primary residence of the person with the disability. I have 3 children who have left home and all have purchased their own homes. Their homes are their primary residences for taxation purposes and not subject to Capital Gains Tax. We have purchased a property one street away from our home that we intend for our son with the disability to move to within 5 years. When and if we donate this property to the Trust, it will be subject to Capital Gains Tax even though the Trust rules acknowledge that this is his primary place of residence. That is fair as we have this property rented at the moment and avail of negative gearing on the property.

However were we to put Bryan living in the property before we established the Special Disability Trust, the property would still be subject to Capital Gains Tax from the date of purchase. If at a later stage we donated it to the Special Disability Trust. or should Bryan have to change his location when we die so that he could live nearer his sisters, the property would again be subject to Capital Gains Tax from the date of purchase. This is very unfair and possibly discrimination. If the property is his primary residence then there should be no Capital Gains Tax applied to the property from the date that it becomes his primary residence.
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The restrictive nature of the use of monies to support the person with a disability should be eased. People supported by the trust should be entitled to the things in life that we all take for granted.

My son works part time in supported open employment and indeed I should like to see him working full time if possible. He works locally in a job that was created for him by a local business. Because of his disability he will never be able to earn enough money to pay for the support and care that he needs. He has some word recognition however cannot read effectively. He cannot handle money and has no concept of time. He needs constant supervision to manage his daily life. We pay for private health care for him, his clothes are mostly tailor made, we pay for a gym membership and a personal trainer to try to keep him fit and healthy as he is unable to participate in the regular sporting activities that a 21 year old without an intellectual impairment would do. Under the current restrictive nature of what is deemed reasonable care none of the above mentioned costs could be deemed reasonable care and should be expected to be paid for from his income. He could never afford to pay for any of these items himself if he is also to pay for food, electricity, gas, telephone, transport etc. Where would he ever find the money to have the luxury of a holiday? That is something that we all able bodied people take for granted.

In relation to the Social Security (Special Disability Trust) Guidelines 2008 which I have attached, on Page 5 of the document Item 19 has been added since the original guidelines were published. 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 itemised fees which are specifically for the care needs of the principal beneficiary resident in that service."

This Item appears to be suggesting that people who are receiving funded accommodation and support will now have the advantage of being able to pay the daily fee charged by an approved provider from the trust, whereas the very reason that the trust was established was to help those families who had the means to help themselves and were not in receipt of a funded accommodation option. Does this ruling mean that those in supported service provider accommodation now have an advantage over those living in accommodation provided by families through the trust as they will not have the stringent reporting requirement of what is considered reasonable care?

The government should investigate and consider the introduction of a Special Disability Savings Plan as introduced in Canada or a savings plan that would be treated with the same tax rules as contributions to Superannuation.

I feel that the government should investigate the possibility of establishing a disability savings plan. Plan Canada has a savings plan that has a co-contribution from the government.

My thoughts are that something could be established along the lines of a superannuation fund that parents could contribute to from the time of the birth of a child with disability or from the time of diagnosis of an acquired disability. The fund could not be drawn down on until the person was eligible for the Disability Support Pension. Then possibly the fund could start feeding income into the Special Disability Trust at a rate that would sustain the care and accommodation needs of the beneficiary on an annual basis. The family members could continue contributing to the fund throughout their lifetime ensuring that there were sufficient funds to keep the trust sustainable. Funds from the savings plan could only be distributed to the trust. Taxed at the same rate as superannuation and with residual funds on the death of the beneficiary be taxed in the same way prior to distribution of the assets to other family members.

Concluding Comments

I am not a tax expert; however it seems to me that the establishment of the Special Disability Trust failed to look properly at the tax implications, the restrictive nature of what are considered to be reasonable care needs of the beneficiary and the reporting requirements of this Trust.

Regardless of what the outcomes of this inquiry are, my family and I will continue to care for our son until we die, if we remain well enough. However the government needs to look at the long term implications of having a short sighted view of the global picture of living with and supporting people with disability.

If any of you would care to consider the impact of disability on family life I ask you to look at this submission as a document that has taken untold hours of careful thought and consideration and lobbying of politicians to get as far as a Senate Inquiry.

This is not a cry for another tax dodge.

We could easily join our friends and peers and become part of the self funded retirees and grey nomads who start living, after a hard life of educating and raising five beautiful children. We could spend our assets on ourselves and our other four children but we will not. If government thinks that we are here trying to find a way to evade tax think of how much cheaper we can provide individualized care and lifestyle to a marginalized portion of our population.

I would like to thank in particular Senator Rachel Siewert for helping us get this far. I would also like to thank all those who instigated the establishment of the Special Disability Trust, in particular Senator Kay Patterson and also Mr. Ray Walter who has devoted the last six years of his life to this issue. Ray is passionate about advocating for people with disability and in my opinion should be included in the Australia Day list of honors for service to people with disability.

I also would like to ask the committee to tell me why my correspondence to Kevin Rudd, Bill Shorten and Jenny Macklin via email since the Rudd government came into power, has not been acknowledged. I sent emails to them and the response was a computer generated reply. Copies of my emails were also sent to Sheila McHale MLA State Minister for Disability Services in Western Australia who had the decency to reply in person. There is no point in having an email link that amounts to nothing short of a waste of my time and the tax payer’s dollars.

My last request is that the committee makes public the full and final report of consultations that were chaired by Ian Spicer in late 2006, regarding Succession Planning for Carers. A summary report was available but the previous government has refused to release the final and full report. I challenge this government to publish it.

I am also passionate about the future care of my son. If the Senate Committee will not be holding a hearing in WA I am willing to go to Canberra at my own expense should they require further commentary.

Yours sincerely

Phillis Breheny