

**SUBMISSION TO THE SENATE COMMUNITY AFFAIRS COMMITTEE OF
INQUIRY INTO SPECIAL DISABILITY TRUSTS**

To The Secretary
Senate Community Affairs

Thank you for the opportunity to make comment to your inquiry into Special Disability Trusts. I am the sister of a 52 year old man with mild to moderate Intellectual Disability. He currently lives in a Homeswest owned unit without any formal support, but relies heavily on his family for assistance with medical, money matters and dealing with Government departments. He has tended to reject formal disability services and so his family is his primary source of support. He is in receipt of the Disability Support Payment and his income is supplemented marginally from his sheltered workplace.

I also hold a degree in Social Work, obtained in 1979, and have worked in the field of disability services and advocacy for 29 years.

I learned about the Special Disability Trusts approximately 2 years ago and thought it may be something that may be appropriate for my brother and his future. I tried to understand the structure and limits of the Trust and quite frankly, I became bamboozled and confused about how it would work and if my brother was eligible or could benefit by it. I also felt embarrassed that despite being a university graduate I could understand VERY LITTLE of the information provided. I thought that if I had so much difficulty in understanding the information, how would people with limited education and understanding fare?

I tried on several occasions to re-read the information, but my continued lack of understanding, made me delay any further attempts to try again. However from my reading about Special Disability Trusts, I would like to offer the following points for your consideration.

1. I think it is a positive move that provisions are opened for people/family members to make financial provisions for their family member with a disability. My parents in their 70's had much anguish in their wills in providing fairly for all of their 4 children, including making sure my brother was well provided for. My father passed away 4 years ago and made financial provision for my brother by setting up a fund to be administered by myself and to be made available to my brother when my mother passes. He was reluctant to place the burden of administering this fund on me but felt he could not trust a non-family member or organization to work in my brother's best interests. My father and mother are not wealthy but put away what they could, including the selling of assets in order to ensure my brother had money for his future. I am unclear if a Special Disability Trust would benefit my brother, in preference to what has already been set up, because the guidelines are so confusing.
2. It appears very cumbersome and confusing about the tax implications of any profits from the money earned within the Trust. It would seem an onerous task

- for the administrator of the Trust (Who is that by the way?) to keep track of all the comings and goings of funds and making sure the Tax laws are not broken, or indeed guidelines of Centrelink payments.
3. It is very hard to know what kinds of expenses a family member with disability may need into the future. My parents made provision for my brother based on what they know of his needs now and an educated guess about the future. A resistance to set up a special disability trust is based on wanting to avoid setting up money for certain services that are needed now ,but that if the money in the Trust dries up the essential service dries up too. Would there be a back up plan to finance the gap? I wonder how flexible the Trust would be to changing where the money would be spent. Having our own fund feels more flexible in providing for my brothers' needs.
 4. In terms of the \$500,000 limit of an asset (eg a house) seems fair enough in terms of gaining a tax benefit, but it also implies to me that one needs a very substantial amount of money to make a Trust worthwhile. In order to provide a house for my brother to live in my Mother would have to leave him her family home. I know she is very keen to be fair to all her children and this would place her in a dilemma if she felt pressured to provide a home for him. As he is already a client of Homeswest, he has the surety of a place to live for the rest of his life and so a Special Disability Trust would not serve any additional benefit in terms of having a roof over his head.

In summary, our family has not taken up the option of setting up a Special Disability Trust for my brother with a disability because the guidelines are too confusing and inaccessible, they appear to imply one needs to place the majority of parents assets and income to make the Trust provide a substantial enough stream of income to give meaningful service provision, and too cumbersome and complicated to manage.

As an advocate, I also have the concern that simply because Special Disability Trusts are available that some families may feel an obligation to sacrifice financially for most of their lives to set up a fund for one family member's future, because our Government funding levels are not keeping up with needs for disability services. There is an uncomfortable feeling that Governments are encouraging families of people with disabilities to bear the burden of paying for services themselves to avoid their own responsibilities to provide adequately for citizens who are vulnerable.

I hope this feedback gives some clarity to why this particular family has not taken up the option to set up a Special Disability Trust.

Yours faithfully
Mrs Elizabeth Pretsel