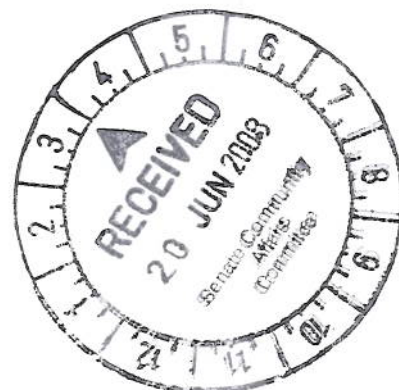


The Secretary,
Senate Community Affairs Committee
Box P.O. 6100
Parliament House
Canberra ACT 2600



Dear Mr. Humphery,

Thank you for the opportunity to submit my comments regarding Special Disability Trusts.

I realise my submission should be presented by electronic means, but this is not possible. However, I feel it is an opportunity to contribute to this Inquiry fully realising this may not be accepted.

The aim of the Trust is excellent, and I am surprised that there have not been more participants. My submission will only be related to our own experiences, and the parents I have spoken to recently about the Trust.

Information about the Trust was released by Senator Kay Patterson in October 2005. I also read some media releases in the press, and this was followed by a folder of information posted to me by Senator Patterson's office. So, I was well informed of the availability of this Special Disability Trust, but the parents¹ I spoke to were not aware of such a Trust.

My experience with parents I volunteer with during our fund raising, is that very few of them read a newspaper and rely on TV and radio for their news. This is interesting to someone like myself who is an avid newspaper reader (Australian and Sydney Morning Herald).

I know Senator Patterson held a meeting at Epping sometime last year, but we were away and unable to join in on this occasion. Something as considered as the Trust enabling parents providing the means for people with a disability to be looked after when their parents or friends who are responsible for their welfare are no longer able to care for this person, is a great step forward towards solving the never ending torment of 'what will happen to my child when I die?'.

¹ 'Parents' refers to parents with a child with a disability

The first comment I wish to make is that the original documents were not designed with enough simple detail. To be sure, I took one look at the content, thought it a great idea.....for other people! This is because I looked at the \$500,000 limit and thought it for people in a much better financial position than we are. There was no detail in how X numbers of dollars a month could go to a fund, just an outline of how parents on the pension can gift up to \$10,000 a year. There is great information in Division 1 about Special Disability Trusts, but most parents would look at that and consider they would have to consult their solicitor for a translation into a simpler form.

Our daughter was born 51 years ago, and we moved to the city for a good education and opportunity for her. We have two other children, and our lives are pretty well typical of most parents I know, or know of. The big thing is, for parents, the ongoing tiredness. Physical and mental, in the raising of a child with a disability in Australia. Trying to pay a mortgage, raise other children (care of these siblings is of paramount importance) care for you disabled child, supplying money for all the special things needed by this child, such as toys, different foods, services of all kinds, (in the early days we even paid for the Education Department Special Schooling). The never ending fund raising, the constant calls to attend meetings and seminars, and all this goes on until you die, with the never ending thought of what will happen to my child when we die? Families are now often scattered, not only through Australia but all over the world, and the last thing a parent would do to their other children is hold them back from living their own lives, wherever that is. In later years you then may have to undertake the care and attention that goes with your own and in-law parents aging and infirmity. Usually you and your husband are the ones in the family to do this extra caring, as you are there.

Services for the child with a disability.....I really feel I cannot add to what the Senators must be well aware of. Services are fragmented, hard to get, respite is impossible, and quite often expensive. This brings me back to the other point I would like to make, apart from the tiredness, the family with a disabled child will, sadly, be a one income family. Should this family be able to secure some Government funding, with one parent working full time and maybe a part time job for the other parent and if there is a service to take their disabled child, all this part time salary and the welfare will be swallowed up in expenses, such as possibly a special vehicle, equipment and fees. They may even be able to pay a babysitter

for a precious night out, or save for a weekend away if respite, by some chance is available.

In short, most parents struggle through the whole of their life, and very few would ever have enough money to put into such a Trust. Many of us have created a Trusteeship for our disabled child using the proceeds of the sale of our main asset, our family home. For those without this asset the future is very bleak.

In conclusion, I would like to put forward suggestions which may assist with getting the message out to parents.

1. Make sure all written material is easy to read and understand.
2. Advertise the Trust in the Centrelink's publications, The Seniors Newspaper (only NSW, I think) and The National Seniors Assn. Newsletter.
3. Each State has a Council of The Ageing, as we have in NSW, and I am sure they would welcome information for their newsletters.
4. Information could also go to Law Associations to inform lawyers to advise their clients. Maybe such an Association could consider setting up a pro bono program, possibly through Centrelink.
5. Advertising in material aimed at older people will ensure they in turn advise younger parents who possibly would appreciate such advice.

I would like to offer my thanks to Senator Patterson and the Hon Julie Bishop for all the work involved in setting up this Trust, and I am sure that Committee will receive invaluable information to help take this Trust to be a progressive, vibrant support for families.

Sincerely,

A handwritten signature in cursive script that reads "Jo McKerrell".

(Mrs.) Jo McKerrell OAM