

To the committee,

please find attached our submission to the enquiry into Special Disability Trusts.

Although we are considered a high income family, our family does not make use of the provisions to establish a Special Disability Trusts for two reasons;

(1) Over the past five years our family has spent close to \$160,000 on interventions for our children and we must budget around \$30,000 per year from our after tax income. Because we are a high income family we are subjected to means testing (often informal) which excludes us from many benefits. Receiving carer payment means that we cannot get family tax benefit part B. Benefits are given with one hand and taken away with the other. If we were allowed to keep some money rather than empty our pockets at every turn to compensate for the lack of services for our kids (which we surely have paid for in our taxes) we would invest. We are scared for our children's future if the community can opt out of providing for them. Tax rebates for self funding medically necessary interventions are negligible. We are tired of paying so much tax to a government that tells our kids to "bugger off".

Our children have a disability (autism) that is not legally recognised as a disability in the state of Victoria. Further Autism is not generally not recognised as a treatable disorder by Australian Medical professionals and the Medicare system. Appropriate health and education services for our children are not provided by the state, this forces us to self fund medical treatment (using Australian doctors but without access to Medicare for pathology and pharmaceuticals.). We must also pay for educational services and subsidise costs for teacher assistance and training. All of these expenses are paid from after tax income. Govt needs to recognise that people have lifestages of earning. If you are required to pay full cost from after tax dollars with negligible tax rebates during your earning years you cannot invest very much.

(2) Special Disability trusts are not the most tax effective way for us to invest. It is more attractive to put money into superannuation. Our children should be allowed to have self managed superannuation funds from childhood that is not locked away until retirement age.

I hope that the voices of caring families will be heard and acted upon. Caring families could make a full time job out of responding to all of the government enquiries that lead nowhere. It is degrading and humiliating to tell your story of heartbreak and injustice over and over to a government that wont act.

Yours sincerely,

Mrs Wendy Kiefel