

10/06/2006

## **Submission to Senate Inquiry on Disability Trust.**

### **To whom it concerns**

I am aware of the existence of legislation establishing special disability trusts for people with disabilities. As the parent of a son with a significant disability I have given the establishment of such a trust some thought and concluded that it did not have any attraction or advantage to me or my family in its current form. It did not have any incentive for me to try to provide for my son's future at this stage.

Many parents of children with disabilities worry about the future of their disabled children when they are no longer able to be the primary care provider. I am sure that the Senators are well aware of the burden that parents and family caregivers are under while providing 24 hour care for their disabled children. It cannot be replaced by state run services either in financial terms or empathetic terms. I have considered the establishment of a special disability trust as an effort to help defray some of the financial burden that will fall on others when I am dead and that will help maintain the quality of life which my son enjoys. The current legislation while it has many laudable features including the strict rules on what the resources can be used for, at the same time lacks incentives for me to establish such a trust. I strongly support the concept of such a trust. Ultimately I have to contribute positively to support our disabled son.

I urge the Senate Committee to enact recommendations to provide incentives for interested parents and relatives like me to set up an effective and flexible trust for my son prior to my death. In this way I could ensure that it will be functioning smoothly and in accordance with the terms of the trust prior to my death. I strongly believe that parents are the best people to set up such a trust as they have most to gain and are working in the best interest of both the disabled and the wider family.

I am no expert in incentives, but from my point of view a tax effective incentive is of interest to me. It may make the difference in deciding to set up a trust earlier while I am working rather than delaying it to later when it may be less effective and affordable.

Caring for those in our society who are less fortunate than ourselves is one of the hallmarks of our social system and values. When those amongst us are prepared to go that extra metre and prepare for the future, we should be encouraged. Time passes all too quickly and delaying reasonable planning and legislation until a future time is not desirable.

I want to plan for the future care of my disabled son and I need wise counsel and guidance to do this. Can I rely on the Senate to do this?

I wish you well in your deliberations. The previous provisions for Special Disability Trusts was not attractive and poorly taken up. I urge you to produce a Mark II, as it is a great idea but the mechanism is not quite right yet.

### **Regards**

Frank Breheny