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WRITTEN SUBMISSION FOR SENATE COMMUNITY AFFAIRS COMMITTEE
PARLIAMENT HOUSE,
CANBERRA. ACT. 2600.



INQUIRY INTO DISABILITY TRUSTS.

RESPONSE TO THE TERMS OF REFERENCE.

Background reference.

We Rosalie & Tony Sexton are the parents of a 31 year old son with Down Syndrome & for the past 4 years a significant psychiatric illness. We have endeavored over the past 31 years to provide our son with a high quality of life through changing philosophies set by Government Agencies. Providing him in his life with what we hoped would be with support, the equivalent of his peers, ie, education, occupation, recreation & eventually independent accommodation. From 1977 with our participation in a pilot early intervention program for children with an intellectual disability we have worked towards his & our independence, spending considerable time, energy & resources, emotionally, physically & financially. We have had support from Government Agencies but this has been at considerable cost due to the fractured & dysfunctional nature of provision & management.

As recent retirees on a modest income who in their working life had many restrictions because of their son's care needs we see no change in our circumstances in the near future as we continue to provide all of the above?

Planning for our future & the future of our son cannot take place while we are in this situation.

We know many families experiencing the same situation.

It is our belief that the following should be considered by the committee.

1. We find the understanding and requirements for the trusts are very complicated. They are not consumer friendly.
2. The benefits of setting up a trust are not apparent other than replacing or subsidizing Government funding for care and accommodation for people with a disability.
3. If the trust fund is used for care & accommodation, agency administrative costs & cost of living increases would deplete the trust very quickly.
4. Management of a trust fund is of concern as it is difficult to assess, project & arrange for the future particularly in the long term.
5. The effect of a trust fund on the disability support pension in the short & long term is unknown, ie how long will the trust last? What will be the effect of spiraling cost? Who can predict those costs?
6. We have some insight into the difficulties that a trustee faces in managing the affairs of a trust recipient. This cover everything from advocacy to care and financial management. Our knowledge comes from a lawyer friend holding this position.
7. I, Rosalie in a former occupation as a registered nurse working in the disability field observed differences and difficulties in the management of insurances monies for those with an acquired disability compared to those with a disability without insurance.

8. We feel trust funds should be initiated & used for the purpose of complimenting the quality of life of a person with a disability who does not have the same opportunities as others.
9. Parents of a person with a disability need to look after their own financial well being to insure that their needs & quality of life is taken care of before locking up monies in a trust fund - which may or may not be utilized. This in itself is a daunting and complex process
10. With the present situation of an appalling lack of supported accommodation parents are forced to provide care & at considerable cost to themselves, supplement their child's monetary needs. Planning for the future for them is often impossible. Planning for their child with a disability in this situation could place all at a distinct disadvantage.
11. The high cost of aged care in the future is frightening for many & mitigates against locking up funds in trust for either themselves or their children.
12. Other commitments such as siblings need to be taken into consideration, ie fair division of estates.

In summing up we feel for the "ordinary" Australians who as parents have a child with a disability trusts are not an attractive or viable way of securing their child's future. People with sufficient funds to invest in a trust for their child's future do not face these problems and are a minority. It is possible that the 22 trust funds established fall into this category. An agency recently quoted the supported accommodation cost for our son at \$90,000 a year.

ROSALIE & TONY SEXTON,

Rosalie Sexton
Tony Sexton