

From: Ms. Valerie Johnstone

To: Senate Inquiry into Special Disability Trusts

Over the last few months I have had quite a few long conversations with various members of the Special Disability Trust Team; it was mentioned that there was a Senate inquiry underway and whilst I am aware that the closing date has passed I have been encouraged to make a submission.

About Us

I am a widow, have a significant vision impairment and a social worker by profession. I am the primary support for my adult daughter, Fiona, who has a cognitive disability (Downs syndrome). I believe in independence and living in and of the community hence my role as being one of enabler, my belief in focussing on abilities and addressing issues/barriers, we have succeeded remarkably as Fiona has lived independently in a unit that I purchased since Feb '97. Her skills and confidence have grown from strength to strength and it is this that I do not want to jeopardise and have started my investigations into various elements of long term care planning

Issues for persons with disabilities re Housing

The two main issues are **tenure** and **reasonable rent** (less than market value) SDT would be a good structure to do this it would seem.

Other considerations are :

- being settled in one's space sooner rather than later certainly provides many opportunities for skill development, gaining confidence in the business of living and active citizenship.
- Pwd often experience an acceleration of ageing and wear and tear of their bodies, hence the impact of disability could be exacerbated.
- Living in known neighbourhood is beneficial, existing networks.

Issues for Persons/ Family Members setting up SDT

- the eligibility criterion is dependent on information from recipient of Carer Payment or Allowance and another from Medical Practitioner. Well, I have never claimed for a Carer Pension or Allowance! The forms do very little to acknowledge that a person with a significant disability may still have well developed independent living skills, physically able, but nonetheless need the security of SDT for the abovementioned reasons
- persons/families who have purchased a property incur cost; for myself and others it is a clear decision that the purpose is to provide tenure and affordable rent to their son/daughter who has a disability – in fact there is a foregoing of return re capital and rent received is directed towards costs with very little additional monies – nonetheless income.
- the costs of establishing and maintaining SDT – stamp duty (little acknowledgement from State that this is not a for profit transfer, etc.

- Just placing a property in SDT creates a “dry trust” , there needs to be further \$ contribution from settler to maintain as well. Other costs could be payment of trustees and accounting costs, tax implications,all adds up over many years. Hence, many costs to be incurred with little incentive
- The timing of SDT set up within my/person lifetime (now) seems far too difficult; If set up as “dry trust” (only property) the trust does not have monies to meet costs - I am told that the pwd will not be able to claim RA, so even if Fiona pays the reduced amount to the SDT to cover costs , how do I know that this will be capped? And of course I am even further behind in loss of income for quite some years.
- Whilst I recognise that establishing the SDT is purchasing security/of insurance for care and accommodation of Fiona, it would seem that there could be consideration for everything to be set in place (eligibility, deed, monies transfer) and a mechanism for it to come into being when situation is reviewed at regular intervals (5 yr (, or on my passing. Legally, Fiona is my financial dependent, and it is this that I am trying to address, and minimise possibilities of challenge etc.

Recommendations:

as a concept the SDT is a good one, some of the abovementioned issues can be addressed I am sure, however, the overall effectiveness and efficiency of such initiatives only come into their own when as the uptake increases. Yes, there could well be benefits from “carrots” e.g. bonuses, to get family members to start thinking about and taking up SDT for their adult children .

There is a role for the States and Territories obviously, stamp duty offsetting claims to public/CRU accommodation and opportunities for CSTDA conversations

Certainly a publicity campaign is critical to development of SDT.

Given that there is the development of the National Disability Strategy underway, and the many articles of the United Nations Convention of Human Rights for People with Disabilities being considered in such deliberation this inquiry may well find opportunities for drawing on various thinking and intergrating and /or embedding in policy the objectives of SDT that will ultimately be for the benefit of many Australian citizens who experience disability.