

28 January 2011

Ms Naomi Bleaser
Community Affairs References Committee
PO Box 6100
Parliament House
CANBERRA ACT 2600

Inquiry into Planning Options and Services for People Ageing with a Disability

The Future Living Trust Inc. (formerly the Hawkevale Trust Inc.) is pleased to respond to your request to provide a written submission in relation to the above inquiry. This submission is best read in conjunction with the submission made by the Hawkevale Trust to the The Productivity Commission Inquiry into Disability Care and Support dated July 2010.

The Future Living Trust Inc. is a not for profit, non government funded charity that provides services to people with developmental disabilities and their families. The Trust is an incorporated body founded in 1989. Services provided by the Trust include:

- Wills and Estate Planning and Guidance
- Managed Trust Funds
- Personal Support Services (arranged visiting and advocacy)
- Personalised Accommodation Options

The Future Living Trust's mission is to provide a means for families of people with developmental disability to make reliable plans for the future and assist in the implementation of those plans when family are no longer able. The Trust came about as a result of parents asking 'what will happen to my child when I am no longer here?'. The combination of services the Trust provides to parents, families and people with disability are unique.

This submission is representative of the views of a number of the families that the Trust works with. They are not conclusive and are instead a snapshot of the types of issues that ageing parents of people with disability consistently encounter. The submission attempts to offer solutions to the four terms of reference that address "Access to options for and services to assist people with a disability and their cares to plan for the future".

The submission is written relating to people with developmental and intellectual disability only.

(a) Inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers;



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Whilst there are many issues, one of the main inadequacies of funding and planning options as the Future Living Trust see it, from speaking with many ageing carers of people with disability, is the uncertainty. Parents who are carers need firm guarantees about future funding of services. They need commitment from the government that funding will actually be there for their child when it is needed. Without firm guarantees ageing parents who are carers simply cannot make a valid plan for the future that provides any real peace of mind. For instance:

An ageing parent might be happy to have their adult child with disability living at home with them but wants to set things up so that at some point in time – when perhaps they are too old, too frail, or pass away, their adult child with a disability will move to a group home. At the moment this isn't possible. Parents can only apply for group home accommodation at the time it is actually needed (with that need being determined by others and in competition with other families), not with any future plan in mind. Parents need to effectively plan for a time when their child will move out of the family home and into a group home with an absolute guarantee that the funding will be there at that time. Pre-approved funding on the basis of need but deferred until parents decide an appropriate time to take up the funding would provide a solution to this dilemma.

Alternatively a parent might decide through their Will to leave the family home in trust to their son or daughter with disability to remain living in after the parents have both gone. The parents know that their adult child with disability will need funded care to remain living in the family home but the parents are unable to get any future commitment or guarantee about the provision of that funded care. This means that parents 'take the chance' that funded care will be provided in the future and 'someone' will apply and make the arrangements for it. In putting together a plan for the future most parents find this aspect extremely difficult because they can't formally tie in all the loose ends. Again, pre-approved funding for this future care would provide a parents peace of mind.

Parents also see the Special Disability Trusts as not meeting the needs of their children even with the recent changes that came into effect in January 2011. Many parents do not have the financial resources to set up such a Trust anyway, and are heavily reliant on government funding for the lifetime care and support of their child with disability.

(b) Ways to ensure the continued quality of life for people with a disability as they and their carers age;

It is important to ensure ageing carers can access funding when they feel the time is appropriate, and for the services they choose and need. This would include funding for additional support at home to enable ageing in place, funding for respite support for both carers and the person with disability whether that be day activity funding or overnight, weekend or week long respite, access to funded group home accommodation for their child with disability when they decide it is needed – not after years on the waitlist.

Access to skilled and independent advisors to assist families plan for the future and work with the family to develop an individualised plan is also critical. People with disability also need advocates who can look out for their welfare after their parents have gone. This advocacy can take various forms but it needs to be set up by the parents during their lifetime so that there is continuity for the individual into the future. The Future Living Trust provide advice



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services at no cost to a limited number of families each year as this service receives no funding. With funding we could do so much more. We also provide future advocacy services on a fee for service basis that parents can contract with us in preparation for the future. Also important is the issue of workforce retirement transition for ageing people with disability. By this time of life many adults with disability no longer have parents who are alive. They have also generally spent 40 or more years of their lives actively involved at work. Effective transition to retirement is critical so that they can move into this next phase of life and remain involved, community connected, and active. Retirement activities need to be better funded and more accessible. Consideration for the individual is also paramount to ensure the best retirement options.

- (c) *The types of options and services that could be developed to help people with a disability and their carers to plan for the future;*

Parents need independent advice and assistance in understanding all the options available to them. They then need advice in formulating a plan for the future dependant on the specific needs of their family. The plan must incorporate both the needs of the ageing carer, the needs of the adult child with disability and the future needs of that individual when the parents have are no longer around. At the Future Living Trust in Western Australia we attempt to provide this information in a format that is comprehensive and we work with the family and the DSC Local Area Co-ordinator to ensure the best possible plan that incorporates accommodation options, future advocacy, and financial management. The Future Living Trust assists parents with trust and estate planning and over the years has formulated specific policies to deal with the legal complexities involved. As a charitable Trust however, we are restricted in the number of parents we can assist as these types of advice services as they are not funded by disability services or FACHSIA in any way. Funding independent providers such as Future Living Trust to provide advice to assist parents of people with disability formulate a future plan would provide many more families with much needed peace of mind.

Consideration might also be given to funded independent legal services for parents so that the cost of making Wills and drawing up Trust documentation is negated. Legal advice in the area of disability is specialised so a list of experienced lawyers specialising in this area and operating in conjunction with groups like the Future Living Trust would greatly assist parents.

- (d) *Any other matters which would assist carers to find an adequate and appropriate answer to the question: 'What happens when I / we can no longer care?'*

Many ageing carers of people with disability, particularly intellectual disability, are restricted from accessing accommodation options such as retirements villages because there is no structure in place that allows ageing parents to take their adult child with disability with them to a retirement village and for that adult child to remain living in the village with funded care and support after the parents have passed away or moved to nursing home care. It is critical that aged care and disability services work together to find solutions that allow ageing parent who are carers a full range of accommodation options.



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Another issue for people ageing with disability is the appropriateness of their accommodation. As people with a developmental or intellectual disability age, with some experiencing early on-set dementia, they need age appropriate accommodation made available and the transition to that accommodation made easy. The option for the individual themselves to choose is important - to be able stay living in their own home with additional supports, to remaining in their group home with people they know and be provided additional supports to do so, or to choose to live in age appropriate accommodation within the community such as retirement village or nursing home through an ACAT assessment. Again aged care services and disability services need to work together in order to provide the best solution for the individual.

We would be happy to provide further information if required.

Yvonne Parnell
Executive Officer
Future Living Trust Inc.
(Formerly The Hawkevale Trust Inc.)
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