

**SUCCESSION PLANNING FOR CARERS – HAWKEVALE TRUST
SUBMISSION - DECEMBER 2006**

TO:

Succession Planning for Carers
Carer Policy Section
Department of Families, Community Services and Indigenous Affairs
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CANBERRA MAIL CENTRE ACT 2600



THE HAWKEVALE TRUST

Creating Long-term Living Solutions for People with Disabilities

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EXECUTIVE SUMMARY

The Hawkevale Trust Inc. is a charitable not-for-profit organisation incorporated in Western Australia that was established to assist parents and family of persons with a disability (principally an intellectual development disability) to seeks answers to the question: “*Who will care for my child when I am no longer able to provide the care?*”

In the course of providing its services (which at this stage are supervisory services, personal funds management, accommodation and life planning advice services, and not direct care) it has gained experience with families dealing with the issues that the Discussion Paper raises.

Key Points:

- Families are daunted by the complexity of the task of planning the future for their family member with a disability and there are limited resources available to assist families work through those complexities. We submit that more free or subsidised resources should be made available to educate and assist families for planning the future, preferably through experienced agencies and community based not-for-profit organisations.
- Planning the future raises key family questions that have significant emotional and family structure issues as well as financial ones: e.g., the decision that a the family member with a disability should move to independent supported living instead of staying at home, as part of a transition prior to the passing of their primary carers. . The funding and other financial incentives (such as the Special Disability Trusts arrangements recently announced by the Federal Government) need to be flexible so that they do not inappropriately favour one care solution over another.
- The potential for family financial arrangements to detrimentally affect pension allowances and incur additional tax liabilities strongly concerns many families. While the Special Disability Trusts arrangements recently announced by the Federal Government appear to offer welcome tax and social security benefits to encourage family financial support of persons with a disability; our initial impression is that the stringent compliance rules may limit the potential for these trusts to be used in a meaningful way to help families.
- If the compliance rules are as restricting as our first impressions indicate, there may be a case for allowing for an exemption for smaller non-complying funds dedicated to a person’s personal needs which are not so directly related to

their disability. The involvement of an accredited organisation in the management of those funds may be one safeguard that could encourage the tax and social security authorities to consider such an exemption.

- In the area of intellectual disability the issue of the legal capacity of the persons with a disability to deal with their own financial affairs significantly affects the choices available for planning and arranging secure long term arrangements. While recognising this is mainly an issue of State and Territory law, changes in the Guardianship and Administration laws of each jurisdiction to allow the involvement of accredited not-for-profit organisation as guardians may provide an answer, particularly where there are no family members remaining.

SUBMISSION IN DETAIL

Introduction

The Discussion Paper ‘Succession Planning for Carers’ succinctly sets out the relevant issues that members of the Hawkevale Trust’s Board have been dealing with at a policy and personal level for a substantial period, in the case of some Board members in excess 20 years. Given this, the Hawkevale Trust welcomes the opportunity to submit a formal response for review based on these issues.

The Hawkevale Trust is a not-for-profit organization incorporated in Western Australia in 1989 with the aim of seeking to answer the question raised by many carers and parents of disabled children, “*Who will care for my child when I am no longer able to provide the care?*” Understandably, this question is still being raised today (as seen on page 2 of the discussion paper) as it is evident there are many factors and issues that are still paramount in the decision making process of the parents and carers involved.

As an organization trying to deal with this on a daily basis, the issues we see that are proving to be of major concern to parents and carers are those relating to funding, accommodation and caring (although the Hawkevale Trust does not directly provide caring services, but does deal with caring in an over-seeing role). As result of issues and concerns raised with us, the Trust endeavours to provide a range of services that ensures that parents, families and people with developmental disability are given the opportunity and assistance to plan for the disabled family member’s future needs and provide a range of safeguards to ensure they receive a secure quality of life.

What prevents parents and families from planning for the future?

The Hawkevale Trust’s own surveys indicate that parents are well aware of the need for planning but do not intend to deal with the issue in the immediate future. We speculate, based on direct experience with families, that young parents are put off this difficult task for several reasons including a feeling that the future is a long way off and that there are no long term effective structures to allow them to plan financially in the long term outside their own wealth creation plans. We also speculate that older parents, who are generally more ready to deal with the issue, are daunted by their own limited resources and the complexity of the decisions to be made.

The Executive Officers (and Board members, to a lesser extent) of the Hawkevale Trust meet with families of persons with a disability regularly. The families are either existing or potential users of the Trust’s services. The Trust is often unable to provide a service that resolves the family’s needs, but in many of these cases is able to offer resources (such as information, introductions or contacts) that the family can pursue

to achieve their aims. Accordingly the Trust is familiar with the range of issues that face families planning for their family member's future.

From our discussions with many parents and carers of persons with a disability, most, even the elderly ones, have indicated that they would prefer to look after the child in the family home, rather than placing them in care. Their reasons range from "It is my child and I want to look after them", to not being able to find appropriate accommodation that the family feel comfortable and confident with, as well as many having the mind set of "My child is only twenty, how can I possibly know what the future holds!" Although all are very understandable reactions, the problem this creates is that there is a lack of planning and, when the crisis arises, arrangements are found not to have been put in place. This means when the carers do pass away, or are no longer able to look after their child, an accommodation placement, other than crisis care, is rarely available at the time when it needed most. In our opinion, one of the greatest challenges is convincing families to change this 'mind set' which is held by many parents.

Another factor that can affect these decisions is where both the parent(s) and the person with a disability have pension entitlements that are pooled for their combined living expenses. Expenses that were otherwise shared, such as rent and services, may be difficult for the remaining parent to bear alone. This may be a factor in being reluctant to put a transitional plan in place for the child to move to more independent living accommodation.

Although at the Trust we try hard to convince parents and carers to carefully plan for the future and to make these essential transitional arrangements, it is something we feel that could possibly be handled more strategically by the different levels of government to ensure that this particular issue is raised earlier in life as opposed to later. This could be tackled by making parents and carers of disabled children feel that, although faced with enormous difficulties and adversities, moving out and transitioning to a new environment is a normal progression in every child's life.

However, most parents do not have the money to provide for total care of their child so they have to rely on government support and government policies. Locating and obtaining the necessary funding from government agencies is a difficult and time consuming task which daunts many parents.

The Trust has tried to assist parents who are able to provide a degree of financial input by offering a visiting service., That service is "The Personal Support Service" which is set up so that when the parents pass away, or are no longer able to look after their disabled child, the Hawkevale Trust sets up a volunteer visitation service to oversee that the disabled person is looked after well and, if not, it is our responsibility to make sure that the service providers do something about it. It is akin to the Trust being in an "in loco parentis" role, so that while the Trust is not directly providing services on

a day to day basis, it is acting much as the parent of the person with a disability who is living away from home would have acted if they had remained alive and well. This is something that most parents are really looking for as well as the assurance that accommodation and quality of life is also ensured.

The Trust charges an actuarially calculated amount to cover the administration costs of its Personal Support Services, while the visitation is done on a voluntary basis with the Trust reimbursing travelling and sandal gift expenses. The parents who have Personal Support Services contracts with the Trust work with us to put in place transitional arrangements so that there is a plan in place to make sure that the transition from home to external accommodation and care is not too traumatic. Despite the Trust's best efforts though, there have been situations occasionally where the transition was not without trauma due to places not being available.

What could be done to encourage private provisions within families?

This question has been the biggest problem in planning for the future. There are a few issues that are to be considered:

- Many families do not want to leave big amounts of money in trusts that can be detrimental to the pension or is not fair to other siblings.
- The red tape that is required by siblings to look after money.
- If there are a few brothers and sisters then who handles the money and how are they recompensed for doing the work?
- What are the safeguards in the process?
- What are the charges if it is handled by outside individual or organizations?
- How quickly is the money made available when required?

The Hawkevale Trust also offers a "Managed Trust Fund" service that allows families to leave with us funds for particular or general purposes. Other commercial and government bodies do the same although often at a higher cost, or only for larger sums. Our Managed Trust Funds are often associated with a Personal Support Service or other service the Trust offers. The Managed Trust Funds have proved popular and seem to address all of the issues raised above.

The Government's endeavour to assist family members to look after their disabled relative with Special Disability Trusts appears to be step in the right direction, although it appears that the practical use of these Trusts may have some issues. On a brief review, it appears that the Managed Trust Funds established by the Hawkevale Trust will not comply as Special Disability Trusts because the funds can be used for expenses not uniquely related to the beneficiary's degree of disability.. This seems to be likely to cause many families to turn away from the Special Disability Trusts as they will need to constantly concern themselves as to whether an item of expenditure might cause the Special Disability Trust to fail to comply.

Perhaps this could be overcome if there was some alternative test that applied to smaller funds with a limit of a lesser amount - say up to \$50,00, indexed for CPI. This would avoid what appears to us to be an inevitable result from the current proposal, which is the need to set upon two funds, one which complies with the strict Special Disability Trusts rules, and another which is non-compliant but allows for “normal” spending.

Some families do see that it is solely the government’s role to look after the disabled people in the community and so this attitude has to change. The Special Disability Trusts will release some of the government’s responsibility for this role. However, many families may not have the resources to set up a complying Special Disability Trust fund.

We believe the issues mentioned above indicate that Special Disability Trusts should be made easier to administer for families, as many families would flounder with the detail. The Hawkevale Trust (and many similar organisations) sees itself as having a role in assisting families to set up complying Special Disability Trusts if they can usefully help persons with “severe disability”, but the compliance issues do concern the Trust at this early stage.

One area where the use of Special Disability Trusts might run into a major problem is the setting up of group homes. If a family sets up an individual home funded from a Special Disability Trust then that might be a waste of resources as it in many cases it would be less expensive to establish a group home. The question arises as to whether parents could use the Special Disability Trust arrangements to set up a joint trust with various sources (different families). The ability to move money from Special Disability Trust to another Trust if the Special Disability Trust’s beneficiaries move from one group home to another should also be considered.

If the compliance rules are as restricting as our first impressions indicate, there may be a case for allowing for an exemption for smaller funds dedicated to a person’s personal needs not so directly related to their disability. The involvement of an accredited organisation in the management of those funds may be one safeguard that could encourage the tax and social security authorities to consider such an exemption.

Are other informal arrangements or schemes needed to assist parents or carers’ who wish to provide for their child with a disability over time?

The potential variety of responses to this issue with different families is too great to mention here. Each time we meet with families another issue arises. The Hawkevale Trust looks at all of the issues with each family and tries to accommodate the family’s need as much as we can.

The biggest problem is that people with an intellectual disability are not able to use their own devices to make decisions in relation to their finances in the same way that many people with a physical disability can. This is a great disadvantage and really needs to be investigated to see what actually occurs rather than what is reported.

Among the options that should be investigated is a contributory savings plan for disabled children that will allow parents some taxation relief on the money going into the trust. (much like a like a superannuation fund).

Another issue to be considered is if the parents want to leave the family home in a trust to be used for the disabled individual. The Hawkevale Trust provides a service for this, but understands that various issues with taxation and Centreline implications. These may be ameliorated by the Special Disability Trusts but, for the reasons mentioned earlier, these may not be attractive to families..

Are there innovative models of accommodation that would assist parents and families make provisions for their child with disability?

A change to be considered here is when a brother or sister takes on the role of parent. We suggest that provision could be made for the ability to set up a Trust that can support them in needs to be classified and will not affect the tax of that family or the pension. It is imperative if we want families to do that then we should support them in every way we can. The trust set up should be handled by an outside body to oversee any requests made by the brother or sister. The feeling we have is that families will be willing to set up a Trust of this nature if it is explained clearly.

In the area of intellectual disability the issue of the legal capacity of the persons with a disability to deal with their own financial affairs significantly affects the choices available for planning and arranging secure long term arrangements. While recognising this may mainly be an issue of State and Territory law, changes in the Guardianship and Administration laws of each jurisdiction to allow the involvement of accredited not-for-profit organisation as guardians may provide an answer, particularly where there are no family members remaining

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