## SENATE COMMUNITY AFFAIRS COMMITTEE INQUIRY INTO SPECIAL DISABILITY TRUSTS

### **Submission from The Hawkevale Trust (Inc.)**

#### Context

The Hawkevale Trust ("the Trust" or "HVT") 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?".

As an organization assisting people trying to deal with this question it is the Trust's view that parents and carers have greatest concerns about funding, accommodation and caring services. While the Trust does not directly provide caring services, it endeavours to provide and develop options that ensure that parents, families and people with a 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 that they receive a secure quality of life.

## **Special Disability Trusts**

The Trust's understanding is that the purpose and intent of Part 3.18A of the *Social Security Act 1991* ("the Act") is to enable the establishment of Special Disability Trusts which will provide security of assets held in favour of a person with a disability, but will be such that the holding of those assets in trust will not unduly prejudice that person's eligibility for Centrelink benefits. (It is noted that the Trust's clients are only those who receive benefits under the Social Security Act, rather than through the Department of Veterans Affairs.)

# Reluctance of parents and carers to seek establishment of Special Disability Trusts

In the Trust's experience, there is a general lack of understanding in the community about the work of the Trust and similar organisations (eg Public Trustee). We believe that this, in part, reflects a general reticence in the wider community to face issues of mortality and associated issues, most notably complex testamentary issues. The divergence of 'mum and dad' assets (eg share portfolio, superannuation and property acquisition, family trusts) only increases this complexity.

We are not surprised at the observations of The Senate on 15 May 2008 (as reported in the Terms of Reference for this inquiry) about the small number of Special Disability Trusts established. To us this is symptomatic of the belief by some families who see the government as being solely responsible for looking after people with disabilities, and of the community reticence referred to above, rather than a judgment on the merits or otherwise of the trusts. However, in saying that, it must also be

considered that many families may simply not have the resources to set up a complying Special Disability Trust fund.

We turn to two specific client groups of parents of people with a disability or their carers: viz. younger parents and older parents.

- (1) In the case of 'younger' parents (eg up to age 40), we note the following:
  - They are young themselves, and may not yet be seriously dealing with their own mortality. They are also focused on family life, career, mortgage and recreational interests.
  - They perceive that the issue of care for their disabled child is still a long way off in time.
  - Their children will be legally dependent until age 18 and the issue of independently held assets is almost non-existent in this group of people. (Ancillary to this is that the child is likely to be *actually* dependent on the parents throughout their (the parents') lives, and so the parents feel that while they are fit, strong and healthy, there is no need to worry.)
  - These parents will want to keep options open and even though their own generic and fail-safe testamentary provisions might be made (eg dividing their assets equally among their children), they might not yet have the assets or see the need to lock any away at this young stage of their lives.
- (2) In the case of 'older' parents (eg aged 65 and over), in our experience the issues become more diverse and complex, but the following observations are offered:
  - If their own resources are limited (eg they have moved into aged care, or only have a principal residence without significant superannuation or other cash assets), they do not see the relevance of putting significant sums away in trust for their child.
  - There is, particularly among the parents of 'baby boomer' people with a disability, a lack of understanding of trust and asset management a lack of understanding inhibits people from entering detailed arrangements committing significant assets.
  - They may have arrangements in place already for their child. For instance, parents may have entered arrangements with care providers (eg in group homes) for a significant portion of pension benefits to be paid for care, food and accommodation (eg on a monthly basis), plus allocations ('allowances') of money for recreational pursuits, entertainment and group activities. It is our observation that, once such reasonable outlays are made, there is little accumulation of wealth for a person with a disability.
  - They may have arrangements in place for siblings or other relatives to care for their children.

In addition, we observe that there are constraints on the range of permissible purposes for which a Special Disability Trust may be used. Specifically, the SDT may only be used for expenditure associated with the beneficiary's degree of disability. This seems likely to cause many families to turn away from SDT's as they would constantly need to concern themselves as to whether an item of expenditure might cause the SDT to fail to comply. Perhaps this could be overcome if there was an alternative test that applied to smaller funds. This would avoid what appears to an inevitable result of an SDT, which is the need to set up two funds, one that complies with the SDT rules, and another that is non-compliant but allows for 'normal'

spending. It must also be considered that where an individual receives State-based funding, an SDT may be regarded as unnecessary.

## Part 3.18A of Social Security Act 1991

The Trust has perused the Part which is relevant to this inquiry and has no comment regarding its content or construction.

We do, however, have significant interest in the underlying purpose and intention of the Part

It is our contention that, since its inception, The Hawkevale Trust has aimed to provide the security which parents seek (for their offspring with impairments) of such significance that those children cannot manage their own affairs.

Among its services, the Trust offers advice to parents who seek to make provisions in their Wills for the benefit of their children with a disability. Such advice is aimed at helping the parents to achieve their desired purposes and level of 'peace of mind'. Solutions vary according to individual circumstances.

Where parents seek to place assets, either by way of property or cash, into trust, we offer several services.

For placement of cash, a "Managed Trust Fund" facility is offered, by which the parents enter a trust deed with HVT which enables us to administer the funds for the benefit of the individual, in accordance with the trust deed. While the funds are held by HVT, and therefore not an asset of the individual, they are assets test exempt however, the income earned each year is taxable and may attract an income test.

In the case of property, we have some clients who bequest property to the Trust on condition that the Trust will operate and maintain the property for the benefit of the person with a disability. We enter such arrangements on condition that, upon the death of the beneficiary, the property reverts wholly to the Trust.

Finally, and also in the case of property, the Trust has entered several joint ventures with parents of people with a disability by which the Trust has acquired or constructed housing properties, using (in whole or in part) assets donated to the Trust by parents, with the use and ultimate disposal of the property being as described in the previous paragraph.

#### Conclusion

It is our belief that the Trust can, where appropriate and necessary, provide for its clients trust arrangements that are largely consistent with Part 3.18A of the Act. The relatively low take-up of Special Disability Trusts is, in our opinion, symptomatic of the 'disability sector'. The essential inhibitors of people entering any significant arrangements relate to lack of awareness, and the desire for long-term security in the arrangements they make. This latter point is significant and relates to the very use of the word 'trust' – there is no greater act of trust that a parent can make than to have confidence that their wishes will be complied with when they no longer are here, or have capacity to ensure so. It is a big step for them to take and requires significant consideration, reasoned thought and emotional commitment.

We have confidence that the services provided by the Hawkevale Trust are well designed and implemented to meet parents' needs.

We believe that it is desirable for agencies such as ours to become endorsed and better known in the sector and the wider community as having the expertise and the product portfolio which will enable parents to have confidence that their wishes will be fulfilled without any disadvantage for their child.

Members of the Trust are available to provide further information to the Committee as required.

This submission has been approved by the Mr Laurence Iffla, Chairman of the Hawkevale Trust.

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