SENATE COMMUNITY AFFAIRS COMMITTEE

INQUIRY INTO SPECIAL DISABILITY TRUSTS

"Families wish to ensure that their sons and daughters with disabilities are able to have a good life that involves family and friends, a place to call home, economic security, a sense of purpose and opportunities to participate and contribute to the community."[i]

INTRODUCTION

It is understood that the proposal for Special Disability Trusts arose from approaches by families who were caring for their son or daughter with a disability to the then Minister for Family and Community Affairs, Senator the Hon Kay Patterson. Many families had advised that while they believed their child may have limited opportunity to access ongoing government funded supported accommodation, they also wished to make provision ,or part provision, from their own family funds for ongoing care when they could no longer provide it themselves. They indicated that such an approach was constrained by the terms of the Social Security Act through the impact that such a provision might have on the entitlement of the person with a disability to a Disability Support Payment and its related benefits.

As a result of this and related factors, families argued that there was no opportunity for them to plan for a transition from family care to viable alternative arrangements when the family care came to an end. There was, they indicated, limited opportunity to provide a residential property for the use of the person with a disability or for a family or others to fund all or some of the rental costs. More importantly, however, it was pointed out that there were significant restrictions on the way in which funds could be set aside to meet all or part of the support costs of a person with a disability without destroying their rights to social security.

Special Disability Trusts were, therefore, designed as one option that provided an opportunity for some families and others to make a contribution to the cost of providing long-term supported accommodation to people with disability.

On the 13th October 2005 the then Prime Minister announced that the Government would legislate to facilitate the creation of Special Disability Trusts. Subsequently, the Minister Senator Patterson established an Advisory Group to provide a report to her on how such a proposal might be best implemented. I acted as Chair of that Group.

The Group was requested to report to the Minister to:

1. *define what is a 'severely' disabled child;*
2. *define who is a parent or immediate family member;*
3. *prescribe the care and accommodation needs the trust should be able to pay for;*
4. *identify methods to ensure that the severely disabled child and parents are protected.*

The Advisory Group prepared a report to the Minister in March 2006. That report made a number of Recommendations and Findings, many of which have been implemented.

While this submission to the Senate Inquiry is made in my personal capacity, it will be in continuing support of those that remain outstanding as well as adding proposals that emerged subsequent to the legislation being introduced.

In the preparation of that report to the then Minister, it is important to note that the Recommendations and Findings were drafted by the Advisory Group in a context where there was no firm evidence before it to indicate the possible extent of the "take up" of the new trusts or the likely cost to tax revenue. Some very general estimates had been made by various government agencies but it was clear that the reality might prove to be quite different. Consequently, the rules proposed for establishing the trusts were drafted cautiously, being a first step only, with the hope that they could be revised and extended in the light of further evidence and experience.

That Advisory Group also held the view that Special Disability Trusts were not a broad-based response to meet the substantial unmet accommodation needs of people with disability. The view was that these trusts were designed to assist some people with disability to access appropriate supported accommodation and thus partly reduce the existing and future unmet need. The number of families that may be assisted could be quite small at the outset but would grow as the facility became better known or should the conditions governing the creation of the trusts made more flexible following further reviews. It was not, however, a universal solution.

Under these circumstances, this Inquiry of the Australian Senate is timely and appropriate.

Following the implementation of the scheme, I was requested to facilitate a number of consultations throughout Australia, which were designed to explore the broader issue of succession planning for carers. Consideration of the Special Disability Trusts became an important part of that consultation.

These consultations were not in the form of public meetings but involved a wide range of carers, disability advocates and related groups. The purpose of the activity was to seek comprehensive views on succession planning for carers that would assist Departmental officials prepare further proposals for the consideration of the Minister.

While I was not involved in the preparation of the Report to the then Minister, it contained a number of critically important observations about the lack of any ability for carers to plan for the ongoing care of a person with disability.
It identified an overall lack of accommodation and support options, access to information and advice, the complexity in planning to meet the "whole of life" needs of a person with disability, limited existing options for families to partner with governments and the inability of many carers to engage in any planning when the demand is to meet today's needs. It also made a number of comments about Special Disability Trusts which reflected many of the findings of the earlier Advisory Group.

A summary of the Report on the Succession Planning for Carers is published on the Department of Families, Housing, Community Affairs and Indigenous Affairs web site and can be accessed at:
www.facsia.gov.au/carers/succession_planning_report/part2.htm

I would commend that summary report to the Inquiry.

However, two important conclusions arose from both these reports. They are:

1. Special Disability Trusts are not the total answer to ongoing support for people with disability and may have a limited appeal only. They do, however, provide a useful tool to assist with planning for the future even if other solutions are eventually taken up; and

2. Special Disability Trusts are only one side of the issue and will never be successful unless there are options available for families to access through the trust structure. At the moment, disability services are crisis driven as an emergency management activity rather than facilitating planning for the future. This makes it difficult for families to plan if they do not know what the options might be now or in the future. If long-term accommodation or support options are not available, for example, families will see little point in planning for the future let alone establishing a trust to make available funds to finance non-existent services. This means that any review of the Special Disability Trusts cannot be considered in isolation but must be part of a wider debate about the provision of accommodation and support services generally and especially their expansion through partnership arrangements between governments, disability service organisations together with families and the wider community. Special Disability Trusts should not be about the provision of appropriate accommodation and support services for people with disability but rather be viewed as another way in which some of the costs of these services might be met.

ISSUES OF CONCERN TO FAMILIES

During these consultations and through subsequent discussion with the disability community, a series of concerns have been drawn to my attention especially by ageing carers who are providing care for a family member with a disability. These concerns, I believe, could impact on the uptake of Special Disability Trusts to varying degrees and need to be reviewed as part of any process of making the facility more attractive to families who have a caring role. Some of the major issues are set out below:

1. **What is “severe” disability?**

   Definition of “severe” disability may be too restrictive. While there is an appreciation of the importance of using an existing assessment process to determine the extent of the “severity” and thus the eligibility to create a trust, it was believed that it might operate to inappropriately exclude some people. For example, it may exclude some who might not require the degree of care needed to qualify for a Carer Payment or Carer Allowance but for whom privately funded support would be the difference between true independent living and ongoing family support or supervision. In addition it is argued that there are many people with disability who are employed in disability business services and other day placement activities whose carers may not fit the eligibility criteria but for whom a Special Disability Trust would be an excellent and desired option.

   It was also important to note that people with episodic conditions including mental illness and brain injury, might be excluded under the eligibility test. This would be detrimental to a significant group of families.

   A more flexible eligibility test could be considered especially as the evidence is that the take up has been less than originally thought. However, in drawing that conclusion every effort should be made to utilise an existing assessment test rather than creating a new one.

2. **What costs can the trust meet?**

   The application of funds by the trust was also seen as both restrictive and unclear even though significant discretion was in the hands of trustees and the Department/Centrelink.

While there was an agreement that "accommodation" costs such as rent/housing, medical and personal care costs were appropriate, these do not take into account the fact that a *"home is simply not a bed"*[i]. Accommodation must take into account the social, emotional and health needs of a person with a disability as well as ensuring that they have a compatible living arrangement with others and are able to participate in and contribute to the community. Without these being included, a person with a disability could be supported in accommodation through the operation of a trust but could be excluded from a vital range of activity which creates the quality of life that is an essential part of "independent" living.

The other need is to recognise that people with disability are usually unable to move into accommodation without a process of transition. This means that they will need to gain independent living skills before they transition to any new arrangements. This would include access to short term trial living arrangements such as respite, in home training to develop living skills, travel training and so on. Transition is an essential part of making any new arrangements supported through a trust, successful.

Expenses that relate to these factors should, therefore, be eligible to be paid from the fund.

An additional concern arises from the requirement that the costs of care provided by family members is excluded from those that could be met from the trust. While the reason for this is well understood as being necessary to avoid trusts being manipulated inappropriately, many families have indicated that the blanket prohibition can create real problems. Families that cannot obtain professionally trained carers, as is often the case in regional and remote areas or those that have to fill in when professional carers are not available cannot receive payment for their services even if they may have to give up their own paid employment to do so. Also, many families may not be able to find a professional carer who can take their child with a disability on a holiday or regular social outing. At the moment they cannot receive a payment for their time and it is unclear whether they can receive a contribution to out-of-pocket expenses. Greater flexibility to allow the trust to meet a broader number of costs would make it more attractive to families and others even if those costs are closely defined.

3. **Complexity of trust structure.**

   For many people the trust structure is seen as complex and legalistic with quite onerous responsibilities on non-professional trustees. By the same token, the only option to self management is to appoint a professional trustee and that is viewed as expensive and could use up a significant amount of the earnings of what are fairly small trusts. While alternative low cost management arrangements have been discussed the issue remains unresolved with the consequence that Special Disability Trusts may be avoided as a solution.

4. **When will a trust be needed?**

   While significant number of families may see Special Disability Trusts as a useful option, the time at which they need to be established will vary. For instance, if a person with a disability is being cared for at the family home there is little point in establishing a trust unless there is some alternative care arrangement available. At the moment, such an alternative care arrangement may be available if the family is "in crisis" but even that is not guaranteed. It is not possible in most cases just to rent or purchase a house or apartment and move the person with the disability. The location is critical to ensure that support is available, that it is close to day care activities, transport and related facilities. More importantly, people with disability do not want to become isolated so their living companions, whether disabled or not, need to be part of the accommodation planning. Of course, for many families the only way in which they could develop alternative accommodation and support arrangements would be to join other families in similar situations and to pool resources. At this stage, there are few effective networks through which families can identify others with whom they might wish to partner. All of these factors identify a whole host of complex but related issues.

Further, and as has already been noted earlier, many people with a disability will require a "transition program" to be implemented before a relocation or alternative care arrangements can be made. Training in living and related skills will have to be completed which will be costly and complicate the relocation process.

These are not easy issues to resolve. There are few, if any, agencies to assist families to find compatible people to share accommodation so it is mostly left up to each individual family to use their own networks to make the match and develop all the alternative care and accommodation arrangements. The consequence of this is that it becomes such a very difficult task for caring families who are engaged in a demanding and totally time consuming caring role. They have neither the expertise nor the energy to undertake such a task. The consequence is that people with disability are simply staying in the care of their family late into their lives until a crisis arises. While the need for a Special Disability Trust may be recognised as appropriate by some families the lack of support, guidance and suitable options simply makes the effort seem inappropriate.

A flow on from this is that while some family members with caring responsibilities may not see an immediate need to establish a trust they may still desire to make provision for their family member with a disability following their death. Consequently, it is believed that many families are putting into place the mechanism for establishing a trust as part of their will and estate planning. It is unclear whether any estimate can be made of the number of trust structures that are attached to wills but anecdotally, at least, it appears to be greater than the number identified by the Department/Centrelink.

5. **Capital gains and related tax issues.**
   As the need for a Special Disability Trust depends on particular events, such as the prospective beneficiary moving into alternative care arrangements, available funds would have to be identified and paid into the trust as one or a series of lump sums at the time it is established. As the trusts are liable to pay tax and especially capital gains tax, significant obligations might arise in the management of a trust. However, this is especially stark when capital gains tax (and stamp-duty) may have to be paid if a contributor liquidates an asset for transfer to a trust. In addition the trust itself would become liable for tax on its earnings and capital transactions. These issues could discourage family members from making contributions or even establishing the trust in the first place and amendments to allow certain tax issues to be deferred until the trust is wound up, would appear compelling.

6. **Tax issues.**
   The taxing of the trust at the highest marginal rate also has raised other concerns that could operate as a disincentive to creating trusts. Most families want to have the opportunity to plan for the care and security of their family member with a disability from the earliest time possible. This for some would

be immediately after the birth of the child with the disability of from the event in later life when the disability is acquired.

In these circumstances, the most desired option for families is to be able to establish a trust and to make contributions over time so that the fund can grow through a combination of earnings, capital growth and ongoing contributions. In this way it would be seen in the same light as superannuation funds which accumulate funds over time to meet a demand for financial support, say in thirty years time when funded professional care is required because the care can no longer be provided by the family.
Such an approach would encourage ongoing planning for the future of the person with the disability as well as opening up trusts to a wider range of families for whom large lump sum contributions might appear to be beyond their reach.

However, under current taxing arrangements, the growth of a fund would be eroded significantly as the highest marginal tax rate is applied to any undistributed income. This makes it impossible for a person to grow a fund for the future through the application of modest but regular contributions over time and there is compelling logic to treat these funds in the same way as superannuation.

The continued application of the existing tax regime to Special Disability Trusts will continue to be a major disincentive and exclude many families from utilising this facility.

7. **Incentives for trusts.**
   Many families have expressed the view that while they would wish to contribute to a trust to whatever level of funds they may be able to afford,

they have also observed that no government incentive operates to encourage them to do so. While a family's love and concern for their member with a disability may be incentive enough for some, they contrast that with the incentives that apply for people to make provision through superannuation for their older age. As is recognised by government, greater private provision for older people reduces the demand for assistance from public funds. In order to facilitate this government has responded with incentives through fund and personal tax incentives and even including a system of "co-contribution" with public funds matching private contributions in specific circumstances.

Special Disability Trusts are seen as preparing for the future of people with a disability in much the same way as superannuation secures the future of people who are ageing.

A similar low tax regime to that applying to superannuation funds could be considered for these trusts or deferring tax until the trust comes to an end. In addition, more favourable consideration could be granted to those making contributions to a trust. Some families have suggested that contributions might be made tax deductible while others have proposed that if it became possible for contributions to be made on a regular basis and over time that they be paid from pre-tax earnings on a salary-sacrifice arrangement. Again a system of co-contribution could also be considered.

8. Increasing the trust cap.

When the then Prime Minister announced the intention to create Special Disability Trusts with the ability to accumulate up to $500,000 there was little evidence provided on why the cap had been set at that level.

In the absence of any justification for the cap, what has become apparent is that for some disabilities at least, an amount of $500,000 may not be sufficient given the high costs of disability. While it is recognised that this cap would be moved in line with the Consumer Price Index, the high cost of support for some disabilities would suggest that much greater amounts are required and that a cap of $1,000,000 might be justified.
Clearly any review upwards of the cap would encourage the up take of the scheme.

9. **Promoting trusts.**

The availability of Special Disability Trusts as an option for making private provision for a person with a disability is not well known, or if it is known the detail is often sketchy. Both these factors could operate as a disincentive to people taking up the facility.

Experience has shown that with the exception of a few specialists, financial advisors, lawyers and accountants have a very superficial knowledge of Special Disability Trusts with the consequence that as they are not "top of mind" they are rarely promoted as a first option to clients. Anecdotal evidence would suggest that Special Disability Trusts are initially considered at the suggestion of the client rather than proposed as a solution by the professional. As already noted, of course, there are a number of excellent exceptions to this among a few professional groups who provide specialist disability advice.

Nevertheless, it would appear that professional development programs covering these trusts could result in an increase in the number of people considering their applicability.

In addition, a significant number of disability organisations and advocacy groups also appear not to be promoting these trusts as an option for families caring for a person with a disability. Many may see themselves as not competent to provide any advice or information or that it is beyond their role or responsibility. However, for many families it is to their disability organisation that they turn for information and it is important that these organisations are provided with appropriate information and encouraged and funded to promote trusts as an option for some families. As part of this process it would be critical to facilitate their ability to make referrals to an appropriate person or organisation.

An added dimension would be to assist disability service providers to explore how they might develop services that would seek to partner with these trusts in order to meet the needs of some of the beneficiaries. There would appear to be an opportunity for service providers to develop products that could be marketed to trusts to provide accommodation or support or both. If families could see that accommodation and support options were available through organisations with which they had a confident relationship, they may be encouraged to establish a trust to provide the necessary funding. At this stage there is little innovation being undertaken in these areas and is unlikely to occur without assistance. One way in which this could be facilitated might be to research existing innovative accommodation programs and services and publicise them as examples of desired practice. I am critically aware that groups of families are coming together to try to plan a way forward, however few know what innovative accommodation options exist in their city or around the country. A clearing house for information would be of great assistance.

An extension to that would be to fund disability service providers to pilot innovative accommodation options or to provide assistance for service providers to retain consultants and other specialists to develop and trial a variety of products.

Of course, it is also a fact that some families caring for a person with a disability have little effective connection with a disability service provider. For those families the ability to obtain information on trusts is very limited. Consequently, they are less likely to take up a trust option unless there is a concerted effort by government or Centrelink to provide the necessary information or counseling.

10. **Changing community opinions.**

A final reason for the slow up take of Special Disability Trusts could arise from the view held by some in the community that it is governments' role to provide for the welfare of people with disability and that any move to private provision will lessen the need for them to meet that obligation through the provision of adequate funds or services. Governments will, it is feared by some, be "let off the hook". Coupled with this is a view held by some that by facilitating private provision, somehow governments will be encouraged to grant a priority in service to anyone with a disability who can bring with them resources that could supplement the cost of those services.

There is no clear evidence that these views are widely held and it is also unclear if they have impacted at all on the decision of families to explore the appropriateness of Special Disability Trusts. They are, however, views that have been expressed informally and perhaps identify a need to consider a community discussion on the advantages of partnership arrangements.

CONCLUSIONS

In addressing the concerns noted above consideration might be given to the following actions:

1. Special Disability Trusts should be seen and supported as an innovative way of meeting the needs of a section of the disability community but is only one part of a plan to satisfactorily deal with the enormous unmet need nationally for support and accommodation for people with disability.
2. As part of a broader reform process, consideration be given to negotiation with States and Territories to ensure that the needs of people with disability are dealt with equitably but in a way that embraces the notion of partnership arrangements with the families of people with disability.
3. Special Disability Trusts cannot be reviewed in isolation to the overall issue of adequate support and accommodation for people with disability. This must recognise that if there is a desire to assist people to plan for the future care of their family member governments must assist in developing a range of options around which planning can occur. At the outset this means that governments must move from a crisis and emergency management model to one which embraces planning and partnering with the community.
4. As Special Disability Trusts are a new and relatively untested proposal it will take some time for the advantages to be understood and embraced by the wider community. While the current up take is somewhat disappointing this should not be viewed as meaning that the process is inappropriate and therefore should be discontinued. Rather, it identifies the need for modest change to improve its acceptability together with a program to promote its benefits over a sufficiently long timeframe. In this respect the following areas for change might be considered:

- Provide a definition of " severe disability" that is more flexible but which uses existing assessment processes;
- Expand the items of cost that can be met through the trust and especially those that relate to quality of life issues;
- Review tax and related issues to encourage families to plan for the future of their family member with a disability especially providing the opportunity to contribute to a trust so that funds can be grown over time in a manner similar to existing superannuation arrangements;
- Review tax arrangements and especially the application of capital gains tax so as to remove the disincentive of transferring funds to a trust and its liability to pay that tax possibly by differing that tax obligation until the trust has come to an end;
- Through the development of "master trust" type scheme create a process through which a trust might be administered at a low cost drawing on experience from the administration of superannuation funds;
- The need to explore an acceptable range of incentives for families to establish Special Disability Trusts including the appropriateness of a scheme for co-contribution by government; and
- Consider increasing the cap on the trust to reflect the high cost of disability.

5. Recommend the implementation of an information and promotional campaign to the disability community in order to outline the benefits of Special Disability Trusts. This should include the provision of information as well as assisting them in the dissemination of information to their clients and their families. It should also explore with disability service providers ways in

which they might partner with the trusts to better meet the accommodation and support needs of their client beneficiaries.

6. Provide training and information to the professional legal, financial and trust advisors in order to ensure that appropriate advice is provided on the options that are available to families who care for people with disability.
7. Give consideration to supporting agencies that can broker accommodation options with particular support for those who are able to facilitate appropriate and compatible accommodation placements. This should include the opportunity to bring families together to plan for the future.

The inquiry by the Senate Committee is both welcomed and timely. It provides an opportunity to not only up-date what is an innovative and valuable scheme but also to explore ways in which it may be extended and made more applicable. There is little doubt that as existing carers age and become less capable of providing the care for their family member with a disability, it is critical that their needs can be met in a way that respects the dignity and the rights of all involved.

That task should not be beyond us and the creation of an effective regime of Special Disability Trusts must be seen as part of that process.

I.O. Spicer AM
June 13, 2008

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[i] Comment at Succession Planning for Carers consultations 2006