

NATIONAL COUNCIL ON



DISABILITY

National Council on Intellectual Disability

Submission

Senate Inquiry into Special Disability Trusts

13 June 2008

National Council on Intellectual Disability (NCID)

Rob Allen, President

Mark Pattison, Executive Director

PO Box 771

Mawson, ACT 2607

02 6296 4400

ncid@ncid.org.au

www.ncid.org.au

Senate Inquiry into Special Disability Trusts

Introduction

The National Council on Intellectual Disability (NCID) was established over 50 years ago by parents and friends in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with intellectual disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.

It must be recognised that the Special Disability Trusts address the needs of a minority of families living with disability. Regardless of the criteria that are attached to the Trusts and how these can be changed in an attempt to include more people, the fact remains that the majority of families living with disability do not have excess resources to set aside for the future.

This does not mean that the criteria should not be changed and that the Trusts are not a useful financial planning tool for some families. The main purpose of the trusts was to enable family members and people with a disability to set aside funds and in doing so not to jeopardise their eligibility for the disability support pension (DSP) and the Aged Pension. With the general community emphasis on family financial planning and families having a greater regard to the future financial needs of all their children, many families are making the necessary arrangements well outside of the pension waiting period.

In making recommendations for changes to the criteria in regard to the Special Disability Trusts the National Council of Intellectual Disability is mindful that the Trusts will not meet the needs of the majority of families living with disability and so

we begin our submission with a number of key issues for all families living with disability.

General comments

This is an important issue for people with intellectual disability and their families and NCID's Board has spent considerable time consulting with members and holding extensive discussions on the Special Disability Trusts.

Following our wide-ranging consultations NCID would like to make the following comments:

- i. In establishing the Special Disability Trusts NCID acknowledges (and appreciates) that the Government is responding to a call from some families and that the Trusts will address their needs and hence be beneficial to this select group.
- ii. The original proposals for the Trusts arose from families who have the resources to purchase a house or flat for their son or daughter and found that there were pension consequences for themselves and their daughters and sons in doing so. *In addition it must be recognised that most families provide financial support to their sons and daughters as the Disability Support Pension does not cover a person's living expenses (board and lodging) plus transport, day services and therapy costs.*
- iii. The establishment of the Special Disability Trusts to allow families to continue to provide for their sons and daughters as detailed above (ii) and does not disadvantage either party in terms of their pension is welcomed by all. Also the ability for families to 'save' funds by setting up a Special Disability Trust for their daughter and son that has preferential tax treatment would enable families to provide greater assistance of the kind listed above.
- iv. **But, if the purpose of establishing the Special Disability Trusts is for families to fund existing government support responsibilities then NCID opposes the Trusts as it would mean that people with intellectual disability would receive less than they currently do; as current family support for 'extras' will be diverted to providing essential 'care'.**

-
- v. We currently live in a time when governments are extremely reluctant to provide funding to people with disability. The unmet need list grows year by year as governments refuse to commit to planning and budgeting for the needs of families.
 - vi. The establishment of Special Disability Trusts to provide **solely** for the care needs of people with severe disability is a failure of governments to provide adequate support and accommodation to Australians with disability.
 - vii. For many years families have lived in an environment where the practise of 'user pays' is dominant. In particular day services are expecting families to pay fees and transport costs; many families have told NCID that because the DSP is insufficient to meet these costs (and the person's daily living expenses) it is the families that must pay them. The concept of 'user pays' has grown over the years but this is the first extension of it to a 3rd party; ie, an imposition on an individual(s) who does not receive the service.
 - viii. There continues to be a real concern that the Special Disability Trusts will create a two tier system where those who are able to contribute to care costs will have 'top-up' funds provided in a service of their choice and where those who are unable to contribute to the care costs (or are unable to do so to a substantial degree and on an ongoing basis) will be a parental responsibility until both parents die and then they will only get a basic service with no choice.
 - ix. The emphasis of the Special Disability Trusts is on the financial situation of the family not the individual who in many instances are reliant on the Disability Support Pension. With their children already living in poverty there is a real danger that by putting funds into a trust (to fund essential support) both parents and children will be driven into poverty.
 - x. The optimum situation would be that the Special Disability Trusts were implemented after governments had established an entitlement to daily living support funding (including accommodation) for people with disability at a minimum level that enhances community participation and an 'ordinary life'. Within this context the Special Disability Trusts would be an 'add on'. An opportunity for families to assist/support their children beyond the minimum, eg, transport, therapy aids and holidays.
 - xi. NCID believes that the Special Disability Trusts should, as a minimum, have similar features as Superannuation Funds, eg, contributions to the Trusts to be

tax deductible, the Trusts to pay little or no tax on income and distributions to the named recipient to be tax free.

Issues of Concern

1. Definition of *immediate family member*.

The definition is important as only an *immediate family member* can place funds into the 'Trust' and receive the benefits (see 2 below).

The legislation defines an immediate family member as a parent (natural, adoptive or step-parent) grandparent or sibling.

Those not included who may have a special relationship with the child with disability and may want to assist the *principal beneficiary* (see 2 below) are uncles and aunts and godparents.

Recommendation: that the definition of immediate family member be either removed so that anyone can contribute to the Special Disability Trust or that the definition of immediate family member be greatly extended.

2. Who will benefit from the Special Disability Trusts.

Immediate family members who make a contribution to the Trust will not have that amount included in their assessable assets test for eligibility for the aged pension.

"Under the Social Security Act, there are limits to the assets a person can hold without those assets affecting their entitlement to social security payments. Further, a person who gives away an asset is treated, for a 5-year period, as if the person still owned the asset when assessing entitlement to social security payments. The operation of these rules has made it difficult for immediate family members of a severely disabled person to set up a trust to ensure the disabled family member's continued care without their social security payments being affected."

Though this benefit is limited to the 5 years before they are eligible for the Aged Pension. If they make a contribution outside of this period then there will be no negative effect on their Aged Pension.

The income from the trust will not be assessed as income for eligibility for the Disability Support Pension. This is a major benefit to the person with disability (the principal beneficiary); though it does raise a number of questions about how income from other forms of trusts, etc are treated and also how the ATO will assess this income – particularly as the Special Disability Trust will not be a discretionary trust, having a named beneficiary. Also, the Bill and the Explanatory memorandum made no mention of whether the Trust will be viewed by the ATO as a charity.

Additional issues are, Capital Gains Tax on the placement of property into the Trusts and the sale of property by the Trust to buy a more appropriate housing; and the restriction of the benefit to families members only in receipt of the Aged Pension or eligible for the Aged Pension within 5 years (or Veterans Pension).

The lack of clarity about the range of financial instruments that are available to families living with disability and uncertainty about tax and subsequent income considerations have not assisted families in making informed decisions about the Special Disability Trusts

Recommendation: Given the highly restrictive nature of the Special Disability Trusts that the Government seek the views of experts on how the Special Disability Trusts equate with other arrangements and provide all people with disability and families with clear advice as to what the range of options are.

Further that the Government review the negative tax consequences that mitigate against the original intention of the Special Disability Trusts.

3. Definition of ‘Severe Disability’

The definition in the Bill is given below.

(2) If the principal beneficiary has reached 16 years of age: (a) the beneficiary must:

- (i) have an impairment that would qualify the person for disability support pension; or
 - (ii) be receiving invalidity service pension under Part III of the Veterans' Entitlements Act; or
 - (iii) be receiving income support supplement granted on the ground set out in subparagraph 45A(1)(b)(iii) of the Veterans' Entitlements Act; and
- (b) the beneficiary must:
- (i) have a disability that would, if the person had a sole carer, qualify the carer for carer payment or carer allowance; or
 - (ii) be living in an institution, hostel or group home in which care is provided for people with disabilities, and for which funding is provided (wholly or partly) under an agreement, between the Commonwealth, the States and the Territories, nominated by the Secretary under subsection (3); and
- (c) the beneficiary must have a disability as a result of which he or she is not working, and has no likelihood of working, for a wage that is at or above the relevant minimum wage'.

The question remains as to whether the Trusts should also be available to all people with a disability or all people with a disability who are unable to 'work for a wage that is at or above the relevant minimum wage' (in addition to the criteria above).

It is arguable that all people with disability have additional housing and support needs because of their disability and therefore any 'income' spent on these needs should be exempt from the DSP assets test (and income tax).

Recommendation: That all people with a disability be eligible to be a beneficiary of a Special Disability Trust – at a minimum that it applies to all people who receive a full or part DSP, but that the ABS definition of needing assistance in one or more daily activities be made the criteria.

4. Special Disability Trust financial limit

The Special Disability Trust upper limit has been set at \$500,000, indexed

each year. This is a low limit given the cost of housing and also the return that can be achieved for ongoing support.

Recommendation: That the upper limit for the Special Disability Trust be set at a minimum of \$1,000,000, indexed each year.

5. Definition of care

The sole purpose of the Special Disability Trusts 'must be to meet reasonable care and accommodation needs of the beneficiary'.

Reasonable care and accommodation needs are not defined, though the Bill does make provision for the Secretary (by legislative instrument) to 'make guidelines' which are then binding on the Special Disability Trusts.

Recommendation: That the 'definition of care' be greatly extended to include any support equipment or service a person with a disability requires and where the person is in receipt of a DSP that the definition of care be further extended to include such things as holidays and personal entertainment items.