

## Special Disability Trust Inquiry

People With Disabilities (WA) Inc – PWD(WA) is the peak disability organisation representing the rights, needs and equity of all Western Australians with disabilities

### Background

PWD(WA) has been involved for many years in assisting parents and carers in planning for the future of their children/adults with a disability. In 2001 a forum was held for parents, many of whom were older and very concerned about how to provide effectively for their children when they are no longer here. Parents desperately want safeguards in the system to protect their sons/daughters from exploitation of any kind and to ensure their effective. Over the years PWD(WA) has encountered many cases of financial exploitation of people whose family members have thought that they have left them sufficient funds to look after them for the rest of their lives. Unfortunately, some have been exploited by unscrupulous people who take advantage of their situation and lack of understanding of financial matters. This and other issues were raised at the forum.

This forum was followed by a series of workshops which were conducted over a year and expertise was offered by lawyers, accountants, financial planners, representatives from the Office of the Public Advocate and Centrelink to name a few of the presenters.

At the completion of the workshop series, an information package was compiled to ensure that the relevant information was disseminated to carers both in the country and metropolitan areas. A legal manual written with parents in mind, was developed by a law lecturer at Murdoch University.

In addition a legal document was developed by law firm Deacons titled '**Residential Property Ownership for Disabled Persons in Western Australia**; A guide for parents and guardians from a tax and asset protection perspective'. Some of these initiatives have been useful for some parents.

PWD(WA) also has a program, Disability First Stop - DFS which is aimed at parents or individuals who have recently been diagnosed with a disability. This program has brought many people in touch with the agency. Parents frequently contact DFS and ask for information at that point., including how best to ensure and protect the future of their child.

As PWD(WA) staff do not have legal expertise, they are encouraged to contact Centrelink. Unfortunately people often return saying that the information they have been given is not at all helpful. Sometimes information has in fact been incorrect and has caused more problems than necessary.

In terms of the current arrangements most of the difficulties associated with setting up trusts have not been eliminated, particularly in relation to encouraging parents to do so and ensuring that they are in no way disadvantaged.

The needs of children/adults with a disability are not well understood and the desire of parents to make specific arrangements for their child when the parents are no longer here, is also poorly understood. There is an enormous difference between planning for an adult with a disability and one without.

The following are some of the issues that parents have brought to the attention of PWD(WA) in relation to Special Disability Trusts;

- Capital gains tax is a major concern. Placing a residence into a special disability trust by sale of the property when full time residential care is required, can incur this tax, particularly given the rise in value in the property market in Perth in the last five years. A further issue is that many people with a disability, particularly if significant, tend to age more quickly than those without so full time care may be required earlier,
- Tax on a property which is the main residence of the person with a disability should not be treated as an asset of that person or the parents. To apply tax in this way is both unfair and discriminatory,
- Tax on unexpended income each financial year can also be an impediment given that the income can be used for when the person's abilities and health could be declining,
- Rules for accommodation and care are strict and quite complex,
- The type of expenditure on what funds can be spent is restrictive,
- There should be a list of approved Service Providers to assist parents,
- Costs associated with establishing a special disability trust and annual accounting costs are prohibitive.

The above issues are the main reasons that very few parents have taken up the options under the current proposals. While a large number of people have contacted Centrelink regarding establishing a trust, the above are the major reasons that they have not been followed through.

There is clearly interest in the concept of a trust, but the currently proposed system is flawed, from the perspective of parents; certainly those who have contacted PWD(WA).

In conclusion it must be stressed that parents of children/adults with disability are trying extremely hard to make the best possible provisions for their sons/daughters. If they can afford to do so, they want to do this without any expectation of governments meeting these costs. Placing barriers and unnecessary expenses in the way of this endeavour, will not provide the impetus for parents to make their own plans for their own children, therefore putting the costs back to government. It is imperative that these issues are addressed.

In order for this initiative to be constructive and valuable, incentives must be offered rather than obstacles put in the way. Otherwise the government will continue to be called upon to fund future financial measures for people with disabilities who do not have family support. This is a critical area in terms of assisting and encouraging

parents to make their own arrangements and not disadvantaging their own circumstances in any way.

It is crucial that it is clearly understood that parents who have a child/adult with a disability have provided, in most cases constant care for most of the years of their lives. Care and protection is paramount and they only want the best for their child.

In most cases they have struggled with numerous problems and need to have their minds set at rest as they themselves are ageing, not to be penalised in any way.