# Submission to the Senate CSDTA inquiry.

I am the mother of a 26 year old Australian who is severely physically and mentally disabled. Our son has always been cared for by his family. I do not provide statistical data to support this submission, as I am sure other people with access to up to date figures will be able to enlighten the committee to this data.

The first point I would like to bring to your attention is that I only found out about this inquiry by accident. As stakeholders with a clear and intimate interest in the future direction of funding for disability services, I feel the Senate has been remiss in not ensuring that people such as our family were informed that this inquiry was under way. Of course, by not letting such people know they had an opportunity to voice their concerns and opinions, you save yourself from having to listen to their comments, which was probably the motivating key to your lack of action.

The issue of funding for the distribution of services to those with disabilities can never be resolved
-with a blanket approach for all service users.
-without consideration for the real workers and mainstay of the disability sector – the families/unpaid carers of people with disabilities. You do not have just disabled individuals to consider where that person is being cared for in the family home, but disabled families who Government continues to turn a blind eye to, and treat with contempt.
-with just a Commonwealth or just a State based system without radical change to the way services and funding are currently delivered. People have tired of the 'blame game' ping-pong match between the States and the Commonwealth, and clearly disability services are in a mess nation wide.
-without consideration for how health is funded and the impact this has on people with disabilities.

## The blanket approach

People are unique. People with disabilities are extremely unique. The issues they face are unique, and the impacts of those issues on their families are unique. The abilities of that family to deal with those issues are unique, and THE SUPPORT THEY REQUIRE IS UNIQUE. I hope this is clear to you!
A blanket approach is not the answer. People with disabilities and their families or advocates need to be able to direct the support they require. For some, support will entail provision of all life needs including accommodation. Support will need to be provided by service providers, full time carers and health workers. For others, the family may be in a position to provide some of that support and accommodation. The support funding required in this case may not be as great as others, but is no less important. It will

certainly be somewhat different, and the delivery of services will need to accommodate the needs and desires of the other people involved in the dynamic – the family members.

Consideration for families/unpaid carers of people with disabilities.

Many families wish to care for their disabled child/parent/sibling in the family home, but the system as it stands does not make this an option anyone in their right mind would contemplate.

Although guaranteed permanent, safe options to the family home don't exist, the Federal Government relies on the (stupid) generosity and loyalty of relatives such as our family to provide 24 hour care, 7 days a week without pay. To call this by its true name is to call ourselves 'slave labor'. I would say that the Federal Government does not care if we slaves live or die, but that would be incorrect, because it is very inconvenient when one of the slaves dies - what to do with the person they were caring for now? It is going to cost a lot more for alternative care.

The government flogs the slave constantly until it dies. Not only are we on call every day of every week, with little chance of a break from the caring role, but we generally have to live without a social life, often without a working life, and often in poverty. 'We' does not refer just to the person who has the caring role, but to the whole family unit. Siblings suffer socially, academically, emotionally and financially. Parents also often have no social life or community support, and struggle with the emotional stress of not just having a totally dependent person to care for, but limited funds with which to try to make life a little more bearable. Self worth and an optimistic outlook are non existent.

On top of this is the stress of having to deal with the unfair and uncaring 'social security' system – so complex that even the staff can't interpret the rules, and so unjust that a carer is stripped of every ounce of privacy about their life in order to receive the few lousy dollars they are given as 'support' – in my case $120- a week for a 24/7 commitment. When your husband receives a raise in his income, your payment goes down. You can not get ahead, but if you are lucky you will not break one of the convoluted rules that govern your carer payment and end up with a debt.

How you can even consider means testing the carer payment is beyond logic, and why recipients are governed by the same rules as aged pensioners cannot be explained by any sane excuse. We are treated like scum, but in fact have been an economic asset to the federal government, saving them billions of dollars each year for a long time.

Some months ago I wrote to then Minister Kay Patterson regarding this issue, and the whiney response I received went something like – 'we would like to do more, but there are no funds available'. The following week the Treasurer announced a $14billion surplus in the budget – none of which was directed our way. I am sure none of the people on this committee would do the amount of work we do for a lowly sum such as that we receive. We are treated like scum.

Families have to give up their own life to care for a person with a disability. It is impossible to cope with the strain under the present system, and families everywhere are in crisis. Families are providing the same services that other 'formal' service providers offer, often to a much higher standard.

THIS SHOULD NOT MEAN THAT THE GOVERNMENT/S WALK AWAY FROM THEIR COMMITMENT TO PROVIDE SUPPORT AND DUMP ALL CARE AND

RESPONSIBILITY BUT NO RIGHTS ON THE FAMILY – IT SHOULD MEAN THAT THE SUPPORT IS DIRECTED TOWARDS THE FAMILY LIKE IT WOULD BE TOANY OTHER SERVICE PROVIDER.

Most service organizations are bureaucrat heavy. Over 30% of all state funding for people with disabilities to access services goes towards administration costs. While the administrative staff drive around in government funded vehicles (fancy 4WD's that can take little Penny to Pony Club on the weekends – true story), families have to find the funds to replace their own aging vehicles at their own expense, even though much of the wear and tear has arisen from transporting the person they care for to appointments, etc, and from wheelchairs and other devices bashing the interiors to pieces. This is unfair, especially when so many of us are limited to one income.

Families are the backbone of the support for people with disabilities. If they continue to be ignored to the point where they can no longer cope, this nation will need to rethink its whole social policy, as there will be a lot of vulnerable people left homeless and some serious decisions will need to be made about future strategies.

## Commonwealth/State based funding.

There is no doubt that the delivery of disability services under the present system is not working. The unmet needs in all Australian states are of unacceptably high percentages – and it is fact that not all the needs within each state are registered with the appropriate authorities. The problem has been exacerbated by the shifting of blame from state to commonwealth, and vice versa. Both levels of government need to unite in their desire to see the living standards of the most vulnerable members of our society improve urgently, and stop wasting time and energy on unproductive discourse.

In my state, service provision is the responsibility of the top-heavy heaving sloth – Disability Services Queensland. This is in general a faceless, expensive organization that fails to deliver all but the most meager services. In recent years funds have been wasted on such expensive exercises in patronization as the 'Carer Recognition Policy' – which has done nothing to improve the lives of carers or the delivery of service to themselves or the people they care for. Advertisements currently in the media talk of new disability service standards – I for one have not seen them. They also talk of how much the lives of people with a disability have improved – how? I have seen no evidence. What I have seen is that there are not sufficient funds to provide a good life experience for people with disabilities in Queensland, and that funds are being taken back if they are not used each year –not because they were not needed, but because there are not enough service providers to accommodate the number of clients needing support IN THE WAY THE QUEENSLAND GOVERNMENT HAS DEEMED THEY MUST BE SUPPORTED. See – no accounting for an individual's unique needs – just a blanket solution, whether appropriate or not, and not enough service providers to follow through with the support, so it looks like the funds weren't needed, and they are recovered. Unfortunately families are not seen as 'service providers' and are not allowed to access those funds.

At least at this stage, Queensland carers are not as disadvantaged as those in Victoria, where new disability legislation aims to cut them out of the loop altogether with regard to their rights in caring for their loved one. This is not a sensible or productive course of action.

## Disability funding seen in conjunction with health funding.

The decision to change the system of service provision within the disability sector cannot be addressed without also addressing the issue of health funding for people with a disability. Currently many factors that make life easier for people with disabilities and their families/carers, are dealt with under the portfolio of health rather than disabilities. This includes such essential items as mobility devices, incontinence aids, communication aids and rural health services. In Queensland, a wheelchair can be made available on ‘permanent loan’ from the health department. It can take up to 2 years from the time of application to the receipt of the chair – but at least you get one eventually. Incontinence aids are available – but not necessarily ones that are appropriate – that isn’t a priority – the cost is. Rural health services are being pulled out of hospitals all over the state, and access to these services can have dire consequences on the ability of a person with a disability being able to remain in that area permanently. Access to transport for people with a disability is often dependent on whether sufficient funding is provided through Home and Community Care, which is funded by the health department. This all impacts on the person’s ability to access services, even when they are available, and my experience has shown that sometimes the service is there, but transport is not funded, so the person cannot attend.

I hope my submission has highlighted some of the issues that need to be addressed during this inquiry. Change is essential to both the delivery of disability services nationwide, and to the social conscience of politicians at all levels. The social values of this wonderful country are being torn asunder as both our State and Federal Governments continue to put economic growth with focus on corporate wellbeing ahead of the needs of the nation’s human face – the ordinary people. While Prime Minister Howard gloats about the (tenuous) economic wealth some Australians apparently enjoy, the social fabric of our country reflects the reality of life for many other Australians - one of neglect and wastage. People with disabilities AND THEIR FAMILIES are left to fend for themselves emotionally, physically and financially. They are prohibited from participating in the average lifestyle most Australians take for granted by hard nosed economy-driven policies that fail to acknowledge the rights of this sector to participate equally in contemporary Australian society.

Society is judged by how its weakest and poorest members are treated……there is a lot of work to be done before our leaders can be proud.

Deborah Edwards