Senate Community Affairs Reference Committee

Inquiry into the Funding and Operation of the Commonwealth State/Territory Disability Agreement.

CASA

(Committed About Securing Accommodation for People with Disabilities)

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Submission

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CASA

CASA is a parent group that has over two hundred members. We came together over the lack of funding for desperately needed services. Accommodation being the major concern by our families.

We were formed in 1999. We are a united and committed body of parents, with a vision of securing permanent supported accommodation for people with disabilities, and supporting their rights to plan to live independently in the community, when the time is right for them and not reliant on a family crisis. Our goal is to make the governments aware of the critical unmet need in accommodation, respite and therapy services for people with disabilities.

Preamble

Our families welcome the inquiry into the CSTDA, as they feel that they fall through the cracks, they live with the uncertain future of **“what will happen to their son or daughter when they die?”**

In a prosperous country like ours how can the governments allow seventy, eighty or ninety year old still care for sons or daughters, while there own health is failing.
In the agreements preamble it has statements like:

“It provides a framework that will guild and strengthens the relationship between the Commonwealth, State, and Territory Governments in working together, and with others, to make a positive difference in the lives of people with disabilities and their families.”

Families are let down as neither of the tiers of government have taken the leadership role into addressing the critical accommodation shortage. Another statement is that:

“People with disabilities and their families are valued and are equal participants in all aspects of life.”

For our families to achieve this we need appropriate services and supports. Are we equal when we are required to continue caring when our children should be living an independent life and families can enjoy their twilight years knowing that their child is in a safe secure environment.

We feel that the CSTDA needs to be clearer on who has responsible for what, and in the first CSTDA it stated that the funding was a shared responsibility, and the administration was a States responsibility. The later agreements are not so clear, it is there but it is how it’s interpreted.

What is needed in the 4th CSTDA

A new agreement must work for people with disabilities and their families, for it to achieve this it must:

- Reflect a genuine commitment from the commonwealth, State and Territory Governments to people with disabilities and their families.
- Demonstrate a commitment from the Commonwealth, State and Territory Governments to work in partnership.
- Provide a PLAN to resolve the unmet need for support services and a commitment of funding to achieve this.

- Guarantee, from the Commonwealth, State, and Territory Governments, the increase in funding required to resolve the unmet need for accommodation and respite services and to ensure the adequate and effective provision of services in the future.
- Funding for Systemic and Individual Advocacy.

Advocacy

In the CSTDA agreement there is a requirement of having a National Disability Advisory Council, this is the family's voice to the Minister. In August 2005 this was closed down, and the National Family Carers Voice also came to an end, they were to be united to become the National Disability and Carers Council. This committee has still not been announced. The families once again feel that their voices have been silenced, or not deemed important.

Family carers are often confused, exhausted, frustrated and disempowered. They feel that because of the demands of their caring role, and their low profile that their work has in the community, and at the government level, that they don't have a voice in the decision making. This lack of representation and structural advocacy is also compounded by governmental policies which are, in some states, based on philosophy, rather than individual need.

The next CSTDA must highlight the need for both individual and systemic advocacy, and an allocation of appropriate funding.

Families

The CSTDA must look at the unmet needs, if the services were delivered at a timely manner families wouldn't reach a crisis situation, and end up with a family break down. Some families have agreed to their situation to be used to highlight their need.

FAMILY ONE:

Mother in mid 50's, caring for three members of her family. 15 year old son with severe intellectual and physical disabilities, needing PEG feeding every three hours, positioning in his wheelchair, bathing. He is unable to communicate and at night needs changing and repositioning in his bed. 21 year old son has kidney disease, he has had a kidney transplant but still needs dialysis three times pre week, and he is severely depressed and has tried to commit suicide once. Dad is undergoing treatment for cancer, and is so depressed will not come out of hi s bedroom. Mother applied for some in home support to allow her to spend time with he husband and other son. She was refused funding.

FAMILY TWO:

Mother and father and four children, eldest son has severe intellectual disability through the triple antigen injection, now at the age of twenty one, only has three days post school options, mother has to be at home can't go to work because of the son's placement. Son requires constant 24 hour care, suffers from seizures, constantly stays awake at night, has no verbal skills, is incontinent, cannot feed himself, needs toileting and dressing and cannot do anything for himself. The son also makes continuous sounds, has behavioral problems which affect the other children; they find it difficult to do their homework because their brother will rip up or chew the work. They can't bring their friends home because of their brother. They have been applying for out of home accommodation, without success. They can't get regular respite as respite services are booked solidly.

FAMILY THREE:

Mother 84, son 52, father died three years ago, mother had some bad experiences when the son was in his teens, and refused services for her son. The son has help around the family business until mum and dad retired, since then has been at home with his parents. Mother is worried about the future of her son as her own health is failing. Due to the past, mum is reluctant to look at group homes, but supports will need to be put into place so that he could stay in the family home and his sister and brother could oversee his care, as they can't have him living with them.

Summary

In summing up, our families would like the next CSTDA to look at whole of life planning for the person with the disability. The Governments knows from point of diagnoses that they will need supports through out their lives. If they planned from point of diagnoses families wouldn't end up in a crisis situation.

If accurate data was kept we would know the level of unmet need, and exactly what the unmet needs are in Therapy, Respite and Accommodation.

The last resort for families is to apply for accommodation, but there is such pressure on families because of the lack of vital services, this leads to family break down leaving one parent to carry on in the caring role.

We would like to see all levels of government working together to see that people with disabilities and their families are treated as valued member of their community, and have the right supports to achieve this.

The CSTDA must have a clear framework to deliver support services to allow people with disabilities and their families to have a valued life.

IN ENGLAND

When I was over in England I was told about two reports, they are on the MENCAP web site: (www.mencap.org.uk)

- Valuing people with profound and multiple disabilities. This is a good report that looks into the needs of people with profound disabilities. It was written in response to the White Paper “Valuing People”
- White Paper “Valuing People” on web site www.dh.gov.uk. This paper plan for the needs of people with disabilities from 2001 to 2025.

These two paper outline the issues we are facing and they now have a plan and vision into the future. This is what families want from our GOVERNMENTS.