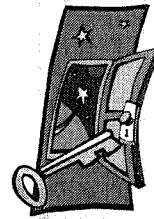


House Standing Committee on
Family, Community, Housing and
Youth.

Inquiry into the better support for Carers

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 group consists of parents of children and adults that live with disabilities, these are life long conditions, and require care from a baby till they die. All have said **“That if there was appropriate services for the child the stresses on them would be alleviated.”**

We welcome this inquiry and hope the finding from this along with the Senate inquiry into the CSTDA last February (2007) will recognize the valuable contribution to the community that family carers and people with disabilities make, and the need for whole of life planning for our children so they can have there rights met like any other citizen of Australia.

Most of our families especially the primary carers have to give up their careers to provide support for their child all do this out of love. This comes at a high cost to the families, financial, emotional, and health. The lack of acknowledgment of their role in society, and government department causes further stress on families. Most families relying on one wage or welfare payments haven't the ability to save neither for their own future nor of their child. They don't have access to superannuation so the poverty continues on after their caring role ceases.

With the lack of funded services family cant exit the caring role until they are aging themselves, the families have no choices or rights. We have a retiring age for workers at sixty five, our families are still caring into their seventies or eighties often providing twenty four hour care, and living with the fear of **“Who will look after my child when I die”**

The Role and Contribution of carers in society and how this should be recognized.

Carers don't want medals or awards they just want "a far go" They work long days for no pay. They put their own health at risk, and often do this on their own. Marriage breakdown is very high when you have a child with special needs. Our families are more than likely to have two caring roles, their child from birth and then their parents as they age.

We would like to see our contribution recognized by planning for the needs of our child, to have appropriate services. The means testing on the carers pension less restrictive or abolished completely. A superannuation scheme for the primary carer to acknowledge their contribution to society.

Carers need trained staff in government departments that recognize the carer's needs and take notice of the important role they play in the person with a disabilities life. They need seamless transition between departments, when you have a child with dual diagnoses you are often pushed between disability and health departments while they decide which is the major disability, in stead of treating the child / adult as a person.

The Barriers to Social and Economic Participation for Carers

Most of our families have been out of the workforce for many years and have lost skills or qualifications are out of date, and find it really hard to re-enter the workforce. In the England, the have a programme where the Carer can participate in a City and Guilds course whilst they are still in there caring role. They can work at their own pace, through an internet programme. The aim is to prepare them to re enter the workforce when they cease their caring role. They will have a certificate that will give them the relevant qualifications to pursue their career of choice. Maybe the same programme in Australia using Tafe or University.

The main barrier that stops carers from social participation is lack of support services for the person they care for. Respite is very hard to come by or the cost of the service is too

High for the carer to pay. Many carers are on welfare or have limited finances having to juggle which bills to pay.

Practical measures to better support carers

Education: Post caring courses to enable a carer to resume employment once their caring role ceases.

Education: to make their caring role easier, so they know how to use equipment properly and safely. Understand the medication that they are administering to their child or adult. Information sessions on what is available to them and where they can go for help.

Education to service provider to include the carer in health care plans, and GP's to include carers needs when assessing the needs of the person with a disability.

Financial: Carers pension to not be means tested, many of our families are living on one wage because one of the parents have to stay home with their adult child with a disability because of the lack of support services.

The cost of equipment and incontinence aids put further strains on the household finances, transport cost escalate. The cost of modified vehicles is out of the reach of many families, leaving them to struggle lifting their child/ adult into cars and them having to lift the wheelchair as well.

Information: Timely and appropriate to information to help carers make informed decision about the caring role. Many families often say it is a maze out there, you never know what is available to you, usually to hear it through other families.

Strategies to assist carers to access the same range of opportunities and choices as the wider community

Appropriately funded services for the person they care for, by implementing a social care levy. This would stop the constant applying for funding and give the carer the choice to be able to exit the caring role when the time is right for them and the person they care for.

Adequate financial support, with a superannuation scheme to stop the life long dependence on welfare.

Educations to prepare the carer to re- enter the work force.

Carer friendly work places with flexible work hours.

In Conclusion

I will finish by repeating the overall thoughts from our group “If there was services for our child or adult son or daughters we would not be living in such stressful situations” We just want a FAR GO!!! We want to know that our child will be looked after in a safe, secure environment before we die. We would like to enjoy our retirement the same as any other people in society, why should we still be caring into our seventies or eighties. We don't want to see our other children have to take on the responsibility of their siblings after we die; they have their own lives and responsibilities to take care of.