

ACC 15/10/08

Submission No. 1287

(Better Support for Carers)

**The Committee Secretary
Inquiry into Better Support for Carers
House of Representatives
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600**

October 2nd 2008

Dear Secretary

We would like to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's inquiry into Better Support for Carers.

Firstly we would like to thank the Committee for visiting the Albury region on October 1 for a public hearing on this important issue and for allowing further submissions can be tabled. Over the last few years we have attended a number of State and Federal public hearings on the issue of people with a disability and the role of carers but it appears that little has changed. I hope that this Committee can deliver some meaningful outcomes.

Addressing the terms of reference of the inquiry:

1. *The role and contribution of carers in society and how this should be recognised.*

We are the parents of Rachel who is aged 19 years and her three siblings. She is severely disabled having cerebral palsy, severe developmental delay and uncontrolled epilepsy and is totally dependent for every need.

For the last ten years she has attended Wewak Street Special School and accessed respite care during the school week at Mercy Centre Lavington. These current arrangements of sharing the workload for her care between our family, Mercy Centre Lavington and Wewak School has enabled Rachel and her family to lead as normal a life as is possible with a severely disabled family member.

We have fought hard to develop this system for Rachel and our family. It has allowed us time to better manage Rachel's health issues, deal with the minefield of government bureaucracy such as Centrelink and devote time to our other children's needs. We as a family feel that we have the time to contribute to our local community and have a proud and high self esteem of the role of a carer.

Many carers do not have this opportunity or the energy to fight for their disabled child. They are consumed by just coping from day to day and suffer from depression and poor self esteem. During the Albury round table session I was upset to hear one of the Committee say that carers should be able to have access to physiologists and anti depressant medication to help carers cope with the stress of their daily lives. This is not a solution. *All carers should have the opportunity to respite or supported*

accommodation so that they themselves can have meaningful lives. This is the only solution.

2. Barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.

At the end of 2008 Rachel's current arrangements will cease. Once a disabled child either turns 18 or leaves school, governments, both Federal and State, seem to assume that either your child miraculously recovers or at worst dies. What limited services that were available and the continuity of those services seem to completely evaporate.

All the hard work that we have put into developing the structure for Rachel's current arrangements will cease. What we are now facing is:

- Her father will have to give up full time employment as Rachel's physical needs are too demanding for her mother. Even part time work will be difficult to obtain even though Rachel will be able to attend a community participation program from 10am – 3pm.
- As we live out of Albury, the lack of services of community transport, and Rachel's increasing physical size, a wheel chair accessible vehicle will need to be purchased by our family.
- There will be significantly less time to devote to our other children.
- Placing Rachel into shared accommodation situation for high support disabled adults for a cost of \$70,000 annually.
- Possibly selling our home, moving to Albury and building a purpose built house to accommodate our family and pay for some carer assistance.
- Increased family stress.

These issues are common to many families and severely affect people's capability to seek employment and a meaningful existence. The financial barriers to all these options are large and there is limited if any State or Federal tax incentives or funding available to work towards suitable solutions.

3. The practical measures required to better support carers, including key priorities for action; and strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

- The root of the problem is the total lack of supported accommodation and respite services, particularly for young adults. Until this is seriously addressed the issues of carer isolation and depression will not be solved. A group of Albury parents have been lobbying for a small cluster model for housing 15 young adults. It appears the most cost effective solution for a number of families.

This accommodation model would consist of:

- Flexible, quality, 7 day a week care;
 - Management by a board consisting of parents, a service provider with a proven track record in the development and management of supported accommodation services and possibly a case worker;
 - 2 houses and a series of self contained units on the same land:
 - One house accommodating five adults with severe disabilities in a high needs facility. It would require high levels of staffing which would then be able to provide some supervision of the other house/units;
 - One house accommodating five moderate people who may have limited opportunity to gaining employment in the community but are able to access community based day programmes;
 - Up to 5 units accommodating low needs people requiring limited supervision and who have the capacity to participate in the local community.
 - Other support services such as health care and community participation programs being able to “plug in” additional services as requested by families.
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- Tax incentives or deductions for parents should be allowed on supporting a severely disabled family member. For example:
 - Purchase of equipment;
 - Cost of privately funded accommodation;
 - Out of pocket health costs.
 - Changes to the asset and income threshold for carer payments. For example if Rachel’s father ceases work next year he will fail the assets test. Therefore he will not be eligible for carer payments. This is unjust.
 - Reviewing the terms of the special disability trust. It is designed for older parents/carers who can gain benefits from gifting concessions. There is no incentive or flexibility for parents in their late forties.
 - There is duplication between the Federal and State systems, which means large amounts of the funding dollars are squandered on duplicity of bureaucracy. The current system is disjointed, wasteful and politicised.
 - Parents should be able to more easily access the “ears of government” and influence policy as they are at the coal face.
 - Governments need to acknowledge that disabilities vary and the solution is supporting a range of models that provide flexible and quality services. *Historically the agenda and debate seems to revolve around “what is the right model”? The agenda is being driven by people who have limited understanding as to the complexities involved with having a disabled family member. There is no right or wrong model.*

- Government paid caseworkers/brokers should be available to support parent groups with their expertise. These people need to be:
 - Better trained as to what to what is available at both the Federal and State level. Currently there are both transition support workers (Federal) and caseworkers (State) with neither really seeming to have any idea as to what the other is doing. There only needs to be one representative who is well versed about both levels of government. At this time it appears they have less knowledge than parents.
 - Able to provide the group with what services are available and how best to tackling as they issues.
 - Directed by and work on behalf of family groups to solve problems.

I thank for you the opportunity to table a submission to the Committee

Yours Sincerely

Jim and Rosemary

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