

**Supported Living**

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2<sup>nd</sup> July 2008

**Submission No. 584**

(Inq into better support for carers)

A.O.C. 8/7/08

TO: Committee Secretary,  
Standing Committee on Family, Community, Housing and Youth,  
P.O., BOX 6021, House of Representatives,  
Parliament House,  
CANBERRA. ACT. 2600.

Dear Secretary,

We wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's enquiry into Better Support for Carers. Carers group is for people who care for someone with an intellectual disability. Carers in the group are parents, siblings, grandparents. On the day we collected this information four parent carers were present.

This submission is based on the outlined supplied to carers regarding the enquiry.

Yours faithfully,

*A. Bretherton*

On Behalf of

UnitingCare Supported Living Carers Group

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### **Regarding the role of Carers the following points were made:**

- Back up support when all else fails. Support in all daily needs; this is not a normal role: e.g. most children grow up and leave home whereas for Carers there is a continual need to support their sons or daughters with daily living skills.
- Organise the day for the person we care for
- Translate everyday life into terms the person with a disability can understand
- To think for the person with a disability
- To be a go between (between paid carers, agencies etc.)
- As Carers get older they don't have the energy to care or fight
- A Carers life revolves around the person with a disability – their life is no longer their own.

### **Contribution to Australian Society**

- Many hours of unpaid care this includes 24 hour support or 24 hour stand by
- Carers always need to be available and consider the other person before making plans
- Carers need to be prepared to change plans frequently

### **The following problems are faced by carers**

- There is a lot of stress on the life of Carers
- Not being able to go on holidays together (husband and wife) because of the caring needs
- Build up of frustration from the pressure of caring
- The person with a disability can often “gobble up your life”
- The effect of caring on the personal relationship between husband and wife – focus always on person with a disability so relationship suffers. Often they (Carers) are too exhausted when their son or daughter is in respite to spend time together

### **Financial struggles faced by Carers**

- Holding down a job can be difficult due to needing to be available for person they care for
- One Carer worked from home through their child's life in order to build up a nest egg for the future; now due to having this their pension is being cut. The hard work to financially secure their child's future means erosion of the “nest egg”
- If the person with a disability lives independent of carer there are still costs of caring which could be supplemented by an increase in pension e.g. a

telephone seen as essential to maintaining connection with family and in case of emergency.

- Older carers struggle to get additional services due to only being on pension
- Extra support for carers would assist them in maintaining good health e.g. free or subsidised gym or pool membership

### **Concerns for the future**

- "I am going to die one day"
- Need for more group homes
- Need for flexible forms of accommodation
- Ongoing worry
- Being here means Carers can catch things when they fall apart but when they are gone what will happen?
- If you have no extended family, what will happen then?

### **Ideas/Solutions/Strategies to support Carers**

To counter stress more personal support

- This may be subsidised or free access to gyms, swimming etc.
- Regular breaks which are financially supported (places of rest and recuperation which perhaps could be sponsored by Government or Corporate)
- Individual support for Carers – more than just the Carers Group which is really helpful but more time for individual Carers
- Extra support for carers when life goes awry – one Carer cannot go away with partner because of need to be around to make decisions and caring responsibility e.g. someone available for emergency situations
- Better information from Government bodies would be useful e.g.: too many places/organisation hold information that could be helpful

### **Specific needs of Carers**

- Limitations when unwell. E.g. if a carer is hospitalised there is no-one else to do the running around
- Carers would like a funded specific Advocacy organisation for their needs. This would be people who are trusted, experienced staff with skills to step into the breach of 24 hour care where needed. (or know what is needed and how to organise this) This would be people who would be able to make crucial decisions and stand in the place of the Carer. This service would have ongoing connection with the Carer/s not a one off.
- It is currently not easy to find a way through services. A much more accessible way through the complexity would be good. One carer

despite having a Social Worker for many years had not been informed that they were entitled to rent allowance and mobility allowance

- Accessible information would assist people from Non English speaking background.
- Carers are tired of forms. Why do they need to keep completing forms attesting to the disability of the person which does not change? Other forms which frustrate carers are:
  - Mobility allowance
  - Rent assistance

### **Medical Issues for Carers**

- One carer had experienced extreme difficulty in having blood taken from her son. Questions arise about consent, medical skills etc.
- Concern that some medical practitioners do not have a good attitude to people with disabilities and that some also did not know how to handle the situation well – carers need to be present and advocate support for person with a disability.
- Carers would like to see Doctors and other medical practitioners e.g. nurses, physiotherapists, have training and skills in this area. This could also apply to current medical staff although educating them was seen as difficult.
- Carers would like a register of Doctors competent to work with people with disabilities.
- Cost of health care is an issue and carers thought that there could be a discount given through private health insurance (subsidy) This was seen as important because the cost of care often exceeds public health provision
- There could also be a system of mandatory standard cover with private health insurers till a certain age e.g. 25 years of age.