



ACC 4/8/08
Submission No. 1213
(Inq into better support for carers)

2nd July, 2008

LYNN

COMMITTEE SECRETARY

STANDING COMMITTEE ON FAMILY, COMMUNITY,

HOUSING & YOUTH

P.O. BOX 6021

HOUSE OF REPRESENTATIVES

PARLIAMENT HOUSE

CANBERRA ACT 2600

Dear Secretary,

I am the mother & primary carer of an intellectually disabled young man, who has autism. I wish to make a submission to the House of Representatives' Standing Committee on Family, Community, Housing & Youth's Inquiry into Better Support for Carers.

I could write a book relating my experiences of living with & caring for a person with this type of disability, from childhood to adulthood, as Mark is now 30 years old, however, I do not have the time. To help your inquiry with some of the issues affecting carers, I will relate some of these experiences from my personal perspective.

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mark is fortunate to live in a family home where his parents are still married to each other. mark's father, Peter, assists me with his care whenever necessary & whenever mark will let him. Mark prefers my attention & supervision more than other carers' e.g. he will sit at the kitchen bench for quite a long period of time just to be with me & follows me around the house, even when I need to go to the bathroom, unless I am able to enlist Peter's help to mind him.

mark is very demanding, self-centred, manipulative, compulsive, obsessional, noisy, is sometimes self-abusive, has challenging behaviours & anxieties, which affect the whole family. We love & care for him & often share fun times with him, but we do not have, what would be called "a normal family life".

To cope with his anxieties about self-harm & destructive behaviours, mark has developed self-restraining techniques for himself (he ties himself to his lounge chair) which enable him to sit down to watch TV & play playstation games or to listen to his collection of records, or CD's. This does give us a break from his need for close supervision & constant self-centred questions.

When Mark was a young child & diagnosed, by the age of two, as having an intellectual disability, I experienced a long period of grief, depression, & denial & finally, acceptance of his disability. It was only when he was in his late teens, after a psychiatric assessment, that I accepted the diagnosis that Mark also has autism.

I took on the primary caring role for Mark, and his sister, as my husband was commuting to work and was away from home for long hours each day during the week.

As well as all that goes with running a household & bringing up two children, I was also having to consult with doctors & professionals about Mark's diagnosis, filling out endless forms, attending preschool intervention programmes, coping with two different types of schooling, mainstream & special; plus writing daily communication to teachers, mostly in relation to Mark's challenging behaviour & anxieties, while endeavouring to shower, dress & encourage a tearful, reluctant, highly anxious child to go on the bus which picked him up to go to school.

There was also the wet or dirty bedding & pyjamas to wash every day as Mark was incontinent until he was 21 years old.

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Until recently, Mark has had sleeping problems, & therefore I have been constantly deprived of sleep, over 30 years - this situation has changed a little since Mark has been taking medication which tends to calm him down enough to send him to sleep at a reasonable time at night.

Damage to property has also been an expensive problem, & affects our family's social life - as we are unable to take Mark to most of our family's & friends' houses or have them to ours. We have only been on vacation a couple of times in 30 years, these occasions were more stressful than restful.

As a young family we experienced some financial hardship, & were on a tight budget. I also had a feeling of isolation as other mothers in the neighbourhood were re-entering the workforce when their children started school. At this time, I decided to attend a local art class, while Mark was at school, using the family allowance, I was able to afford the fees & materials. I found this to be a valuable experience - a mentally stimulating & creative activity - & an escape from my intense role as a carer of a child with a disability.

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I still attend this art class a couple of hours every week & still find it an enjoyable & therapeutic experience.

When Mark was 10 years old, & his sister was 13 & starting high school, I was lucky to have a friend advise me to apply for a part-time position, similar to hers, at the local hospital - with hours to suit a mother of school children. This was successful & 20 years later I continue to work in the same department at the hospital, on alternate weekends & for a few hours during the week, while Peter cares for Mark. My managers at work have always been considerate about my other role as a carer when having to make decisions about work & leave arrangements.

Part-time work has enabled me to not only make an economic contribution to household expenses but also gives me a feeling of self-worth, self-confidence & an opportunity to have social interaction with others away from home.

When Mark left school at 18 years of age, however, my caring role changed again.

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Mark attended school for 30 hours per week; Post school options programmes only have funding for a person with high needs, providing one-to-one care, for an allocation of 15 hours (3 days) per week. As a result of this & having Mark at home more often, I had to reduce my hours at work.

We have been successful, however, in accessing respite hours from a couple of respite services & these amount to a few days per month plus, in recent years, every Saturday afternoon, for which we are very grateful. Mark does not access overnight respite as there are no service providers able to offer accommodation for Mark's high needs & challenging behaviours, at this time.

In recent years, I have experienced some major health problems, for which I have been treated, my main problem now is panic attacks. Even though I maintain a good sense of humour & have developed a high level of tolerance for Mark's challenging behaviours, caring for someone with this type of disability is exhausting & respite is always very much appreciated.

Five years ago, I experienced the illness & loss of my own mother, who was a carer herself, & now, I give

emotional support & cook meals for a widowed father, & while Mark is at Post School Options I take an elderly aunt to do banking & shopping & at least once a week, we help our daughter with her two young children, it is a busy life.

Of course, high on our wish list is that Mark would be settled in appropriate permanent supported accommodation before we are too sick or too old to help with the transition from the family home, as we know that this will be a very stressful process for Mark. (See attached submission to the Australian Government Disability Supported Accommodation Program, which Peter & I submitted in October, 2007.)

Apart from the difficulties associated with caring for a person with a disability, I feel there are positive outcomes from this experience & have developed quite a few skills I would not otherwise have had & met many people; professionals, teachers, parents, carers, etc, & made some friends along the way.

I believe most parents/careers of a person with a disability would want to

- have counselling at the time of diagnosis & an ongoing programme to help them develop the skills to cope in their role as a carer & to deal with problems such as challenging behaviours, etc.
- Also, good quality early intervention programmes, education & training for the person with a disability;
- Financial support for utilities, aids, modification to housing, etc;
- Opportunities for carer to access courses &, at least, part-time work;
- Flexible & overnight respite with highly skilled, well paid support workers, with no competition for funding for these services.
- Access to good quality appropriate o/night respite accommodation.
- The main worry for parents of children with a disability would be the future when they are no longer able to look after them - transition to supported accommodation should

be done in a thoughtful, considerate,
caring manner for all concerned.

yours sincerely,

LYNN