

A.O.C. 16/6/08

Submission No. 46

(Inq into better support for carers)

June 8th, 2008

Secretary
Inquiry into Better Support for Carers
Standing Committee on Family, Community, Housing
and Youth

Dear Secretary,

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

Carer: Diana

Who do I care for?

Husband, [REDACTED], aged 61, Parkinson's Disease.

Son, [REDACTED], 19, Autism Spectrum Disorder.

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My role as a carer began nearly 20 years ago with my son [REDACTED] who was diagnosed as having "mild to moderate autistic learning difficulties"(quote taken from report by Dr Gillian Baird, Guy's Hospital, London, March,1994).

This was the initial diagnosis which did not occur until my son was nearly 6 years of age so, sadly, he received no early intervention of any kind. How pleased I am to acknowledge that diagnosis is much better for autistic youngsters in 2008 whilst this is of no benefit to my son who has now left school and is involved in post-school options programmes and day centre activities. He does not work. Because my son has speech and is able to communicate effectively most of the time; he can also behave rationally; he is physically quite capable (he is now quite a good golfer), we often think ourselves very fortunate.

However, his skills hide many difficulties. He has many of the sensory issues associated with autism such as sound sensitivity to loud noises, coffee machines, his father's cough

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and many other day-to-day sounds that are quite a normal part of life.

██████ is not able to drive or use public transport because of the anxieties brought about by his autism.

Caring for ██████ was easier when he was at school. Since leaving school in 2006 I have found that I am now the main transporter of ██████ to whatever activities he is involved in. This is particularly difficult with night driving as I am now 55 and feel insecure and unconfident driving very far after dark. As money is always an issue in our household plus dealing with the practicalities involved with ██████ sound sensitivity, taxis, with their constant beeping dashboard computers, are not always the answer to ██████ evening outings. I would like to see more money spent on transport for those with disabilities. Setting up of good, well-run and funded programmes, is of no value if reliance is then placed on the carers to transport the person to and from the venue, in my case particularly if it is late at night.

More respite options for ██████. Because ██████ can be reasonably capable it is hard to place him in suitable respite. He has tried several situations with Bethany Care and Gold Coast Family Support Group that have been unsuitable because of the mix of disabled people. ██████ gets nothing out of a situation whereby he is cared for with severely physically disabled people or with those who have severe intellectual and emotional problems. What about some respite that is centred around those young people who are **MODERATELY** capable and would relish the opportunity to experience new things ie. fishing, surfing, bushwalking? We need more sensibly thought-out respite options. ██████ *NEEDS* such an environment with peers of similar capabilities to his own. At the moment I receive one evening every eight weeks from Southern Star Community Services. This is the only respite service that ██████ will attend, having not enjoyed the other respite options offered. And if he doesn't enjoy them, then I suffer as his carer. It is fair to say that the number of alternatives offered are severely limited and totally inadequate.

Speaking personally, I would also like to receive more help of a "mentoring" type for ██████. This would take the strain off me as I am constantly worrying that I can't attempt to "travel-train" ██████. Can't take him on outings that I know he'd enjoy; can't offer him the company of someone who could be a peer. I am his mother and it is not feasible to imagine that I can still be "all things" to ██████ at his age. I noticed that the 2020 Summit produced an idea of merit which might be valuable here. Why not allow students to do some regular voluntary work of the mentoring type mentioned above to receive some relief from their HECS debt? For instance, someone studying behavioural psychology would have an interest in autism related to their future career and therefore be an ideal mentor for a young person like ██████.

This initiative would ensure that the benefit would have immediate positive impact on the carer (me), the autistic person ██████ and the student.

Frankly speaking, some of the initiatives regarding programmes for young people with disabilities often fail for reasons not anticipated.

As an example of what I am observing, I instance a current programme which my son ██████ is attending, sadly on his own!

It is a programme that involves highly-trained workers who run a creative art session. Quality-wise it is very successful, but attendance-wise, it is a failure.

Such initiatives are going to continue failing from time to time for various reasons that have nothing to do with the quality of the program itself. Often it can be because the transport is difficult, the location is distant or there are no provisions for food and drink supplied or sometimes the program is not marketed properly, so not enough potential customers even know of its' existence!

In order to achieve success, I believe, a series of questions with answers being mandatory before funding is made available.

The type of questions posed could be as follows:
(Using an ART PROGRAM as the example.)

1. AIM:
2. TARGET AUDIENCE:
3. LONG TERM GOAL:
4. SHORT TERM GOAL:
5. LOCATION:
6. TIME:
7. TRANSPORT:
8. COST TO CUSTOMER:
9. REFRESHMENTS:
10. REQUIREMENTS:
11. SAFETY AND SECURITY:
12. MARKETING AND ADVERTISING COST/
BUDGET REQUIREMENT:
13. INFORMATION CONTACT:
14. EMERGENCY PROCEDURE:
15. FOLLOW-UP RESEARCH AND QUESTIONNAIRE

THE FIRST STEP IS TO IDENTIFY AND QUANTIFY A "NEED".....I.E.POTENTIAL ATTENDANCE.

Too often an event is booked, announced, often in an ad hoc manner. Also, too often, it is assumed that everyone has a car, doesn't need refreshments and the good worth of the program is immediately flashed by "osmosis", needing no marketing push!

That's often why some programs fail.

I realise that the above-mentioned is a slight deviation from the purpose of this review, however, I feel that it needs to be reported as it **DOES** impact on the carer.

My husband, [REDACTED], who is 61, has suffered from Parkinson's Disease for the past 11 years. His condition is deteriorating. He is now only able to work part-time in our small home-based business. Some days he can do nothing and needs constant support to do even the simplest things.

I am now beginning to find [REDACTED] illness quite a strain as I am woken up many times during the evening in order to help him with medicine, toileting etc.

My days consist of helping [REDACTED] and assisting [REDACTED] plus being the only driver in the family. Several minor health issues have started to impact on me and I now wonder how long I can go on being the primary carer for two adult men.

I enrolled in a course to help me with employment opportunities because our financial position is not good. However, I have not been able to complete this course because of caring duties and overall tiredness. (I enrolled in a post-graduate course at Griffith University to study for a Certificate in the Teaching of English to Speakers of Other

Languages in 2006. I believe that if I had been able to complete this course then I would have been able to find part-time employment given that this is a field that is much in demand).

What specific services would help me?

1. More in-home help with [REDACTED]. As [REDACTED] is mentally very capable he doesn't want to take respite in a hostel situation and I completely understand this desire. As I write this, I have 3 hours of help per week from "Blue Care" that is specific to [REDACTED]. Occasional overnight stays from Commonwealth Carelink are greatly appreciated (4 nights this past 12 months) but are simply not enough and cannot be accessed on a regular basis. I have no family help nearby to give me much-needed respite.

2. More domestic assistance. Queensland Health send a person to clean on a fortnightly basis - 2 hours. Running a home with two disabled men is exhausting. There is always housework, ironing, washing, shopping. When do I get time to study or even do a yoga class?

3. Financially, I receive the Carer Allowance from Centrelink. This is welcome but not nearly enough as most of the services I use for [REDACTED] and [REDACTED] ask for a contribution from me. This adds up. For instance, the overnight stays from Commonwealth Carelink, whilst I acknowledge that they are expensive, ask for a contribution of \$50 on each occasion. The Carers Bonus is welcome and I hope it is here to stay as it does make a practical difference to my life as well as having an emotional impact - I feel recognised and appreciated!

At this point I must acknowledge the help given to me by Autism Queensland, Parkinson's Gold Coast, Autism Gold Coast and Carer's Queensland. Particular mention to Autism Gold Coast who have provided me with a wealth of resources, information, camaraderie over the past four years when I re-located to the Gold Coast. This is exactly the type of organisation that is needed at "grass roots" level and may I suggest that more funding be made available to keep regional organisations like Autism Gold Coast up and running particularly in this age of electronic and media ascendancy. Support groups such as the above-mentioned must have continued monitoring in both an organisational and financial manner in order to progress and grow successfully for the future.

In conclusion, I will re-iterate what you have no doubt heard and read many times before; being a carer is a lonely and isolating experience.

There are many things I don't do because of my caring duties; many places we don't attend because of the possibility that [REDACTED] might "misbehave; many social events that we cancel at the last minute because my husband's Parkinson's is just too severe to make it comfortable for me and for him.

My worries have also been regurgitated many times I'm sure. What happens next? What happens when I can't take care of [REDACTED] and [REDACTED] any longer? Well, I know what will happen.

It will be over to you. The government, at all levels, will have to take over. This is why we need to work together now and help each other.

I look forward to reviewing the recommendations you make as a result of the Inquiry into Better Support for Carers.

Thank you for taking my views into consideration.

Yours sincerely,

A handwritten signature in black ink, appearing to be the name 'Diana' written in a cursive style.

Diana