

**Submission No. 880**  
(Inq into better support for carers)

Name: Cynthia

Position: Mother of 2 children, one of which has multiple disabilities

I would like to write a much longer submission, but to put it very simply I don't have the time. Most of my time is spent trying to survive my caring role and trying to track down non-existent or inadequate services.

My son Nicholas is nearly 8 years old. He has intellectual disability, severe autism (we're not talking Aspergers, the trendy side of autism. We should be so lucky!), cerebral palsy, profound deafness and hydrocephalus. Nicholas has had numerous surgeries and will have more in the future.

The governments of this country are not ready for children like Nicholas. Years ago such children would not have survived but the services that are needed are simply NOT in existence and not enough. A little hand out to carers such as carers bonuses is just a drop in the ocean. It actually does nothing to address the systemic faults in the health/welfare/education sector.

I will put my thoughts in point form according to the four areas in the terms of reference.

**1. As a carer, I feel that my role is**

1. Undervalued, hugely physically exhausting and emotionally draining. My son is eight years old and not toilet trained. Changing his dirty nappies is getting harder. He is totally non verbal, but this does not mean he's quiet. He yells a lot. He totally dominates the household with his behaviours and needs and I worry about the effects on my 3 year old daughter.
2. A life sentence, from which there is no escape except via death. Nobody except carers in similar circumstances will ever understand the unrelenting nature of life with such a child. Nicholas will never be independent in adulthood

**2. As a carer I face the following problems**

1. Exhaustion
2. High anxiety levels
3. Depression
4. Long wait Lists for Case Management

5. Long Wait Lists for Respite
6. Long Wait Lists for Residential Respite
7. Long Wait Lists for Holiday Care
8. Inability to work due no after school care for my son at his special school (most special schools have no after school care or holiday care, which is a complete disgrace, as carers of children with disabilities even more than others need work as respite from their caring role and also the extra money a job would bring)
9. Unresponsive, inequitable/complicated respite/ funding system which even those that work in it have stated many times to me is complex beyond belief and they themselves only understand parts of it. Between Yooralla, UCCO (Uniting Community Care Options) and CCRC (Commonwealth Carers Respite Centre) there are different options that may be accessed, but good luck to you if you can work it out! What you are told depends who you speak to and when. I have often received conflicting advice from the same organisation.  
I am tertiary educated and speak English well. Others that aren't as lucky are often in trouble. You have to be your own and your child's advocate. If you can't do it, you miss out, it's as simple as that.
10. Huge administrative load dealing with paperwork for Nicholas' medical/educational/funding applications etc etc. It's almost like a full time job except I don't get paid for it. If I did get paid it would probably be at the rate of Administrative Officer (HEW 6), the level I used to work at in a Faculty in the University of Melbourne (last time I worked that was over \$50,000 a year)
11. Fears for my future and that of Nicholas. All other issues pale into insignificance when you look at future options for Nicholas as an adult. There is simply not enough residential care for people like Nicholas and **NOTHING IS BEING DONE ABOUT IT!**

### **3. As a carer, I need help with**

Accessing respite options so that I, my partner Jeff and daughter Zoe have more frequent and regular breaks from Nicholas

Dealing with my anxiety, depression and anger at the state of my life. Currently I am seeing a psychiatrist and taking medication. I know many other mothers doing the same

Dealing with Nicholas' difficult behaviours. He goes to a brilliant special school (Bulleen Heights) but when he's home on school holidays it's incredibly difficult to cope, a situation not helped by the lack of suitable holiday programs.

Planning for Nicholas' future and mine. Who will look after him when we cannot? There is no certainty of what will be available

#### **4. I think the Government can better help carers by**

Streamlining the provision of respite care and funding for such care. At the moment the system that exists in Victoria is a dog's breakfast, complex beyond belief and what you access depends on luck, not need in many instances (see point in section 2, above)

Providing extra funding for respite, both in home and residential. The wait lists in Victoria are a joke. It has taken over two years on a waiting list for us to access occasional residential respite with Yooralla for Nicholas. **Let me put this clearly: the need is huge and the services paltry.** Many people will struggle for years without help.

Providing after school and holiday care for children attending special schools. This is a fundamental right which many of these children have no access to. I can only speak for Victoria, but from speaking to other parents other states are even worse. **All parents of children with disabilities should be able to work if they so choose.**

Stop the buck passing between state and federal governments. Work together to achieve the above. Carers do not care who does what. We just want it to happen.

Shifting dramatically the way that residential care for disabled adults who are unable to be independent is delivered.

What is needed is a system like that of nursing homes for the elderly, but for young adults. These need to be homes where such adults with disabilities are looked after by trained staff and lead as much as possible fulfilling lives. Organisations such as ABLE provide this for multiply disabled adults. They get nowhere enough funding. Much, much more is required.

The government has no idea what is going to hit it in the next decade. There is an epidemic of children like Nicholas who survived a traumatic birth and multiple disabilities and will be becoming adults without a future. Who will look after him when we cannot? In the past such children would not have survived. **Why did the doctors save him when the services that he will desperately need in the future are not there?**

I would like an answer to this question in particular. And here my energy and time have run out. Nicholas is screaming at me because he wants to eat, and his nappy needs changing and my daughter is also looking for attention.

I hope this enquiry actually achieves something for carers. I would like to be informed of any outcomes.

Cynthia