

## **Inquiry into Disability Care & Support - Productivity Commission**

**August 15 2010**

Dear Sir/Madam

I am the mother of a 12 year old daughter with Autism Spectrum Disorder. Although she showed signs global developmental delay from birth, she did not receive an official diagnosis until she was 5 years old. As a consequence we missed out on the intensive early intervention and support that is widely accepted as necessary to improve the outcomes of people with autism.

The challenges that come with caring for a child with a disability are sustained and significant. They affect all areas of life – family life (especially siblings), marriage, mental health, physical health, social life, finances – the list goes on.

### **Things I would like to see in a new system are:**

#### **1. Case worker/contact person**

As soon as a problem is evident – in my daughter's case – from birth, a case worker should be assigned to the family. Together with the parent/carers, he/she would work out a care plan. This person should oversee, facilitate and co-ordinate all services likely to be required- both immediate and future. Services would include medical, dental, behavioural interventions, recreational opportunities, educational, respite and carer support, allied health – psychology, occupational therapy, physiotherapy, independent living skills, accommodation options.

All information from people and services involved in the care of the person with disability should be stored centrally so as to be accessible to all involved (with permission ofcourse). This would stop the current necessity to supply reports, forms, information - multiple times.

#### **2. Child Protection**

I want the right to choose the gender of care worker for my daughter in out-of-home respite services. Currently at one service my daughter attends, it is common practice for a male carer to be rostered alone overnight. Apart from risks associated with only one carer on duty (should he fall ill or have an accident), it also poses other risks of possible abuse.

Respite is not a medical setting. I am trying to teach my daughter self-protective behaviours and as such I don't want her to think it is normal for a male to provide her with personal care – toileting, personal hygiene, menstrual management etc. I know she is also uncomfortable with this.

#### **3. More well-trained care workers**

Better recognition in the form of remuneration for care workers. We need to make this a more attractive career choice so as to alleviate the current shortage of competent and committed support workers.

There should also be ongoing training offered. In the past I have been allocated a care worker with no training or experience with autism – clearly not suitable.

#### **4. Assurance for the future**

I want a plan for future accommodation and care for my daughter when we are no longer able to care for her. This is the cause of much mental anguish for carers.

#### **5. More respite/carer support options:**

- a. Care workers should also be able to look after siblings if required. My daughter is much happier if her younger brother is at home with her when we have a care worker in. It is a better experience for everyone.
- b. Choice of care worker – I would like to be able to nominate my own carer. Currently, I can only do that if they have registered with the particular brokering service – even though may be registered with another. I have lost workers because of this.
- c. I would like access to a trained care worker while on holiday. We don't go on family holidays because of difficulties presented with behaviour and the inability of our daughter to participate in active or adventure pursuits eg skiing, hiking, theme park rides etc. This will be a life-long issue and it means her brother misses out too. We don't necessarily want to go away for a week without her – even if it were possible get respite for that amount of time. We would like a carer to accompany us for all or part of the holiday.

#### **6. Post-school**

Post-school option hours should be similar to working hours - not school hours. I will need to continue to work beyond my daughter's school years. I will need her to be at an assisted employment or post-school option during working hours 9-5 in order for this to be possible.

#### **7. Medication**

Medication forms for respite and education facilities should be standardised. I currently have to get different forms completed by a doctor (costs time and money) for each service we use.

Thank you for the opportunity to provide some input into this inquiry. I sincerely hope that this will be the start of a more supportive and responsive environment for carers and people with disabilities.

Pamela Good