22 July 2010

Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Dear Sir/Madam

Our 13 year old daughter has autism. As she gets older we become more and more concerned about her future. We are very lucky that she has been enrolled at a wonderful independent school called Giant Steps which is at Gladesville NSW since she was very young because apart from her school, the only other services that we have been able to successfully access is a once a fortnight respite program run by the Benevolent Society. Even for her school to operate, parents must raise up to $3m every year on top of government funding. This is an even greater strain on families who are already struggling to cope with the demands of having a child with autism.

It seems that services for people with disabilities vary greatly from area to area and are mostly run by independent charities. We have been unable to find a suitable overnight respite service in our area, even though other families we know at her school access overnight respite regularly in their area. Our daughter has had to travel for 1 ½ hours every day to attend her school. There needs to be equal services provided to all people with disabilities, no matter where they live. The need in each area should be identified and services should be provided to meet the demand.

The level of well trained competent staff in disability services seems to be quite low and staff turnover in disability services is very high. We have found that some respite workers are unable to cope with our daughter and this has meant that services have been withdrawn. Her school is able to cope perfectly well with her because its staff are well trained, supported and paid according to their skill level. Service providers need better training from experts and staff need to be paid according to their skill level. If this is done then good staff would be retained. Some service providers throw poorly paid, inexperienced workers into roles they aren’t able to cope with and they soon leave. Time and money is then wasted trying to replace them with equally poorly paid, inexperienced workers.

As our daughter gets older we have discovered that there is virtually no residential services available for adults with disabilities and even the day programs are not full time services. It seems the burden of caring for your child becomes even greater when they become adults. Funding for adult services depends on a complicated assessment process that involves having to make protests to get the services that your child needs. This should not be how it works.

Full time day services (this means 9 am – 5 pm 48 weeks a year) needs to be provided to all adults with disabilities. In addition overnight respite services need to be available to all families for at least 1 night a week plus an additional 4 weeks overnight care so families can take holidays. I believe that providing this level of respite would take a huge burden off families and less families would be forced to surrender their adult children into state care.

I have witnessed an improvement of services to children with autism over the past 10 years but there is still a long way to go. Services and funding for preschool children is much better now than when my daughter was first diagnosed, but these services need to continue into adulthood for those who still need them.

I feel the key to success for all involved is better and more allocation of services and the funding to go with it (especially overnight respite services) and better training and pay to workers.

Thank you for your time and interest. Should you require more information, please contact me.

Yours faithfully

Leanne Maccallum
Parent