

3 July 2008

From: Dr Rozanna

Contact phone:

To: Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
Canberra ACT 2600

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.

I write to you in two capacities. Firstly, I am the proud mother of a seven-year-old autistic boy. Secondly, I am an academic engaged in researching the experiences of mothers in metropolitan Australia who have a child with autism spectrum disorder. I am currently affiliated with the Children and Families research Centre at Macquarie University. My research is focused on the early childhood years and has involved an intensive process of conversation and interview with many mothers of autistic children over the past two years. I would like to share with you some of my observations and findings based on this research, as they are pertinent to the Inquiry.

A widely cited and respected 2007 report has found that there is one child with an Autism Spectrum Disorder (ASD) on average in every 160 children in Australia. In turn, this means that half a million Australians live in families affected by ASD (MacDermott *et al* 2007: i, ii, 15). There is no doubt that these numbers have risen dramatically in recent decades, placing an enormous strain on services and a challenge that government is struggling to meet. There is an enormous cost involved—social, financial and emotional—to individuals, to families and to the community.

Currently, parents of children with autism spectrum disorder have to navigate through a complex landscape of inadequate services and facilities. The bureaucratic and timetabling demands of this navigation frequently mean that one parent, generally the mother, can no longer work. Further financial stress may be caused by the felt imperative to fund expensive private therapies. Recent government initiatives have gone some way towards ameliorating these financial hardships. Nevertheless the cost of many therapies is still

substantially more than parents will be recompensed for and the availability of those services will continue to fall greatly short of both need and demand.

Following diagnosis, parents begin the arduous task of finding and accessing appropriate early interventions for their autistic child. They quickly learn that this is a field immersed in debate and controversy, with different practices and treatments evolving from vastly different philosophies (Roberts and Prior 2006: 29, 36, 76). They also quickly find that some intervention programs cost a great deal more than others. Interventions chosen relate strongly to the financial situation of families and their ability to access large sums of money, sometimes by mortgaging their house or drawing on superannuation early. Even when the funds are available, services are often full and children may sit on multiple waiting lists. Although parents are constantly told that early intervention is absolutely critical to ensure their autistic child has the greatest chance of 'improvement' (Corsello 2005: 82; Roberts and Prior 2006: 16), access to these services often seems like a desperate lottery. For those with more limited financial resources, options are even fewer. Driven by the twin dynamics of the inadequacies of scientific understandings of autism and the desperate necessity for hope, parents continue, often over many years, to try a bewildering, and expensive, array of advertised and rumoured treatments.

Aside from the constant pressures of treatment 'choice', parents must also learn to engage with an unwieldy disability bureaucracy. In the early years this may include therapists who visit the home, attendance at early intervention centres, the search for an appropriate child care setting and the half-hearted surveillance of government agencies and disparate funding bodies. A little later, efforts might be made to access 'respite care'; here there may be a struggle with inadequate services or staff and a potentially fundamental shift in orientation as one is described repeatedly as a 'carer' rather than a 'parent'.

Most of the work of navigating this complex service landscape, and of making treatment choices, is undertaken by mothers. Early intervention programs for developmentally 'delayed' children have flourished in the space once occupied by institutionalisation and residential care. In other words, the burden of care has shifted to families. The sheer hard work involved in having a child with autism, in terms of both everyday care and of access to services and treatments, also often means that one parent is no longer able to work or only able to work part-time. That parent is nearly always actually a mother.

The effort of seeking services and treatments, and the continual sense that one may not be doing enough for a child, a kind of constant panic that a window of opportunity may be closing down if one doesn't act with sufficient speed or acuity, is enormous and the costs, both financial and emotional, are vast. Parents are often reminded that the more intense the treatment, the more beneficial the outcomes. The cost per year of one private behavioural intervention in Australia was \$53,200 for 30 hours of therapy per week. Such costs are standard (Roberts and Prior 2006: 134). For those who are unable to or who choose not to expend such vast sums of money, even standard interventions, such as speech therapy or nappies for the child who cannot be toilet trained, quickly add up. Conservative estimates consistently suggest that it costs at least three times as much to

raise a child with a disability as it does to raise a child without a disability (Dobson and Middleton 1998).

Assessing the emotional costs of raising a child with autism and of accessing services is less clear-cut. But we do know that parents of ASD children experience greater stress than do either parents of children with other disabilities or parents of children without a disability. Obsessive behaviour, sleep disorders, food intolerances, phobias and intense anxiety all take their toll (Roberts and Prior 2006: 24, 74). Further, the time needed to pursue treatments, attend educational seminars or simply ferry a child from one therapist to another all interfere significantly with the taken for granted activities of daily life.

This lack of services and choices is often experienced most forcefully as a child reaches school age. Students with autism present a baffling and challenging array of learning difficulties and abilities to even the most competent teachers. The issue of what kind of education is best suited to children with autism and their families is riven by debate, with some groups advocating complete integration into mainstream schooling and others pointing to the advantages of either partial integration or complete separation with specialist educators trained to remediate the effects of autism. This is an ideological minefield. However, parent decisions regarding school placement are necessarily determined largely by what is available rather than by social justice arguments. Regardless of which treatment programs are undertaken in the early childhood years, most students with autism require ongoing support in school (Roberts and Prior 2006: 50).

Longitudinal studies suggest that life adjustment for adults with autism is, in many respects, much the same as it was a century ago—most adults with ASD are unemployed, friendless and do not live independently (Sigman, Spence and Wang 2006: 339, 340). I cite this grim fact in order to convey something of the enormous gap between the public rhetoric of inclusion and the everyday lives of children with autism and their families. In this gap, carers fight daily battles fought to secure interventions and therapies or to find appropriate classroom placements. Mothers frequently continue to play a caring role throughout their child's life. Fiscal constraints and changing expectations about mental health care have resulted in desegregation or 'community care'. In practice, this means that an adult with autism may continue to live in the family home, generally with their mother, until the time of her death. Mothers are acutely aware of this and, from the time of diagnosis, generally now when a child is two or three years old, they begin to fret about this potentially closed future.

The Government could better help carers of autistic children and adults by:

1. Supporting research on carers of individuals with autism.
2. Expanding financial support and services to carers.
3. Expanding training for autism services and investigating the issue of financial remuneration for those who work in support and educational services, including respite.
4. Expanding access to psychological support for carers, with particular attention to the emotional needs of parents at the time of initial diagnosis.

5. Expanding access to respite services, with special attention to the shamefully neglected needs of older carers.

Thank you for taking my views into consideration as part of the Committee's inquiry. I look forward to reviewing any recommendations you make to improve the life of carers in Australia.

Yours sincerely,

Rose

Rozanna

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