



Autism Spectrum Disorder: Parent education and skills training: a practical and effective way to help.

Dr Avril V. Brereton

Why do we need to work with parents? Isn't early intervention for the *child* with autism?

Autism is associated with burden and stress for parents (Howlin et al., 2004; Tonge et al., 2006; Tonge et al., 2004). The demands placed upon parents caring for a child with an ASD contributes to a higher overall incidence of parental stress, depression, anxiety and adversely impacts upon family functioning and marital relationships compared to parents of children with other intellectual, developmental or physical disabilities (Dunn et al., 2001; Yim et al., 1996; Tonge et al., 2006). Glidden & Jobe (2007) investigated levels of parental concern and worry and found that parents of young people with special needs had more concern about their children than parents who did not have children with special needs.

Mothers of children with autism are more likely to suffer from depression than mothers of children with ID without autism and mothers with typically developing children (Bristol et al., 1993; Olsson and Hwang, 2001; Yirmiya and Shaked, 2005). They may also have a heritable vulnerability for depression (Bolton et al., 1998). A recent study of the association between parental stress and ASDs found that 66% of the parents with high stress indicators were those whose child recently needed special services (Schieve et al., 2007). Psychological distress in parents of children with ASDs has been associated with behavioural disturbance shown by the child with an ASD (Fombonne et al., 2001; Konstantareas and Homatidis, 1989); gender and age of parents (Factor et al., 1990; Hastings and Brown, 2002); and levels of social support received by the parent (Harris, 1991; Henderson and Vandenberg, 1992; Wolf et al., 1989). Financial worries have been associated with higher rates in work loss and medical costs in families with a child with a developmental disability compared with parents of typically developing children (Hecimovic and Gregory 2005; Parish et al. 2004).

Issues of Quality of Life (QOL) have been recently reported (Lee et al., 2007). QOL domains such as social activity, family burden, family activities, schooling, independence and parental concerns about their children's quality of life should be considered when determining the impact of autism rather than examining symptoms alone. It has been suggested that an improved understanding of how QOL is affected by autism may lead to better recognition of the needs of young people with autism and their families and the necessary services and supports can be put into place. Lee et al., (2007) found that children with autism and their

families have compromised quality of life and that families with children diagnosed with autism reported more profound QOL effects than families of children with ADD/ADHD or typically developing controls. Families of children with autism were significantly less likely to attend religious services, more likely to miss school and less likely to participate in organized activities. Parents were also more likely to quit their job because of child care problems. Parental concerns over their child's learning difficulty, being bullied, stress-coping and achievement were overwhelming in the autism group relative to the comparison groups.

What do we know about parents of adolescents and adults with an ASD?

There is some evidence that family stress is greater when the child with autism is an older adolescent or young adult (aged 15–22) compared to a younger adolescent (aged 10–15) (Donovan 1988). Hare et al, (2004), reported on the findings of a study that investigated the social and psychological needs of parents caring for a young adult with an ASD (aged 16 years and over) and provided information relevant to planning services. A strong association was found between unmet needs and parental emotional distress. Parents reported a need for more autism specific interventions and services for adults with ASDs. Most families were found to receive little family and informal support although the levels of formal support, such as respite and day care, were quite high. Parents no longer attended support groups that they had previously attended when their children were young. Hare et al, (2004) suggested that parent support could be usefully reassessed to take account of changing family and developmental needs, given that the majority of the parents scored 'caseness' for long-standing mental health problems. Services also need to recognize the significant levels of parental long-standing psychological distress, together with their socio-economic disadvantage. Parents in the study were also found to have a reduced capacity to care for their family member with an ASD and reduced ability to negotiate effectively with the service systems and to take and act on advice. Better understanding of these factors also requires recognizing two distinct sets of needs, those of the parents/carers and those of the family member with ASD.

Can parent education programmes help parents?

Yes! Parent training has long been regarded as an important component of early intervention programs for children with autism (Harris, 1994). There is evidence that parent training contributes to the effectiveness of behavioural treatments (Schreibman, 2000) and, for example, enhances functional communication in young children with autism (Moes and Frea, 2002) and may result in improved parent/child interactions.

At Monash University we have worked with families of young children for many years. In particular we have been concerned that at the time of diagnosis there was no evidence-based programme that parents could attend to teach them more about what autism is, how it affects their child and what they can do to help. Parents also need time and a place to discuss their reactions to the diagnosis, how they feel about this and the effect on themselves and their wider family. With funding from the Australian National Health and Medical Research Council we were able to develop a parent education programme to help parents at this important and often difficult time in the life of their child and family.

The "Preschoolers with Autism: A parent education and skills training programme" was developed at Monash University (Tonge et al., 2005) for parents of young children recently diagnosed with autism. Ten 90 minute small group (4-5 families) sessions alternate with ten 60 minute individual family sessions over a 20 week period. Facilitators receive training in the procedures for each session and follow a manual that delineates each treatment on a session-by-session basis (Brereton and Tonge, 2005). A large, randomized controlled study of the impact of this parent education and behaviour management training on the mental health and adjustment of parents provided evidence that a parent education and skills training program for parents of young children with autism was of benefit to their mental health and well-being. Not surprisingly, this applied particularly if parents had pre-existing

mental health problems such as depression and anxiety disorders. One and two year follow up showed that therapeutic effects lasted over the follow up period.

We encourage early intervention services to offer programmes specifically for parents that sit alongside the child focussed interventions. This is in line with international research that endorses family centred practice, active partnerships with parents and considers the needs of the whole family. Parent support and education that helps build parent confidence, understanding of autism, and practical skills at the critical time after diagnosis has been shown to improve parental mental health and well being that lasts beyond the early intervention years (Tonge et al., 2006).

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