



## Working together with parents in the preschool years (Part 2)

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### How can we help parents and carers of young children with autism?

Autism is associated with considerable personal suffering and is a significant burden and stress for parents, families and carers. Stress and anxiety have been found to be higher in parents of children with autism when compared to parents of children with other intellectual and developmental disabilities and can adversely impact upon family functioning and mental health, including stress on the marital relationship. Several studies have found that mothers of children with autism were at a significantly greater risk of developing clinical depression than mothers of children with intellectual disability (ID) without autism and typically developing children.

Clearly, we need to find ways to help parents and carers of children with autism. Harris (1994) suggested:

#### Effective coping skills (parent training)

“...parent training appears to be one essential experience that should be available to every family of a child with autism” (Harris 1994).

Young pre school aged children spend most of their time with their family at home. Children with autism are no different to other young children in this respect. It therefore makes good sense to help parents and carers improve their day to day coping skills. Centre based Early Intervention programmes are certainly important but considering the majority of the child’s time will be spent with parents/carers at home and not at the local EI centre, we need to help families manage daily life with their children in the home setting.

One coping strategy that has been shown to be effective for parents of children with autism is parent training to teach families the kinds of management procedures that will enable them to understand and control their child's disruptive behaviours and increase the parents' abilities to help their child master new adaptive, play communication and social skills. Research on the effects of structured and systematic parent training, such as the "Preschoolers with autism" programme (Brereton and Tonge, 2005), has shown that parents can learn these skills and become more effective teachers for their children. Importantly, this type of programme is also effective in lowering parental stress and improving parental mental health and adjustment. Parents report that knowing "what to do and how to do it" makes them feel more in control and positive in their parenting skills.

### **A good social support network**

Some families have found that a support group that enables members to share their feelings, emotional responses, and enlarge their social networks to include other families who can help when things are tough is very helpful. Support groups can also be a focus for ongoing educational programmes and social activities for the family.

A support group that helps parents to learn how to utilize community resources and advocate on behalf of themselves is also important.

Sibling support groups can be helpful in exploring the issues confronted by brothers and sisters of the child with autism. Not all sibling responses are negative. For example, teaching siblings the skills to enable them to play with their brother or sister can be beneficial for the whole family. Some siblings report that caring for a brother or sister with autism has helped increase their self esteem, sense of empathy and interpersonal skills. Siblings should not be expected to take over parenting roles or responsibilities but the sibling support group can provide the opportunity for older siblings to learn some basic management skills. Issues such as - understanding what autism is and why the child with autism behaves as he/she does feelings of jealousy because of the attention that the child with autism receives anger about rejection by their peers and worry about the "inheritance" of autism can be discussed in a sibling support group.

### **Family cohesion**

Parents can have different reactions to having a child with autism. Research has shown that mothers experience a greater personal impact than fathers who have a child with autism. Most often the mother has the responsibility of child rearing and the father has work outside the home. This may account for the difference between mothers' and fathers' perceptions of the impact on their lives of having a child with autism. A recent study found that fathers were more upset by the stress their wives experienced than by being the father of a child with autism.

It has been found that the mother's life satisfaction is enhanced when the father assumes his fair share of care of the child. Feeling emotionally supported by one's partner is important when trying to respond to and meet the special needs of the child with autism. Adjusting to these needs can bring additional stress to all the members of the family.

Each family member, siblings as well as parents, need their own space and parents need time together. Making the time available for this space can be difficult and the challenge is to find a balance between closeness and distance, between being part of the family and being a separate person. Planned, regular respite care as well as enlisting the support of a social network can be helpful in achieving this.

Families can be extremely vulnerable to those who offer “cures” at this time. Information about early intervention services for the child, local parent support groups, access to parent training and education, education for carers and other professionals involved with the child, family support and respite care are all important.

## References

Brereton A, Tonge B (2005), *Pre-schoolers with autism: A parent education and skills training programme*. London: Jessica Kingsley Publishers.

Harris S (1994), *Treatment of family problems in autism, Behavioral issues in autism*, Schopler E and Mesibov G eds. pp 161-175. Plenum: NY

Tonge, B., Brereton, A., Kiomall, M., Mackinnon, A., King, N. & Rinehart, N. (2006). Effects on parental mental health of an education and skills training programme for parents of young children with autism: A randomised controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*. 45 (5): 561-569.

### Websites:

[Autism Victoria](#)

[Early Childhood Intervention Services - Victoria](#)

[Association for Children with a Disability](#)