



Grandparents of Children with Autism

Dr Avril Brereton

Reactions to the diagnosis of autism vary from family to family just as the road that leads each family to diagnosis can be different. In most cases it is parents who instigate the assessment and diagnosis process, but in some families, concerns may be raised by a relative who knows the child well, particularly a grandparent who has had the experience of watching his/her own children developing and growing and subsequently grandchildren in the wider family.

The diagnosis of autism may come as a shock to some parents who did not seek an assessment but were referred by a health professional or teacher. They may not believe it, be angry with the professionals who have made the diagnosis and reject it totally. Some parents may be overwhelmed by feelings of sadness and guilt. Some families we have worked with are initially more concerned about the reaction from members of the extended family, particularly their own parents and worry about how to tell them about the diagnosis.

What *is* common to all families is the need for accurate information about autism and what services are available to them. 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.

But what about Grandparents?

What do we know about Grandparents’ reactions to a diagnosis of autism in the family and their need for information, support and education/skills? I have chosen some published studies about grandparents and autism to discuss this topic.

1. Grandparents of children with disabilities:

In 1997, Hastings wrote a review of literature about grandparents of children with disabilities. There had been no literature review of this topic prior to Hastings’ paper. Grandparents’ reactions to a child with a disability appear to be the same as parents’ reactions, including, shock, devastation and loss. Some studies also reported that grandparents had feelings of sadness and anger at this time. Most studies up to 1997 had focussed on the grandparent relationship with the child’s parents. The impact

of child disability on this relationship was investigated from two perspectives: grandparents may behave in ways that increase the burden on families or they may behave in ways that reduce the burden. In other words, some grandparents are a source of stress and some are a source of support. Examples of support were grandparents visiting once per week, helping with shopping, household tasks, having children for overnight stays at least once a month and occasional or regular financial support. Maternal grandparents more frequently provided support than paternal grandparents.

Few studies have looked at the problem of grandparents placing an additional burden on parents of a child with a disability. In a study of children with epilepsy, over three quarters of the families identified a grandparent as unhelpful and a source of stress, usually because grandparents tended to encourage parents to be overprotective. Some studies also found that parents of the child with a disability had to support their own parents who were mourning over the loss of the expected grandchild at the very time that they themselves needed extra support. In other cases, grandparents had difficulty understanding the nature and level of their grandchild's disability and believed that nothing was wrong with the child.

2. Grandparents of children with Autism:

Harris, Handleman and Palmer (1985) asked parents and grandparents to describe their view of the child with autism and the impact of him/her on the parent and the relationship between parents and grandparents. On the whole, grandparents took a more positive view of the child than parents did. In particular, maternal grandmothers had a more positive view of the child with autism than their daughters did. They also showed a good understanding of their daughter's experiences and were sensitive to their feelings. Maternal grandparents tended to have more to do with their grandchild than paternal grandmothers and grandfathers. Maternal grandfathers tended to have a less optimistic view of the child with autism than their wives did. In an Australian study, Gray (2002) followed families of children with autism for ten years to gather information about families' social experiences. He also asked parents about grandparent issues. Initially he found that parents of children with autism reported that their parents were critical of their child raising skills and frequently denied that the grandchild had autism. However, on 10 year follow up, Gray reported that for most families, relationships between parents and grandparents improved as the reality of the child's autism and disability was confirmed over time, and the grandparents became more accepting of the situation.

More recently, Margetts et al, (2006) conducted a research project that examined the experiences of 6 grandparents of children with autism. They found that three key themes emerged from the interviews:

1. the parental bond (describing experiences of the parental bond to their adult child as well as their grandchild with autism);
2. striving for answers (grandparents were wrestling with questions to which there were no easy answers, such as how to support their child without undermining them, relying on "experts" for help and advice, struggling with not knowing and trying to understand the cause of autism in their grandchild); and
3. keeping intact (grandparents worrying and feeling responsible for the wider family in response to the child with autism).

Overwhelmingly, grandparents discussed their need for support.

This study made the following recommendations:

1. Grandparents should be regarded as a potential major support to parents at the crucial time of assessment and intervention
2. Grandparents should be regarded as a potential source of information and key candidates for receiving information on the child and autism
3. Grandparents can act as advocates in lobbying for help for the grandchild, and for the whole family, and they should be supported by the clinical service in this role. (p 572)

Importantly as a result of the study, the PDD team made changes in its work with families. Families were asked if they wanted to bring grandparents with them to the assessment. They did note that not all families took up this opportunity.

Intervention and Support for Grandparents: What can we do?

There is no doubt that being the grandparent of a child with autism presents particular challenges. Grandparents need to be involved - *but not directly*, need information - *but not as a parent*, and need support - *whilst recognizing the greater pressure on parents*.

Grandparents may be confused about what autism *is*, why their tried and true parenting skills don't work on the grandchild with autism. They may also be completely bamboozled by obsessions, likes and dislikes, fussy eating, sleeping problems and resistance to change. Just as parents learn about the core features of autism and how they impact on children, access to education and information is important for grandparents too. Grandparents are often excluded from the normal information networks available to parents and feel that professional workers should include them when information is shared. When grandparents are given the opportunity to become more knowledgeable about their grandchild's autism this may help parents, because at least within their family, there is someone who has some knowledge and understanding.

Hillman (2007) made several recommendations for education, practice and policy for the growing number of grandparents of children with autism. Educational needs include accurate and up to date information about autism. Programmes and curriculums should be designed to help grandparents to define their role as grandparents of a child with autism and give concrete skills to help them to communicate with their children (the parents of a child with autism), connect with support groups and help with advocacy for their grandchild. Custodial grandparents also need essential information about services available for education, respite care and financial support.

There are some support groups for grandparents of children with autism, particularly in the US and UK and in some states in Australia (e.g. South Australia) and some websites have dedicated sections for advice to grandparents.

How to include grandparents

- From a practical point of view, ECI professionals could begin by talking with families of children with autism that they are working with about grandparent issues in their family.

- Include grandparents from the start. Check with families when they are coming in for assessment as to whether or not they wish to include grandparents in the assessment process in some way. This may be at the initial interview or at the later feedback session.
- The series of three workshops delivered by ACT NOW (Autism in the Preschool years) provides an opportunity for professionals to attend with parents but perhaps this could include a specific invitation to grandparents.
- Some grandparents have successfully attended the Preschoolers with Autism Parent education and skills training programme to learn “alongside” their adult children. Some families opted to bring in their parents to a special individual session to talk about family issues or more generally to help grandparents understand how autism is affecting their grandchild and what new behaviour management and communication strategies were being developed.

References

Gray, D. (2002) Ten years on: A longitudinal study of families with autism. *Journal of Intellectual and Developmental Disability*, 27: 215-222

Hastings, R. (1997) Grandparents of children with disabilities: A Review. *International Journal of Disability, Development and Education*, 44: 329-340

Hillman, J. (2007) Grandparents of children with autism: A Review with Recommendations for Education, Practice and Policy. *Educational Gerontology*, 33: 513-527

Margetts, J, Le Couteur, A, Croom, S. (2006) Families in a state of flux : the experience of grandparents in autism spectrum disorders. *Child: care, health and development*, 32: 565-574

Websites

Grandparents Autism Network www.ganinfo.org/tips.aspx

Asperger information for Grandparents www.udel.edu/bkirby/asperger/grandparents.html

Stress on Families ASA website www.autism-society.org/site

NAS (UK) www.autismspeaks.org.uk/grandparents_network.html

ACT NOW fact sheets www.med.monash.edu.au/spppm/research/devpsych/actnow/factsheet.html

Books

Voices from the Spectrum Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom. Eds. Ariel and Naseef. Paperback, ISBN: 9781843107866, 272pp, 2005

Children with Autism and Asperger Syndrome Pat Howlin. John Wiley & Sons, 1998