

Autism Spectrum Disorder (ASD): Thinking about the family - Grandparents of children with ASD

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Reactions to the diagnosis of ASD vary from family to family just as the road that leads each family to diagnosis can be different. Some parents may be overwhelmed by feelings of sadness and guilt, and others can be worried about how to tell their own parents about the diagnosis.

Grandparents usually want to be involved, and need information - *but not as a parent*, and need support - *whilst recognizing the greater pressure on parents*.

Issues for Grandparents

Grandparents' reactions to a diagnosis of ASD in the family can vary. They can be the same as parents' reactions, including, shock, sadness and loss, but grandparents can also be dealing with issues quite separate from parents of a child with ASD¹.



There is no doubt that being the grandparent of a child with ASD presents particular challenges.

Grandparents may be confused about what ASD *is*, and why their tried and true parenting skills don't work on their grandchild with ASD. They may also be confused by the child's special interests, likes and dislikes, fussy eating, sleeping problems and resistance to change.

Support for Grandparents: What can we do?

Just as parents learn about the core features of ASD and how they impact on children, access to education and information is important for grandparents too. When grandparents are given the opportunity to become more knowledgeable about their grandchild's ASD this may help parents, because at least within their family, there is someone else who has some knowledge and understanding.

Recommendations for including grandparents of children with ASD².

Grandparents need:

- ✓ accurate and up to date information about ASD.
- ✓ programmes that help to define their role as grandparents of a child with ASD
- ✓ concrete skills to help them to communicate with their children (the parents of a child with ASD), connect with support groups and help with advocacy for their grandchild

How to help grandparents:

1. Include grandparents from the start. E.g. 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.
2. The series of three workshops (*Children with ASD in ECEC settings*) provides an opportunity for professionals to attend with parents but this could include a specific invitation to grandparents as well.
3. Some grandparents want to attend parent education sessions, such as the *Preschoolers with Autism programme*, to learn “alongside” their adult children. This can help grandparents understand how ASD is affecting their grandchild and what new behaviour management and communication strategies are being developed and used at home.

References

1. 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
2. Hillman, J. (2007) Grandparents of children with autism: A Review with Recommendations for Education, Practice and Policy. *Educational Gerontology*, 33: 513-527

Websites:

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

Asperger information for Grandparents:
<http://www.udel.edu/bkirby/asperger/grandparents.html>

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