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**Conference or Workshop Item**

**Title:** A matter of perspective – whole families’ experiences of living with autism

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**Version:** Presented version

http://nectar.northampton.ac.uk/5816/
Why carry out this research?

Our understanding of family life in families that include children on the autism spectrum is predominantly based upon research carried out with parents. Moreover, assertions and assumptions are often made about families or parents based solely upon maternal reports.

This study sought to understand how the presence of autism was experienced and understood by different family members within the same families.

How was the research completed?

Consultation was undertaken by interviewing 14 families in one UK county.

Interviews with children on the autism spectrum were individualised with differing levels of structure and visual supports.

Different Family Experiences

**Mothers**
- accepted the impact of autism upon themselves
- felt isolated
- experienced stigma,
- were worried about the impact of living with autism on their other children,
- and worried about the future

**Fathers**
- tended to withdraw (from day to day care and contact with professionals)
- played down the difficulties faced (though viewing their family as in greater need of support than others)
- used humour to deal with problems, and worried about the future

**Children on the autism spectrum**
- generally positive about family life
- were unaware of the stresses and issues perceived by other family members
- but difficulties at school and isolation were common themes

**Siblings**
- accepted living with autism as normal
- highlighted the importance of the sibling bond
- spoke of restricted opportunities, stress and embarrassment

This sorting tool enabled one child on the autism spectrum to express his likes and dislikes

What does this mean?

Families have a shared but differing experience of the difficulties and stress of living with autism.

Different family members may experience and react to living with autism in different ways.

Professionals and researchers need to take this into account when working with and thinking about these families.

Thanks to Prof Rita Jordan and Dr Karen Guldberg at the Autism Centre for Education and Research, University of Birmingham. More detail about the consultation process with the children on the autism spectrum can be found in Preece, D. & Jordan, R. (2010) British Journal of Learning Disabilities, 38, 10-20.