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A matter of perspective – whole families' experiences of living with autism

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Why carry out the research?

- Our understanding of family life is largely based on research with adults
- Assertions often made/conclusions drawn regarding **families** and **parents** based on **maternal** report (researchers and professionals)
- Growing literature including mothers and fathers, but experience of whole families, and family experience of children on autism spectrum, remains under-researched





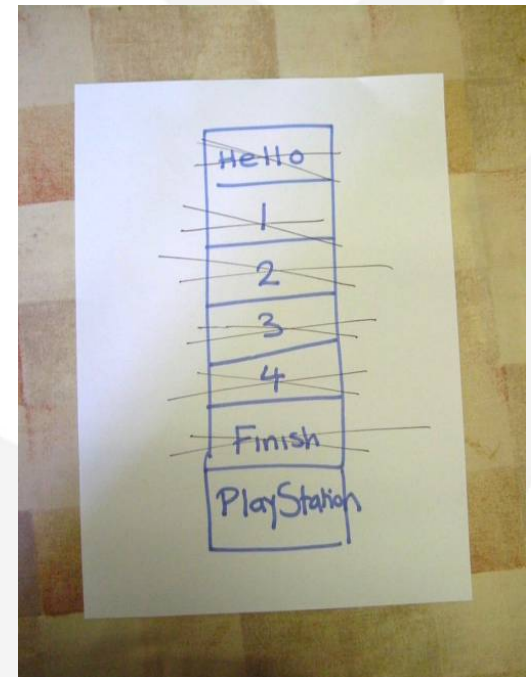
How was the research carried out?

- Qualitative study, underpinned by family systems theory (Seligman & Darling, 1997)
- Research designed in collaboration with families that included individuals on the autism spectrum
- Families questioned about day to day family life and informal/formal support
- Dimensional sampling used to select families for consultation (inc. child's age, diagnosis, family composition, ethnicity, services accessed, urban/rural)
- 14 whole nuclear families consulted: 14 mothers, 8 fathers/partners, 10 siblings, 14 children on spectrum





Consultation methods: interview, observation, documentary analysis, structured activities





Findings

- All families used multiple and varied coping strategies
- Most were enmeshed to some degree – ‘united against the outside world’, with few external sources of support
- Parental/sibling roles blurred – often a source of guilt
- Family functioning significantly affected
- Range of adaptation to living with autism – anger to hyper-accommodation
- Different individuals in same family could hold very different perspectives, experiencing and conceptualising presence of autism in family very differently





Different themes

- **Mothers:** isolation, stigma, acceptance, concern about other children, uncertainty about future
- **Fathers:** withdrawal, minimisation of difficulties, humour as coping strategy, uncertainty about future
- **Siblings:** living with autism as normality, restricted opportunities, stress, embarrassment, sibling bond
- **Children on spectrum:** generally positive about family life, unaware of negative impacts of autism, isolation, problems outside nuclear family unit (especially at school)





Conclusions

- Professionals and researchers need to
 - acknowledge the range of perspectives that can exist within families, and between family members
 - be sensitive to gender differences and differences between subsystems within nuclear family
 - develop research and interventions that take account of and help us understand these differences





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A matter of perspective – whole families' experiences of living with autism

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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.



14 Families consulted

14 Mothers (aged 34-63)

8 Fathers/partners (aged 29-63)

10 Typically developing siblings (aged 9-24)

14 Children on the autism spectrum (aged 7-18)

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**



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

Siblings

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

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

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. (2016) *British Journal of Learning Disabilities*, 38, 10-20.



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