



This work has been submitted to **NECTAR**, the **Northampton Electronic Collection of Theses and Research**.

Conference or Workshop Item

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

Creators: Preece, D.

Example citation: Preece, D. (2013) A matter of perspective – whole families' experiences of living with autism. Poster presented to: *10th Autism-Europe International Congress, Budapest, Hungary, 26-28 September 2013*.

Version: Presented version

<http://nectar.northampton.ac.uk/5816/>



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

Dr David Preece

University of Northampton, UK

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 29–65)

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**

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



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.