Conference or Workshop Item

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

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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
For more information - email david.preece@northampton.ac.uk or speak to me at my poster.