

RCN Research Society Marjorie Simpson New Researchers' Award 2011

The impact on children's development of having a child with Autism Spectrum Disorder (ASD) in the family.

Background

Younger siblings of children diagnosed with Autism Spectrum Disorder (ASD) show some developmental delays in similar domains to children diagnosed with ASD. These cannot be presumed to be wholly associated with genetic influences or risk, although that has been the main supposition (Yirimiya et al 2006). Few studies have examined the impact of social and interactional factors within the context of the home and family, on the development of social and communication skills of young, subsequent siblings of children diagnosed with ASD, as well as the development of the child with ASD. This study adds to the extant literature by focusing on the impact of the specific social and interactional factors within the family context, on all the children's social and communication development.

Examples of these social and interactional factors include;

- The impact on parents of having a child with a disability, and the connection of this to family coping, adaptive behaviours and overall functioning (Heiman et al 2008; Olsson et al 2008; McConkey et al 2008)
- The impact of the child with ASD's adaptive skills and learning behaviours, including any challenging behaviours, on family relationships and functioning, and the development of younger siblings (Goin-Kochel et al 2008; Sillar et al 2002).
- The impact of family informal supports and formal service accessibility and provision, together with parent education on the social and communication development of the child with ASD and the other siblings (McConkey et al 2008; McConkey et al 2007; Feagan 1991; Pakenham et al 2004).
- The importance of siblings and parent's roles in the social and communication development of the child with ASD and any other siblings.

Methodology

A mixed-method, longitudinal study design was chosen as advocated by extant literature on younger siblings of children with ASD. A family systems theory approach (Sturge-Apple et al 2010; Bowen et al 1978) is taken to this research, as this enables the examination of family interactional environment and functioning on children's development. Data on family functioning will be collected at three time points six months apart using validated developmental measures, a demographic questionnaire and a parenting stress measurement tool for the quantitative measures. The family will also be videotaped during naturalistic play sessions involving the child with ASD, their younger sibling and the parent, at the three time points over a data collection period of 12 months in total for each family. Quantitative data, and observed interactions will be reinforced by semi-structured interview with the parent also at each of the three time points.

Participants

10 families recruited from two HSC Trust Autism Service caseloads in Northern Ireland, and the local Autism Charity, Autism NI, parent support groups and family support service, who meet the following inclusion criteria;

- Families with a child with a diagnosis of ASD up to the age of 10 years who have a subsequent born sibling aged 12 to 24 months at commencement of study.
- Families can be of any ethnic group or family structure.

Data Analysis

A case study approach to analysis will be used (Yin 2004). Case studies have been defined as research examining a small number of naturally occurring cases (Hammersley 1992), within their context and they typically involve a combination of data collection methods (Green et al 2008). Essentially, each family and the data gathered therein will be individual case studies. The data will be compared within the individual families and also across all the 10 participant families in the project, giving a within case and across case analysis. This

analysis is intended to identify the above impact and its nature, as well as to explore how the social, interactional factors being assessed within families in the study contribute to this impact and why.

Expected Outcomes

Exploration of specific interactional factors within the family context and the influence these factors have on the development of children in the family where a child has ASD, will inform future development of family-centred services.

Supporting Statement

I would like to attend the RCN International Nursing Research Conference because I became aware during my attendance at this conference in Gateshead in May, 2010, that this would be an excellent platform for me to communicate to research and nursing colleagues, the preliminary findings of my research project pilot study.

The RCN Research Society's commitment to actively publicising the nursing contribution to user involvement in research has inspired me to design an abstract and presentation for consideration at this conference entitled;

“Are You Listening?” – parents descriptions of factors necessary for optimal child development and family functioning when a child has Autism Spectrum Disorder (ASD).

This is a co-presentation with a parent participant in the above research study, who, with the two other families involved in the completed pilot phase of this research, consistently describes a primary emerging theme of the importance of being listened to by professionals, family members and friends, when their child is diagnosed with ASD.

The aim of my research is to approach the concept of family functioning when a child has a disability from a belief that families are already doing many things in day to day living that promote optimal child development. The purpose of this research is to identify what individual families find helpful, as well as observing the development of the children over time. This is done while examining specific factors of the family's interactional environment that past research has identified as influencing children's development.

The parent's and children's involvement in the research design, data collection and dissemination of findings will be described by the parent presenter and myself. This presentation will highlight how involvement of participant families in all aspects of the study has resulted in more robust conclusions and enhanced implementation of the pilot study findings into the main research project.