Dear Peter,

My name is Rosemary - here is my photo

I have met your brother Ian and, if you agree, I would like to meet you too.

On Sunday I will come to your flat with Ian and we can have a cup of tea.

We can look at some photos of things you do with Ian. If you like we can make a poster.

Then after about an hour I will go home. I hope we meet soon.

Best wishes,

Rosemary Tozer

The Department of Health Sciences

The University of York

Involving People with Autism and High Support Needs in Research – Exploring Sibling Relationships in Adult Life

Rosemary Tozer, Aniela Wenham & Karl Atkin

Sibling relationships are life-long and two-sided, with siblings sharing a unique history and understanding. Exploring these relationships from both perspectives offers insight into their value and meaning as they develop over time.

Methods employed included:

- Illustrated social stories to prepare for and agree to meeting the researcher;
- Photo elicitation – the use of family photos to aid communication and draw out memories;
- Making a collage of favourite photos and pictures;
- A camera to record the meeting;
- Participant observation of a favourite activity, such as visiting a café, and other sibling interaction.

Results

Most siblings met a researcher and appeared to enjoy doing so. None did not take part because of their refusal or anxiety.

Several siblings said their brother or sister liked meeting new people

A close bond and understanding and a shared history was observed between siblings who took part.

Effective communication between siblings showed the importance of gesture, expression, movement, touch and humour, as well as an individually adjusted verbal style.

The advice, support and presence of the non-disabled sibling(s) was crucial to the success of the research encounter.

Conclusions

Involving people with autism and high support needs as active agents in research about their lives is possible and necessary to gain a fuller picture of their experiences and relationships.

Adult siblings play an important and unique role in advocating for and supporting their brother or sister in social situations.

Autism specific research methods need to consider the added dimensions of avoiding possible stressors, fitting research around an individual's routine and preferences, and employing methods that do not necessarily rely upon eye contact or verbal understanding.

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Perceived barriers to their inclusion include:

- Verbal communication methods may be inappropriate or misunderstood
- Abstract concepts rather than concrete experiences are difficult for people with autism to understand and direct questioning can be stressful
- People with autism are made anxious by new experiences and new people
- Using non-verbal or other innovative methods is time-consuming and costly
- Gate keepers – family members and support staff can either be supportive or hinder the possible involvement of research participants

Background

An ESRC funded 18 month qualitative study exploring the experiences, roles and future support needs of 20 adult siblings aged 25+ of people with autism plus severe learning disability. Despite moves towards more participatory research, people with high support needs are usually excluded from relevant studies.

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Research Methods

A literature review identified possible non-verbal methodologies that might enable autistic siblings to take part. A range of resources were developed and adapted to the individual on the advice of non-disabled siblings and key supporters. With their sibling’s agreement and advice, 12 siblings with autism also met a researcher, usually with their brother or sister. Four siblings chose not to involve their brother or sister with autism. The aims of the meetings were to get a ‘feel’ of the sibling relationship and observe how it worked in practice and see what the siblings with autism could demonstrate and communicate about their relationships.

“’My brother enjoys meeting new people, but don’t ask him direct questions”

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“’My sister enjoys looking at photographs – she’ll be able to name all the family members!”

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