

ADULT SIBLINGS of PEOPLE with AUTISM and HIGH SUPPORT NEEDS: their experiences, perspectives & future support needs.

Are you aged 25+ and have a brother or sister with autism and a severe learning disability? If so, you may be interested in taking part in a research project about people with life experiences similar to your own.

The Economic and Social Research Council (ESRC) has funded an 18 month study at the Department of Health Sciences, University of York, to find out more about the perspectives of siblings once they are in their adult years. Rosemary Tozer and Karl Atkin will be the researchers.

Why are we doing the research ?

Adult siblings often find themselves taking on increasing responsibilities and advocating for a disabled brother or sister as their parents get older, even though they may no longer live nearby.

Support services can overlook the contribution or concerns of adult siblings who may be important figures in the lives of people with autism, whatever their level of disability.

How will we do the research?

We plan to talk to 20 adult siblings about their relationships with their brothers or sisters with autism now and when they were growing up. We are focussing on those whose brothers or sisters have autism and a severe learning disability, and whose difficulties in communication and sometimes behaviour can make relationships harder in their families.

We want to find out what kind of information, advice and support might help them feel more confident to play the role they wish in the lives of their brothers or sisters in the future. As part of this, if the non-disabled siblings agree, we would like to meet their brother or sister and include them in the research too in a way that suits them. For example we could meet them informally in a familiar setting and use non-verbal ways to communicate.

Each sibling taking part will also be asked to nominate a key professional in the care of their brother or sister. He/she will be invited to take part in an interview about their experience of working with adult siblings and how to involve and support siblings with future planning.

What would taking part involve?

You would be interviewed by a researcher at home or wherever you felt most comfortable, for about an hour and a half. You would be free to stop the interview for a break or withdraw from the research at any time. Although we would like to record the interview to have an accurate record of what you have said, we would ensure confidentiality to the research team. No names will be attributed to any comments or opinions we might use in reports.



At the interview we would discuss with you whether it would be appropriate for us to meet your brother or sister and, if so, the best arrangements for doing so. We would also ask you to suggest a professional who has worked with the family who could be approached to interview. We will not share anything you have told us with this professional, or anyone else, without your permission. However, during the interview

you may mention something which suggests that your sibling or another member of your family has been, or is, at risk of harm. If so, we are able to suggest sources of support, but may also have to inform the appropriate authorities after discussing this with you.

What happens to the information we gather?

All the information we collect from siblings, people with autism and professionals will be looked at carefully by the research team and the main ideas and issues written up in a report for the ESRC. We will raise awareness of sibling issues and publicise our findings as widely as we can through the press and in journals and at conferences.

We will also write summaries of our findings for adult siblings and support workers and for those planning policies in social care. We plan to work with Sibs, the UK charity for siblings of disabled people, to put together useful information for adult siblings which will also be accessible online. Those who take part in the project will have the chance to contribute to this or comment on a draft.

If you would like more information about the research, with a view to taking part, please contact :

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More information about the ESRC is available at : www.esrcsocietytoday.ac.uk

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