More support needed for adult siblings of people with autism
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An 18-month qualitative research study by the University's Department of Health Sciences, funded by the Economic and Social Research Council (ESRC), explored the experiences of adult siblings at different life stages and identified their support needs now and in the future.

They found that sibling relationships are lifelong and two-sided, often characterised by strong feelings and loyalties. However, the significance of these relationships has generally been overlooked in policy, practice and research, with little support available to siblings.

Dr. Rosemary Tozer, from the Department of Health Sciences, said: "At present, the needs of adult siblings are not considered in practice, although their particular experiences and perspectives could make a valuable contribution in policy and service development."

"Our research identified that not enough practical and emotional support is provided to parents and siblings on how to manage a child's autism and we are recommending that this support should be provided as a matter of course, not just in a crisis."

The study involved 21 adult siblings from 17 families, aged between 25 and 67, who were interviewed about their past and current sibling relationship and their hopes and fears for the future. It also involved 12 of the siblings' brothers or sisters with autism and a learning disability. Apart from two young men who lived with their parents, the siblings with autism were in residential homes or supported living. In addition, 11 professionals, including key workers, house and care managers, nominated by the siblings, were interviewed.

Dr. Tozer said: "Siblings have a vital role to play. They can offer an important supportive, long-term relationship to a brother or sister, especially for those who have difficulties in communication and social understanding, and whose social contacts are often limited to paid staff."

All siblings interviewed commented on a lack of advice for their family from professionals about how to deal with autistic behaviours. Many also mentioned the difficulties associated with late diagnosis of autism, especially for those whose brother or sister was now aged 40 or above. Disruption to family activities, worries about stressed parents and lack of understanding from peers and other family members dominated many accounts.

Dr. Tozer said: "Siblings will have experienced disruptive behaviours associated with their brother or sister's disabilities. They are also likely to have had extra caring roles while growing up, perhaps leading to mixed feelings about how much they can contribute to the support of their sibling in adulthood. They have to negotiate their own concerns for the future, such as the possibility of taking on extra responsibilities as their parents age, alongside other family commitments."

"However, despite the challenges of childhood, most siblings described close relationships with their brother or sister with autism. This was evidenced by a shared history and understanding, use of humour, gesture and effective communication. Siblings described the love and protectiveness they felt for their brother and sister as well as sadness at the lack of reciprocity and limitations of communication in their relationship."

Among the recommendations of the study, "Adult Siblings of People with Autism plus Learning Disability - their experiences, perspectives and future support needs", are:

• Continuing advice and guidance about parenting and how best to support all children in the family should be available from diagnosis and at key points.
Siblings should be offered the choice to take part in reviews to discuss future planning. Social care providers, practitioners from all relevant disciplines and commissioners need to be ‘sibling’ aware and value and support whatever positive contributions siblings make to their brother or sister’s life. The involvement of a third party to help families negotiate future plans may be needed; at present this rarely happens proactively.

Provided by University of York


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