‘The Soundtrack to my Life’: supporting adult siblings of people with autism plus learning disability – a research study

Rosemary Tozer (rosemary.tozer@york.ac.uk), Aniela Wenham & Karl Atkin | November 2009 - April 2011

Background

An 18 month ESRC funded qualitative study at the Department of Health Sciences, University of York has explored the experiences, current relationships and roles and future support needs of adults (aged 25–67) with a sibling with autism plus a severe learning disability. Sibling relationships are lifelong and two-sided, but their significance to both parties is overlooked in policy and practice, as staff relate primarily to parent carers. As parents age and die and within the Personalisation agenda, siblings are likely to find themselves taking on a role in overseeing their sibling’s package of care, for which they may feel ill-equipped.

Methods

21 adult siblings from 17 families in different parts of England took part in detailed qualitative interviews about family life when young, their current role and relationship with their brother or sister with autism, and their hopes and fears for the future. If agreeable to them and practicable, the researchers met their sibling with autism in an informal context such as a favourite café. Family photos were used in meetings with both sibling pairs together demonstrated a life-long bond, through an unique understanding, shared history, and individualised communication style.

Findings

• Open family communication, & informal and formal support could help siblings whilst growing up, but many recalled family isolation and a different normality.
• Young siblings’ sometimes substantial caring roles had rarely been recognised, and emotional support/practical advice from professionals was largely absent.
• Despite a ‘chaotic’ & stressful family life focussed on the autistic child when young, many siblings now described close relationships with their autistic brother/sister, though lacking in reciprocity.
• Some had unresolved emotional issues within their families which had affected their adult life; nearly half had sought counselling; & most would value opportunities to share their experiences with other siblings.
• Sibling pairs were willing to take over a degree of responsibility from their parents, to ensure quality of life for their brother/sister, while meeting their other commitments and having a life of their own.
• Siblings were concerned about helping their brother or sister prepare for and manage the death of parents and wanted advice about the care system, as well as financial arrangements and future planning.
• Service personnel generally saw siblings as a potential resource or substitute parents, rather than peers with a particular history & relationships, and different perspectives to parents.

Practice Implications

• A whole family supportive approach throughout the lifecycle would recognise the needs of siblings of all ages and assist families to negotiate future plans.
• Support staff can foster current relationships and help with future planning, though most siblings had no or minimal contact with care managers.
• Invitations to reviews, social events, sending letters/e-mails and photos of activities, plus continuity of carers, helped siblings feel part of their brother/sister’s life and develop trust with providers.
• Siblings who have not already had children of their own may want information about genetic risks and should be referred for genetic counselling.
• Service providers, care managers and voluntary organisations could play a crucial role in helping families to negotiate a transfer of responsibility from parents to siblings as parents age, in a way that suits everyone.
• Adult siblings can contribute valuable insights and ideas to the planning and delivery of services, including those to younger siblings.

REFERENCES:


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

(Project reference number: Res-000-22-3805.)

Sibs, The UK charity for people who grow up with a disabled brother or sister, can be contacted at info@sibs.org.uk