

Adult Siblings of People with Autism plus Learning Disability– their experiences, perspectives and future support needs

SUMMARY OF RESEARCH PROJECT FINDINGS

Introduction

Sibling relationships are lifelong and two-sided, often characterised by strong feelings and loyalties. However, their significance when a sibling has a severe disability such as autism has generally been overlooked in policy, practice and research. Siblings can offer a supportive, long term relationship to a brother or sister who has difficulties in communication and social understanding and whose social contacts are limited to paid staff.

Siblings will have experienced disruptive behaviours associated with their brother or sister's disabilities[1]. They are also likely to have had extra caring roles whilst 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.

'You think is it actually going to be there forever, is it going to be, like the sort of, soundtrack to my life, autism you know, there in the backdrop.'

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SISTER, late 20s



The Research Project

An 18 month qualitative research study, 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. We chose siblings of people with autism plus (usually severe) learning disability because they have some of the highest support needs. It has also been suggested that siblings of people with autism spectrum disorders are more at risk of negative psychological outcomes [2].

We spoke to 21 adult siblings from seventeen families, aged between 25 and 67, about their past and current sibling relationship and their hopes and fears for the future. In two families, all three siblings took part. Fourteen were women and seven were men, living in different parts of England. Only two were currently living with their brother or sister with autism. Apart from two young men still living with their parents, the siblings with autism (11 men and 6 women) were in residential homes or supported living. The travelling time between siblings ranged from five minutes to five hours. Contact between siblings varied from around once a week, if nearby, to a few times a year if they lived at a distance.

Twelve of the siblings with autism and a learning disability met a researcher informally, such as on a trip to a favourite café. Family photos were used to aid interaction and memories and some siblings made a scrapbook or collage of people and activities that they enjoyed together. This contact helped the researchers better understand the sibling relationship. To explore sibling issues within services, 11 professionals, including key workers, house and care managers, nominated by the siblings interviewed, took part in a telephone or face-to-face interview. The findings of the project and recommendations for policy and practice are summarised here.

Growing Up Together

Reflecting on the Past – ‘my normality is different’

Although in their mid twenties and older, siblings were able to recount in detail and reflect on their experiences of growing up. Aspects of their accounts have parallels with the young carer literature [3]. For some, these recollections were hazy and several thought they had ‘blocked’ out more difficult times. Nonetheless, most could talk about some happy memories, such as family outings or holidays, especially if their sibling was remembered as being content and other relatives were around to give them attention too. Many also recalled traumatic events involving their brother or sister such as their removal into care, violence against parents, or embarrassing incidents in the neighbourhood. A few, however, said that other things had affected them far more during childhood, such as their parents’ divorce or a parent’s ill health. Generally, life was often described as ‘chaotic’ as the family struggled to manage their sibling’s autism and sometimes bizarre behaviours, often taking on autism friendly but rigid routines.

‘Most days he’d be running around scribbling on the walls, pulling the curtain down, flooding the bathroom, putting toys down the toilet. It, it felt chaotic, yeah.’

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SISTER, mid 30s

Isolated and Uninformed

All siblings 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 and sister was now aged 40 or above. Some families had had supportive relatives or close friends nearby to help with either child. Others described negative attitudes or misunderstanding from grandparents and others which increased the family’s isolation and self-reliance. Younger adults had benefited from respite care for their sibling, though this was patchy. Older adult siblings recalled a fear of large

institutions which made their parents reluctant to ask for help and required them to fight for provision such as appropriate schooling. A few siblings had attended a support group when younger, but varied in their response; one remembered that she just wanted to spend time with her own friends.

Involved and Included?

Several siblings had shared a bedroom with their brother or sister with autism, highlighting how they were inevitably involved in caring, while some tried to teach skills such as reading or cooking. Both brothers and sisters described themselves as a 'parent child' or 'third parent', attending appointments or school reviews from an early age. However, they felt their contribution was unnoticed by professionals. Some were especially angry that they had not been more involved or consulted when younger in decisions about their brother or sister. Even when they were not expected to care substantially for their sibling, or where there were other siblings to share tasks, their lives felt constrained by their concern for their brother or sister. Disruption to family activities, worries about stressed parents and lack of understanding from peers dominated many accounts.

Looking back, adults in the study often wished their parents had received advice about parenting both or all their children and that there had been more open communication in the family. Some felt they had buried themselves in their schoolwork, or gained an early independence, spending as much time as they could away from home.

'I used to be really into the Batman TV programme, as many children were, and I'd say, oh I'm too mature for this now, I am not going to watch it any more. So I decided I was an adult by the time I was twelve because I was parenting the, the whole family. I was really scared, I mean many years of sleepless nights worrying what was going to happen to my parents, what would I do about my brother, 'cos it would be me that had to look after him.'

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BROTHER, late 40s

Leaving Home

During their teenage years, many siblings said they had resented their disabled brother or sister. They had to choose friends and boy/girlfriends who could cope with meeting their sibling. Some said they had not thought much about the future while others worried a great deal what would happen if parents died. The majority of those interviewed had left home to go to University or college. While some relished their new freedom, many found this a difficult time and worried about those left at home. This made them feel different to apparently more carefree peers.

'I didn't really want to leave, there was a lot of guilt. Watching Thomas and, you know, just wanting to be I suppose to be there around to look after him, but not, also at the time perhaps not realising that I needed to start my own, you know, sort my own life out'

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SISTER, mid 30s

Those who did not leave home at this point sometimes found it harder to make a move from the family home or if they did, stayed living nearby. Others explained how they returned to live at home later, sometimes for financial reasons, although in at least one case, this was to help with or take over a sibling's care.

Adult Roles & Relationships

'I think it's just nice to spend time with her and being part of her life and she sees me as part of her life... having that bond there.'

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BROTHER, mid 40s

Despite the challenges of childhood, most siblings described close relationships with their brother or sister with autism. This was evidenced by the reassurance they provided when meeting the researcher; based on 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. Those who saw their brother or sister more occasionally felt more distant from them. Some siblings said that they still 'parented their parents' who relied on them for support and care, while others shared tasks with parents.

'Push and Pull'

Greenberg and colleagues [4] talk about 'push' and 'pull' factors when making sense of adult siblings and mental illness. Many siblings we spoke to described feeling torn between their other relationships and commitments – such as those associated with partners, their own children, friends and parents, or work, study or hobbies – and what they could offer their brother or sister with fewer networks and opportunities. Some had taken their brother or sister on holiday on their own or with their own families, or did activities their siblings would not have experienced otherwise. Whatever the level of contact, they saw themselves as peers, of the same generation, who could offer something different from their parents. They wanted their siblings to have a contemporary lifestyle.

As they grew older, siblings were more likely to be involved in attending reviews and taking on roles associated with financial and care arrangements, especially if parents had died or become frail. Some siblings reported that provider organisations had been helpful in informing them about arrangements, but in most cases, they had to put themselves forward. Professionals rarely offered proactive advice and support. Greater involvement evolved as parents aged and their own children were more independent. Several siblings were motivated by helping gain peace of mind for parents so that they could enjoy their retirement. Even so, many expressed a desire to be primarily a brother or sister rather than a 'carer'.

'You love him to bits and you have these breakthrough moments that just make everything wonderful, but then a lot of the time you think this isn't rewarding, you know, this is just hard.'

SISTER, late 20s

Impact on Adult Lives

Nearly all the women in our sample were in 'people' professions such as teaching, nursing or social care; feeling they were continuing their skills in supporting others. Likewise, one sibling saw a connection between country walks with his brother when young and his work with the environment now. However, nearly half the sample had sought counselling to help them come to terms with their experiences when growing up, which they now associated with depression, low self esteem or anger. Some had found this positive; others wanted more specialised help with counsellors who understood sibling issues. Many siblings also wanted help from a third party in negotiating a move from home or discussions about the future with parents. Most had not met other siblings of people with autism but were glad when they did so.

Genetic Implications

Siblings expressed concerns about potential genetic risks – complicated and uncertain in autism – especially if they had not yet started a family. Some said their teenager children had raised questions too. A few had sought genetic counselling; this was rarely a satisfactory experience, if concerns were not taken seriously or little meaningful advice was offered. For nearly all, partners' reaction to their brother or sister had been a big issue. In some cases it contributed to the end of a relationship. Partners who included the sibling with autism in family life and did not resent calls on time and attention were especially appreciated. This is why some siblings thought their partners' needs should be considered too as well as those of their own children.

Future Hopes and Fears

Mixed Views

Siblings varied in their views about the support their brother or sister received in their care setting. Many expressed pleasure that their siblings were settled, seemed happy and had a varied timetable of activities. Siblings wanted a fulfilling life for their brother or sister but some had noted fewer opportunities as their sibling grew older. Comparisons with their own lives and choices were mentioned as a source of sadness. Others were worried about their sibling's health and diet,

medication and level of care. A few felt that a sibling had lost skills and their behaviour and mental well-being had declined, while in care, while others said he or she had matured and developed.

A Home for Life?

Some siblings with autism had experienced moves in their middle years; this was despite assurances from professionals that he or she had a 'home for life'. Current budgetary constraints and changing policies in social care also contributed to a lack of confidence that their brother or sister's placement was secure. Siblings appreciated the chance to develop good relationships and mutual respect with service workers which was possible with continuity of staff. They welcomed news about their brother or sister's life and especially valued communication with or about them. Some who had less regular contact lacked confidence with their brother or sister and said they sometimes felt judged by staff. They wanted to be supported in whatever role they played with their sibling.

'She's my sister, I love her, but I don't have the sort of relationship that I have with other people because she can't understand the way I think and probably I can't understand the way she thinks. But I'm totally dedicated to her welfare and want her to have as much fun and enjoyment in life as possible and, you know, be happy in herself, and when things go wrong, I will always try and sort it'.

SISTER, late 50s

Sibling status

Some siblings felt unsure of their status either legally or as part of good practice in services. They had felt left out of important meetings, perhaps unintentionally, but believed they had a useful contribution to make in their sibling's life, offering a perspective which was different from, but just as valid, as that of their parents. Some saw positive opportunities for their sibling from Personalisation while others feared change for financial reasons and the loss of aspects of their sibling's life through changes in care provision.

Death and Bereavement

A few siblings had lost both their parents and/or made the transition to being their brother or sister's nearest relative and first point of contact. Most had at least one parent still actively involved in the care of their brother and sister. How to prepare their sibling for a parent's death and support them through their grief was a source of great concern. Those who had experienced a parental death valued the input and collaboration of staff; others, however, had to muddle through with little advice.

'I kept saying "Oh do you want me to come over?" You know, when I had the kids, oh I should go, really go and meet Adam (key worker), I should really get involved. And she (mother) kept saying "You've got your own little family to deal with, plenty of time for all this when I'm gone, don't worry." But I, I just think she didn't think she was going to die'.

SISTER, late 40s

All siblings also wanted more discussion with parents and to know their wishes. Sometimes this was a difficult subject to broach with parents and siblings would have liked more support from professionals to plan ahead.

Professional Perspectives

Siblings Valued

The professionals we interviewed varied in how much they had thought about siblings as a group distinct from parents and in how much experience they had in working with siblings. Frontline staff such as key workers or house managers had the most contact. One, for example, described siblings as a 'lifeline' once parents had died. Another thought it was valuable for people with autism to experience family life with nephews and nieces, though others noted that someone with autism could also be jealous of their sibling's lifestyle. Some practitioners worked hard to involve siblings and other family members in the life of the person with autism, inviting them to social activities and outings. Only a few had given more detailed thought to the meaning of these relationships for siblings and some of the potential difficulties involved. Some

staff pointed to a range of closeness in all sibling relationships. One suggested that younger adult siblings had had more contact when growing up than in previous generations and were less affected by the stigma of disability.

Understanding Siblings

Most professionals acknowledged the childhood impact on siblings in terms of parental attention focussed on the child with autism, and possibly witnessing violence, and knew that resentment and rivalry could last into adulthood. However none showed previous awareness of siblings' earlier involvement in caring, so perhaps did not understand fully their experiences when growing up or their feelings of responsibility and wish to be consulted now. Some professionals had experience of sibling relationships which they saw as taking advantage of the person with autism, and related such behaviour to early resentment, immaturity or disadvantage. Professionals did recognise siblings' busy lives and other responsibilities, but most interviewed clearly saw siblings primarily as a 'resource' rather than a 'co-worker' or 'co-client' [5]. Professionals were especially critical of limited/sporadic involvement or unreliability. One suggested that siblings felt uncomfortable with other residents and another felt supported visits to either parents or siblings could help.

Supporting Siblings

One care provider felt more could be done to help siblings and parents discuss the future and plan the 'transition' from parental to sibling care, in a way that suited everybody. It was noted that parents were often reluctant to admit they could no longer cope or wanted siblings to take a bigger role [6]. Some staff saw working with families as a priority and wanted to become more 'sibling aware'. They felt it especially important to encourage sibling involvement long before there was a crisis and thought this could be developed in the first instance by asking parents about earlier relationships between siblings and talking to siblings about their

situation and what contact or news they would like from staff. Such approaches, however, were on an individual basis and not, as yet, integrated into policy and practice.

'As they get older they're trying to keep the parents happy and reassured that, you know, we will take over this role, but also deal with how they're going to do it as well. So it's probably a three-way, they've got their sibling that's got autism, their parents, you know, I wouldn't like to be in that position. You know, it must be difficult for them'.

HOUSE MANAGER

Ways Forward in Supporting Siblings

Supporting siblings need not have substantial cost implications; increased awareness and understanding of individual perspectives and inclusion in existing person-centred work are key:

- 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 such as transition.
- Professionals need to do more to recognise the significance and value of sibling relationships and roles across the lifespan.
- Adequate and appropriate practical and emotional support to manage a child's autism should be available to parents and siblings as a matter of course, using a 'whole family approach' as recommended in recent Government guidance about carers (2010), rather than only in a crisis.
- Siblings could be regularly invited to take part in reviews, to discuss future planning and transition as they affect their brother or sister. Siblings should also be offered information and advice to facilitate this.
- Families may need the involvement of a third party to help negotiate future plans; at present this rarely happens proactively.
- Social care providers, practitioners from all relevant disciplines and commissioners need to be 'sibling aware' and in particular, value and support whatever positive contribution siblings make to their brother or sister's life. Siblings may require specialist help such as counselling & genetic counselling.
- 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. Including their views and involving them in decisions can happen as part of the process of routine care.

Good Practice Ideas

- Think 'sibling' when working with any family and consider the likely impact of growing up with someone with severe autism.
- Ask siblings for their views; value their opinions; negotiate how they want to be involved in their brother or sister's life; and develop an ongoing dialogue with them.
- At the same time, respect that siblings will vary in the amount of support they are able to give; this might also change over time.
- If siblings find it hard to interact or spend time with their brother or sister offer suggestions or support without undermining their skills and confidence.
- Find ways for siblings to keep in touch, such as through photo records, diaries, e mail or Skype, or more practical ways of supporting visits.
- Help families to discuss and plan for the future, including bereavement, and a transfer of responsibilities in a way that suits everyone involved: parents, siblings and their partners, and the person with autism.
- Find opportunities for the person with autism to develop wider networks such as a 'circle of support' so that siblings are not alone in protecting their interests.
- Consider ways of enabling siblings to meet each other – they will have at least one thing in common!

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*Other summaries and information about the project can be found (www.esrc.ac.uk).
For further information please contact Rosemary Tozer (rosemary.tozer@york.ac.uk)
or Karl Atkin (karl.atkin@york.ac.uk).*

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Useful Contacts

Sibs, the UK charity for people who grow up with a disabled brother or sister, can be contacted at info@sibs.org.uk for information and advice and sibling resources
Web: www.sibs.org.uk

The National Autistic Society

Web: www.autism.org.uk
Helpline: 0845 070 4004
autismhelpline@nas.org.uk

Foundation for People with Learning Disabilities

has information and resources about future planning, circles of support and supporting fathers
Web: www.learningdisabilities.org.uk

