**Continuity, Commitment and Context: Adult siblings of people with autism plus learning disability**

**Rosemary Tozer, BSc(Econ), BPhil, MA, DPhil**

Research Fellow, Seebohm Rowntree Building (Area 4), Department of Health Sciences, University of York, York YO10 5DD

Tel and email: 01904 321908 and rosemary.tozer@york.ac.uk

**Karl Atkin, BA (Hons), DPhil**

Professor, Seebohm Rowntree Building (Area 4), Department of Health Sciences, University of York, York YO10 5DD

Tel and email: 01904 321355 and karl.atkin@york.ac.uk (Corresponding author)

**Aniela Wenham, BA (Hons), DPhil**

Research Fellow, Seebohm Rowntree Building (Area 4), Department of Health Sciences, University of York, York YO10 5DD

Email: aniela.wenham@york.ac.uk

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**ABSTRACT**

Sibling relationships are usually lifelong and reciprocal. They can assume particular significance when a brother or sister has a learning disability. Until recently, adult siblings of people with disabilities such as severe autism have been ignored by policy, practice and research. This qualitative paper contributes to an emerging literature by exploring how adult siblings, who have a brother or sister with autism (plus learning disability) and living in England, give meaning to their family (and caring) relationships and engage with service delivery. We spoke to 21 adult siblings using semi-structured interviews and met with 12 of their siblings with autism. Our analysis, using a broad narrative approach, demonstrates the continuity of the sibling relationship and an enduring personalised commitment. The nature of this relationship, however, is sensitive to context. How non-disabled adult siblings relate to their childhood experience is fundamental when making sense of this, as is their need to fulfil other social and family obligations, alongside their ‘sense of duty’ to support their disabled brother or sister. Sibling experience was further mediated by negotiating their ‘perceived invisibility’ in social care policy and practice. Our work concludes that by understanding the way relationships between siblings have developed over time, adult siblings’ contribution to the lives of their brother or sister with autism can be better supported for the benefit of both parties. Such an approach would support current policy developments.

**What is known:**

* Sibling relationships are lifelong and reciprocal, but characterised by ambivalence.
* Until recently policy, practice and research have struggled to engage with the experience of adult siblings of people with significant disabilities, such as autism and severe learning disabilities.
* Adult siblings have the potential to support their disabled sibling, particularly as parents age.

**What this paper adds:**

* The extent to which the nature of sibling relationships is not fixed and highly sensitive to context.
* The importance of understanding the contingent and complex nature of family relationships in realising the potential of adult siblings’ contribution to the lives of their brother or sister with autism.
* An understanding of how enhancing family relationships can be beneficial, throughout adulthood and particularly at times of transitions, while suggesting areas for future research.

**KEY WORDS:** Autism, learning disability, sibling relationships, family caring. (4498)

**INTRODUCTION**

Siblings can offer an important supportive, long-term relationship to a disabled brother or sister (Heller and Kramer, 2009). However, once children have grown up and moved out of the family home, their significance when a person has severe autism has generally been overlooked by social care (Conway and Meyer, 2008). Nonetheless, concerns about older carers of people with learning disabilities as they age and die, has led to a renewed interest in the potential of the next generation to take on some of their roles (Rawson, 2010). An interest further supported by recent policy initiatives such as ‘personalisation’ (see DH, 2007) and UK strategies for improving care for those who have a learning disability (DH, 2009). Taking this as its starting point, our paper explores how adult siblings - who have a brother or sister with severe autism - give meaning to family relationships, as a way of understanding the role of social care in facilitating these relationships.

**Sibling relationships and autism**

Previous work - mostly from North America and largely informed by large surveys of families - has a strong psychological focus and less of a concern with connecting the experience of family care to service delivery, especially when the sibling reaches adulthood (see Heller and Arnold, 2010). Parental views also dominate, along with an inclusion of a wide spectrum of autistic behaviours (Meadan et al., 2010). This research is, however, helpful in highlighting the impact of autism (and learning disability) on family relationships (Seltzer et al. 2005; Hodapp and Urbano 2007; Orsmond and Seltzer, 2007a & b; Petalas et al., 2009); and in particular, how non-disabled siblings have to deal with the reactions of others (Ross and Cuskelly, 2006) Barr and McLeod, 2010); assume additional family responsibilities, when compared to their peers; and accommodate an unpredictable family life (Bigby, 1997; Hodapp et al., 2005; Orsmond et al., 2009). The research also demonstrates the strong emotional bond found among siblings (Rittenour et al., 2007), along with how non-disabled siblings’ perspectives, offer a different and sometimes alternative view to that of their parents (Petalas et al., 2009; Mansell and Wilson, 2010).

Adult siblings – consistent with normative values and expectations associated with family relationships – generally, anticipate taking on more of caring role as they and their parents’ age (and die) and once their own children, have moved away from home (Bowey and McGlaughlin, 2007). Adult siblings can assume an important role as advocates, particularly at times of transition (Hare et al., 2004), especially if there have been previous, strong family bonds (Heller and Arnold, 2010). Tensions, however, can emerge (Connidis, 1992). Developing a career, the need to work, dealing with ageing parents, establishing their own family and bringing up their children occur alongside responding to the varying support needs of their disabled brother or sister (Orsmond and Seltzer, 2007a). Such supportive relationships might also need to accommodate feelings of previous or current resentment (Dorr and Virgo, 2010). All of which, suggests a degree of negotiation and contingency; and introduces a key analytical theme, which also assumes significance in relation to policy and practice.

**Policy and practice**

Recent policy statements recognise that society ‘depends to a large degree on the care and continuation family carers provide (DoH, 2008, section 1.17). There is, however, little mention of adult siblings, who are often seen as a taken-for-granted, backdrop to family care (Dorr and Virgo, 2010). It is, therefore, perhaps not surprising that service practitioners can find it difficult to facilitate productive family relationships, in a way helpful to an adult with autism (Mansell and Wilson, 2010). Policy and practice, while increasingly able to support siblings’ in their role as ‘young carers’ (Conway and Meyer, 2008), especially struggles to recognises the nuanced and long-term consequences of being an adult sibling of someone with autism and severe learning disability (Bowey and McGlaughlin, 2007).

Moves towards ‘personalisation’ and ‘whole-family’ approaches offer an opportunity to recognise the potential of adult siblings to offer continued long-term support to a disabled brother or sister (Costigliola, 2010). Nonetheless, the extent siblings can involve themselves in the lives of their disabled brother and sister remains ill-defined, largely subject to the discretion of individual practitioners (Knapp et al., 2009), despite legal provisions for their inclusion in care arrangements (Clements and Thompson, 2011). The Autism Act (2009) does little to resolve this problem and while understandably and appropriately emphasising the rights of people with autism, follows a long tradition of community care policy, which struggles with balancing the needs of the person with learning disability, alongside the need to involve families (see Grant et al., 2010). Further, policy on family care is necessarily part of a broader political and social process (see Sointu, 2005), requiring a mobilising of resources and negotiated choices, which among other things, reflects how different members, including those with autism, experience and sustain family care (see Finch, 2007). Connecting with how family responsibilities become negotiated over time and across the life course is an important part of this process (Pickard, 2011)

**STUDY AIMS**

After gaining ethical approval from a University Governance Committee, our study - using semi-structured qualitative interviews - examined the relationship between adult siblings, where one of them had autism, plus a severe learning disability. The material generated in exploring this broad research question was used to understand the extent to which (non-disabled) adult siblings’ perceptions and experience of family relationships, created demands for - and expectations about - service support. We specifically focused on siblings whose brother and sister had autism, plus severe learning disability because they have some of the highest and most complex support needs (Macks and Reeve, 2007).

**Method**

We established an independent project advisory group made up of social care practitioners, representatives of third sector organisation, policy makers, adult siblings and academics. The meetings proved helpful in suggesting interview topics; commenting on our analytical themes; advising on dissemination; and providing a check on the ethical conduct of the project.

No representative sampling frames exists for adults with autism (or their families); a problem also evident in previous research. Using a convenience sample, therefore, seemed a suitable solution. Participants were recruited through a national support networks for siblings of people with autism and learning disabilities. Newsletter articles invited adult siblings to take part in the research. We interviewed all those who expressed an interest in the research.

After gaining formal written consent, we asked (non-disabled) adult siblings about their experiences of family life and their specific experiences of growing up with a brother or sister with autism; about their current relationship with him or her and how that had evolved; and about their future hopes and concerns for both themselves and their sibling. They were also questioned about their past and present contact with professionals, such as teachers, health and social care staff. These siblings were interviewed on their own without their disabled sibling present. The research team, by conducting all fieldwork, ensured consistent quality control and shared understanding of significant issues during fieldwork. To provide greater context to our work and to gain a better understanding of the sibling relationships from the perspective of both parties, the research team, then met with 12 siblings with autism, such as on a picnic or walk or in a café. In all but one instance their (non-disabled) brother or sister was present (the researcher having taken their advice about what sort of meeting would suit the person with autism so as to reduce potential anxiety). Family photos were used to evoke memories in meetings with both sets of siblings and to generate a discussion about family life. Some siblings made a scrapbook or collage of people and activities that they enjoyed together.

**Analysis**

Our broadly narrative analysis connected (the non-disabled) adult siblings’ biographical experience of the present with their accounts of the past and reflections on the future (see, Riessman, 2008). All interview material was audio-recorded (with permission), transcribed and organised according to thematic analytical headings using Atlas ti (v5.2). In practical terms this meant detailed familiarisation with transcriptions and field notes, followed by iterative debate among the three authors to identify *a priori* and emergent themes: a process closely steered by the research questions, the existing knowledge base, policy assumptions and the experience of those we interviewed (see Silverman, 2009). This informed our coding framework, which was used to identify themes specific to each individual account, as a means of understanding a particular case. These themes were then compared across cases to highlight potential similarities and differences. We also had contextual material from our engagement with the sibling with autism, in which we could understand more about the nature of family relationships. Finally, two feedback sessions with twelve sibling participants along with suggestions from the project advisory group assisted our interpretation. These discussions helped confirm and prioritise themes, in addition to the key messages for policy and practice.

**FINDINGS**

The research engaged with the experiences and perspectives of twenty one adult siblings, aged between 25 and 67, from seventeen families, in different parts of England. Our sample included 14 women and 7 men, who supported 8 sisters and 13 brothers with autism, aged between 25 and 65 years old. Our approach to sampling generated a reasonably diverse range of ages and family contexts, although there was a tendency for siblings to represent higher socio-economic groupings. There was also little ethnic diversity: a feature of using national third sector organisations as sampling frames (see Atkin et al., 2010). Apart from two young men living with their parents, the siblings with autism lived in residential homes or supported living.

Three inter-related themes help us understand (non-disabled) adult siblings’ perceptions of family relationships and expectations of service delivery. The first represents their reflections on growing up with a disabled brother or sister. This connects with the second theme, which is about their present experience. These two themes demonstrate the continuity of the sibling relationship and an enduring personalised commitment. The nature of this relationship is, however, sensitive to context. Siblings believe practitioners struggle with such complexity and this introduces our final theme, siblings’ negotiation of their perceived ‘invisibility’, when engaging with service delivery. All names appearing hereafter are fictional.

**Growing up together**

Sibling reflections, when interpreted with the benefit of hindsight, gave a valuable insight into the long-term consequences of growing up with a brother or sister with autism. Most siblings recalled a home life which ‘revolved around autism’. Autism associated behaviours and communication difficulties meant most siblings had experienced a ‘chaotic’ and often stressful family life. A sister in her mid-thirties commented:

Most days he’d be running around scribbling on the walls, pulling the curtains down, flooding the bathroom, putting toys down the toilet. It, it felt chaotic, yeah [S010].

Siblings recalled their parents’ stress and were especially aware of their parents’ struggles in getting recognition and appropriate (formal) support to meet the autistic child’s needs. This established an early mistrust of service provision, which – as we shall see –some siblings did not always overcome, irrespective of how long ago it occurred. Some siblings described supportive relatives or close friends, whom they said, made a positive contribution to their childhood experiences (as also suggested by Margetts et al., 2007). Wider family and social support, however, was not always helpful. Several siblings described negative attitudes or misunderstanding from family members, such as grandparents, as well as peers and friends. This, according to the siblings, increased the family’s sense of isolation but also self-reliance (a difficulty also identified by Benderix and Sivberg, 2007).

As part of this process, siblings frequently recalled their and their parents’ efforts to maintain ‘normality’ in social situations (see also Cree, 2003); and consistent with a more social model of disability, it was the (perceived) reactions and responses of others, which were identified as much a problem, as much as the consequences of the disability itself. This problem continued to the present day. To this extent and more generally, siblings could be seen as inhabiting two worlds; one at home where disability was the norm; and the outside world where it was not (a point also made by Stalker and Connors, 2004). Assuming caring responsibilities was part of that norm.

*Being a young carer*

Most siblings we spoke to reflected on how they felt a sense of obligated duty to their disabled sibling and assumed considerable caring responsibilities from an early age, in a way consistent with the current research on young carers (see Dearden and Becker, 2005). Siblings remembered playing with their siblings to relieve stressed parents and doing household chores to give their parents a break. They also described attending appointments or school reviews from an early age. A sister in her late forties explained:

I remember playing on the beach, and there’s photographs of me [aged three] washing my feet at the tap with Richard [brother, then aged five], and apparently that’s when I took charge, when I realised he needed help [S009].

A brother, in his forties, said:

So I decided I was an adult by the time I was twelve because I was parenting 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? Because it would be me that had to look after him [B004].

Others spoke of brother or sister’s vulnerability and their need to protect them. This was often fundamental to their later sense of obligation and again another theme that resonates with our understanding of young carers. A sister in her mid-forties explained:

He would get out of the, the garden or let himself out the door and, you know, I do think that, I probably did live my life in a bit of a state of being on alert, you know, in case he did go, and then when he did, going off to look for him and, you know. So probably when I started to take him out myself I was, very kind of overly aware of, of how vulnerable he was [S013].

*A different normality*

Most siblings attempted to normalise the past as best they could. A few siblings mentioned how other events had affected them far more during childhood, such as their parents’ divorce or a parent’s ill-health. Most siblings could also describe happy memories, especially if their sibling was remembered as being content. A sister, in her mid-forties, explained.

I mean it’s just who you are. It’s normality, isn’t it, for an autistic sibling? That’s your normality, and I would have thought it very strange to have siblings who aren’t autistic [S014].

Striving to develop their own version of ‘normalcy’ was common to most siblings’ accounts and is also a feature of the broader literature (see Whiteman et al., 2011). Maintaining normalcy, however, was not easy and according to those we interviewed, created a tension, when they attempted to reconcile memories within the context of the present. This explains some of the contingency evident in their accounts. At times, adult siblings felt positive about their relationship with their autistic brother or sister, while at other times, they expressed more negative views, associated with the impact of autism on their lives. It is worth adding that such ambivalence is recognised as a feature of *all* sibling relationships (see Cheal, 2002). The context of autism, however, created a particular dynamic and siblings’ accounts of their current relationship demonstrated this.

**Current sibling relationships**

Current relationships continued to reflect siblings’ sense of responsibility and commitment. A brother in his early forties explained:

I would have said that’s all the way been, been the same all the way through life with her and it probably developed there. But obviously I looked out for her because there was nobody else around and that’s why we are sort of close together [B019].

To this extent, siblings’ accounts are consistent with the broader literature, suggesting that those who took on strong advocacy role and assumed responsibilities for their disabled sibling when younger are more likely to have had a lifelong close, emotional relationship (Bigby, 1997). Many siblings, for example, described how when they first left home, they relished their new freedom, but could also feel guilty and worry about those they left behind. Those who did not leave home, when in their late-teens or early twenties, found it increasing difficult to move out from the parental home, particularly since they were aware of how much their parents and their sibling with autism relied on them. This explains why several siblings said they decided to live close to their parents, so they could continue to help out. Others indicated that they could only move on with their own lives once their brother or sister had themselves made a successful transition into adulthood. This, however, was not without its consequences, especially when considered with the benefit of hindsight. A sister in her mid-thirties explained:

I didn’t really want to leave. There was a lot of guilt. Watching Thomas and, 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 [S010].

*Closeness and contingency*

Despite stressful experiences when growing up, most siblings described a close relationship with their autistic brother/sister. Siblings talked of a life-long bond, based on a unique understanding and shared history. A brother in his forties said:

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 [B021].

Close bonds were evidenced by the reassurance siblings provided when their autistic brother or sister met with the researcher, along with their use of humour, gesture and effective communication. Despite this, a sister in her late twenties made a common observation:

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, this is just hard [S003].

Such feelings contributed further to siblings’ sense of contingency and ambivalence. Several siblings specifically said they continued to have unresolved emotional issues and at times, resentment about the past experience. These, they said, had affected their adult life and their relationship with their parents and siblings with autism. As evidence of this, nearly half of our sample had sought psychological counselling to help them come to terms with the past, which they associated with their current depression, low self-esteem or anger. This ambivalence also explained why current relationships could have some degree of variability, mediated by how siblings constantly (re)negotiate the past. Nonetheless, some siblings, despite not having an easy relationship with their brother or sister with autism felt committed to offering support. This might include supporting parents, especially mothers, particularly as parents aged and in some cases struggled to continue their caring role (also see Seltzer et al., 1991). Many siblings, for example, were aware of how they were gradually becoming more involved in the care of their sibling with autism. For some, this meant rekindling or even reinventing their relationship. Even so, many expressed a desire to be primarily a brother or sister rather than a ‘carer’.

When making sense of adult siblings relationships, where one has been diagnosed as having a mental illness, Greenberg et al (1999) talk about the importance of understanding ‘push’ and ‘pull’ factors, which alter according to context and over time. The experience of the siblings we spoke to confirmed this. Many siblings described feeling torn between their other relationships and commitments – such as those associated with partners, their own children, friends and parents or work - and what they could offer their brother or sister with fewer networks and opportunities. Balancing other demands on their time, while maintain contact with their sibling, created a constant dynamic; explaining an on-going variability in siblings commitment. Siblings, whose own children had now left the family home, for example, often had more time to devote to their sibling with autism. Dilemmas about what they could or wanted to do with or for their brother or sister (or parents) was common. Understanding how individuals have to constantly (re)negotiate a range of competing family obligations assumes particular importance; a process also influenced by the life course.

Siblings did not want to get into a pattern of support that was then difficult to sustain. They wanted flexibility rather than establish an expected commitment. Siblings mentioned how their own lives involved more spontaneity and unpredictability than that of their parents. Siblings also reflected on how they juggled their feelings of love and protectiveness for their brother and sister, with their sadness and frustration at the limited reciprocity in their relationship. Some specifically expressed a sense of loss at not having a typical, mutual sibling relationship, while others normalised this, by saying they knew of siblings who were not especially close. Nonetheless, they saw themselves as peers, of the same generation, who could offer something different from their parents. They wanted their siblings to have an enjoyable lifestyle, similar to everyone else.

**Negotiating invisibility?**

A lack of formal support available to them, as they grew up was mentioned by all siblings. As we have seen, the idea of supporting young carers is a relatively new one. Some of the siblings - who are now in their fifties - also grew up at a time when collective attitudes to learning disability were different to what they are now. Nonetheless and interestingly, frustrations with past support occurred irrespective of age. All commented on how professionals involved with their family, when they were young, largely ignored their caring responsibilities and rarely offered information, advice or support. A sister, who was in her late twenties, summarised the views of many:

Professionals weren’t really interested in me…They weren’t bothered…no-one sat down and said this is what’s going on [S005].

Some were especially angry that they had not been more involved or consulted in decisions about their family. This resentment was still evident today, particularly since siblings felt practitioners continued to fail to acknowledge previous caring responsibilities. Siblings associated these perceived failings on the part of early interventions to their current lack of confidence when dealing with their brother or sister; and especially their struggle to accommodate difficult behaviour and maintain appropriate and meaningful communication. Current evidence supports this, by emphasising how an early understanding and explanation of autism can help siblings accommodate their brother or sister’s behaviour in the longer term (Ross and Cuskelly, 2006). Further, having been ignored or on the periphery of service interventions while growing up, some siblings now found it hard to seek or accept help, because of, what they described as a lack of trust.

Many siblings expressed pleasure – and were greatly reassured – when their siblings were settled, seemed happy and had a varied timetable of activities. Siblings wanted a fulfilling life for their brother or sister. Comparisons with their own lives and choices available to them were often a source of sadness. A brother in his mid-forties explained:

Ithink she would have been, she would have loved to have been married and had a family. I think that is definitely Sally. But I mean she loves my daughter, for instance [B006]*.*

Most siblings - whatever their view of their sibling’s care arrangements – expressed concerns about staff turnover, organisational changes and policy shifts, both in terms of the impact on their brother or sister and on their own responsibilities. This further added to the anxieties over the future, which to them seemed uncertain and unpredictable. Siblings were equally worried that they would have to deal with such uncertainties, with little formal support.

Siblings appreciated the chance to develop good relationships and mutual respect with social care workers. They also 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 unfairly judged by staff. They wanted to be supported in whatever role they chose to adopt. A sister in her late fifties said:

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 [S017].

Some practitioners were praised for their sensitivity in recognising this. On her mother’s death one sister [S011] had been reassured by her brother’s long term key worker that she did not need to continue her mother’s very regular pattern of contact. Such good practice also demonstrates the kind of support siblings would find helpful and they specifically praised organisations that worked hard to include them in the life of the person with autism. According to most siblings’ accounts, however, practitioner’ responses in helping facilitate greater involvement in the life of their brother or sister with autism was variable. A sister in her late twenties, explained:

I’ve had so much lip service, and I think don’t you dare patronise me. I know far more about this than you do [S005].

Most siblings felt they had to be proactive and put themselves forward and ask for advice. Anxieties were compounded by siblings’ uncertainties over their legal status or about the extent they could insist about becoming involved in their sibling’s care: a tension identified in the literature (see Clements and Thompson, 2011). A few reported being left out of important meetings - perhaps unintentionally – and feeling aggrieved, as they believed they had a useful and valuable contribution to make in their sibling’s life. Siblings felt a particular need to initiate discussions within the family - and especially with their parents – about planning for the future, including sensitive topics such as the death of a parent (see also Mansell and Wilson, 2010) Siblings, however, expressed frustration at the lack of planning on the part of services. Some remarked that they only seemed to be considered when a problem emerged, with little sense on the part of service practitioners that previous and on-going negotiation could make the solving of a current problem a lot easier.

**DISCUSSION**

Our findings suggest that by acknowledging and including siblings, as part of routine practice, social care would not only maximise disabled siblings’ quality of life, but also ensure a more productive and fulfilling context for family relationships, which would be particularly beneficial at times of transition (see also Davys et al., 2010). This would be consistent with present policy initiatives associated with ‘personalisation’ and ‘whole family’ approaches, which recognise how family members can improve the life opportunities available to people with disabilities. Recent reports in the UK, questioning the quality of adult care for those with a learning disability, emphasise the importance of implementing such approaches (Care Quality Commission, 2012). Facilitating adult sibling involvement, however, might not be straightforward and our research specifically emphasises the need of social care to understand how adult sibling relationships are rooted in unique but complicated past experiences, which are mediated by current circumstances and future expectations (see also Mascher and Boucher, 2007 and Gass et al, 2007).

Three inter-related themes explain the ensuing contingency. First, most siblings had maintained a consistent involvement in their brother or sister’s life but struggled to provide continuous support, due to the need to balance other social and family obligations. Second, sibling involvement was conditioned by their past experiences, including their relationship with service provision. Third, siblings constantly juggled their commitment to their brother or sister, from which they derived pleasure, with frustration at the difficulties of maintaining a reciprocal relationship. Siblings would have liked practitioners to see them as individuals with a unique history and perspective. The ambivalent, contingent and changing nature and constant re-interpretation of family relationships does, however, create risks for service practitioners. Practitioners are likely to prefer a more defined commitment, often confusing ‘flexibility’ with ‘unreliability’, which they associated as being potential harmful to the well-being of the person with autism (see Preece, 2010). For siblings, however, ‘flexibility’ was seen as a ‘normal’ feature of sibling relationships and one with which they felt service delivery should be able to work with.

Before we explore this further, it is worthwhile reflecting on the limitations of the study and the implications of this for our discussion. Our sampling strategy largely showed a selection bias towards those siblings who wanted to be involved in the care of their brother or sister. Policy and practice would – of course, need to engage with greater diversity, including siblings who might struggle to care. We also had little to say about the potential impact of social inequalities in negotiating caring relationships. Our focus on severe autism also meant our sample included siblings who now lived in residential and supportive living rather than with their families. Such care arenas might struggle with family engagement. Future research would benefit from reflecting these various expressions of diversity.

Engaging with the different types of involvement siblings might want in their brother or sister’s life, while also bearing in mind that siblings’ involvement may fluctuate over time, depending on their other commitments would seem key when developing successful social and community care. As would the need to take in to account the changing needs of the person with autism, alongside the changing ability of other family members, such as parents to offer care. Person centred planning can offer practical opportunities to facilitate this. Sibling details, for example, could be noted on individual records and, with permission, shared with other agencies, particular when new care arrangements are been discussed. Such plans could also include the sorts of contact the sibling with autism would like with their brother or sister and the support (non-disabled) adult siblings would like from care providers. What is recorded should be agreed with both siblings and it is especially important that the preferences of the person with autism are not overlooked. Engaging the views of the person with autism should not, however, be underestimated and nor should balancing them alongside the needs of other family members (see Jenson and Fraser, 2010).

The difficulties in achieving this balance, for example, could explain practitioners’ preference for focusing on the individual care needs of the person with autism, rather than seeing them as part of a broader, reciprocal family network (Marcus and Mesibov, 2011). This is an area where further research, focusing on how best to accommodate the sometimes diverse needs of different family members would be particularly useful. Our research, providing a (non-disabled) adult siblings perspective, suggests they would like support staff to negotiate more with them; and to establish how each could help the other, in the spirit of ‘co-workers’ (see Twigg and Atkin, 2004). These siblings also expressed needs as ‘co-clients’ and in particular their need to take on extra responsibilities as parents’ age. They would prefer to negotiate this, before a crisis occurred and more specifically wanted information and support about care options, financial arrangements and advice about bereavement support for their brother or sister, to help him or her with the loss of a parent. As siblings in turn age, they might also want support with planning ahead.

In conclusion, becoming more ‘sibling aware’ and recognising, valuing and supporting siblings could be a keystone to progress in social care. This as is not without risks, but a failure to work with contingency creates potential and long standing difficulties, in which neither the needs of the person with autism nor their families are met. Janet Finch (2007) suggests that understanding family life (which of course, includes the person with autism), as a set of activities, which take on a particular meaning, at a given point in time is more analytically productive than trying to define what families do. Interventions such as personalisation and whole family approaches could be formulated to work with these assumptions and adapt a more individualised definition of family caring, without presupposing a predefined standardised experience of family life. Some of the policy literature, especially in long standing conditions, has begun to take note of this; emphasising the broader discontinuity between policy and individual accounts, while reminding us of the political nature of such interventions (see Bury et al., 2005). Personalisation and family life is socially negotiated, defined by the social space in which it takes place. Recognising this would not only benefit the person with autism, but also other family members, thereby creating a more conducive setting in which to enact policy and practice. This could be further supported by research on how to connect the complexity of family life with interventions, along with a focus on how service providers and organisations they work in, conceptualise adult siblings in their day-to-day work.

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