**The Sibling's Perspective: Experiences of Having a Brother or Sister with an Intellectual Disability and Behaviour Described as Challenging**

**Introduction**

The majority of individuals with an intellectual disability live with, or with the support of, their families (Seltzer *et al*., 1991). Throughout these individuals’ lifetimes their most long-standing relationships will often be with their sibling(s) (Conway and Meyer, 2008). However, research on the experiences and needs of siblings, especially adult siblings with a brother or sister with a more severe disability, remains limited (Howlin *et al*., 2014; Rosetti *et al*., 2018).

 Tozer *et al.* (2013) discuss the concept of a different normality when growing up with a sibling with autism. The family’s life seems to revolve around the child with a disability, with heightened responsibility and different family relationships.The roles and responsibilities of siblings are generally different for individuals whose brother or sister has a disability. Research has described an asymmetrical relationship between siblings, especially where the sibling without a disability is older. Such siblings may take a teacher or helper role rather than the more typical playmate relationship (Stoneman *et al*., 1989). Their responsibilities may include both domestic work and the direct care of their sibling (Becker *et al*., 2001), in effect becoming surrogate parents.

 The sibling’s life may also include the anticipation of taking future responsibilities for their brother or sister. In a study of future plans of older carers, in the minority of families where such plans existed, living with a sibling was the favoured option (Bowey and McGlaughlin, 2007). Even where this option is not anticipated, many siblings express a commitment to their brother or sister and a desire to be involved in their lives on an ongoing basis (Tozer and Atkin, 2015).

 Despite the above mentioned difficulties and responsibilities, many siblings report that the relationship with their brother/sister is positive (Hodapp and Urbano, 2007), loving and strong (Atkin and Tozer, 2014). While relationships between neurotypical siblings may change over time, drifting apart during adolescence and young adulthood, and then reforming later in life, relationships between a sibling and their brother or sister with a disability may be more stable and remain close throughout their lives (Orsmond *et al*., 2009).

 There remains limited understanding of the significance of the sibling role, both for siblings themselves and their brothers/sisters (Becker *et al*., 2001) and their possible needs for support in their own right. Providing opportunities to interact with other siblings with similar experiences may increase self-esteem, help develop coping strategies, improve quality of life and enhance understanding of disability (Naylor and Prescott, 2004). Different kinds and levels of support are likely to be required at different ages (Tozer and Atkin, 2015).

 As noted above, existing research on siblings is very limited, particularly with respect to adult siblings. Some of the research carried out has perhaps focused too much on the difficulties and stresses of having a brother/sister with a disability and not attended to the broader picture. Small samples mean that findings are heavily influenced by participant recruitment strategies and, as a result, findings in different studies are often inconsistent. For instance, findings from research on child siblings may not be generalizable to adult siblings.

 There is also a lack of control of individual differences between siblings. Orsmond *et al*. (2009) found that their sibling participants reported very differentiated experiences. For example, siblings reported more positive relationships when their brother or sister presented fewer behavioural challenges. Female participants with a sister with a disability reported the most positive relationships. Inconsistent findings across different studies may then reflect the make-up of the samples used.

Some research on sibling experiences has rested on information obtained from their parents. However, the parent’s perspective may influence their account of the sibling’s adjustment (Moyson and Roeyers, 2012), leading to findings which mirror parental experiences more than those of siblings. This may have influenced the above-noted focus on the difficulties and stresses of being a sibling with the guilt experienced by parents, they may believe, not giving their typically developing children as much attention (Mulroy *et al*., 2008) leading them to overestimate the negative impact this might have.

The current study investigated the perspective of adult siblings of individuals with intellectual disabilities and behaviour described as challenging. Interviews with siblings focused on past and present involvement with the support of their brother or sister and how their experiences were different to their peers without a sibling with a disability. Additionally, interviews focused on the adult siblings’ perspectives of their own lives: their feelings, attitudes and personal experiences surrounding having a brother or sister with an intellectual disability and behaviour described as challenging.

**Method**

## *Participants*

 Participants were recruited through advertisement in organisations focused on challenging behaviour and through events sponsored by organisations for family members of individuals with disabilities. Participant either attended the events or family members provided information about the research study to the participant. Participants were required to be over 18 years old and have a sibling with a learning or intellectual disability and, in their initial conversation with the author, behaviour described as challenging. Participants who contacted the author by email were sent an information sheet and consent form, and an interview time was arranged.

 Six participants agreed to be interviewed. Five of the participants’ brother or sister lived in residential care/supported living, while regularly visiting family members. One participant lived with their brother. All participants were legal deputies for their brother or sister, or unofficial, next-in-line family carers. Further participant details are listed in Table 1.

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| Table 1: Participant Details  |
| Name  | Age | Gender | Gender of Brother/Sister | Birth Order of Brother/Sister | Diagnosis | # of other siblings |
| Christine  | 22 | F | M | Younger (3 years) | Cerebral Palsy, rare chromosome disorder, autism | 0 |
| Ann | 24 | F | M | Younger (2 years) | Profound autism, severe learning disability | 0 |
| Alice | 22 | F | M | Older (16 months) | Severe autism, learning disability, ADHD, bipolar disorder, PTSD | 1 |
| Kate | 26 | F | F | Older (5 years) | Autism, epilepsy, chromosome abnormality | 2  |
| Margaret | 49 | F | F | Older (2 years) | Brain damage at birth | 1 |
| Carol | 53 | F | M | Younger (8 years) | Down’s Syndrome, autism, bipolar disorder | 3 |

## *Procedure*

 Ethical approval was obtained through the University of Kent before participants were contacted. In order to more fully understand siblings’ individual experiences, interviews were semi-structured and analysed qualitatively.

 Interview topics were identified through reviewing relevant literature. The author conducted all interviews, five by telephone and one by Skype. Interviews were audio-recorded and transcribed verbatim. Interview length ranged from 35 to 124 minutes (average 72 min). The author started each interview with questions pertaining to personal information. Interview questions, while varied in accordance with the semi-structured nature of the interview, included reference to responsibility, relationships and support as shown in Table 2.

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| Table 2: Sample Interview Questions |
| Responsibility | * What responsibilities do you have for your sibling?
* Has your family talked about future plans for your sibling?
* From your perspective, was your childhood different? If so, why?
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| Relationships | * Throughout your life, how would you describe your relationship with your family?
* What is your relationship like now with your sibling compared to how it was when you were younger?
* What were your childhood friendships like?
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| Support | * Have you been provided any support (i.e. support groups, professional assistance, ect.)?
* Were these support systems helpful? What did they help you with most? Why did you join or participate in these support groups?
* Would you have wanted more support?
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 Participants were able to stop the interview or have the recording/transcript deleted at any time. After the interview, participants were given contact information for support organisations that participants could contact following the interview, if needed. As soon as interviews were transcribed, pseudonyms were given to the participants and their siblings. All information about the participants remains anonymous. Only the authors were able to access the original audio-recordings which were subsequently deleted.

## *Analysis*

 Interviews were analyzed using Interpretative Phenomenological Analysis (IPA) since its focus on the analysis of individual perspectives of lived experiences (Smith and Osborn, 2008) was consistent with the purpose of the study.

 After transcription, interviews were read and notes made identifying topics of importance to each participant and commonalities were highlighted. From these summaries, corresponding themes were identified. Using NVivo, quotes from each interview were categorized into different main themes and subthemes. Any themes that were covered by another theme were merged and any subthemes that were not highly supported were deleted.

## *Validity*

 A number of strategies were used to safeguard the validity of findings:

* The research was discussed with one participant in advance who also advised on the content and relevance of interview questions.
* The interviewer kept a reflexive journal in which she recorded observations and critical reflections of each interview, especially with respect to preventing/detecting any leading of the interviewee.
* The second author reviewed one interview transcript and the resulting coding to ensure that the interviewee’s perspective was being accurately represented.
* A summary of findings was sent to participants so that they could, if necessary, raise concerns about their accuracy. No such concerns were raised.

**Findings**

Four major themes were identified in the analysis of the interview - personal impact, relationships, responsibilities and support. These major themes were broken down further into related sub-themes, which are listed below under each theme. All participants discussed topics that relate to three of these themes. Five out of the six participants highlighted aspects relating to support.

## *Personal impact*

Career

Five participants noted that they were or will be in a profession that involves people with special needs. The other participant said that she had considered a career in the field but realised it was not a good fit for her personality. Participants saw their careers as not just reflecting their family experience of special needs, but also arising from a passion to improve peoples’ lives. They knew firsthand the impact that their job could have on individuals and their families:

*‘(…) Which is a massive benefit of having a sibling with autism. She's sort of made me feel a lot of empathy for families* and *children with autism. That's completely why I went into that area.’* (Kate)

*‘(…) I feel like I have this sort of guilt and this need … I think there is a gap, that I need to sort of help people and make a difference, which I don't think would have been there if Jack hadn't been around.’* (Christine)

Personal characteristics

Siblings reflected on their own personal characteristics in the light of their experience as a sibling:

*‘I think he has made me more empathetic* and *sort of more patient with people, to try to underst*and *what they are going through.’* (Christine)

‘*I don't know whether because of my brother* and *sister, I have become more independent or was more independent* and *therefore I was able to cope with it but I do quite like doing things for myself.’* (Margaret)

Struggles

Most siblings felt their experience had a positive impact on their life, albeit also creating significant challenges. They were affected, for example, by the stress and responsibility of life with a person with additional needs, both in the past and presently:

*‘I think we had to accept things that were very difficult for us to have to accept at a young age.’* (Alice)

*‘I have to be physically present in his bedroom at night to stop him from self-injuring. For the last two* and *half years, I've slept in a camp bed on the side of his bed.’ (Carol)*

*Relationships*

Asymmetrical sibling relationship

All participants noted the asymmetry of their relationship with their sibling with a disability and, where comparison was possible, how it differed from relationships with their other sibling(s):

*‘The relationships are so different. Me and my brother are like friends now, whereas me and my sister, I care for her. It's not an equal relationship, whereas my brother and I have an equal relationship.’ (Kate)*

*‘I think we have quite a different relationship. It's not like a brother/sister relationship; it's more like he's like my child sort of thing. I have a lot of responsibility for his well-being* and *that he's happy.’ (Christine)*

Close but distant family

All participants said that they would describe their family as ‘close’ and collaborative:

*‘I'd say it's made us pretty close. Especially with the troubles that my brother has, my mum and I would like… I guess support each other.”* (Ann)

Participants also reported that some family members responded differently to the responsibilities. As a result, more distant relationships developed with family members who were perceived to not take on their expected role:

*‘But, there is anger with my dad because in my eyes, he has walked away from his responsibilities at some of the worst times in Ron's life* and *some of the worst times in our lives.’ (Alice)*

## *Responsibilities*

Responsibility as a choice

The participants interviewed were all actively involved in their brother or sister’s life. Participants saw acquiring this responsibility as a choice while acknowledging the limitations on their choices:

*‘Somebody had to. I was the obvious person… My career was always going to be teaching.’* (Carol)

*‘It's kind of something I'm expected to do but I kind of would do anyway.’* (Ann)

However, there is a sense of obligated choice: in the siblings’ lives, there are sometimes other people that did not take on the caregiver role. Alice explained this when comparing herself to other family members:

*‘(…) I do choose to take on the responsibility but it is with the knowledge that if I didn't, Ron wouldn't … have the life that he does now. He certainly wouldn't have the future that he can have and should have and will have if all goes in the right direction. It’s sort of a difficult one that because my brother and my Dad have both actively chosen to not take up the responsibility and maybe wouldn't expect that I would do that…’* (Alice)

The little grown-up

Participants characterised themselves as ‘more mature’ than their peers and correlated that to their brother or sister:

*‘... But as a sibling, it's partly responsibility you have for your sibling* and *partly kind of having to take care of yourself when your parents are busy.’ (Ann)*

*‘I always saw that as a good thing, that I gained a lot of independence* and *responsibility. I grew up knowing how to look after myself* and *my mum didn't have to do everything for me.’ (Kate)*

Compromising attention

Some participants reported being angry as children or feeling neglected by their parents:

*‘There were hard times around that really because I could run a race and my mum and dad weren't there whereas everyone else’s mum and dad were… I think it was a lot of compromising.’* (Alice)

However, such comments were accompanied by a realization of the need for the disparity either at the time or later:

*‘He was accepted as... the person that needed the most. It didn't bother any of us; I know it bothered my mum* and *dad.’* (Carol)

 *‘I'm going to say it was uneven but I think it was kind of necessary.’ (Ann)*

Taking on added responsibility

Though participants described various degrees of responsibility, they all expressed a feeling of impending additional responsibilities for their brother or sister. Most participants’ brother or sister are likely to remain in a residential setting rather than living directly with them - however all participants saw themselves as the next-in-line carer:

*‘I think there will always be that nagging feeling in the back of my head that I know that I have a lot of responsibility now but one day, that responsibility will be even bigger.’* (Alice)

A few participants emphasized a desire to relieve their parents of anxiety about the future. Carol had assured her parents at an early age that she would take on the primary care responsibility. She described the challenge of the sudden shift of roles and her initial reaction to the unexpected added responsibility:

*‘When my mother suddenly took ill, it was still unexpected. I wasn't ready at that point. I didn't expect to take on that full role at that point but that's how it happened.’* (Carol)

## *Support*

Ongoing need for support

Participants noted that support surrounding people with disabilities is typically directed to the individual with the disability and their parents and even this may be perceived as inadequate. Where support for siblings is provided, it is likely to be focused on young siblings. Participants expressed a need for ongoing support:

*‘If there is still not enough support for parents, but there is still more support than there is for siblings; that in itself is saying a lot.’* (Alice)

*‘I have to go through a lot… it can have a big impact on siblings* and *they need to be accounted for, as well.’* (Kate)

Mutual support between siblings

Participants commonly mentioned the importance of mutual support between siblings. Friendships built on a mutual understanding that eliminates the ‘elephant in the room’ (Christine) were reported as providing the most useful type of support:

*‘(…) You equally feel supported at the same time. It doesn't just feel like you are being counselled by someone or being listened to by someone who doesn't understand… you are able to offer support to them in the way that they are able to offer support to you... It doesn't matter how old they are or how different your lives are or anything when you're talking to a sibling, you're talking to a sibling and that can make such a huge difference.’* (Alice)

**Discussion**

Participants reported that their siblings with a disability had a significant impact on their lives. Their overall attitude toward having a sibling with a disability was that, despite the sometimes severe difficulties, they could not imagine their lives any different. On the whole, participants reported a positive outlook. Participants attributed personal characteristics such as empathy, patience, acceptance and independence to having a sibling with a disability, as well as this having influenced their career choices. It can be interoperated that participants saw their sibling experience as one of the defining features of their lives.

This experience appears to have had a major impact on their family relationships both with the sibling and with others. Some relationships were much closer because of mutual dependence, others, in the context of differing responses to the difficulties faced, became remoter or even hostile. Perhaps because of these kinds of issues, as well as the defining nature of the sibling experience, participants wanted more ongoing support, including, and perhaps especially, facilitated contact with other siblings.

 Due to the convenience nature of participant recruitment, the sample lacked variability both in gender and in type of relationship with their sibling. The accounts provided may represent common perspectives of female siblings of individuals with profound disabilities and challenging behaviour that have an active role in their brother or sister’s life, but may not generalize to other siblings. Participants ages ranged from 22 to 53 years old. Though participants’ accounts were similar, disparities in answers, specifically relating to support, should be further analyzed. In addition, most participants were obtained through an organization that provides support to people with disabilities and their families. Potential participants not in touch with such an organization may report different perspectives and experiences. The study also reports the subjective experiences and attributions of a small number of self-selecting participants. Their view, for example, that aspects of their personalities had been shaped by their experiences as a sibling, while certainly reflecting their own beliefs, should be tempered against the possibility that it is those very personality characteristics that have enabled them to cope well with difficult experiences. Other limitations include the nature of the interview questions. Interview questions were based on previous research, which emphasized the negative impacts on a sibling’s life. As a result, participants were not directly asked about positive aspects of having a brother or sister with a disability, though all participants mentioned a positive impact.

Some aspects of the findings differ from previous research. Howlin *et al*. (2014) found that an above average number of siblings reported the occurrence of mental health issues at some point in their lives. Though some participants in the current study stated that they had received professional assistance for stress related symptoms, no other mental health concerns were reported. In addition to reported mental health issues. Becker *et al*. (2001) reported that some siblings had difficulty in transitioning to adulthood. This did not seem an issue for participants in the current study, the personal characteristics they described being more likely to facilitate an easier transition to adult independence. Previous research (e.g. Mulroy *et al*., 2008) with parents has suggested that siblings are affected adversely by receiving less attention than their sibling (Mulroy *et al*., 2008). The current study had mixed findings. Two participants did describe having experienced feelings of inequality at the time, later appreciating why it had happened. However, other participants reported that their parents were more concerned about the attention disparity than they were.

 Some findings were consistent with previous research. Overall, siblings expressed a loving, caring, protective relationship with their brother or sister (Atkin and Tozer, 2014). Participants also did not report the distancing of relationships that is sometimes seen in neurotypical siblings (Orsmond *et al*., 2009). Participants did report having more childhood responsibilities than their peers including having to complete more domestic chores (Becker *et al*., 2001).

 However, it was highlighted in the interviews that participants were not merely recipients of additional responsibilities - they reported wanting to help their parents. Perhaps it is notable that mothers of children with disabilities tend to have better health and life satisfaction when their other children are involved in caring (Seltzer *et al*., 1991). While, beyond childhood, participants believed their decisions to take on responsibilities for their siblings were free choices they were also clear about the negative impact on their parents if they had not made these choices. Participant choices extended into the future in a way that acknowledged their commitment to taking on a “parental” role might assuage the concerns reported by older carers about the future care of their adult children (Bowey and McGlaughlin, 2007).

 The findings from this study could be used as a foundation for the development of more effective support for siblings. Siblings sometimes assume caring responsibilities with respect to a sister or brother with a disability but often without even the limited support parents might receive (Conway and Meyer, 2008). Most participants emphasized their dissatisfaction with the support provided throughout their lives. Though, for some, counselling was helpful, others viewed it as ineffective and felt that support provided by other siblings was more useful. Feelings of isolation were alleviated through meeting people with the same experiences, who could understand their situation without explanation (Naylor and Prescott, 2004). Naylor and Prescott (2004) also noted that the overall quality of life of siblings increased when provided more adequate support.

 Effective support for siblings should therefore provide opportunities for the sharing of experiences and should not be limited to childhood. Further research should be conducted to evaluate the effects of life-long support for siblings, including an analysis of when support may be needed the most. By listening to the expressed needs of siblings, support systems can be improved and developed (Tozer and Atkin, 2015; Naylor and Prescott, 2004).

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