“I would not change [my] sibling for the world, Maybe the world can change for my sibling”: the experiences of adult siblings of people with developmental disabilities.

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RESEARCH ARTICLE OPEN ACCESS

"I Would Not Change [My] Sibling for the World, Maybe the World Can Change for My Sibling": The Experiences of Adult Siblings of People With Developmental Disabilities

Elizabeth Moran-Morbey[1] | Chloe Blackwell[2] | Tom Ryan[3,4] | Nikita K. Hayden[3,4,5]

[1]Education Studies, University of Warwick, Coventry, UK | [2]Centre for Research in Social Policy, Loughborough University, Loughborough, UK | [3]iHuman, University of Sheffield, Sheffield, UK | [4]School of Education, University of Sheffield, Sheffield, UK | [5]CIDD, University of Warwick, Coventry, UK

Correspondence: Nikita K. Hayden (n.hayden@sheffield.ac.uk)

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ABSTRACT

The sibling relationship is complex, unique and important. When one sibling has a developmental disability, siblings can be important sources of care, support, advocacy and friendship for one another. We drew on online survey data from 456 UK adult siblings of people with DD. Siblings provided written responses to a prompt about their sibling experiences (> 80,000 words). These data were analysed using qualitative content analysis and organised using the Siblings Embedded Systems Framework (SESF). The SESF helps us to consider how complex interacting mechanisms and factors surrounding siblings, families and wider systems at a local, national and international level, can influence siblings' outcomes, experiences and relationships. Overall, siblings shared a range of experiences related to their: mental health and wellbeing; personal characteristics; sibling relationships; intra-familial experiences; caring experiences; experiences accessing support services; community experiences; and views on the discrimination and ableism that their disabled siblings experienced. Siblings reflected on the interconnected and dynamic nature of their experiences. We found the SESF to be a useful way of presenting an account of the data overall, as well as to explore the impact of societal factors on siblings' experiences. Siblings' structural, political and social contexts impacted their personal lives. Please refer to the Supporting Information section to find this article's Community and Social Impact Statement.

1 | Introduction

The sibling relationship is important, as we spend a significant amount of time with our siblings growing up, and our sibling relationships have an 'important influence on who we are, and on our future relationships beyond the family home' (Hayden and Kassa 2024). Siblings hold a unique and complex relationship with one another (Davies 2023), yet siblings are underrepresented in disability studies (Meltzer and Kramer 2016). Sibling relationships are perhaps even more important to siblings where one is disabled, as 'siblings are able to offer friendship and support where elsewhere in society, many disabled people continue to face discrimination and exclusion' (Hayden and Hastings 2022, 6). Sibling relationships are, in most cases, the longest relationship people will have in their lives (Davies 2023). Consequently, as welfare provisions are reduced and we move more towards family-based care settings, there is a growing reliance on siblings in the care plans of people with developmental disabilities (Tozer, Atkin, and Wenham 2013). Siblings make up a significant proportion of those caring for people with learning disabilities[1] (Brennan et al. 2023). Those interested in the care of people with developmental disabilities[2] should therefore be interested in siblings' unique roles, support needs and experiences.

Previous sibling disability research has often focused on siblings' psychological outcomes. For example, large-scale quantitative studies examining siblings' psychological outcomes have identified negative psychological outcomes for siblings (Hayden et al. 2023). Often these studies are justified and positioned in relation to siblings' caregiving potential, emphasising the need to ensure siblings are psychologically 'healthy' and able to take on unpaid family care roles (Hayden and Hastings 2022). In terms of qualitative studies, findings have included reflections on inclusion and personal growth (Mauldin and Saxena 2018), as well as focuses on siblings' educational and psychosocial outcomes (Zaidman-Zait, Yechezkiely, and Regev 2020). Studies on siblings' outcomes are often positioned through a more individualistic or familial lens, focusing on how the sibling with developmental disabilities impacts the non-disabled sibling's life. There is often little attention given to the wider structural reasons for these outcomes, leading to the reinforcement of neoliberal ideas of individualism (Goodley 2014; Hayden and Hastings 2022) and deficit narratives around the families of people with developmental disabilities (Hastings 2016).

Further work is necessary to understand siblings' experiences beyond this individualistic focus. The Siblings Embedded Systems Framework (SESF) was developed by Kovshoff et al. (2017) to contextualise siblings' experiences. The framework helps us to consider how complex interacting mechanisms and factors surrounding the sibling, the family and wider systems at a local, national and international level, can influence the outcomes, experiences and relationships of siblings of autistic people. Although the framework was developed to explore the experiences of siblings of autistic people, it may also help to advance our understanding and conceptualisation of people with other developmental disabilities as well (Hayden and Hastings 2022). Further empirical work is necessary to ascertain whether the SESF has utility beyond autism sibling research. In brief, Kovshoff et al. (2017)—drawing on family systems theory, bioecological systems theory and diathesis-stress psychological frameworks—consider sibling experiences across four levels: (1) within-sibling factors, (2) the microsystem and mesosystem, (3) the exosystem and (4) the macrosystem. Within-sibling factors include demographics, genetic and psychological factors, and how siblings interpret their experiences. The microsystem and mesosystem level considers factors such as siblings' immediate and wider family, events, peers, school and workplace experiences, the community and social media. Social media also forms part of the exosystem, which also includes the media, local political and social structures and formal and informal support. The macrosystem considers factors at the structural level, including constructs related to religion, wealth, class, political structures at the national and international level, cultural attitudes and ideology (e.g., about disability, care, family).

The SESF does have its limitations, however. A criticism of the SESF is that it may lack the nuance and sophistication necessary to study such complicated, dynamic and entangled social constructs such as that of the family (Hayden and Hastings 2022), and indeed, the complex constructs of disability and care. The SESF was developed by drawing on existing theories and existing empirical sibling autism studies. The limitations of the studies which informed the development of the SESF may also limit the SESF's generalisability. For example, existing sibling disability research generally remains psychological and individualistic in nature, with samples that are predominately white and from English speaking countries. This is likely to limit the utility of the SESF in various social, cultural and international contexts. The authors of the SESF acknowledge themselves that their model lacks a 'complete picture' of how microsystem level factors impact siblings' outcomes across the lifespan (Kovshoff et al. 2017), which may be exasperated by the lack of longitudinal studies in the field available to inform the SESF.

There has been a tendency in sibling disability research to over-focus on within-sibling factors at the microsystem and mesosystem level. For example, qualitative studies have explored the impact of having a disabled sibling on the non-disabled sibling (within-sibling, Moyson and Roeyers 2012), sibling relationships (microsystem, Richardson and Jordan 2017) and the school context (mesosystem, Pavlopoulou et al. 2022). These within-sibling, microsystem and mesosystem focuses are important for understanding and supporting siblings. However, there are a lack of studies exploring siblings' experiences at the exosystem and macrosystem level. This is a problem, because focusing at the individual and familial level risks reinforcing deficit narratives about people with developmental disabilities and their families. Furthermore, without understanding siblings' more structural and societal experiences and contexts, we argue that it would be very difficult to fully understand the complexity of siblings' experiences, and therefore know how to better support siblings.

Understanding macrosystem factors is fundamental in understanding siblings' psychological and interpersonal experiences. For example, some statistical analyses have included more structural variables in their models, such as constructs related to poverty and socio-economic status (Hayden et al. 2023; Hayden et al. 2019). Lower socio-economic status was found to be associated with poorer outcomes in child siblings' behavioural and emotional outcomes (Hayden et al. 2019), and higher levels of subjective poverty were found to be associated with poorer outcomes in adult siblings' outcomes related to mental distress, mental wellbeing, quality of life and health (Hayden et al. 2023). Therefore, it is important that we consider these more structural variables in sibling disability research, at the macrosystem level. A more macrosystem level factor that has been included in sibling disability research has been the role of gender in siblings' experiences and outcomes. Lee and Burke (2018) found that the majority of quantitative studies included in their systematic review found that sisters were more likely to be a carer for their sibling with developmental disabilities compared to brothers. However, gender is often treated as merely a within-sibling variable, rather than also as an ideological and societal construct.

Qualitative sibling disability studies, particularly those with a more conceptual, sociological or interdisciplinary focuses, have also included a focus on more structural and ideological factors that impact siblings' experiences. Meltzer, for example, has brought together disability studies and sibling research (Meltzer 2018; Meltzer and Kramer 2016; Meltzer and

Muir 2021), critiquing individualisation and exploring feminist perspectives in sibling disability research. Meltzer's (2018) work seeks to understand siblings' experiences of disability without individualising or medicalising disabled people and their families. Richardson and Stoneman (2019) explored the experiences of Black sisters of people with developmental disabilities, drawing on disability/critical race theory. Their intersectional approach raised important findings about the ways in which siblings' perceptions of stigma and disability were associated with cultural understandings of family and kin and their multiple identities. Once again, by applying a more macrosystem focused approach, the discussion was shifted away from individualistic understandings of disability to more nuanced discussions that incorporated wider structural factors at the macrosystem level. Conceptual work by Richardson and Jordan (2017) has also focused on more macro-level factors impacting people with developmental disabilities and their siblings, including: oppression, marginalisation, inclusion, empowerment and transformation. Collectively, these studies highlight the value of conceptually driven qualitative studies in examining complex sibling experiences at the individual, familial, community and societal level.

1.1 | Research Questions

In this study, we analysed the qualitative written responses from an online survey of 456 adult siblings of people with developmental disabilities living in the United Kingdom (UK). Our main research question was: How do UK adult siblings of people with developmental disabilities perceive their sibling experiences? We also had a more conceptual subsidiary research question: How can the SESF be used to explore the experiences of a sample of UK adult siblings of people with developmental disabilities?

2 | Method

2.1 | Participants and Recruitment Procedure

There were 456 participants in this study sample. In terms of gender, 402 siblings were female (88.2%), 53 were male (11.6%) and one identified as another gender (0.2%). Siblings' mean age was 36.9 (range = 18–76). Over half of siblings identified as a carer of their disabled sibling (57.5%). Further demographic information, including information about siblings' disabled siblings, can be found in Table 1. The data for this study were derived from the Adult Sibling Survey, a study of 927 adult siblings of people with developmental disabilities living in the United Kingdom. A description of this wider study is included in Hayden et al. (2023). To be included in this study's sample, participants had to live in the UK, had to be aged 18 years or older, had to have a sibling with developmental disabilities aged over 16 years, had to consent to take part in the research study and had to provide a written response to the final open-ended question in the survey. Full ethical approval for the Adult Sibling Survey was provided by the University of Warwick's Humanities and Social Sciences Research Ethics Committee. Data were collected between October 2019 and February 2020. Sibs, a UK charity/non-profit that supports siblings of disabled people, led recruitment to this study. Participants were not provided with any monetary incentive to take part in the survey. Convenience sampling was used to recruit participants through Sibs' national networks, their newsletters and their social media accounts.

TABLE 1 | Participant demographics.

Participant demographics	***n* (%)**
Sibling	
Sibling was female	402 (88.2)
Sibling was male	53 (11.6)
Sibling was another gender *n*	1 (0.2)
Sibling mean age (range)	36.9 (18–76)
Sibling was living with their disabled sibling	87 (19.1)
Sibling was a carer for their disabled sibling	262 (57.5)
Sibling was living in the 20% most deprived neighbourhoods	51 (11.2)
Sibling with developmental disabilities	
Sibling with developmental disabilities was female	181 (39.7)
Sibling with developmental disabilities was male	269 (59.0)
Sibling with developmental disabilities was another gender	5 (1.1)
Sibling with developmental disabilities mean age (range)	35.5 (16–73)
Conditions and diagnoses of the sibling with developmental disabilities	
Learning (i.e., 'intellectual') disability	276 (60.5)
Autism	218 (47.8)
Down syndrome	159 (34.9)
Visual impairment	140 (30.7)
Hearing impairment	101 (22.1)
Mobility impairment	192 (42.1)
Physical health problems	236 (51.8)
Epilepsy/seizures	115 (25.2)

Note: Missing data ranged from 0.0% to 0.7%.

2.2 | Dataset

The Adult Sibling Survey included demographic information about the sibling and their disabled sibling, the sibling's mental health and wellbeing, care responsibilities and their sibling relationship with their disabled sibling. Although the Adult Sibling Survey was predominantly a quantitative survey, the final open-ended question asked: 'Is there anything else you want to tell us about being a sibling of someone with a learning [i.e., intellectual]/developmental disability?' Out of 927 siblings who took part in the Adult Sibling Survey, 456 siblings answered this open question, writing more than 80,000 words between them (mean = 177.66 words; range = 8–715 words). Supporting Information S1 includes group comparisons between siblings who did and did not choose to write a response to the final open question about their sibling experiences. These written responses are the focus of this qualitative study.

2.3 | Analysis

There was significant variation in the depth of siblings' responses, we therefore wanted to select a flexible analysis method. We chose conventional content analysis (Hsieh and Shannon 2005) to analyse these data over thematic analysis because our data collection technique (an online writing prompt) was relatively less in-depth than other qualitative data techniques, such as qualitative interviews. Conventional content analysis leans more towards description, but still allows for a satisfactory level of interpretation, moving beyond manifest content analysis if desired (Vaismoradi and Snelgrove 2019).

Conventional content analysis requires researchers to read and immerse themselves in the data, to develop codes through this process, and then to code the full dataset using these codes, deriving categories that are grounded in the data and sometimes themes (Bengtsson 2016). To conduct the analyses, the first author immersed themselves in the data by reading the dataset, making notes and annotations using an iterative process and adapting codes to reflect the meaning within the text (Hsieh and Shannon 2005). The first author then developed a draft coding framework which we then piloted. We used NVivo software to conduct the analysis for this study. The coding framework was piloted by E.M.-M and N.K.H, double coding 20% of the dataset. E.M.-M. and N.K.H. then discussed the codes and finalised the coding framework. E.N.-M. then coded the full dataset. We reviewed these codes in detail before deriving descriptive categories and then more conceptual and abstract themes from the data. We noted parallels between our findings and the SESF. Through further discussion between E.M.-M., N.K.H., and C.B., we then interpreted and structured our findings in relation to the SESF rather than thematically. Presenting our findings in this way provided us with a useful structure for describing the text overall (Vaismoradi and Snelgrove 2019), as the SESF provided a holistic overview of siblings' lives.

3 | Findings

In this section, we have combined our results and discussion to improve readability and minimise repetitiveness, allowing more room for analytical depth. Supporting Information S2 provides a description of codes and example participant quotes. Supporting Information S3 provides a description of study categories. Drawing on the SESF (Kovshoff et al. 2017), our findings are structured as follows: (1) within-sibling aspects of siblings' experiences, (2) the microsystem and mesosystem level, (3) exosystem level factors and (4) wider factors at the macrosystem level.

3.1 | Within-Sibling Level

Siblings identified self-motivation, independence and confidence as important personal traits that supported them in their role as siblings. Some siblings observed that they developed these characteristics through their relationship with their sibling with developmental disabilities:

> I have grown up to be a very independent individual—while I think this is partly in my nature, I believe that my sibling needing a lot more support than me growing up has contributed to this. If I wasn't as confident by nature, I think this would have been a lot more challenging for me and I may have not ended up the way I am today, unfortunately.

Participant 851886, Age 22, Female

The sibling above wrote about how the development of these personal attributes was a combination of their nature, and their sibling experiences. This sibling reflected on how the development of confidence and independence were perhaps necessary to support their resilience. Siblings also attributed the development of various personal traits to their experiences growing up with a disabled sibling in the existing literature. For example, in a study of 1160 adult siblings, Hodapp, Urbano, and Burke (2010) found that siblings believed that their sibling experiences contributed to them being more: empathetic, understanding of differences, compassionate, responsible, aware of injustices and aware of family dynamics. The siblings in our study tended to refer to their personal attributes as developing over time, as they grew up with their siblings, and matured. For example, siblings described developing a greater acceptance of—or at least becoming less fazed by—how people might react to their disabled sibling. Siblings described growing up with a disabled sibling as helping them to foster a greater understanding of their disabled siblings' needs, as well as an appreciation of why their disabled sibling needed more parental attention.

Siblings wrote about their own mental health and wellbeing in relation to their sibling experiences. Some siblings wrote about feeling overlooked or unimportant; feeling guilt, shame and fear; developing people-pleasing tendencies that they felt had caused them harm in their adult relationships; and having specific mental health conditions, such as depression and anxiety:

> Pushing my own feelings down caused me to develop clinical depression and anxiety as a young teenager, and humiliating outings with my sister in public resulted in me rarely leav[ing] the house with my family and only under duress. This eventually led me to live with agoraphobia for many years which I have only recently overcome with the help of a counsellor. I have abused alcohol and drugs since I was 14 to cope with my feelings of anxiety and low self-esteem, and still struggle when overwhelmed with strong feelings about my family life.

Participant 134949, Age 25, Female

Many of these siblings attributed their own mental health problems to being a sibling. Although society often understands mental health as an individual problem (i.e., 'within-sibling'), the SESF challenges this, categorising mental health as an outcome that is influenced by all levels of the system. For example one sibling wrote that:

> Many times in the journey of the past 5 years I have been suicidal and anxious due to the phenomenal stress of fighting for my sister to have a decent life.

Participant 352312, Age 57, Female

Quotes like this sibling's emphasise how inappropriate it would be to understand this sibling's experiences as an individual psychological or familial problem. Their experiences are instead intertwined with stresses caused at a much more structural level.

In retrospect, some siblings described holding resentment in childhood towards their sibling or their parents for the differential treatment that they received. Some siblings explained the loss of these negative feelings as they grew up:

> I think it's quite hard being a sibling of someone with a learning disability especially when you're younger because you're often overshadowed by their needs, however as you get older you realise that the attention they get when they're younger is just to make up for the lack of attention they receive when they're older from prospective employers and more discriminative members of the general community.

Participant 328461, Age 20, Female

What is interesting in this quote, is that the sibling positions their own very individual and personal experiences—of feeling like they got less attention as a child—to wider societal and community issues of ableism and discrimination that disabled people are subjected to. What we also see here, is an account of the way in which the sibling and the family somehow seek to compensate or offset this discrimination for their disabled family member. Although, many siblings described feeling very affected by the differential treatment received from parents, and not all siblings were able to lose feelings of resentment over time like the sibling above describes. Similarly, not all siblings described 'growing a thicker skin' in response to the discrimination of siblings with developmental disabilities out in public, like another respondent wrote. For some siblings, the exposure to discriminatory behaviour time and time again was a mounting pressure:

> What has been harder has been the continuation of this as I've grown up. Being out somewhere and hearing a throwaway remark degrading someone with [Down syndrome] followed by howls of laughter absolutely knocks everything out of me. I don't know how to react, even if I am out having a good time my mood instantly changes. I find it impossible to enjoy myself because I just cannot understand the ignorance and insensitivity of people.

Participant 537275, Age 29, Male

Again, we can see here that a sibling's experiences in the community had a significant impact on their own personal (within-sibling) experiences. Overall, there is a sense from these siblings' accounts that these within-sibling factors are not isolated from the wider family, community and societal system that siblings are embedded in, as argued by Kovshoff et al. (2017). For some siblings, there appears to be a significant, almost violent interaction, that occurs at the boundary between siblings' personal lives and their social lives.

3.2 | Microsystem and Mesosystem Level: Sibling, Family, Peer and Community Relationships

3.2.1 | Relationship With Sibling

Siblings often expressed that having a sibling with developmental disabilities was a 'normal' part of life for them. More than this, siblings described their relationship with their disabled sibling as helping them to learn much about life, such as patience and acceptance. They expressed pride in their sibling with developmental disabilities:

> I am so proud of my sister. She works so hard and is such a source of joy and light in the lives of everyone who knows her.

Participant 275229, Age 23, Female

> Growing up, I was very proud to have a sibling with a disability and would explain my brother to my classmates.

Participant 348998, Age 18, Female

Many of the siblings in this study highlighted positive relationships with their siblings with developmental disabilities. Although existing research has tended to assume that sibling relationships in this population were less positive than other sibling relationships, this assumption has little empirical substantiation, with many sibling relationship studies finding similar relationship quality between siblings, whether or not one sibling in the sibling dyad was disabled (Hayden et al. 2022). The sibling relationship was also described by siblings as reciprocal, even if this manifested in different ways:

> It may seem to others like a one-sided relationship, but my sister is really kind and thoughtful and gives back to others in a less obvious way. I feel privileged to be her sister and friend.

Participant 295380, Age 26, Female

This sibling highlights that their relationship with their sister, and how much their sister offers in their relationship, was not acknowledged or understood by others. Siblings also identified negative aspects of the sibling relationship. For example, communicative differences were felt by some respondents to present a barrier to closeness and connectedness, with one sibling explaining:

> I want to be friends with her and spend time with her, but it's hard when we can't communicate at all and I have no idea what's going on in her head or how to be close to her, and as a result I feel quite profoundly disconnected from her.

Participant 318791, Age 20, Female

This sibling highlighted the desire for a closer relationship with their sibling with developmental disabilities, and although they acknowledge communication as a barrier, they do not position this barrier as a lack inherent to their sibling. Instead, this sibling seems to situate this barrier as something mutual, understanding that 'we can't communicate' and that they themselves lack the ability to understand their sibling with developmental disabilities.

Some siblings did share challenges in their relationship with their sibling with developmental disabilities. For example, siblings shared that caring for their sibling with developmental disabilities was difficult when their sibling with developmental disabilities would physically hurt them or other family members. Siblings also described the difficulty of managing the competing demands of sibling care work and other family or work commitments. Meltzer (2017), for example, reported how for one sibling, their caring role meant that 'I couldn't just entirely be her sister' (Meltzer 2017, 8). Their caring role disrupted their sibling relationship in some way. The process of juggling competing demands between care and other commitments highlights the need to challenge discourses around family care as the default expectation. Notably, these competing demands for siblings could intensify because of the good relationship that a particular sibling shared with their sibling with developmental disabilities. One sibling shared that:

> I am still a secondary carer to provide respite for our parents as they're both over 60 now. Despite having my own family and home, we have arranged dates in place for him to spend time with us. My other siblings do not have this, as I have a closer relationship to him due to being closer in age and growing up together.

Participant 857243, Age 29, Female

This finding is substantiated by the sibling literature, where more positive sibling relationships were found to be associated with being a carer (Lee and Burke 2018). In the next section, we will delve beyond the sibling dyad, and consider how the wider family was seen to impact siblings' experiences.

3.2.2 | Intra-Familial Factors

There were intra-familial factors that siblings also felt affected their experiences. Many siblings talked about their wider family, particularly their parents, and how they contributed to siblings' perceptions of their experiences. For example, following on from the sibling relationships section, some siblings felt that their parents had played an important role in fostering their relationship with their disabled sibling:

> I have a very good relationship with my brother, my parents made sure of this. We spent a lot of time together as children and I learnt to understand him and to be empathetic very early on in my life.

Participant 203735, Age 31, Female

> He and I have been blessed to enjoy a supportive, loving family environment, and I have no doubt this has been key to my overwhelmingly positive experience of having a family member with [developmental disabilities]. I wouldn't change a thing.

Participant 429516, Age 31, Male

Parents, therefore, may have an important role in encouraging closeness and mutual understanding in siblings' relationships with one another. These quotes highlight that it is important to understand the sibling dyad relationship within the context of the wider family.

Siblings reflected on what was important for them to receive from their families, which included: having their social and emotional needs met (e.g., acknowledgement of academic achievements), having the opportunity to engage in different learning and leisure activities (as a family and as an individual), feeling supported and encouraged to pursue interests and progress, feeling equal to their disabled siblings, feeling heard on issues relating to their own needs and being consulted on important family decisions regarding the present and future care of their sibling with developmental disabilities. Siblings described how these needs could change shape, although they would not necessarily diminish, in adulthood, and siblings described how these unmet needs affected their sense of wellbeing. For example, many siblings reported that as adults they wanted to be consulted about their siblings' care. This sibling described how they had experienced a:

> ...lack of awareness or acknowledgement within the family unit of my feelings, needs, thoughts or beliefs as a sibling (ongoing as an adult), or those of my brother [and a] strongly negative and hostile response to my attempts to communicate my own thoughts or feelings regarding my sister [with developmental disabilities].

Participant 884930, Age 44, Female

Family communication regarding the needs and care of the sibling with developmental disabilities was, for many siblings, not simply about the sibling feeling respected. Being excluded from family decisions had practical implications, negatively impacting on the sibling's preparedness for future care work once their parents could no longer provide care, and therefore negatively impacting the care of the person with developmental disabilities. This is something Tozer and Atkin (2015) highlighted in their research, arguing for care practitioners to more actively involve siblings from an earlier age to ensure that transitions in care, from parents to siblings, go smoothly, with siblings already involved and able to advocate for their disabled siblings.

Reflecting on childhood, siblings reported that their sibling with developmental disabilities received more of their parents' attention, and for some siblings, they wrote about how this contributed to feelings of loneliness and resentment. While some siblings described an improved balance or emotional processing over time, others wrote that their feelings of being under-prioritised continued into adulthood. Being treated equally in the family was not just about feeling a sense of fairness, but also about having needs met and having access to opportunities:

> Being a sibling is like living in a constant shadow, always in the background and never being a priority in the family, even though this is no one's fault, [it's] unavoidable and unintentional, it still has negative effects on one's confidence, self-belief and contributes to massive frustrations.

Participant 677540, Age 25, Female

A common issue parents experience is the need to provide differential parenting to their children, and then their children perceiving this as unequal treatment (Hayden and Kassa 2024). Although 'unequal treatment is not the same as unfair treatment' (Hayden and Kassa 2024), it is important that siblings have their needs acknowledged by their families.

3.2.3 | Peer Relationships and Understanding

Siblings described feeling different from their peers, and some siblings wrote about how this contributed to feelings of social isolation. Siblings wrote about family isolation, as well as difficulties faced when others would make negative comments about their disabled sibling or disability more widely.

> Having a sibling with a disability has perhaps presented challenges to me whilst growing up, challenges different to those of my peers, which especially at a young age can be difficult.

Participant 850623, Age, 24, Male

> I was aware that other kids saw me as different, were kind of cautious around me, maybe even scared of me.

Participant 525803, Age 52, Male

The quotes above highlight that not only did these siblings feel different from their peers, but that they believed that their peers saw them as different. This could be described as disability or discrimination by association, or courtesy stigma (Goffman 1990), whereby proximity to or association with a stigmatised person can lead to experiencing stigma by extension.

Some siblings described having small friendship circles and being selective of the people they spent their time with. Siblings wrote that they distanced themselves from people who used pejorative language relating to disability. Some siblings described keeping their family life secret to avoid being seen differently or because they were unsure how to bring their disabled sibling into conversations. Conversely, other siblings liked to talk about their disabled sibling. In both cases, siblings wrote that it was difficult to connect to people who did not share the experience of having a disabled sibling. Finding friends with similar experiences was therefore viewed as highly beneficial to siblings' sense of wellbeing:

> My only wish concerning my sister's disability is that I had been put in contact with other siblings in my position from an earlier age, I think this would've helped me understand I am not the only sibling who experiences this.

Participant 680745, Age 20, Female

> I didn't identify as a sibling until really recently, and it's been a really important part of understanding my own childhood and adult anxieties/mental health.

Participant 917672, Age 29, Female

There was a sense, however, that having friends or access to a community of people who were also siblings was not a common enough sibling experience. A recent realist review identified that a key component of sibling support was providing an opportunity for siblings to realise that 'I am not the only one' (Marquis et al. 2022). Therefore, the benefits of siblings providing peer support to one another appears to be established practice.

3.2.4 | Experiences Out in Public and in The Community

People with developmental disabilities and their families can find it difficult to go out due to the needs of the person with developmental disabilities not being adequately met due to practical, environmental and social barriers that are encountered. These difficulties can contribute to feelings of isolation for disabled people and their families. Experiences of discrimination from the general public were mentioned frequently as negative sibling experiences. Negative encounters with members of the public included name calling, pointing, laughing and staring, which siblings most often described as 'frustrating'.

> Sometimes it is hard as many people do not know how to react to someone with a learning disability and when out in public I find people stare at my sibling which I find frustrating.

Participant 803350, Age 23, Female

> It still baffles me that people have [a] very negative reaction to disabilities out in the community, my brother gets treated very differently when he is a human being an[d] has fought hard for his life, he deserves to be here.

Participant 386622, Age 28, Female

As explored in the first section of the findings, within-sibling factors can form an important part of how negative interactions are interpreted, and the extent to which they are perceived to impact overall wellbeing.

Given the aforementioned issues around social exclusion and difficulty finding peers who understand disability and/or informal care work, family members may wish to join groups for disabled people and carers. One sibling explained how:

> It has helped me and my family connect with others and have a social life with a local sports and social club for people with disabilities.

Participant 259676, Age 32, Male

However, joining groups for disabled people and carers did not necessarily guarantee a greater sense of inclusion and belonging. Frequent experiences of discrimination made it difficult for people with developmental disabilities and their families to go out. Many siblings felt that much of the discrimination they and their siblings with developmental disabilities experienced was due to a lack of understanding among members of the general public. Finding others with personal experiences similar to theirs was important to siblings.

3.3 | Exosystem Level: Professional Support Services

The main exosystem area that siblings wrote about was professional support services for themselves and for their siblings with developmental disabilities. Adequate professional support for a person with developmental disabilities was highly important to siblings. For example, one sibling wrote:

> We are very luck[y], my siblings live in supported living and have an amazing staff team. I am so grateful to them. This support allows me to be foremost a sister.

Participant 812338 Age 41, Female

Siblings described wanting to trust professionals (e.g., care providers). They also wrote about the importance of feeling that service provision was stable and could not be stripped away. Experience of professional care played a role in influencing siblings' interpretation of life for their disabled sibling and of their own experiences of being a sibling to someone with developmental disabilities.

> We live in fear of my sister's services being cut and the incredible impact that would have on my family. Currently things are good but we are never safe, it could be taken away at any time.

Participant 895129, Age: 41, Female

> I find it very hard to trust anyone with my brother. I have witnessed him being mistreated, abused and neglected in medical, educational and care settings and although these things have been reported, the damage is done for us both.

Participant 326763, Age 37, Female

This last clause is illuminating. We understand that abusive care harms the person who received that care, but this sibling is highlighting that the abuse and mistreatment that their disabled sibling received also damaged or harmed themself. Both of these quotes highlight a lack of trust in care provision. These concerns about care provision must be understood within the political context of disability and social care in the United Kingdom. Scandals involving the neglect and abuse of people with developmental disabilities in care homes, such as at Winterbourne View, have highlighted severe disablism and ableism problems in the United Kingdom.

Another factor influencing sibling experiences was related to the level of support and recognition that siblings received themselves. Siblings described a lack of input from professional services for supporting siblings' mental and physical wellbeing. Several siblings described how there was support for parents and their siblings with developmental disabilities, but there was not much in place for them as siblings. Siblings wrote that:

> I feel that people don't understand what living with someone with disabilities is like, even support workers.

Participant 429633, Age 19, Female

> I don't feel like there is a lot of support for me out there to help me manage mentally and physically.

Participant 314653, Age 22, Female

Siblings recognised the challenge of securing adequate support for all family members, including for their siblings with developmental disabilities and parents, but siblings felt that sibling support was especially scarce. The lack of recognition for the informal care work performed by siblings for people with developmental disabilities was identified as particularly problematic, given that many siblings expected their role as carers to increase as their parents aged. For example, siblings wrote that:

> I am frustrated that his social worker and psychiatrist are dismissive of me, of my knowledge of my brother and of my commitment to him.

Participant 207116, Age 38, Female

> Siblings are rarely acknowledged as family carers but we are a growing group who often take over when our parents die. There are support networks for parents but fewer who really acknowledge the significant role some siblings take.

Participant 452993, Age 64, Female

Siblings often described feeling that professional services did not understand the vital role that siblings could play in the lives of their siblings with developmental disabilities. They reiterated the importance of being included in professional discussions about their disabled siblings to understand and advocate for their care needs. Yet, many siblings felt excluded from these key discussions:

> I am often ignored by 'professionals' when discussing my sibling's care with answers being address[ed] to either my parents or questions being completely ignored.

Participant 695448, Age 29, Female

Siblings play important roles in the lives of their siblings with developmental disabilities, and this needs to be better recognised by professionals so that care teams and people with developmental disabilities are able to benefit from what siblings have to offer.

3.4 | Macrosystem Level: Cultural Attitudes and Ideologies Around Disability

Siblings commented on their experiences from the perspective of a broader, societal context. They wrote about cultural attitudes towards people with developmental disabilities and their families, including negative ideas of people with developmental disabilities, underrepresentation of people with developmental disabilities and their siblings, and lacking remuneration for family carers. For some siblings, their written responses were explicitly political:

> We also get a lot of letters from PIP[3] where we are constantly having to prove my sister with Down syndrome and autism IS DISABLED. I feel the conservatives[4] are against us. And now we have to pay for her transport to and from activities. And that's £50+ a day. I feel there is no more support for young carers and carers and disabled people anymore and it's heart breaking.

Participant 746694, Age 19, Female

This sibling described having to fight for welfare payments for their disabled sibling, that they were fully entitled to, and ultimately losing some of these funds. Many disabled people and their families would be unable to afford an extra £50 a day in expenses, and so these political decisions to cut services for disabled people have 'heartbreaking' consequences. There have been significant changes and reductions to state welfare for disabled people in the United Kingdom for more than a decade.[5] Goodley, Lawthom, and Runswick-Cole (2014) attribute these service cuts to neoliberal ableism, whereby disabled people are excluded from society for falling outside of desired societal 'norms'.

As discussed in the section on professional services, siblings felt that services lacked acknowledgement of family members' needs, including those of siblings. A lack of acknowledgement of family members as informal carers also featured in the broader welfare system, as siblings reported that family carers lacked remuneration:

> Carers are so let down by society, they are so unrewarded and often in such desperate circumstances.

Participant 895129, Age 41, Female

> It would be lovely if family members were better recognised and financially supported to fulfil their care duties—especially as we are saving the state hundreds of thousands of pounds in care bills.

Participant 892967, Age 41, Female

Hayden and Hastings (2022) also discuss this sentiment, suggesting that a system whereby family carers take on the primary responsibility of care for their disabled family members ultimately 'serve[s] the state as it encourages families to take on individual responsibility for family members who need support and care, thereby reducing dependency on a capitalist state, allowing them to reduce the provision of high-quality welfare services' (Hayden and Hastings 2022, 14). Therefore, there are important political and ideological factors driving siblings' experiences of caring, whether or not siblings choose to take on a caring role.

Siblings gave many examples of challenging negative ideas about people with developmental disabilities, and of becoming frustrated and weary with erroneous understandings of developmental disabilities or use of improper or discriminatory terms to describe people with developmental disabilities. Advocating for siblings with developmental disabilities (e.g., by educating or correcting others) was described as necessary to combat exclusion. Siblings wrote that:

> The challenges of being a brother or sister of someone with a learning disability: when people use out of date terms or have little understanding and constantly having to educate people about her disability.

Participant 345162, Age: 23, Female

> Society has a long way to go before it is fully inclusive and perhaps my only concern for my siblings is being accepted and understood in the wider world—outside of friends and family. Sadly, stigma towards individuals with disability is still prevalent…I would not change [my] sibling for the world, maybe the world can change for my sibling.

Participant 850623, Age 24, Male

As suggested by siblings, one way in which societal attitudes could be improved is through greater representation of people with developmental disabilities. Siblings suggested that the diversity of their disabled siblings' experiences and needs should be understood better, along with the needs of their families. Another sibling shared that:

> With the recent burst in 'Autism Inclusivity' in the mainstream media I believe this has led a lot of people to believe that they have a good understanding of Autism…Due to the severity of my brother's case I find it frustrating when talking to people because they seem to believe they have a good understanding of his situation because they 'understand autism' now…

Participant 230149, Age 24, Male

The media plays an important role in shaping our understanding (or misunderstandings) around disability (Tharian et al. 2019). Although Kovshoff et al. (2017) included the media in the exosystem of their SESF, we can see how media is also an important power structure influencing and driving factors at the macrosystem level as well, such as contributing to cultural and ideological understandings of disability, as well as to political and legislative drives. Combating erroneous and/or discriminatory ideas was described as an emotionally draining aspect of being a sibling of someone with developmental disabilities:

> …what is trying is having to justify how wonderful and complete he is to the outside world, who anticipate I should view him as a burden. Continually having to justify our closeness and his value is exhausting.

Participant 987968, Age 22, Female

> He has every reason to be angry and bitter towards people and the world, but he is the furthest away from this. Instead I often feel like I absorb that anger and express it more than him.

Participant 778841, Age 19, Female

These siblings described feelings of fierce love and protectiveness of their disabled siblings, which came up a great deal across the data. There is a sense here that 'the personal is political'[6]: whereby these dyad level feelings at the within-sibling or microsystem level were also transcending the exosystem and macrosystem levels (Kovshoff et al. 2017). What this observation highlights is first, that the factors identified in the SESF are interrelated and reverberate throughout the wider system within which a family is embedded (an idea inherent to systems theories, Hayden and Hastings 2022). Second, these observations highlight that the experiences of siblings and families of disabled people are not merely psychological or familial, they are political, cultural and ideological. Importantly, it seemed that what many of these siblings wanted others to understand, was that one of the most challenging aspects of having a sibling with developmental disabilities, was the way that their disabled sibling was treated in the community, by services and by society, rather than about the characteristics, behaviours or support needs of the person with developmental disabilities themselves.

4 | Conclusions

Our main research question was about how adult siblings of people with developmental disabilities perceived their sibling experiences. We explored this research question using data from UK siblings and interpreted these data using the SESF. Overall, siblings shared a range of experiences related to: their own mental health and wellbeing; personal characteristics they felt they had developed through being a sibling; their sibling relationships; their intra-familial experiences; their experiences as carers; their experiences accessing support services; their experiences out in the community; and their views on the discrimination and ableism that their disabled siblings experienced. Siblings themselves understood the various aspects of their sibling experiences as interconnected and dynamic. Siblings wrote about how societal and structural factors impacted themselves, their families and their communities. Siblings shared stories about difficulties that their families faced when interacting with the outside world. Siblings reflected on their lives and their childhoods, and shared thoughts about how they expect their sibling roles and lives to change in the future. Many siblings wrote about how they perceived their lives and experiences to be intertwined with their disabled siblings' lives and experiences.

We noticed a tension or conflict at the boundary between siblings' immediate familial experiences and their experiences with their wider family, community and society that also reverberated throughout the four system levels. We can therefore see how national and local political decisions related to the underfunding of disability and care services can affect siblings' psychological wellbeing (exosystem, macrosystem). Siblings exist within the ideological context of individualism, ableism, discrimination and exclusion, and the experiences that they described in this study reflected siblings' ideological context (macrosystem).

4.1 | The Siblings Embedded Systems Framework

Our subsidiary research question explored whether the SESF could be used to explore the experiences of a sample of adult siblings of people with developmental disabilities. The framework is highly flexible and so we were able to successfully use the SESF to provide an account of the data overall. As emphasised by the SESF, and our findings, the factors impacting siblings' experiences are interconnected and interactive, with these factors reverberating throughout the four levels of the SESF. The fluidity and interconnectedness in the model are central to understanding siblings' experiences. However, constructs of change and interconnectedness are complex phenomena. They require a sophisticated conceptual consideration, that is somewhat (and perhaps necessarily) simplified by the SESF (Hayden and Hastings 2022). Hayden and Hastings (2022) highlight that models and frameworks can be useful for helping us to understand siblings' experiences, but that:

> …committing anything to the page makes it somewhat static and permanent…Any theory attempting to model 'the family' as a complex psychosocial construct will inevitably oversimplify the concept

(Hayden and Hastings 2022, 21).

Despite this limitation we encountered when using the SESF, it was nonetheless a highly flexible and useful tool for understanding our data. The model allowed us to both cover the breadth of experiences shared with us by the sibling participants, and it provided us with a framework to explore the more structural and societal-level experiences that siblings reported, a significant area often neglected in the sibling disability field. Although the SESF was developed specifically for siblings of autistic people, we found it relevant and useful when exploring the experiences of siblings with a range of developmental disabilities.

4.2 | Methodological Reflections and Limitations

Siblings were likely influenced by the content of the survey when writing their responses to the final open question. For some siblings, this may have meant that their writing remained close to the content of the survey, and for other siblings, they may have wanted to write about things that they felt we had missed in the survey. There were possible benefits to the data collection method as well. For example, the survey may have also 'warmed up' siblings and prompted them to recall experiences that they wanted to share further information about. The process of writing is different to speaking, and may have helped siblings to reflect and develop their thinking around their sibling experiences. Ethically too, typing written responses meant that siblings could have edited and refined what they wrote before they submitted their responses. When we talk to an interviewer and build rapport, we can sometimes share more than we intend to. Typing written responses potentially allowed our participants to retain some control over what they chose to share. However, writing is also a skill and is not a skill that everyone feels confident in. Some siblings chose not to provide written responses, and this seemed to be related to socio-economic factors, as siblings who took part in the Adult Sibling Survey were more likely to provide a written response to the final question if they had a degree-level qualification (see Supporting Information S1). Our dataset afforded a level of both depth and breadth, consisting of over 80,000 words of dense data, from 456 siblings. Compared to other qualitative studies, however, this study provided less in-depth data about individual siblings' subjective experiences relative to conducting in-depth qualitative interviews. Another important limitation to be cognisant of, is that the dataset was not representative of UK adult siblings. The sample was over-representative of white, middle-class women.

4.3 | Future Research

Future research should consider exploring siblings' experiences of discrimination, ableism and exclusion, both quantitatively and qualitatively. For example, how do families respond to a member experiencing discrimination and ableism? Does the discrimination and ableism experienced by a disabled sibling impact the mental health of a non-disabled sibling and other family members? How do siblings experience and interpret ableism, discrimination and exclusion at a familial, community and societal level? Further research is also necessary to understand the experiences and perceptions of people with developmental disabilities on their sibling relationships. As a research field, we know less about the experiences specifically of brothers, siblings who are Black, Asian or from minority ethnic communities, siblings who are working class or who are experiencing poverty, and siblings outside of the United Kingdom, United States, Australia and Canada. Future research should seek to understand the experiences of these groups of siblings further. It would be important to draw on existing theories and concepts from across the social sciences and the humanities to understand these experiences. There are important social care consequences at both the familial and societal level to understanding sibling caring further. Future research should qualitatively examine sibling caregiving across the lifespan, gender differences in caring, and should explore siblings' identification with the carer label.

4.4 | Implications

We hope that these findings will resonate with adult siblings and sibling support organisations. The findings provide ideas of areas that siblings might need support, such as with siblings' mental health, campaigning and advocating for disability rights, building a sibling community and navigating disability support services. These findings may also provide ideas for supporting parents to support young siblings, such as recognising and finding time for siblings, dealing with siblings' feelings of unfairness and fostering relationships between siblings.

Our findings suggest that siblings are interested in disrupting and challenging public attitudes and stigma around developmental disabilities. For example, although there are numerous media representations of people with developmental disabilities and their families, we know little about what societal impact these representations have had. What roles, therefore, might siblings have to play as allies to their disabled siblings, in challenging and changing societal attitudes to disability? Sibling support organisations may consider the ways in which they can support siblings' roles as advocates and allies to their disabled siblings. Our findings highlight siblings' unique ways of seeing and knowing their disabled siblings. Yet, researchers, clinicians and practitioners focused on understanding and supporting people with developmental disabilities, rarely recognise siblings' expertise (Hayden and Kassa 2024), often defaulting to parents. As researchers and practitioners, we need to explore the various multifaceted roles siblings play in the lives of their disabled siblings and disability communities.

This study qualitatively reported the experiences of 456 siblings of people with developmental disabilities, making it one of the largest qualitative studies of this population in terms of the number of individuals involved. The relative breadth and depth afforded by this dataset is therefore a particular strength of this study. Furthermore, this study included a focus on siblings' more societal, structural or macrosystem level experiences, such as siblings' views and experiences related to the discrimination and exclusion that their disabled siblings have experienced. Sibling disability research retains a psychological and individualised focus. However, we cannot fully understand siblings' psychological experiences without also understanding the discrimination and exclusion experienced by disabled people and their families, these experiences reverberate throughout the different levels within the SESF. Siblings' structural, political and social contexts impact their personal and familial lives.

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Ethics Statement

Full ethical approval was granted by the University of Warwick's Humanities and Social Sciences Research Ethics Committee.

Consent

All participants provided informed consent to take part in this research and for the research to be published and reported.

Conflicts of Interest

N.K.H. has a voluntary, advisory role with the UK charity Sibs. The remaining authors declare no conflicts of interest.

Data Availability Statement

The data are not publicly available due to privacy or ethical restrictions.

Endnotes

[1] Learning disability is the preferred term used in the United Kingdom to describe a construct known in other national contexts as an 'intellectual' disability. Please note when reading participant quotes in this study, that the participants used the term learning disabilities.

[2] Developmental disabilities encompasses a range of disabilities including (but not limited to): learning disabilities, autism, Down syndrome, cerebral palsy, foetal alcohol syndrome, etc.

[3] PIP is a Personal Independence Payment—a UK government welfare benefit paid to disabled people to help with extra living costs.

[4] The Conservatives are a UK mainstream political party. Their political orientation fluctuates, but is generally considered to be right-wing or centre-right. The Conservatives were the governing party in the UK between 2010 to 2024 and during study data collection (2019-2020).

[5] See Ryan (2020) for a discussion of welfare, austerity and disability in the United Kingdom.

[6] The 'Personal is Political' is a feminist political slogan used since the 1960s, and the title of an essay by Carol Hanisch, published in *Second Year: Women's Liberation* in 1970.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.