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The experiences of university students who have siblings with special educational needs and disabilities (SEND): expectations, responsibilities and pressures

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ABSTRACT

This study explores the lived experiences of university students who have siblings with Special Educational Needs and Disabilities (SEND), examining how caregiving roles shaped their transition to higher education and wider experiences of university life. Framed within a social constructivist methodology, the study employed semi-structured interviews to elicit participants' narratives. Findings revealed how students faced difficult choices about whether to move away or live at home, with many decisions driven by a sense of emotional obligation. Those who stayed at home cited the need to maintain their sibling's routines and provide care, often at the expense of quiet study time and personal wellbeing. Students who moved away experienced guilt and conflict with parents, though many described the distance as beneficial for both themselves and their siblings. Across both groups, participants continued to provide emotional support from a distance, illustrating the continuity of caregiving responsibilities. Findings highlight the need for universities to recognise and support students with sibling caregiving roles through flexible policies, empathetic staff practices and targeted awareness initiatives promoting inclusive engagement.

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Introduction

The transition to university is a key developmental milestone marked by increasing independence, identity exploration and evolving family relationships (Arnett 2024; Gale and Parker 2012; Haugland, Hysing, and Sivertsen 2020). For many young people, family experiences prior to this transition shape not only the challenges they encounter, but also the personal strengths and motivations that they bring with them into higher education. For those with caring responsibilities, this transition can present unique challenges that may complicate academic engagement and emotional wellbeing (Becker and Becker 2008; Kettell 2018). However, these experiences may also foster distinct strengths and positive outcomes, such as empathy, motivation and a sense of purpose.

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When considered with regard to higher education, student carers are recognised as those who provide unpaid care to a family member or friend with an illness, disability or mental health condition, which may include providing practical, financial and/or emotional support (Carers Trust 2015). Despite some visibility within research, attention to this group within higher education remains fleeting (Knopf et al. 2022), with many institutions lacking formal identification processes or tailored support for student carers, meaning their specific challenges may be under-recognised (Rawlinson 2024; Runacres, Herron, and Cust 2025). For example, although one review by the National Union of Students (NUS 2013) estimated that between 3% and 6% of the student population may have caregiving responsibilities, the true number is likely to be higher as many may choose not to disclose their status, or university systems may not fully capture this information (Rawlinson 2024).

Within this group are individuals who have *siblings* with Special Educational Needs and Disabilities (SEND), a sub-group of 'student carers' whose experiences remain relatively under-researched, and yet in previous research placed themselves on the 'lowest rung' within the hierarchy of carers (Rawlinson 2024, 7). Within this context, growing up with a sibling with SEND has been associated with both positive and challenging outcomes. Existing research highlights that such experiences can foster empathy, emotional maturity, resilience and a strong sense of responsibility (Gant 2018; Leane 2019), which may positively influence educational engagement and vocational aspirations. At the same time, these family dynamics can involve increased levels of perceived stress (Abney, Patney, and Boles 2026), and substantial caring responsibilities that may complicate the transition to university, affecting academic engagement or emotional wellbeing (Becker and Becker 2008; Kettell 2018).

Existing literature indicates that siblings of individuals with SEND often perform central caregiving and emotional support roles (Hooper et al. 2011; Leane 2019). Entering higher education may therefore disrupt established family dynamics, requiring students to navigate competing responsibilities between self-development and care (Haugland, Hysing, and Sivertsen 2020; Levante et al. 2023), potentially without the structural support afforded to other student cohorts. Such challenges faced by siblings entering university can be understood through broader frameworks of student integration, retention and social inequality (Boudon 1974). These perspectives emphasise how structural and social factors, including caregiving responsibilities, shape student engagement and opportunities for academic and social participation.

Sibling caregiving and family roles

Sibling relationships in families that include an individual with SEND are multifaceted, reflecting both closeness and strain (Gant 2018; Leane 2019). These relationships may foster resilience and empathy, but they also introduce emotional complexity due to potentially imbalanced family roles (Davys, Mitchell, and Haigh 2014; Moyson and Roeyers 2011). Nevertheless, studies have consistently demonstrated that the siblings of those with disabilities often assume caregiving roles that extend beyond normative sibling interactions (Hooper et al. 2011; Leane 2019).

Such roles carry both benefits and challenges; caring for a sibling can enhance empathy, maturity and social awareness (Abney, Patney, and Boles 2026; Gant 2018;

Leane 2019; Moyson and Roeyers 2011), but on the other hand may also increase emotional distress and restrict opportunities for autonomy or education (Knopf et al. 2022; Levante et al. 2023). This sense of family loyalty and emotional obligation may underpin ongoing caregiving despite personal sacrifice (Burke et al. 2012). These responsibilities are often internally motivated rather than imposed by parents and/or other family members, reflecting deeply embedded commitments (Leane 2019). This internalisation of duty may shape the life trajectories of caregiving siblings, particularly as they approach key transition points such as higher education.

Caregiving and transition to university

The transition to university is widely recognised as a period of increasing independence and self-discovery (Arnett 2024; Haugland, Hysing, and Sivertsen 2020; UCAS 2024). For young adult carers, however, decisions about whether to live at home or move away may be complicated by their caring responsibilities and emotional ties to family (Becker and Becker 2008; Day 2019; NUS 2013). Existing research on student carers reveals a complex mix of emotions when negotiating distance from those that they care for (Aldridge and Becker, 1999). This complexity may be further intensified among siblings who, as Giesbers and Embregts (2026) note, anticipate assuming greater caregiving responsibilities as they move further into adulthood. Nevertheless, the perceived persistence of these caregiving identities highlights a moral and emotional compulsion to care that transcends physical space (Burke et al. 2012).

Furthermore, there may be emotional complexity *during* academic study. Whilst some literature recognises that having a sibling with SEND may actively motivate educational persistence, shape subject choice or strengthen commitment to academic success (Broomhead and Smith 2026; Gant 2018; Leane 2019), other empirical studies highlight that the continuous emotional regulation required in caregiving may contribute to stress and exhaustion (Day 2019; Leane 2019). Whilst these responsibilities may coexist with enhanced empathy, purpose and motivation, they can also introduce competing demands that are not always recognised by universities.

Within higher education, this can manifest as reduced academic engagement, lower grades, or burnout (Kettell 2018; Rawlinson 2024; UCAS 2024). However, where students have access to supportive networks, through friends, partners, or understanding faculty, this can buffer negative outcomes by validating both their student and caring identities (Aldridge and Becker 1999). Although policy discourse increasingly recognises student carers, practical support within universities remains inconsistent (Carers Trust 2015; Runacres, Herron, and Cust 2025; UCAS 2024). Much of the existing focus is on mature students caring for parents or children, with siblings of individuals with SEND receiving comparatively little attention (Dent 2021; NUS 2013). This lack of recognition may lead to unacknowledged struggles specifically regarding university students who have siblings with SEND (Day 2019; Rawlinson 2024).

Finally, inclusive education is increasingly understood as a whole-system commitment to recognising and responding to diversity in students' lives, including hidden identities and structural barriers that affect participation, belonging and success (Day 2019; Rawlinson 2024). However, students with sibling caregiving responsibilities occupy an often-overlooked position within this landscape, as their access to learning may be shaped by

familial care demands that sit outside traditional disability or widening participation frameworks (Levante et al. 2023). Examining their experiences therefore contributes to broader debates within inclusive education by foregrounding how institutional practices, flexibility and relational understanding can either enable or constrain equitable participation within higher education.

Existing literature makes clear that siblings of individuals with SEND often carry complex caregiving responsibilities that influence their emotional, academic, and social trajectories (Gant 2018; Hooper et al. 2011; Leane 2019). While previous research has examined sibling caregiving roles, there remains limited understanding of how these responsibilities evolve within the context of higher education, at a time when many are emerging into adulthood (Arnett 2024; Haugland, Hysing, and Sivertsen 2020). This study addresses this gap by exploring how students balance a perceived sense of familial duty with their own developmental aspirations.

Methodological approach

This paper forms part of a wider study exploring the experiences of university students who have siblings with SEND. At the time of interview, all were enrolled on the BA (Hons) Education and Special Educational Needs degree programme at Liverpool John Moores University (LJMU). Examining this group enhances understandings of inclusive education by making visible students whose experiences are rarely captured within policy frameworks, and by highlighting the role of institutional awareness and relational support in promoting equitable participation.

Framed within a social constructivist paradigm, the wider study aimed to;

- (i) explore the lived experiences of university students who have siblings with SEND
- (ii) examine how these experiences influenced their choice of university degree; and
- (iii) consider the impact that this has had on their overall university experience

While the wider research was guided by these broad aims, an inductive approach was adopted, allowing participants' narratives to shape the identification of key themes rather than being constrained by predetermined constructs. Findings relating to aims (i) and (ii), which encompassed a broader range of experiential themes, are reported elsewhere (Broomhead and Smith, 2026).

The present paper focuses specifically on aim (iii): the impact of having a sibling with SEND on participants' university experiences. In light of this, and the inductive approach of the design, this paper is guided by the following research questions:

- 1: How do students who have a sibling with SEND describe the impact of their relationship on their experiences of university?
- 2: What aspects of university life do students perceive as being shaped or influenced by having a sibling with SEND?

Within this focus, participants' accounts most consistently foregrounded issues relating to living arrangements and university life, which emerged as the most salient and analytically robust categories relevant to this aim. Accordingly, this paper concentrates

on these two aspects, while recognising that other dimensions of participants' experiences are explored in related publications arising from the wider study.

Participants

This study adopted purposive sampling to recruit participants with direct experience of having a sibling with SEND. Information about the study was circulated to all students enrolled on the degree programme via the university's virtual learning environment, including the researcher's contact details for students wishing to request further information. Participation was entirely voluntary, and no incentives or rewards were offered.

This paper specifically draws attention to the lived experiences of six female undergraduate students. All participants had at least one sibling with a diagnosed SEND, ranging from complex and multiple disabilities to challenges related to mental health (please see [Table 1](#)). To determine eligibility for the study, inclusion criteria required that students had a sibling whose needs corresponded with at least one of the four broad areas of need (Department for Education & Department of Health 2015), communication and interaction; cognition and learning; social, emotional and mental health; and sensory and/or physical needs. It is notable that five of the six participants were older than their sibling with SEND, which may be particularly significant. As Taylor and Shivers (2011) highlight, birth order in these contexts can be linked to increased caregiving responsibilities, potentially influencing participants' university choices and shaping their overall experiences. Furthermore, we acknowledge the gender imbalance within our participant sample; however, this pattern aligns with previous research that recognises how the majority of student carers are female (Alsop, Gonzalez-Arnal, and Kilkey 2008; Knopf et al. 2022) as well as the broader demographic composition of the degree programme. Participants were not excluded on the basis of year of study, as we recognised how students at different stages of their degree continue to experience and negotiate university life.

Methods

Semi-structured interviews were used as the primary method of data collection, each lasting approximately one hour. This approach enabled participants to share their experiences in their own words, fostering a sense of authenticity and allowing for participant-led insights. The interviews were organised around key life stages, namely childhood, adolescence, and adulthood, allowing participants to reflect on and articulate experiences that were most meaningful during each period. Questions about university experiences were introduced later in the interview schedule. Situating these questions within the

Table 1. Participant and sibling demographics.

Participant pseudonym	Year of study	Nature of siblings' SEND
Megan	1	Autism, ADHD, pre-verbal
Libby	1	Autism, ADHD
Jess	1	Down Syndrome, Autism
Sophie	2	Cerebral Palsy
Elle	1	Chronic Depression
Rebecca	3	Autism, Global Developmental Delay

context of participants' earlier life stages and sibling relationships provided important contextual insight. We purposely kept the questions broad; for example, we asked, 'What is your earliest memory of your sibling?' and 'During your primary school years, what was family life like?', such generalised questions helped to avoid imposing specific themes and/or assumptions on participants.

Data were analysed using Braun and Clarke's (2006) framework for thematic analysis, recognising the researchers' active role in meaning-making. Analysis was initially undertaken across the full dataset, with both researchers independently generating initial codes and identifying potential themes before meeting to compare, refine and develop interpretations. Following this initial analysis, the coded data and themes were revisited in relation to each of the three research aims. While some themes were relevant across multiple aims, others were more closely associated with a particular aim.

The analytical process was not intended to treat the research aims as analytically discrete, but instead recognised that participants' experiences were interconnected and that individual accounts could contribute to more than one research aim. The subsequent organisation of the data by research aim provided a means of identifying and presenting the aspects of the wider dataset most directly relevant to the focus of this paper. For this paper, we focused specifically on the coded data relevant to the third research aim, exploring the impact of having a sibling with SEND on participants' university experiences. Throughout this process, we critically examined our interpretations and assumptions through reflexive discussion, recognising, in line with Finlay (2021, 105), reflexivity and subjectivity as resources rather than threats to credibility and validity.

Researcher positionality

It is important to acknowledge the positionality of the researchers, as we both hold the academic role of Joint Programme Leader for the BA (Hons) in Education and Special Educational Needs at LJMU, the programme from which participants were recruited. Our dual roles as educators and researchers inevitably shaped the research process, influencing both how participants perceive us and how we interpreted the data. While this position granted us valuable contextual insight, it also required careful attention to power dynamics. We were mindful of how participants would have been conscious of our academic authority, potentially influencing what they chose to share or emphasise in their narratives. The conscious decision to frame interviews around key life stages, rather than pre-determined themes, was intended to support participants' autonomy and reduce the potential influence of positional and expert power on their responses (Gibson et al. 2014).

The research was granted full ethical approval from Liverpool John Moores University. However, the ethical considerations associated with exploring students' caregiving experiences extended beyond formal ethical approval, and required an ongoing duty of care throughout the research process. Firstly, pseudonyms were adopted for all participants and any references to family members within the reporting of findings. The researchers remained attentive to signs of emotional distress and were prepared to pause or terminate interviews should a participant become upset or wish to discontinue their involvement. Participants were reminded that they could decline to answer any

question and withdraw from the study at any stage without consequence. Following each interview, participants were provided with information about available sources of local support, including relevant university wellbeing services.

Findings

This section explores the experiences of university students who have siblings with SEND, focusing on the expectations, responsibilities and pressures that they faced. However, it is important to highlight that participants' experiences of caring were not uniformly negative. Alongside pressures, responsibilities and emotional demands, caregiving was also associated with close sibling relationships, a sense of purpose and motivation for pursuing higher education. These positive dimensions existed alongside, rather than necessarily replacing, the challenges associated with caring responsibilities.

Viewed through the lens of inclusive education, these findings illuminate how students' caregiving responsibilities for siblings with SEND intersect with institutional expectations of independence, availability and uninterrupted engagement. The pressures described by participants reveal how caregiving roles can render some students effectively 'invisible' within higher education systems, underscoring the need for inclusive practices that account for diverse family responsibilities alongside academic demands.

Living arrangements

Firstly, the decision to either move away from home for university or remain living at home and commute to classes appeared challenging for many participants. Amongst the six participants reported in this study, four chose to move into university halls, whilst two continued living at home and commuted to university each day. For those who stayed at home, Rebecca and Megan specifically noted that their choices were influenced by their caring responsibilities for their siblings with SEND, and a desire to avoid disrupting their siblings' routines. The quotes below reveal that this decision often stemmed from an internal sense of obligation rather than explicit parental expectation;

I wanted to live at home, I wasn't pressured off my mum and dad, I just thought I can help out more if I stay at home (**Megan**)

I wanted to live at home, definitely, I've always been there, Olivia is always the first thought in my mind (**Rebecca**)

Participant decisions to remain at home were therefore not experienced solely as obligatory. Megan's comment that she could 'help out more' suggests that caregiving also provided a sense of purpose and enabled her to remain actively involved in her sibling's life. Similarly, Rebecca's description of her sibling as 'always the first thought in my mind' illustrates the strength of their relationship and the value that she placed on being physically present. Thus, remaining at home allowed them to maintain valued family relationships and continue a caregiving role that appeared personally meaningful.

However, the decision to continue living at home and commute to university often had an impact on studying, with limited quiet space at home to work on assessments;

The house is never quiet because of Billy, so when we had assignments due I just came to uni to work on them, I don't think I would have got as good grades if I'd tried to work at home (**Megan**)

I've got to be up and go the library ... because I need to get my work done, I can't work at home (**Rebecca**)

Rebecca also highlighted how she needed to step back from her caregiving duties temporarily at times, to protect her own wellbeing. However, this need to withdraw to take time for herself was often accompanied by guilt, especially regarding not supporting her parents;

I always feel the guilt of like, I should be helping them and not think about me (**Rebecca**)

Regarding the four students who moved away from home to university halls (Jess, Libby, Sophie and Elle), this decision proved to be extremely challenging. Sophie and Jess explained that moving away was only feasible because additional care arrangements had been made for their disabled siblings. Meanwhile, Libby explored several universities closer to home, in an effort to find a suitable course that would allow her to commute. Only after exhausting all nearby options did she consider moving away, though she experienced feelings of guilt about doing so. This internal conflict between guilt and the desire to prioritise themselves was echoed by other participants who had also moved away;

I thought my brother would really struggle without me ... but I thought I've got to put myself first, I can't be here forever (**Libby**)

There were just so many emotions, I was happy I was sad I was nervous I was excited but I had to put myself first for this definitely (**Jess**)

I think I needed for myself to leave as well, but it's probably why I came to uni so late [begins to cry] just because I felt really bad about leaving (**Elle**)

I was like I need the space now, and I need the space from what might happen next (**Sophie**)

While Jess reported that her parents were supportive of her decision to move away, both Libby and Elle experienced feelings of guilt imposed by their parents regarding their choice. In particular, Libby described needing to be especially firm and resolute in maintaining her decision to move away;

My parents said 'your brother is really going to struggle with that' ... but I was very stern with them, I said I understand that but one day I am going to have to leave and it's better sooner rather than later (**Libby**)

[Mum was] like, 'Do you have to go?' 'Are you actually gonna go?' like kind of thing ... [it was] not nice (**Elle**)

This highlights that while some parents were supportive, others struggled to accept their child's decision to move away, leading to feelings of guilt and emotional pressure. It also recognises the tension between emerging adults' pursuit of independence and conflicting caring priorities or parental expectations. While it could be tempting to view the guilt imposed on Libby and Elle by their parents as negative, it is important to recognise the immense pressure faced by parents of children with SEND, who often manage the demands of daily life with very limited external support.

Despite these challenges, participants who had moved away reported that, although their siblings with SEND continued to face difficulties, the overall impact of their move had been positive;

My brother still struggles but we've agreed that it is still good to have this distance to get him to learn things by himself (**Libby**)

It's hit him a lot that I'm not at home but it's good for him, and it's good for me too, I love it here, I really like that independence (**Jess**)

These accounts demonstrate that separation from the family home was not experienced solely as a loss or source of guilt. For some participants, moving away created opportunities for positive change for both themselves and their siblings. Caring relationships therefore appeared to generate benefits that extended beyond the immediate provision of support; participants' decisions to step back could facilitate their siblings' autonomy while simultaneously enabling their own personal development and transition into adulthood.

That being said, participants did continue to experience guilt and concern being away from home;

I know what goes on in that house but it's not something that my Mum is going to call me about ... which is what I find a bit difficult (**Elle**)

Mum did ring me a couple of weeks ago to say he didn't have a very good day at school and he said it was because he missed me, and I just felt so, so bad (**Libby**)

Participants evidently continued to feel a strong sense of emotional responsibility for their siblings even after moving away. This was reflected in the ongoing guilt and worry that they reported, recognising the difficulty of separating from family despite pursuing independence during their emergence into adulthood. In addition to this, participants living away from home continued to be a source of emotional support, even from a considerable distance, both for their sibling with SEND and their parents;

I do talk to them a lot [pause] Bella likes to Facetime me when things have gone wrong, but I don't talk to Bella as much as I talk to my Mum (**Elle**)

My brother calls me every night [laughs] so I need to keep time for that (**Libby**)

Based on the above, participants evidently maintained an active caregiving and supportive role despite living away, continuing to provide emotional reassurance to both their siblings and parents. This highlighted the enduring nature of familial responsibility and connection, even across physical distance, and these ongoing caring practices appeared to sustain close and meaningful sibling relationships.

Participants also had to make careful decisions about returning home to visit their family, due to the impact that this could have on their sibling;

I surprised everyone for the first reading week and I went home, but when I left Connor really struggled, and even now when I FaceTime home he won't speak to me because I'm not there (**Jess**)

It's difficult especially if I just want to get in my car and go home, but if he's having a bad week then me being there just makes it worse (**Libby**)

Participants therefore had to weigh the emotional consequences of their visits home, acknowledging that their presence and absence both deeply affected their siblings. It recognises the emotional responsibility that they felt in managing their sibling's well-being alongside their own desire for family connection. Nevertheless, it also indicates the significance of the relationships that they had developed, and the valued role that they continued to occupy within their families.

University life

Participants highlighted the importance of increased understanding and flexibility from university staff regarding the challenges that they faced due to having a sibling with SEND. Megan emphasised that lecturers' empathy and willingness to accommodate students during difficult periods, such as when a sibling is experiencing a particularly challenging time coinciding with assessment deadlines, would be highly beneficial;

It would help if lecturers had more understanding about our lives at home, because if Billy is having a bad week and you've got an assessment due in that week, if you can communicate with them better and there just be that level of understanding (**Megan**)

Similarly, Libby stressed the need for additional support tailored to students who have caregiving responsibilities, including the need to leave unexpectedly to care for or support their sibling;

It would be beneficial for students with siblings who have SEND to have extra support, if they do have to go and look after their sibling it would help quite a lot, but also more widely that understanding of students with caring responsibilities would be helpful (**Libby**)

However, all participants reinforced the broader necessity for universities to recognise and address the unique pressures experienced by students with caring roles. This suggests that students who care for siblings with SEND often feel that their responsibilities are not always understood within university settings. Participants' accounts highlight a desire for greater empathy and communication from lecturers, particularly during times when family caregiving demands overlap with academic deadlines. Both Megan and Libby's experiences indicate that even small adjustments, such as flexibility around deadlines or understanding the need for sudden absences, could make a significant difference to their ability to manage both roles effectively. More broadly, this points to an institutional 'blind spot'; many staff members may be unaware that students have siblings or family members with SEND, meaning that their additional pressures remain invisible. This was reflected in participants' accounts, many of whom noted that they had written extensively about their siblings in their UCAS personal statements, as their siblings often served as the main motivation for pursuing higher education. However, participants expressed uncertainty about whether lecturers were aware of this information.

Discussion

Participants' accounts suggest that their relationships with their disabled siblings during university involved both significant demands and profound rewards. While caregiving

could challenge participants' living arrangements, academic engagement and sense of freedom, it also provided opportunities to maintain close family relationships, offer meaningful support and develop independence. These findings therefore challenge a solely deficit-based understanding of sibling caregiving, highlighting the coexistence of responsibility, connection and personal development. They also provide a basis for considering how universities can support students to maintain valued caring relationships, without compromising their educational participation.

Reshaping the transition to independence

Firstly, our findings highlight the complex and emotionally charged nature of living arrangements for university students who have siblings with SEND. Decisions about whether to move away or remain at home were deeply influenced by caregiving responsibilities, emotional attachment and a sense of moral obligation towards family members; echoing previous research that situates them in a position of 'emerging adulthood in tension' (Arnett 2024; Haugland, Hysing, and Sivertsen 2020; Runacres, Herron, and Cust 2025). For participants who remained at home, the decision often reflected a self-imposed sense of duty and created challenges for academic engagement, as noisy and demanding home environments limited time and space for study. This reinforces previous research which has highlighted how caregiving duties continue alongside demanding academic workloads (Day 2019; Kettell 2018; NUS 2013) but also demonstrates a tension between maintaining valued family relationships and developing independence as a university student.

Those who moved away experienced a different form of struggle; balancing the pursuit of independence with feelings of guilt and concern. This echoes previous literature describing the emotional ambivalence of sibling carers navigating autonomy and familial duty (Levante et al. 2023). However, the present findings extend this understanding by suggesting that independence for sibling carers is not necessarily synonymous with physical separation or reduced involvement in family life. Participants continued to provide emotional reassurance and support from a distance, highlighting the enduring and relational nature of care work (Hooper et al. 2011; Leane 2019).

Guilt was an important part of this renegotiation. Previous research has identified guilt as a recurrent experience amongst siblings who view themselves as responsible for their disabled siblings' wellbeing, particularly if they are absent from caregiving during perceived crucial moments (Davys, Mitchell, and Haigh 2014; Haugland, Hysing, and Sivertsen 2020; Leane 2019; Runacres, Herron, and Cust 2025). The present findings suggest, however, that guilt may operate not only as an emotional consequence of separation but also as a mechanism through which caring responsibilities continue to influence decision-making. Participants could simultaneously recognise the benefits of independence and feel responsible for the consequences of their absence. Their accounts therefore demonstrate that physical distance does not necessarily reduce the psychological dimensions of caregiving; instead, responsibility may shift from direct, practical care towards emotional reassurance and decisions about when to return home.

Taken together, these findings suggest that having a sibling with SEND may shape how university students experience the transition to adulthood and understand their developing independence. For our participants, becoming independent involved negotiating how to pursue their own educational and personal development while continuing

to occupy a meaningful role within their families. Independence was therefore relational rather than purely individual; participants sought greater autonomy without necessarily wanting to relinquish their sibling relationships or caring identities.

Challenge and purpose

The findings also challenge the tendency to understand caring responsibilities primarily through their negative consequences. Participants clearly described significant pressures associated with caregiving, including difficulties studying at home, guilt about leaving their siblings, emotional concern when away from home and the need to negotiate university demands around family circumstances. These experiences are consistent with research identifying emotional, social and academic pressures amongst students with caring responsibilities (Day 2019; Kettell 2018; Knopf et al. 2022; Runacres, Herron, and Cust 2025). However, focusing solely on these pressures risks overlooking the relational value of caregiving identified within the present study. Participants' accounts indicate that caring could provide a sense of purpose and allow them to maintain close and meaningful relationships with their siblings. These relationships appeared reciprocal; participants provided reassurance and support, but their siblings also actively sought them out and valued their presence.

This distinction is important for understanding the implications of caregiving within higher education. If caring is viewed solely as a 'problem' to be managed, institutional responses may focus primarily on reducing the burden of responsibilities. Yet participants' accounts suggest that they did not necessarily want to disengage from their supportive roles. Their siblings and family relationships were important aspects of their identities and, in some cases, their motivation for attending university. The aim of institutional support should therefore not be to separate students from their caring responsibilities, but to enable them to sustain meaningful family relationships whilst participating fully in higher education.

Participant accounts therefore identified the importance of university staff demonstrating understanding and flexibility. More specifically, empathy from lecturers and the provision of tailored accommodations, such as flexible deadlines or the ability to leave sessions unexpectedly, emerged as critical factors for students balancing academic and caregiving roles. Prior research indicates that academic performance can be negatively affected when students are unable to negotiate flexibility or support from staff, resulting in stress, absenteeism or reduced engagement (Becker and Becker 2008; Kettell 2018; Rawlinson 2024). However, such measures should not be viewed as exceptional accommodations, but as part of inclusive practice that recognises the diversity of students' lives.

Institutional invisibility and marginalisation

In addition to this, the concept of 'invisible caregiving' resonates here; students may not disclose or discuss their family responsibilities, leaving universities unaware of their additional pressures (Day 2019). Universities and higher education providers must therefore recognise that many students have *hidden* caring responsibilities that may not be disclosed through formal channels, which may consequently lead to 'institutional

invisibility’ (Rawlinson 2024). Current support systems often focus on students with direct caregiving of parents or dependents, overlooking those caring for siblings (Dent 2021; NUS 2013). Institutions should therefore develop mechanisms to identify and support such students proactively, with recognition of the diversity of caring experiences (Haugland, Hysing, and Sivertsen 2020; Rawlinson 2024). This could include explicit mention of *sibling* carers in widening participation and student wellbeing policies, with additional opportunities for confidential self-identification. This is particularly crucial before students start university, such as during enrolment surveys, although this must go beyond the tick-box for carers on UCAS application forms (Rawlinson 2024; Runacres, Herron, and Cust 2025).

However, the present findings suggest that institutional invisibility is not simply a consequence of students failing to disclose their circumstances. It may also reflect a narrow institutional model of the university student as someone who can participate independently and consistently, without significant responsibilities towards family members. Such assumptions become problematic when students’ academic participation is shaped by unpredictable caring demands. The issue is therefore not only whether students identify themselves as carers, but whether higher education structures allow sufficient flexibility for students whose circumstances do not conform to the assumed model of uninterrupted academic engagement.

Situating these findings within the field of inclusive education highlights the extent to which current higher education structures may unintentionally marginalise students with sibling caregiving responsibilities. Inclusive education emphasises the removal of systemic barriers and the creation of learning environments that respond flexibly to diversity (Day 2019; Runacres, Herron, and Cust 2025). The experiences reported by participants suggest that when caregiving responsibilities remain unrecognised, students may encounter additional challenges in navigating university life and accessing appropriate support. While the present study did not directly examine academic outcomes, these findings point to the potential implications of caregiving responsibilities for students’ engagement and wellbeing within higher education contexts. As such, sibling carers may be understood as a group whose inclusion depends not solely on individual resilience, but also on educational institutions that recognise care, shared responsibility and tailored support as integral to educational equity.

Limitations and areas for future research

This study has several limitations. Firstly, the sample comprised six participants; whilst the use of in-depth interviews supported a rich exploration of participants’ lived experiences during their transition to university, the findings should be interpreted within the context of this specific group. Secondly, the exclusively female sample aligns with existing literature highlighting a gender imbalance in caregiving (Alsop, Gonzalez-Arnal, and Kilkey 2008; Knopf et al. 2022). This reflects patterns of voluntary participation rather than intentional exclusion. Nevertheless, future research should seek broader demographic representation, including greater gender diversity, to capture a wider range of caregiving perspectives. A further limitation concerns that all participants were studying on a degree programme relating to SEND. Their developing professional knowledge and awareness of SEND may have influenced how they interpreted and articulated their

experiences, potentially encouraging greater reflection on issues of inclusion, support and disability than might be evident amongst students from other disciplines. It is therefore possible that students studying on other degree programmes may have emphasised different aspects of their university experiences, and further research across a wider range of disciplines would help to explore the extent to which these findings are transferable. Finally, due to the study's focus, all participants were university students, which may exclude siblings whose caregiving responsibilities prevented them from accessing higher education. Future research in this area is therefore warranted.

Conclusion

Overall, the findings highlight that for students who have siblings with SEND, decisions about living arrangements and university life are not purely logistical; they are shaped by emotional and relational factors. Supporting these students effectively requires universities to acknowledge and respond to the hidden complexities of care that accompany their transition into adulthood and university life. Participants' accounts suggest that relatively small forms of flexibility, such as understanding occasional absence or providing clear channels for negotiating deadlines, may ease the management of competing demands. From an inclusive education perspective, addressing this institutional 'invisibility' is an important issue of equity and points to the need for greater institutional responsiveness to students' caring responsibilities, with potential implications for their academic engagement and wellbeing.

Disclosure statement

No potential conflict of interest was reported by the authors.

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