Disability, Sibling Relationships and Everyday Life: Exploring Mundane Realities as Counter-Stories

By

Tom Ryan

A thesis submitted in partial fulfilment of the requirements for the degree of
Doctor of Philosophy
The University of Sheffield
Faculty of Social Sciences
School of Education
Submitted September 2025

Abstract

This thesis explores the childhood experiences of siblings of people with learning disabilities in the UK. Research around this topic has often reproduced deficit narratives that centre non-disabled sibling outcomes, reinforcing pathological understandings of learning disability. This work sets out to disrupt these dominant discourses through bringing together understandings from family sociology and critical disability studies in order to generate counter-narratives that speak to the everyday of siblinghood and learning disability. To do this, narrative interviews were conducted with 14 siblings (aged 18-32) of people with learning disabilities. As part of the interviews participants were asked to bring along photographs and a timeline of their childhood. The data are presented through narrative thematic analysis, with narrative portraits being offered as a means to centre participant stories in their own words.

The findings provide stories of the everyday of siblinghood and disability, with participants reflecting on sharing bedrooms, dinnertime and other mundane activities. Within these stories are moments of care, conflict, humour and frustration that speak to wider understandings of siblinghood offered by family sociology. Alongside this, insight is given into the role of wider society in sibling experiences, with discussions of support services and public interactions. These narratives contain nuanced understandings of disability, family and siblinghood with participants reflecting on the role of expectations of siblinghood in how they understand their lives and offering conceptualisations of learning disability that disrupt commonplace narratives. Considering counter-narratives, the participant accounts are full of joy, humour and self-reflection that challenge dominant understandings offering crip accounts of siblinghood. Throughout, the thesis offers new understandings of siblinghood and learning disability, presenting holistic stories of the everyday that reject deficit understandings and centre the human.

Acknowledgments

This work was funded by an ESRC White Rose Studentship. I want to thank the ESRC for funding the project and the School of Education at the University of Sheffield for providing a place to learn.

Thank you to all of my participants for offering time and stories to this work. It was a privilege to listen and learn about your experiences. I also want to thank the members of the advisory board for their thoughtful comments.

I am extremely grateful to my supervisors Professor Dan Goodley, Dr Katherine Davies and Dr Will Mason. You have been thoughtful and supportive throughout my studies encouraging me to explore interests and offering invaluable guidance at all stages. It has been such a pleasure working with you all. I want to also thank Dr Kitty Nichols for encouraging me to apply for a PhD and for further support over the last three years.

I would also like to acknowledge all the support friends have offered over this project, be that through proof reading, listening to ideas or just hanging out. In particular Charlie and Josh for lunches and general PhD chat.

Thank you Katie for everything. You have listened to all stages of this thesis being ‘worked out’ with patience and much needed feedback.

Thank you to my family for being there throughout. Mum and Dad, thank you for all the encouragement, this project owes a lot to the joy and fun of growing up in our house. Jack, Catherine, Kiyora and Sora, thank you for all the laughs. Lastly, a special thank you to Rosie, Will, Owen and, of course, Connor, I am very lucky to have you as siblings.

Contents

List of figures

Chapter 1: Introduction

Home video extracts:

The clip starts with me on a chair holding two 'sippy cups', Connor is pointing at me:

> *'He's got two'*

Mum, from behind the camera, replies:

> *'He's got red cheeks hasn't he'*
>
> *'No he said he's got two, he means two bottles!' Rosie adds from out of shot.*
>
> *'He's Tommy two cups' Mum replies*
>
> *'Tommy two cups' Connor repeats*

Connor watches as I place my two cups on the arm of the chair and proceed to knock one off. He picks it up and places it by my lap so it won't fall… I pick it up and drop it again. Nothing happens and the camera is focused on me, looking for the cup.

> *'Connor give it back to Tom' Mum says*

The cup reappears

> *'Tom's sitting on the chair' Connor says looking back at mum*
>
> *'Tom's sitting on the chair isn't he? Oh not anymore he's not'*

I climb off.

The clip changes. Now both Connor and I are on the chair, I'm holding a Bob the Builder book which Connor tries to grab, I start screaming.

> *'Let Tom hold it Connor' Mum, still directing, interrupts.*
>
> *'You tell him who everybody is' offers Rosie.*
>
> *'Bob' says Connor pointing to the character.*

I keep tugging the book.

> *'Tom share with Connor' says Mum.*

I let go in a huff and climb down.

The clip changes to Christmas 2003, we are playing charades. Dad is stood at the front pointing to his ring.

> *'LORD OF THE RINGS' All five of us shout, cheering and clapping.*

Connor is up next.

> *'Go on then, do it for everybody' Mum says to Connor as he reads his prompt.*
>
> *'Ok, film, Titanic, One word'*

We all laugh.

> *'You said it!' Will says.*

Dad starts the cheers, everyone claps and Connor keeps grinning.

Owen picks his prompt and starts doing the action for movie.

Introduction

This thesis explores the experiences of siblings of people with learning disabilities, with the aim of generating narratives that speak to the everyday of siblinghood and learning disability. To do this, everyday stories are presented in the hope of capturing the ups and downs of being a sibling in a manner that centres the humanity of all involved (Goodley, 2023). Sibling relationships are often the longest relationships people have in their lives (Fletcher et al, 2013) and are characterised by close proximity and intimacy that can lead to feelings of love and care, and more visceral emotions almost simultaneously (Davies, 2015a). This is seen in conflict, with this being understood as an everyday part of growing up alongside siblings and not a cause for concern (Edwards et al, 2006). However, when you introduce learning disability into these discussions this understanding is often lost, with questions of non-disabled sibling outcomes becoming a central focus (See Meltzer and Kramer, 2016 for an overview). This thesis challenges this stance, interested in how siblings of people with learning disabilities reflect on their experiences of childhood and raising questions of whether this focus is misplaced.

I chose to start this thesis with some home video extracts from my own childhood. This is in recognition of where the inspiration for this project comes from, my experiences growing up with a sibling with learning disabilities. These examples were chosen as they capture a number of aspects of the everyday of siblinghood that this thesis is concerned with, such as care, humour, conflict, and inclusion. By beginning the thesis with these stories, I not only place myself within the research, I further set the scene for the project to come. Alongside the examples offered, are extensive amounts of footage of the five of us just hanging out, doing our own thing in close proximity. At no point in these stories is learning disability a feature, with any sort of label-based understanding far from any of our engagements with each other. Instead our concerns were everyday, like why did I have to share my book or when will it be my turn in the game. This thesis aims to gather stories of the childhood experiences of siblings of people with learning disabilities that speak to this everyday of siblinghood, providing holistic counter-narratives that challenge deficit understandings.

This chapter sets out the key terms used in the project, siblinghood and learning disability, offering working definitions. Following this, the research aims and questions are outlined. Within this section a summary of the study is provided, unpacking the research approach and offering insight into how the work draws on ideas from family sociology and critical disability studies. The chapter finishes with an overview of the thesis.

Definition of key terms

Acknowledging the need for working definitions of key terms within a research project, and the importance of language choice particularly in a disability context (Gates and Mafuba, 2016), this section outlines how the thesis understands siblinghood and learning disability. Chapter 2 engages with these topics more theoretically. Here, the aim is to give insight into how these terms should be understood when reading the thesis.

Within this work siblinghood is understood through Gillies and Lucey's (2006) notion of a 'technical flexible definition' (ibid: 484), meaning that siblinghood is not presented solely as a biological relationship and instead draws on multiple understandings. Considering this 'technical flexible definition', 'sibling' can be seen to be hard to define. Davies (2023) captures this:

> *'The term sibling needs to include full siblings, step-siblings and half siblings, as well as siblings related through adoption, fostering, donor gametes and relationships that can feel like sibling relationships even when the individuals are not related by blood*

> *or marriage. These sibling-like relationships often include features such as generational proximity, a sense of shared childhood, of companionship or support, even bickering and arguing'* (ibid: 9)

Davies further notes that there is still much that is not covered in this definition, highlighting the wide-reaching meanings that 'sibling' can speak to. Participants were recruited based on the criteria of having a sibling with learning disabilities, but how sibling in this instance was understood was not specified. As this project is not concerned with 'what a sibling is' and further is concerned with sibling experiences of childhood, self-definitions of siblinghood can be seen to adequately allow the research questions to be addressed.

As is encouraged by self-advocacy groups in the UK, the thesis uses the phrasing 'people with learning disabilities' (Gates and Mafuba, 2016). Learning disability is complex to define, and further pursuit of definition can be seen to raise concerns of pathologising (Altermark, 2017), something this thesis is actively rejecting. Recognising this, the project understands learning disability as a construction, drawing on Goodey's (2016) work around inclusion phobia to place the label as one tied to outdated notions of intelligence and other problematic medical understandings. Considering learning disability as a construct does not remove the very real implications of being so labelled. This was seen in the research data, with participants' childhoods spanning the coalition and conservative governments where people with learning disabilities were a target of austerity policies (Malli et al, 2018). Acknowledging the estimated overlap between the labels learning disability and autism, and how this is commonplace in literature (Emerson et al, 2016), this thesis will draw on research that explores both learning disability and autism with the overall focus being on learning disability. As with the term sibling, participants self-defined as having a sibling with learning disabilities in order to take part. This was due to the outlined approach, and also in recognition of

Santinele Martino et al’s (2024) reflections on the problematic nature of making people ‘prove’ impairment. In practice, many of the participants did offer impairment labels when introducing their siblings without being asked. This is revisited later in the thesis.

Setting the scene

As mentioned, this work sets out to challenge dominant pathological understandings of siblinghood and learning disability. The nature of these deficit discourses in wider sibling disability research is outlined by Meltzer (2018):

> ‘*Sibling disability research has traditionally defined the relationships between siblings where one has a disability by what they are not- that is, when compared to the normative view of relationships between siblings where neither have a disability, sibling relationships that include a person with a disability have traditionally been found wanting or damaged in comparison*’ (ibid: 1228).

Meltzer (2018) makes clear how deficit understandings are reproduced, and further the normative discourses that shape them. Traditionally research has often focused on non-disabled sibling outcomes, offering individualising narratives in which the disabled sibling is seen to take up their parents’ time and have a negative impact on non-disabled children in the family (Meltzer and Kramer, 2016; Hanvey et al, 2022). Whilst these discussions are commonplace and further speak to wider problematic discourses around learning disability culturally (Goodey, 2016; Altermark, 2017; Goodley, 2023), it is important to also acknowledge the growing scholarship that challenges this. For example Stalkers and Connor’s (2004) research exploring children’s perceptions of their disabled siblings rejects pathological understandings in favour of an everyday reading that echoes wider family sociology. In their research discussing the experiences of siblings of people with Williams syndrome, Cebula et al (2025) make clear the joy and warmth of their participants' relationships arguing for more research that considers these emotions. Similarly, Moran-Morbey et al (2024) call for recognising the structural factors at play arguing that through this, pathologising deficit narratives can be rejected. As will be explored in chapter 2, this is just a small example of some of the research that has informed this thesis. This work hopes to build on this and further bring family sociology into a critical disability studies space in order to generate new understandings of siblinghood and learning disability.

Research aims and questions

The main aim of this thesis is to explore the childhood experiences of siblings of people with learning disabilities. To do this, 14 siblings took part in narrative interviews which lasted between 1 to 2 hours and were supplemented by the creative methods of photo elicitation and timeline mapping. These interviews were centred around their experiences growing up, looking at the everyday mundane practices that make up family life (Morgan, 2011). Recognising the commonplace deficit narratives in sibling disability research (Meltzer, 2018), the secondary aim of this project speaks to how stories from siblings offer insight into learning disability in families. To do this, the way participants conceptualise disability and siblinghood in their narratives will be explored. This will see understandings from family sociology and critical disability studies brought together in a framework that enables critical engagement with these conceptualisations. Further, in acknowledgment of the commonplace focus on what sibling relationships ‘are not’, this aim will also see the generation of counter-narratives of siblinghood and learning disability that allow for more holistic understandings to be presented. As part of the analysis, narrative portraits are offered throughout the findings chapters in order to give insight into participants' stories in longer extracts that enable the nuance of siblinghood to come through (Rodriguez-Dorans, 2022;

Davies, 2023). By pursuing holistic counter-narratives, I have sought to make this nuance clear whilst ensuring that learning disability is not presented in a pathological, deficit manner.

To address the aims of the thesis, three research questions are offered:

How do young adult siblings (aged 18-32) of people with learning disabilities make sense of their childhood experiences of family life?

This question is centred around how participants understand their experiences, with the goal to generate narratives that speak to their everyday. In doing this I hope to ensure I avoid engaging with their stories from the viewpoint of what they ‘are not’, as framed through a presumption of disability’s influence (Meltzer, 2018). Further, this is an open research question, allowing for the wide-reaching aspects of siblinghood to come through whilst enabling participants to give context that ensures nuanced narratives that recognise the ups and downs of sibling relationships (Davies, 2023).

How do siblings of people with learning disabilities conceptualise disability, family and sibling relationships?

This question focuses on how disability, family and siblinghood are addressed within participant narratives. Considering the pathologising that often occurs in sibling disability research (Stoneman, 2005; Meltzer and Kramer, 2016), this question is interested in the generative potential of sibling stories to offer new understandings of learning disability. To do this, attention will be paid to how these topics arise, centring the proximity and closeness of sibling relationships to explore participant experiences of ‘living alongside’ (Davies, 2023) a sibling with learning disabilities.

In what ways might counter-narratives of siblings problematise dominant pathological models of disability in families?

This question explores the potential of the counter-narratives generated in this study to challenge dominant understandings of siblinghood and disability. Where sibling disability research often centres around non-disabled sibling outcomes (Meltzer and Kramer, 2016; Meltzer, 2018), this question builds on the discussion of the first two questions to offer a counter to these discourses. Drawing on ‘crip theory’ (McRuer, 2006) this question will allow space for affirmative accounts of siblinghood and learning disability to be explored. Through this, the thesis will centre the humanity of people with learning disabilities and their families at a time where this can be seen to be at risk (Goodley, 2023).

To answer these questions participants' stories will be analysed using a narrative thematic approach. This will draw on concepts from family sociology through a critical disability studies lens to offer understandings of the everyday experiences of siblings of people with learning disabilities. Alongside this, the framework outlined in the thesis provides a significant contribution to understandings in both family sociology and critical disability studies. Through a focus on the everyday, the narratives presented reflect the nuance and complexity of sibling relationships (Davies, 2023). They touch on the closeness, frustration, love, conflict, humour and more that are understood as commonplace in sibling relationships (Edwards et al, 2006). Further, where siblinghood and disability research can be argued to often define sibling relationships by what they ‘are not’ (Meltzer, 2018), this project celebrates participants' stories of their childhoods. By drawing on crip theory (McRuer, 2006) and critical disability studies more widely, generative stories of disability and family that centre the human (Goodley, 2023) are offered. This approach ensures stories that are often missing from research around siblinghood and learning disability are centred in this thesis (Meltzer, 2018). Recognising the focus on non-disabled siblings, an advisory board was formed as part of the project, made up of self-advocates and people who work with disabled people. This allowed for input in the research design and analysis ensuring that people with learning disabilities were involved in the PhD project.

Theoretical considerations

In order to address the research aims and questions, this thesis will draw theoretically on family sociology and critical disability studies. The following chapter will discuss these in depth, however time is taken here to introduce this focus. Concepts from family sociology, particularly around sibling relationships and family practices, will be brought into a critical disability studies space. Across these two disciplines, ideas around care, the home, humour, conflict and more will be explored allowing for discussion that centre the nuance and complexity of siblinghood (Davies, 2023) whilst giving attention to how disability is constructed in participant narratives. Recognising the everyday nature of ‘doing family’ (Morgan, 2011), this will be given specific attention allowing insight into the realities of ‘living alongside’ (Davies, 2023) a sibling with learning disabilities.

Considering the role of counter-stories in the thesis, the critical disability studies lens offers a number of approaches to unpacking participant stories that challenge commonplace deficit narratives. This thesis draws on crip theory (McRuer, 2006) to recognise the affirmative potential of participant stories and how they can offer new possibilities of understanding learning disability and family life. Further, the attention given to the everyday ups and downs of siblinghood (Edwards et al, 2006) offers potential to explore how participants reject deficit narratives through considering everyday stories of learning disability. Drawing on Goodley’s (2023) work around centring the human in learning disability research, this thesis offers insight into how people with learning disabilities and their families ‘do family’ (Morgan, 2011). Recognising the tendency to focus on what these relationships are ‘not’ (Meltzer, 2018), this focus on the mundane brings potential for important new understandings to be presented.

Thesis overview and chapter outlines

The thesis is made up of seven chapters, which are outlined in this section. The second chapter explores key literature and provides the theoretical framework for the research. The third chapter explains the methodology of the project, touching on ethical considerations and positionality. Chapters 4, 5 and 6 make up the analysis, with each addressing a different research question. The final chapter provides the conclusion to the thesis, outlining the key findings.

Chapter 2: Literature review

Chapter 2 explores the key literature that has informed this study and aims to provide a theoretical grounding for the work that follows. The two areas of scholarship this thesis is concerned with, critical disability studies and family sociology, are unpacked. Critical disability studies is discussed, focusing on notions of the ‘ideal body and mind’ (Garland-Thomson, 2007; Davis, 2008; Goodley, 2014) and ‘crip theory’ (McRuer, 2006; Löfgren-Mårtenson, 2013; Kafer, 2021). This then leads into a discussion of different models of disability, recognising the theoretical openness that a critical disability studies approach offers to present numerous understandings to draw from. Following this, theorising around learning disability is considered, acknowledging where the models and approaches outlined have previously overlooked people with learning disabilities and how this has been addressed in scholarship. Family sociology is then discussed, focusing on understandings of siblinghood. This is done initially through exploring family practices and family display (Finch, 2007; Morgan, 2011) with a focus on presenting family, and siblinghood by extension, as something we ‘do’. Next, key concepts regarding siblinghood are addressed drawing on understandings of the relationship as both close and more visceral (Davies, 2015a). Alongside this, presentations of siblinghood as ‘backstage’ (Punch, 2008) and the implications of this ‘living alongside’ (Davies, 2023) are made clear.

The second part of the chapter focuses on how these two areas of scholarship can be brought together to contribute to everyday understandings of siblinghood and learning disability. To do this, four themes are chosen that can be seen to provide insight into this topic from both areas of scholarship, these being humour, home, conflict and care. Each of these themes feature in the analysis and further through bringing together literature from family sociology and critical disability studies we begin to see how this thesis could build on current understandings of disability and siblinghood.

Chapter 3: Methodology

Chapter 3 outlines the approach of the study, providing a clear account of how the research was carried out and any key considerations that arose during. Leading on from the literature review, this chapter begins with a discussion of the methodology that centres around narrative research. The research questions are revisited here to make clear how the methodological approach enables each question to be addressed. Following this, the research design is outlined looking at how I carried out the narrative interviews and the creative elements that were involved. Here, the advisory board is discussed, with their contribution made clear. Then, the sampling and recruitment is addressed, with the 14 participants of this study being introduced. Next, the ethical considerations of the project are outlined, including the two amendments that were submitted during the project. Following this, the reflections on the data collection are presented, drawing on extracts from my research diary. This leads into discussion of the analytical approach, and how narrative portraits feature within the work. The chapter concludes with reflections on positionality, both in a personal and more conceptual sense. Here I consider the importance of who does disability research and address the idea of ‘confessional’ positionality statements.

Chapter 4: How do young adult siblings (aged 18-32) of people with learning disabilities make sense of their childhood experiences of family life?

This chapter focuses on the first research question, exploring how participants made sense of their childhood experiences of family life. To do this three key themes are explored, siblinghood at home, sibling care or ‘looking after’ and wider family and outside the home. These themes give an insight into participants’ everyday family lives. Siblinghood at home explores communal spaces, sharing bedrooms and sharing things. Here we see how participants experienced ‘living alongside’ their siblings (Davies, 2023), with the close proximity that often comes with the relationship (Punch, 2008) offering insight into inclusion in the home (Rapp and Ginsburg, 2011).

Sibling care or ‘looking after’ explores how participants reflected on their care relationships growing up. This was centred around discussions of ‘being a young carer’ and the frustrations this label can bring (Meltzer, 2017), responsibility and looking to the future, and the gendered nature of care in families (Read and Wuest, 2007; Kenway, 2023). Throughout this section the complexity of sibling relationships is made clear (Davies, 2023) with participants' reflections on care being informed by both structural factors and also interpersonal considerations that touch on more everyday family practices.

The final section of this chapter moves the analysis to outside of home and the immediate family. This is considered through three areas: family support networks, formal care networks and navigating society. Within these discussions we see the importance of people that ‘get it’ when it comes to learning disability, something the majority of participants reflected on. We also see the importance of good support for people with learning disabilities and their families (Conway and Meyer, 2008; Tozer and Atkin, 2015; Robinson et al, 2016). This theme, and the chapter, concludes with reflections around public interactions and how participants navigated these. This leads to discussions of ‘disability by association’ (Burke, 2010; Scavarda, 2023), with these moments of disablism extending to participants alongside their siblings.

Chapter 5: How do siblings of people with learning disabilities conceptualise disability, family and sibling relationships?

Chapter 5 explores how participants conceptualise disability, family and sibling relationships. This section is interested in how disability arises in participant narratives, and the insights these conceptualisations can give to understandings of disability in the everyday. To do this reflections on disability are explored first, with specific focus on the different understandings of ‘normal’ that participants drew upon during their interviews.

The word normal arose throughout participant narratives and is one that can raise concerns from a critical disability studies perspective (Goodley, 2014; Goodey, 2016). Participants’ references to normal are split broadly into two categories, firstly a hegemonic ‘normal’ that reflects socially accepted ways of being with participants highlighting how their experiences aligned with or differed from this perceived ‘normal’. The second use of normal reflects more fluid understandings, in which participants would refer to ‘their normal’ and how non-normative events became normal for them and their families. Narratives of ‘normal abnormal’ draws on Mallett and Runswick-Cole’s (2016) discussions of cultural narratives of disability and how these inform how disabled people are expected to be. Here, where participants aligned with or rejected these commonplace discourses is explored. Discussions of disability in the everyday considers moments where learning disability comes up in participant narratives but is not the focus, these can be read as almost passing references that capture the everyday reality of ‘living alongside’ (Davies, 2023) a sibling with learning disabilities. To finish the exploration of how disability is conceptualised, overt discussions of disability are unpacked. Here, analysis focuses on where participants spoke directly about their siblings having learning disabilities exploring how this was navigated and the discourses addressed here.

Considering conceptualisations of family and siblinghood, the second part of the chapter focuses on expectations of siblinghood and ‘stickiness’ and ‘known-ness’ in sibling relationships. The discussions of expectations of siblinghood draws on Davies' (2023) argument that we live with the idea of siblinghood as well as our siblings. Acknowledging this, how participants reflected on these expectations of what an older sibling ‘should’ be, and how having a sibling with learning disabilities challenged some of these ideas is unpacked. ‘Stickiness’ and ‘known-ness’ explores participants' stories of their sibling being well known in the local community, and how this impacted them. This builds on Smart’s (2007) conceptualisation of family ties as ‘sticky’, which was later applied to siblinghood specifically (Davies, 2019), to unpack how having a sibling who is well known was experienced by participants and how they linked this to wider expectations of siblinghood.

Chapter 6: In what ways might counter-narratives of siblings problematise dominant pathological models of disability in families?

This chapter addresses the third research question, considering how counter-narratives of siblinghood problematise dominant pathological models of disability in families. This is centred around joy in participant narratives, offering insight into how the stories generated in this research challenge dominant deficit understandings of siblinghood and disability (Meltzer and Kramer, 2016). The chapter draws on Arnett's (2023) understanding of joy as 'an intense, temporary feeling of elation combined with an appraisal of right relation between ourselves and the world, a sense that there is an ideal fit between ourselves and the world around us at that moment' (ibid: 1). This places joy as something that is both an individual emotion and socially experienced and informed.

The first part of the chapter addresses this through exploring how participants used humour in their narratives, looking at humour as a source of joy, sibling teasing, and humour in challenging situations. Humour as a source of joy centres stories of family humour practices (Carter and Davies, 2024) that are fun, this is both in the content of the stories but also how participants choose to deliver them. Here the joy of their childhoods is made clear, with trips out, jokes and pranks all unpacked. Sibling teasing explores how humour was navigated in more 'spiky' moments by participants, drawing on wider family sociology constructions of proximity in sibling relationships (Punch, 2008). The stories are still mostly joyful but there are some instances where participants remember some potentially frustrating teasing. This section reinforces Lampert and Ervin-Tripp's (2006) distinction between teasing and insult, in which they place teasing as something that requires closeness so as to not be misconstrued as insulting. Humour in challenging situations considers participants' stories of how their families would joke in more difficult moments, both to address challenges (Carroll, 2016) and also to ensure their siblings' personality came through in their narrative (Goodley, 2023). Throughout these discussions, the notion of ‘disability humour’ is explored. Distinct from ‘disabling humour’, this conceptualisation offers an avenue to analyse sibling humour without presenting it as problematic (Reid, Stoughton and Smith, 2006). The final part of this chapter explores participant reflections on their own personalities and how they feel their experiences have positively influenced them. Here the generative potential of disability in how we engage with the world is made clear, with participants celebrating how their childhood experiences have shaped them as people.

Chapter 7: Conclusion

The final chapter of the thesis sees the main findings outlined, with each research question addressed in turn. Alongside this, the chapter makes clear the contributions of the thesis looking at how the project builds on understandings of siblinghood and learning disability. This is followed by discussion of the implications for future research and the potential limitations of the study. The thesis concludes with some final thoughts placing the work within a wider UK context.

Conclusion

This chapter has introduced the thesis and made clear the importance of this research. To do this, the key terms were defined, siblinghood and learning disability. Following this, the context of the research was unpacked, exploring how sibling disability research often reproduces deficit understandings. Next, the research aims and questions were explained. Lastly, an overview of the thesis was provided offering summaries of each chapter. The following literature review chapter situates the work within wider research and outlines the key theoretical concepts that will be drawn upon.

Chapter 2: Literature review

Introduction

This thesis sits between critical disability studies and family sociology, drawing on concepts and research from these disciplines to explore the experiences of siblings of people with learning disabilities. To do this, both areas of research will be unpacked and then brought together in the later sections. The exploratory nature of the research questions requires a wide-reaching literature review in which core debates will be highlighted and the place of this thesis within both disciplines will be made clear. Further acknowledging the questions, the everyday will be touched upon throughout. Research exploring siblinghood has often been approached from a psychological perspective (Davies, 2023). Recognising the limitations of this chapter in addressing two distinct disciplines and the critique this approach has faced from a disability studies perspective (Meltzer and Kramer, 2016), this literature review focuses more specifically on sociological and critical disability studies scholarship. The key concepts that inform the analysis are brought together to make clear the framework this thesis will use to explore participant experiences.

Using this outline, the literature review will begin by unpacking disability theory in three sections: ‘Critical disability studies, crip theory and the ‘ideal body’’, ‘Social and cultural models of disability’ and ‘Theorising learning disability’. The first of these sections unpacks critical disability studies and crip theory using the concept of the ‘ideal body’. This is followed by a discussion of the social and cultural models, and their core criticisms. ‘Theorising learning disability’ draws on concepts outlined in earlier parts this section to explore constructions of learning disability. The next section, ‘Family sociology: discussing siblinghood’ introduces the key concepts and approaches to understanding sibling relationships that will be central to the theoretical approach of the thesis. Following this, ‘exploring the everyday’ offers a short summary of the sociology of the everyday, this is in recognition of the wider focus of the thesis and also the sections that follow in the chapter. Next, ‘disability in the everyday’ will be discussed, unpacking research on parenting disabled children, the home as a place to ‘do’ inclusion and navigating stigma in everyday life. This section introduces the concept of ‘disability by association’ (Burke, 2010) which will be returned to in the positionality reflections in the methodology chapter.

The final sections of the chapter bring together critical disability studies and family sociology to demonstrate how these interdisciplinary fields are responsive to four core aspects of sibling life that have been revealed in past literature. The first, ‘Humour and who gets to be funny’ explores the role of humour in sibling relationships and discussions that arise when disability is considered alongside this. The second ‘Considering home as comfortable’ unpacks literature around the ‘family home’, making clear the important role home can play in sibling relationships and also the debates around home within disability studies. Third, ‘Conflict and sharing space’ builds on the reflections around the home looking at how proximity can lead to conflict and how this is understood in family sociology and the considerations this raises from a critical disability studies perspective. And finally ‘Sibling care: a disability reading’ views discussions of sibling care through a learning disability lens.

Critical disability studies, crip theory and the ‘ideal body’

This thesis draws upon a host of critical disability studies theory - and concepts from foundational social and cultural approaches - in a manner described by Hughes et al (2012) as theoretical plunder as opposed to theoretical purity. This ‘theoretical open-ness’ (Goodley et al, 2019) sees engagement with a host of ideas, concepts and theories to challenge pathologising ableist understandings of disability and siblinghood and creates space for more affirmative understandings that allow for counter-narratives. This section of the literature review will explore key theoretical discussions from critical disability studies and crip theory.

Critical disability studies is an interdisciplinary approach to research which looks to disrupt commonplace understandings of disability that are rooted in medicalised and pathologising discourses (Goodley, 2014). Discussions around binaries of ‘dis/ability’ and ‘normal/abnormal’ see a crossover between critical disability studies and crip theory. For example, Goodley (2014) questions normative constructions of the body and mind arguing ‘normativity privileges able bodiedness and minded-ness’ (ibid: 21). This understanding is extended in crip theory arguments which state that disabled bodies fulfil the category of deviant, existing in part to maintain the ‘normal’ (McRuer, 2006). These normative understandings of disability can be linked to medical, psychological and individual models, with Goodley et al (2017) arguing ‘when disability is defined as a problem and when that problem is located in an individual's body or mind, then there is only really one way we can go with disability and that is pathologisation’ (ibid: 1). Through this pursuit of ‘normal’ the foundations of understanding ableism become apparent. For Campell (2009) ableism is:

> ‘*A network of beliefs, processes and practices that produces a particular kind of self and body that is projected as the perfect, species-typical and therefore essential and fully human. Disability is then cast as a diminished state of being human*’ (ibid: 5)

Critical disability studies understands society as inherently ableist (Goodley, 2014), echoing crip theory through the definition of ableism as a rejection of those that deviate from the unachievable goal of the ‘able-bodied subject’. This is argued by Kittay (2001) who understands ableism as the result of an obsession with independency which leads to ‘dependent bodies’ being rejected. In this scenario bodies and minds that deviate from the ‘perfect and species typical’ are dismissed.

Crip theory can be seen as a ‘queer reading’ of disability. McRuer (2006) argues that society relies on both disabled and queer identities to define ‘able-bodiedness’ and heterosexuality as ‘non-identities’ through their place as ‘deviant’ opposing positions. This is captured by Löfgren-Mårtenson (2013) who argues:

> *‘To ensure the survival of the normate, society learns to tolerate the deviant up to a certain limit, whereas the identity of the normate remains flexible. The flexibility is necessary to maintain the dichotomy of normal/abnormal and ability/disability’* (ibid: 415).

Through this understanding, both queer and crip identities occupy ‘deviant’ positions as they go against these compulsory-identities. Crip theory then builds on this further, arguing for adoption of the more celebratory approaches of queer activism by disability movements (McRuer, 2006), through engaging with ‘the disruptive potential of disability’ (Goodley et al, 2017: 4). This attention to the productive possibilities of disability allows affirmative understandings to be centred (Goodley, 2023).

When discussing crip theory, and the subsequent theorising that has come from it, it is essential to acknowledge the overlooking of people with learning disabilities. In their research into sexuality and people with learning disabilities, Löfgren-Mårtenson (2013) notes that McRuer (2006) does not reference people with learning disabilities in their original writing. Citing Sandahl’s (2003) reflections on how ‘crip’, like ‘queer’, should be able to expand to include more groups, Löfgren-Mårtenson goes on to argue ‘there is no conceptual difference between people with different types of disabilities' (ibid: 421). This sentiment is echoed in Consenza's (2010) reflections on the 'discipline divide' within disability studies regarding physical and learning disabilities, with the author arguing for the uniting potential of the term crip:

> *'I hope the term 'crip' will emerge as a critical term that can, in a sense, unite disability 'identities' through a focus on denaturalizing able bodiedness and disrupting normalising forces and discursive practices'* (ibid: 8).

Similarly, Kafer (2021) notes the importance of creating an inclusive understanding of the term 'crip' warning that 'failures to imagine others as crip restrict the coalitions to come' (ibid: 416). This call for coalition recognises the importance of a crip theory and disability studies more widely that works for all disabled people, something that historically has not always been the case (Stalker, 2012). Levy and Young's (2020) research into crip approaches to social care for people with learning disabilities highlights the potential an inclusive crip imagining can have for radical change in people with learning disabilities lives. Drawing on ideas around crip time, the authors reimagine a social care process in which individuals are understood to know what is best for them, instead of just top-down input from medical professionals. Goodey's (2016) reflections on difference echo these crip ideas, with the author arguing 'there is of course another way of looking at difference, we could celebrate it, as diversity' (ibid: 55), noting the difference between 'alternative norms' and 'abnormality'. The celebratory nature of crip theory does bring with it some questions around rejecting 'normal' and the challenges this can bring, this is revisited further into this chapter.

The concept of the 'ideal body and mind' has seen strong critique from critical disability studies and crip theory. McRuer (2006) places this issue within capitalism and the role of labour in society. A similar argument is laid out from Barnes (1996) who notes the material and cultural factors ‘which created the myth of ‘bodily perfection’ or the ‘able bodied’ ideal’ (ibid: 45). Idealised types of bodies and minds are clearly linked to labour, with an ‘able body and mind’ being a central tenet of a ‘good worker’. Goodley and Lawthom (2019) further this reflecting on ‘neoliberal-ableism’ and the emphasis placed on the individual and independence. This individuality is linked to a growing disregard for community and dependency. The ‘ideal type’ this neoliberal ableism is framed around is one of ‘able-bodied and mindedness’ as well as not being reliant on support, be that from the state or from those around them. The ‘ideal body and mind’ has seen numerous critiques from crip theory and critical disability studies (McRuer, 2006; Garland-Thomson, 2007; Kafer, 2021). For example, it is unachievable for all and only leads to frustration around one’s own body (Wendell, 1989). This argument raises questions about what the ‘ideal body and mind’ provides, with it being both unachievable yet central to structures of ableism throughout society.

For crip theory this binary between the ‘ideal body and mind’ and disability is ‘inadequate’ (McRuer, 2006) and a more celebratory view of disability that moves away from this ‘compulsory able-bodiedness’ is required. For McRuer (2006) this is in acknowledgement of ‘able-bodied status as always temporary’ (ibid: 2006) with people falling outside of this category over the course of their lives. This sentiment is echoed by Garland-Thomson (2007) who speaks of a misplaced ‘belief that bodily transformation is predictable and tractable’ (ibid: 114). Berlant (2007) terms this ‘slow death’, which is a recognition of neo-liberal capitalism as ‘always disabling’ even though disability is seen as a weakness within the structures of capitalism. For Kafer (2021) the term ‘temporary able-bodiedness’ works to:

> *'Shake folks loose from their assumptions that bodies don't change, the use of temporarily reminds us all that the abilities we take for granted today may disappear tomorrow, perhaps temporarily, perhaps not'* (ibid: 418).

Kafer goes on to acknowledge that whilst this point can be said with an 'edge, even a snarl', it is often applied in a 'queerly, welcoming sense in which it is acknowledged that the crip community will be there when people need it' (ibid: 418). These challenges to the 'ideal body and mind' present a crip understanding of disability. The rejection of a neoliberal ableist reading of disability creates a space in which more positive, inclusive understandings of disability can exist. Through moving away from individualising conceptualisations we can begin to consider the role of family in our understandings of disability, a topic that will be returned to later on in this chapter.

Social and cultural models of disability

Recognising the theoretical openness offered by critical disability studies (Goodley et al, 2019), this section outlines two approaches to understanding disability that inform this thesis. These are the social model and the cultural model of disability, which can be understood as essential foundational understandings that critical disability studies has built upon.

The social model is widely considered as the British Disability Movement's 'big idea' (Hasler, 1993). The model comes from the Union of the Physically Impaired Against Segregation's (UPAIS) document *The Fundamental Principles of Disability* which states:

> *'In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society'* (UPIAS 1976:14).

Of note is the exclusive mention of ‘physically impaired people’ without reference to learning disability, this is something that will be discussed further on in this section. The notion that ‘it was not impairment that was the main cause of the social exclusion of disabled people but the way society responded to people with impairments’ (Oliver, 2004: 19) led to a radical shift in how disability studies, and wider society, viewed disability. The social model centres the concept of ‘barrier removal’, with social model theorists and activists calling for the deconstruction of ‘barriers’ preventing disabled people from ‘full participation in society’ (Oliver, 1990). This is in direct opposition to medical understandings of disability that use individualised, personal problem framings (Goodley, 2014: 6). Alongside the role of disabling structures, the social model encourages consideration of the material practices that impact on the lives of disabled people. This is rooted in a Marxist tradition, with social model theorists drawing attention to the materiality of poverty and exclusion in the lives of disabled people (Barnes and Mercer, 2004; Oliver and Barnes, 2012).

Whilst a popular model of disability, the social model often faces criticism on account of the impairment/ disability dichotomy that is presented. The argument is laid out by Shakespeare (2013) who argues the social model ignores impairment in favour of focusing solely on disability as a social construction. For Shakespeare, this is the result of academic obsession with theory which leads to ‘scholars sometimes appear[ing] more concerned with deconstructing the category of disability or intellectual disability than in changing the social conditions of disabled people’ (ibid: 2). This argument is also made by Marks (1999) and Dewsbury et al (2004) who question the potential social theory has to impact the lives of disabled people. This critique stems from concern of what the social model offers disabled people, with there being a feeling amongst those who criticise the model that impairment is not adequately acknowledged. An example of this can be found in Crow’s (1992) argument:

‘as individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives’ (ibid: 7). Shakespeare (2013) offers some suggestions for the theorising of disability moving forwards. Building on the criticisms around the overlooking of impairment, Shakespeare calls for an understanding which sees the two as a ‘fluid continuum’ as opposed to a ‘polar dichotomy’ noting how it is ‘difficult to say where impairment ends and disability starts’ (ibid: 26).

Shakespeare’s critique can be seen to overlook learning disability, a criticism that has been levelled at the social model and disability studies more widely (Stalker, 2012). Chappell et al (2001) argue learning disability ‘has been tagged on only as an afterthought in much of the literature generated by the social model’ (ibid: 46). In previous work regarding the impairment/ disability debate Chappell (1997) expressed concern that the impairments being discussed were located solely in the body. This said, the social model offers an interesting perspective in the theorising of learning disability. Returning to Shakespeare’s criticism of the model, learning disability provides a difficult challenge to this argument as it can be argued to be socially constructed, even from an impairment perspective (Goodley and Rapley, 2002). For Goodley (2001) this is an important consideration as often people with learning disabilities have actions ascribed to their ‘impairment’ even if this is not the case. This changes the role the social model plays and therefore it is important for scholars to sit with this potential ‘puzzle’ around the extent of the social construction of learning disability.

A further criticism levelled at the social model is one of overlooking the experiences of individuals in favour of a structural focus. Mallett and Runswick-Cole (2014) refer to this as a focus on ‘shared experience of oppression and discrimination’ (ibid: 123). This is not to say this focus is not relevant or important, but it can be argued individual stories of disability are overlooked in a model that focuses on structural factors. Thomas (1999, 2007) in their ‘social relational model' offers a helpful distinction between 'barriers to being' and 'barriers to doing', which allows for engagement with the psycho-emotional aspects of disablism alongside structural factors. This does not mean a social model framework does not offer insight into individual experiences, for example Goodley (2001) reflects on stories gathered from people with learning disabilities which they believe shows them 'doing the social model' through their actions. These stories of the social model in practice offer a clear place for narrative methodologies in critical disability studies alongside social understandings of learning disability. Whilst the social model is not without shortcomings, it can be seen as offering interesting insight in theorising learning disability, especially when read alongside more recent developments in understanding. Recognising critical disability studies as engaging in theoretical 'open-ness' (Goodley et al, 2019), the importance of the social model can be acknowledged whilst also being mindful of where it falls short or can be 'pushed' forwards (Shildrick, 2013; Owens, 2015), as will be discussed more in the following section.

The cultural model of disability places disability as a social construction, captured by Mawyer (2007) in their reflection that disability 'signifies to many scholars in disability studies a social standing and a web of cultural meaning rather than actual physical or mental ability' (ibid: 64). Through this we see the role of cultural narratives in how disability comes to be understood. This is highlighted in Mallett and Runswick-Cole's (2014) overview of the key arguments of the model:

> *'Bodies are not objectively 'good' or 'bad;' or 'normal' or 'impaired'; rather, views about bodies are the product of complicated cultural processes and practices that shape thinking about bodies within a particular historical moment and context'* (ibid: 23)

This understanding ties to the previously discussed notions of ‘ideal bodies and minds’ with cultural understandings often being centred around discussions of ‘the norm’. For example Davis (1995) reflects ‘to understand the disabled body, one must return to the concept of the norm, the normal body’ (ibid: 23). Similarly, Michalko (2002) argues disability is built on understandings of ‘normal’, with that which deviates from this understood culturally as a ‘problem’. Crip theory can be seen to draw on this, with McRuer’s (2006) conceptualisation of disability in relation to ‘non-identities’ speaking to cultural understandings. These discussions lead us to theorising learning disability, with the cultural model informing much of the work around this topic as will be explored in the following section.

Theorising learning disability

As was shown in the reflections on crip theory and the social model, learning disability is in many cases an under theorised part of disability studies (see Chappell 1997, Walmsley 2001 and Stalkers, 2012 for context). For Consenza (2010) ‘disability studies and activism tends to focus on the cultural production of disability visually marked on the body’ … ‘There is a discipline divide between disability studies and learning disability research’ (ibid: 8). Similarly, Docherty et al (2010) places people with learning disabilities at the bottom of their perceived ‘hierarchy of impairments within the Disabled People’s Movement’, a reflection which Stalkers (2012) argues makes clear the need for more theorising around learning disability. Whilst this chapter has acknowledged how we can draw on ideas from crip theory and the social and cultural models, it is important to recognise the need for specific theorising of learning disability. This section builds on the understandings outlined so far, focusing on learning disability specifically.

For Goodley (2023) the theorising of learning disability needs to emphasise the consistent place of ‘being human’ at the centre of scholarship, with this being essential in achieving depathologising and decolonising narratives. They argue ‘researchers, scholars and activists in the field of critical disability studies have epistemological, ontological, methodological, moral and political duties to take seriously the human praxis of People with Learning Disabilities’ (ibid: 180). Taking this as a foundation of theorising learning disability, we can then turn towards the thinking around what learning disability is. Echoing the ideas discussed around dis/ability (Goodley, 2014) and crip theory (McRuer, 2006), Yates et al (2008) raise learning disability as a social construction stating:

> *‘Learning difficulties* [sic] *is not an essential pathology whose true nature resides outside discourse or a ‘condition’ about which we can unproblematically amass absolute knowledge. It is a discursively constituted object, related to concepts of ‘mental abilities’ that emerge as particular types of problems at particular times’* (ibid: 253).

This reading of learning disability links to the discussion around the social and cultural models, in particular the act of overlooking impairment. On this specifically, Goodley (2001) argues we need to understand learning disability as a ‘fundamentally social, cultural, political, historical, discursive and relational phenomenon’ (Ibid: 210). This raises the notion of impairment, in some cases, being a social construct (Goodley and Rapley, 2002). Here, cultural understandings are also introduced, echoing Mawyer’s (2007) reference to a ‘web of cultural meaning’. Similarly, in their work on learning disability and inclusion phobia Goodey (2016) unpacks the term touching on the ‘social, cultural, political, historical, discursive and relational’ aspects which Goodley (2001) refers to. Goodey (2016) critically asks the question ‘what is real about learning disability?’ (ibid: 3). If it is the result of how we understand intelligence, Goodey argues intelligence is solely a ‘claim to status’ (ibid: 40) stating ‘when we say intelligent, we mean better’ (ibid: 40). In a context of neo-liberal ableism, this argument raises important questions about what the category of learning disability really does, with Goodey taking it to a constructionist conclusion. For Sleeter (2010) there is a concern around the acceptance of the term, or label, with little critical engagement around it. They argue ‘in accepting commonly-used categories for children, we also tacitly accept an ideology about what schools are for, what society should be like, and what the ‘normal’ person should be like’ (ibid: 211). This argument echoes Taylor’s (1996) reflection on learning disability being the result of educational systems that ‘test and classify children’. Considering the previous discussions in this chapter, we can see how the conceptualisation of ‘normal’ being drawn on here sit with those offered in cultural and crip understandings of disability, echoing the ‘ideal type’ (McRuer, 2006) or the ‘able bodied subject’ (Goodley, 2014). Further, these discussions relate clearly to the cultural model of disability and the questions of the reality of learning disability (Mallet and Runswick-Cole, 2014).

Learning disability is often understood in relation to the ‘ideal mind’ or ‘normate’ (Garland-Thomson, 1997), situated as an outsider identity in the process. This is taken further by Mallett and Runswick-Cole (2016) who reflect on the role of ‘normal’ within impairment labels. They refer to the ‘normal abnormal’ to describe the narratives of ‘normal’ disability. Often rooted in medicalised understandings, these shape how we expect disabled people to be and raise the potential implications of an individual’s impairment not matching up with these expectations. Further, they speak of the ‘urge to know impairment’ addressing the wider cultural interest in ‘what’s ‘wrong’ with a person with an impairment’ (ibid: 95). Both the normal abnormal and the urge to know impairment are presented as means of ‘making sense’ of impairment, they draw on the work of Davis (2008) arguing:

> *‘Impairment labels are not just helping to classify and explain diversions from “normal”, but by marshalling the vastness of humanity into discrete “categories of*

> *existence" (Davis, 2008), those "categories" go on to provide new sets of norms for what it means to be within the specified sub-category. In other words, medical diagnostic categories provide, and are used as, essential tourist information for those travelling to or through the land of impairment'* (Mallett and Runswick-Cole, 2016: 110).

Here we see how discourses of 'normal' play a central role in how we understand learning disability, both initially as outside of the 'normal' and then further within the impairment labels themselves. The positioning of learning disability outside of the 'normal' brings with it the potential for disruptive, celebratory readings, such as those offered through crip theory (McRuer, 2006; Löfgren-Mårtenson, 2013) or Garland-Thomson's (2011) reflections around 'misfits'. These understandings offer generative readings of 'non-normalcy' that further cultural understandings of disability. Considering these, it is important to also note the potential implications of falling outside what is considered 'normal' (Vehmas and Watson, 2016). For example Ktenidis (2022) highlights the risks associated with not fitting in, focusing on the experiences of disabled people in school. Critiquing the often celebrated rebellious 'non-conformity' of youth, Slater (2016) argues that there is privilege attached to being able to not conform stating 'the only way to safely live a youthful non-normativity, it seems, is to fit into various other normative constructions' (ibid: 38). These examples reinforce Goodey's (2016) call for considering 'alternative norms' as opposed to 'abnormality', offering a fluid definition of 'normal' that celebrates difference as diversity.

Family sociology: Practices and display

To explore the experiences of siblings of people with learning disabilities, this thesis will draw on theories from family sociology. This section of the literature review unpacks the concepts of family practices (Morgan, 1996) and display (Finch, 2007). This is followed by discussion of how siblinghood is conceptualised, focusing on what makes sibling relationships complex and unique (Davies, 2023), the backstage nature of sibling relationships (Punch, 2008) and Hayley Davies' (2015a) concept of the 'emotional tightrope'.

Morgan's (1996) concept of 'family practices' argues that family is the result of actions that build over time, taking on meaning. Family is understood as something that is 'done', it is this:

> *'focus on doing, on activities, [that] moves us away from ideas of the family as relatively static structures or sets of positions or statuses. Family actors are not simply persons defined as mothers, fathers and so on but they can also be seen as 'doing' mothering or fathering'* (ibid: 6).

Morgan argues that family is not a fixed social institution and offers a theorisation that moves away from the 'ideological baggage the term family brings with it' (Morgan, 1996: 37). Family practices are therefore presented as how we 'do' family, with Morgan noting that these are both culturally informed and particular to specific households. Smart (2007) refers to this as part of a 'cultural turn' in how sociology explores family with the focus becoming the everyday. For Morgan this everyday interest is understood 'both in the sense of those life-events which are experienced by a significant proportion of any population (partnering, parenting, sickness, bereavement) and, equally, those activities which seem unremarkable' (Morgan, 2011: 6). It is also important to note that whilst family practices moves away from understandings of family as a 'structure', practices in themselves are often informed by wider structural understandings. Widmer et al (2008) noted this, arguing 'family practice' fails to 'convey the fact that family relationships, because of their complexity, are likely to remain highly patterned and embedded in the social structures of late modernity' (ibid: 3). In their later work, Morgan (2011) reflected on this arguing that the fact that family is 'done' is not always linked to choice, noting how practices are often 'performed in a routine, taken-for-granted manner' (ibid: 66). They note gender and social class as examples of how practices can reproduce wider structural factors.

Finch (2007) builds on Morgan's work through the concept 'family display', which argues alongside being something that is 'done' family is also 'displayed'. Finch provides the definition:

> *'Display is the process by which individuals, and groups of individuals, convey to each other and to relevant audiences that certain of their actions do constitute 'doing family things' and thereby confirm these relationships are 'family relationships''* (ibid: 66).

From this we see that family display applies between those within a 'family' and then also to audiences outside of it, and it can be understood as context dependent in many cases. Through this family display, people are able to show wider audiences that their family 'works' (Finch and Mason, 1993). Morgan (2011) builds on this, noting how the place of display varies depending on circumstances, with potentially 'non-normative' families seeing a greater need to display that their family 'works'. For example, Jones and Hackett (2011) note the importance of family practices and display in adoptive kinship relationships. Gabb (2011) ties display to questions of legitimacy noting how 'research affords meaning to certain displays and in doing so renders 'others' effectively meaningless within the public domain' (ibid: 39). In this regard it is clear how family practices and display can reinforce normative ideas of family. Whilst we must recognise this normativity, the fluidity found in the concepts can also offer potential for new understandings of family when viewed through a critical disability studies lens. For example, Thomas (2021) refers to families of disabled people ‘cripping’ normative expectations of family. Through this we can consider the potential for display and practices that are inclusive and centre disability. This reading echoes Walsh et al’s (2020) understanding of the ‘transgressive potential to broaden hegemonic norms around family’ (ibid: 356). This ‘transgressive potential’ requires understanding from the audience with Walsh et al arguing successful family display is often tied to certain types of ‘family’. Dermott and Seymour (2011) similarly note the role of the audience, drawing on the importance of an audience that ‘gets it’ for this display to be effective. This is also the case for family practices, with Morgan (2011) arguing they are ‘shaped by legal prescriptions, economic constraints and cultural definitions’ (ibid: 7). Thinking about interactions in public and disability, it is clear how whilst family display can be radical and offer ‘new imaginaries of family’ (Rapp and Ginsburg, 2011; Thomas, 2021) we can also see the potential for unsuccessful family display which can lead to feelings of exclusion or discomfort (Seymour and Walsh, 2013).

Conceptualising siblinghood

Alongside the considerations family practices and family display offer from a critical disability studies perspective, this thesis is concerned with family sociology that focuses specifically on siblinghood. Classic understandings around being a ‘good’ sibling, and the expectations these can generate (Davies, 2023), are often exclusionary and ableist when explored through a critical disability lens. Gillis (1996) argues that these expectations stem from tensions between what people want their family to be, and how it is in reality. Whilst Gillis (1996) is not speaking directly to the ableism embedded in these understandings the point still stands. Family sociology offers the potential to unpack, and critique, normative understandings of being a ‘good’ sibling. For example, Davies (2023) argues that expectations play a strong role in how we understand our sibling relationships stating ‘we do not just live with our sibling relationships, we also live with the idea of siblings’ (ibid: 112).

Davies goes on to explain how siblinghood is a relationship that is understood through normative framings, drawing on May's (2019) notion of 'temporal scripts'. For May (2019) temporal scripts 'set out social norms that describe how we 'should' grow up and grow older' (ibid: 87). These notions of how we 'should' grow up can be seen to quite explicitly align with ideas of 'ability' (Thomas and Sakellariou, 2018), with Davies (2023) arguing that having a sibling that does align with these expectations can evoke strong emotional reactions.

When considered alongside disability, in many cases these normative frameworks do not apply and at times are actively rejected (McRuer and Wilkerson, 2003). Returning to the discussions of disability theory, we see that learning disability is often understood in contention with the 'normal' (Sleeter, 2010; Goodley, 2014). These expectations of what makes a 'good' sibling similarly draw on cultural understandings that, as we know, are unlikely to be inclusive of learning disability. This becomes apparent when research into siblinghood and learning disability is unpacked, with commonplace framings around outcomes for non-disabled siblings pointing to a presentation of learning disability as 'outside' the expected sibling experience (Meltzer and Kramer, 2016). Whilst critical of the role of normativity, Davies (2023) makes clear the importance of expectations of siblinghood in how we make sense of our lives. As was outlined in the thesis introduction, Meltzer (2018) argues that the focus on where siblings do not align with expectations contributes to deficit understandings of learning disability and siblinghood. They argue:

> *'Sibling disability research has traditionally defined the relationships between siblings where one has a disability by what they are not- that is, when compared to the normative view of relationships between siblings where neither have a disability, sibling relationships that include a person with a disability have traditionally been found wanting or damaged in comparison'* (ibid: 1228).

Cebula et al (2025) similarly note how research around siblinghood and learning disability often focuses on the non-disabled sibling's 'adjustment' and with this there is little scope for nuanced understandings of siblinghood to be presented. Returning to family practices and display (Finch, 2007; Morgan, 2011) we see further potential to explore family through how it is 'done'. This conceptualisation allows for crip readings of alternative family practices or 'different norms' (Goodey, 2016) to be explored.

Sibling relationships can be seen as unique and complex (Davies, 2023) which brings with it important considerations for theorising. Rittenour et al (2007) capture this nuance arguing 'unlike romantic or platonic relationships, the sibling relationship is one in which the participants express liking and loving for each other while simultaneously engaging in antisocial relational behaviours' (ibid: 170). The authors note that this comes with almost an 'obligation' of closeness placed on siblings from a young age, which has implications over the life course. This idea of obligation is reflected in Smart's (2007) idea of family ties as something that we would struggle to 'shake off' due to the 'embedded relationships' that build understandings of family and the 'stickiness' this brings. Davies (2015b) develops this concept of 'stickiness' with regards to siblinghood specifically, arguing the relationship's lateral nature plays a core role in how we shape our understandings of the self. Drawing on Carsten's (2003) concept of 'related-ness' and Mason's (2004) of 'relationality', Davies notes how comparisons between siblings, both from others and themselves, can play an important role in shaping our identities. Considering disability here provokes an interesting question around how this comparison is understood when one of the siblings has learning disabilities. In these moments, commonplace practices of comparisons, which are often rooted in developmentalist narratives (Garbriel, 2021), would potentially have to be approached differently (Dyson, 2003).

This relationality is central to sibling relationships, with Mason and Tipper's (2008) research exploring young people's understandings of family showing this. They reflect that 'children and young people are often creative about who they include in definitions of 'my family'' (ibid: 441). This rejection of 'biology' is also shown by those interviewed rejecting prefixes of 'step' and 'half' as they felt they implied a lesser relationship. This creativity in defining families makes clear how 'siblings are made by far more than genetics' (Davies, 2023: 54). These reflections highlight the relational aspects of how we understand those around us and how whilst there may feel an 'obligation' to a sibling relationship in some sense it is still a relationship that is built on experience and not a solely biological one. This relationship requires work, something that is particularly clear in research that explores sibling relationships into adulthood (Rittenour 2007). Indeed, it has been argued that there are similarities between friendships and sibling relationships, particularly as we age in how we look for support and lean on both siblings and friends (Sherman et al, 2006). This echoes Lockwood et al's (2001) findings around the expectation of sibling relationships sharing qualities with friendships. Gilligan et al (2020) draw on Bedford and Avioli's (2012) reflections on how sibling relationships often become more positive with age to further this argument around sibling support. They note the comfort that siblings can bring, particularly in adulthood, with shared history being a central factor.

A further consideration of sibling relationships is that they often transcend multiple social settings such as home (Punch, 2008), school (Davies, 2019) and in some cases friendship groups (Sherman et al, 2006). These examples place siblinghood within the 'everyday', which as previously discussed, is often the location of 'unremarkable' events (Morgan, 1996). For Punch (2008), the complexity and nuance (Davies, 2023) comes in part from this 'backstage' everyday-ness of the relationship. The backstage is a concept from Goffman's

(1969) reflections on performance and identity management. Goffman's 'dramaturgical metaphor' of stages differentiates between the 'frontstage', live interactions between people, and the 'backstage', a place 'the performer can relax; he can drop his front, forgo speaking his lines, and step out of character' (Goffman, 1969: 115). Punch (2008) argues that the backstage nature of sibling relationships creates a situation in which one can 'engage in a backstage informal presentation of self without fear of the consequences of putting on an unpolished performance' (ibid: 341). This 'unpolished performance' has many different outcomes, creating what Hayley Davies (2015a: 80) terms an 'emotional tightrope' where siblings navigate, and balance, close and loving relationships alongside more visceral emotions such as arguing and fighting. Through this conceptualisation we can understand the ambiguity and 'conflictual closeness' that has been ascribed to sibling relationships (Winther et al, 2015: 58). The notion of the 'emotional tightrope' and the 'backstage' will be returned to in the following sections.

Exploring the everyday

This thesis' aims and objectives can be seen to engage with the everyday throughout. As has been shown in this chapter, the family sociology and critical disability studies literature this work draws from is often framed around everyday understandings of siblinghood and learning disability. The rest of the literature review goes on to explore themes of research that specifically fall within 'everyday' experiences. This section offers a short overview of everyday sociology that aims to ground the project within wider discussions around this area.

Discussions of the everyday can offer insight into the wider structures and processes that make up society. For Pink (2012) it is 'where we make our worlds and where our worlds make us' (ibid: 5). She goes on to define 'the everyday' as 'the practices, technologies and localities through which life is lived and indeed through which culture is produced' (ibid: 9).

This can be read alongside the discussion of family practices (Morgan, 2011), which are placed within the everyday as the ‘unremarkable’ events and occurrences that constitute ‘doing family’. Robinson (2015) expands on this, noting how we see ‘the making and remaking of particular relationships through the mundane and the extraordinary aspects of everyday life, in a dynamic process of interaction’ (Robinson, 2015: 916). These examples make clear the importance of the everyday in understanding family life. This boundary between the mundane and the extraordinary is further blurred in the work of Neal and Murji (2015) who argue ‘everyday life social relations, experiences and practices are always more than simply or straightforwardly mundane, ordinary and routine’ (ibid: 812). Through these understandings we begin to see how the everyday is a key site where the social is constituted. This highlights its importance to the thesis, with siblinghood being a relationship that sits within the everyday clearly (Punch, 2008; Davies, 2023).

Considering the focus of this thesis, the everyday can be seen as an avenue through which to explore marginalised experiences. For example Back (2015) reflects on the way class is constructed through everyday routines. Ghisleni (2017) similarly reflects on gendered experiences arguing ‘the framework set up by sociologists of everyday life has provided useful tools with which to deconstruct the gendered character of ordinary conducts’ (ibid: 541). As was discussed earlier in this chapter, learning disability can be seen as a ‘discursively constructed object’ (Yates et al, 2008: 53), with Mawyer (2007) referring to a ‘cultural meaning’ attached to the label. These examples can be read alongside Pink’s (2012) reference to the everyday as where ‘culture is produced’ (ibid: 9) to draw out its importance when discussing learning disability and family life. Further, Neal and Murji (2015) refer to ‘the dichotomy of the everyday conceived as a site of resistance and/ or a site of normativity’ (ibid: 817). It is important to note the reference to the everyday as a site of ‘normativity’, and the potential this offers to further understandings of ‘alternative norms’

(Goodey, 2016) as discussed earlier in this chapter. Alongside this, the reference to resistance in Neal and Murji's (2015) reflections reinforces the importance of the everyday in discussions of marginalised experiences. Pink (2012) similarly refers to 'the everyday as a site for change and for activism' (ibid: 5). This aligns with the political nature of crip approaches (McRuer, 2006) and critical disability studies (Goodley, 2013) more widely. Through this we can consider how an interest in the everyday can offer insight into marginalised experiences both at the micro and structural levels (Back, 2015; Moran-Morby et al 2024).

Disability in the everyday: Parent narratives and public space

As has been discussed, sibling relationships can be seen as rooted in the everyday, and through engagement with disability in the same context we can further unpack where this thesis sits within wider literature. Alongside this, disability offers the potential to challenge understandings of the human and the everyday (Goodley, 2021). This section will explore this, drawing on reflections on parenting disabled children alongside discussion of stigma and disability in public.

The experiences of parents of disabled children provide a narrative that runs alongside those of siblings, touching on ideas of family and inclusion. Thomas (2021) builds on affirmative readings of disability and crip theory to explore the role parents play in challenging dominant deficit narratives about their children. These reflections often centre around normative expectations of children, with parents in Thomas's research keen to highlight their children as having 'normal' childhood experiences. Whilst this could be seen as problematic in the pursuit of 'normal', Thomas' draws on Kafer's (2013) notion of 'cripping' to argue 'recognising that disability can, for parents, coexist with normative notions of 'the good life'' (ibid: 455) is in itself a 'crip act'. This 'cripping' of normative family expectations can be seen to reflect

Finch's (2007) concept of family display and the aim of showing audiences 'this is my family and it works' (ibid: 70). Through Thomas' (2021) presentation the act of showing my family 'works' becomes almost simultaneously 'normative' and radical. This sentiment is found in Stainton and Besser's (1998) siblinghood research which concludes 'if anything, with the exception of the impact of external opinion, it shows the difficulty in generalising about 'families with an intellectually disabled child' as distinct from families in general' (ibid: 64). Thomas (2024) argues this reflection of normativity from parents, whilst providing generative understandings of disability, also highlights a tension between what Rapp (1999) terms 'sameness and difference' (ibid: 293). This tension is in recognition of 'normal' as meaning different things to different families, a sentiment furthered by Rapp and Ginsburg (2011):

> *'Parenting with a difference* [sic] *first reverberates through family life, creating new understandings'... 'over time many use the idioms available to them to reach out beyond the world of kinship to forge a new arena of public intimacy where atypicality is the norm'* (ibid: 406)

Returning to the discussions of 'normal', we see here the fluidity of the term as applied to our own lives. Rapp and Ginsburg speak to the 'reverberations' having a disabled child can bring becoming 'normal' for families as it comes to be a central part of their daily lives. Once again, we see Goodey's (2016) distinction between 'different norms' and 'abnormal' coming through in these reflections on parenting and familial norms.

Thomas (2024) draws on the work of Garland-Thomson (2005a) arguing parent narratives aligned with an understanding of disability as 'human variation' as opposed to 'an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate' (ibid: 1557). The reflections of Thomas' (2024) participants echo Garland-Thomson's (2002) understanding of the ‘essential human-ness’ of disability. This is shared by Runswick-Cole and Ryan (2019) who argue for many parents it is ‘not their children who need fixing but the world around them’ (ibid: 1129). This sentiment of ‘familial inclusion’ is evoked in the memoir of Jan Grue (2021) who reflects on the possibility of another world, a truly inclusive space to exist in:

> *'The closest I have come to another world is my family. The one into which I was born and the one I have received as a gift. The one I have been gifted is the one I have created. It is a fiction, it is an empty space in the world.'* (ibid: 215)

Whilst Grue is physically impaired, it is possible to take their reflections, alongside those previously discussed, and to see the potential of family and home to provide a space where the ‘normal’ (Rapp, 1999 and Thomas, 2024) is the inclusion for people with learning disabilities. A similar argument is made by Kittay (2001) who notes ‘connections with family members are often the only shield against the slings and arrows of an uncaring society’ (ibid: 571). This is not a flawless image, and of course there is not a clean distinction between home and ‘wider society’, but when reflecting on how siblings understand and engage with disability it provides a space in which disability is part of a wider everyday ‘normal’. This is something that will be returned in the later sections of this chapter.

Alongside the place of support services and austerity referenced in Runswick-Cole and Ryan’s (2019) reflections on changing the ‘world around’ disabled children, there is the everyday aspect of being out in public. Moyson and Roeyers (2012) note the stress that can come from feeling as though the outside world does not appreciate your sibling. This sentiment is found also in Petalas et al’s (2009) research where they reflect on the work siblings have to do in dealing with ignorant members of the public. Examples of the problems that can arise in public interactions are ‘patronising talk’ (Fox and Giles, 1996) and ‘staring’

(Blum, 2015). ‘Patronising talk’ encompasses a number of interactions that can be commonplace when people with learning disabilities engage in public life, including ‘baby talk’, depersonalising language, and addressing others in place of a person with learning disabilities (Fox and Gilles, 1996). Staring manifests in two main ways: ‘interested gawking’ at someone perceived to be different or behaving ‘unusually’, and also ‘surveillance’ glances and looks which act to show disapproval at someone's behaviour (Ryan, 2010). With regards to the first type, Barr and Mcleod’s (2010) research into siblings of disabled people’s experiences in public highlights the impacts of being stared at. They call for more work addressing these ‘sometimes upsetting and stressful’ encounters, noting how families have to rely on developing strategies to manage this difficulty. They draw on the work of Opperman and Alant (2003) to argue for a more society-wide approach which encourages inclusion.

For Grue (2021) staring sees one situated within ‘a narrative that has already been written, and that is told by others' (ibid: 48). This echoes Barr and Mcleod (2010) and reflects the role of deficit narratives within wider understandings of disability. Research has also captured the acts of resistance to ‘staring’, with Ktenidis (2022) for example exploring how people with dwarfism counter systemic violence and bullying in school. Eisenhauer (2007) notes how performance art can be used to challenge ableism, calling for affirmative approaches to disability in classrooms which ‘challenge the objectifying and limiting practice of just looking’ (ibid: 20). Alongside staring as ‘interested gawking’, is that which Ryan (2010) refers to as surveillance, noting how ‘parents experiencing this type of stare or comment articulated a spoiled identity; they feel that people thought they were poor parents’ (ibid: 873). This ties into wider reflections around ‘invisible disabilities’ in public, with Blum (2015) echoing Ryan’s reflections on how these stares and glances from other parents work to show their disapproval of your ‘naughty child’. Thomas (2024) draws on the work of Landsman (2009) to argue that this ‘in/visibility’ can play a role in how parents' manage to advocate for the ‘personhood’ of both them, and their children.

These accounts of navigating disability in public spaces lead into discussions around courtesy stigma (Goffman, 1990), or ‘disability by association’ (Burke, 2010). These concepts refer to how those associated with someone who experiences stigma experience it alongside them. Goffman has seen much critique within social science (See Tyler, 2020 for a comprehensive critique). In disability studies this critique has centred around ‘his detached and othering tone, flattened language, short-circuiting of stigma’s operations, assumption of disability as deviance, oversight of what is meant by ‘norms’, and his apolitical, ahistorical and essentialist analysis’ (Thomas, 2021: 452). Whilst acknowledging Goffman’s controversial role in the field of disability studies, the idea of courtesy stigma has been present in discussions around disability and family (Ryan and Runswick-Cole, 2008). Burke (2010) refers to ‘disability by association’ in their research around siblings of disabled people. Scardava (2023) explores this in the case of siblings of young people with learning disabilities, outlining the multitude of ways in which this stigma can manifest. They conclude that stigma ‘has become a weapon to keep people with disabilities [sic] and their family members on the edge of society by perpetuating their otherness’ (ibid: 14). This othering of family members, alongside disabled people, highlights the importance of considering ideas around ‘disability by association’ when exploring sibling experiences.

Learning disability and siblinghood in the everyday

This section of the literature review explores four themes that fall within the focus of the research questions, which are repeated here:

> How do young adult siblings (aged 18-32) of people with learning disabilities make sense of their childhood experiences of family life?
>
> How do siblings of people with learning disabilities conceptualise disability, family and sibling relationships?
>
> In what ways might counter-narratives of siblings problematise dominant pathological models of disability in families?

The questions speak to the everyday of growing up with a sibling with learning disabilities. The four themes focused on in this section are humour, home, conflict and sibling care. These will be unpacked to highlight the debates on these topics from both critical disability studies and family sociology perspectives with the aim to give insight into understandings of siblinghood and learning disability in the everyday.

Humour and who gets to be funny?

Humour is an important part of family life for many (Fiadotava, 2021), with the positive connotations it brings seeing it ‘highly appreciated and often preferred over other modes of communication’ (ibid: 16). Humorous stories often become family stories, retold again and again over time, creating a ‘shared family humour style’ (Everts, 2003). For siblings, humour can be slightly different as the backstage nature of sibling relationships (Punch, 2008) lends itself to humour that pushes boundaries, sometimes being provocative. It is clear how this joyful yet at times provocative aspect of sibling relationships echoes Davies’ (2015a) ideas around the ‘emotional tightrope’. Humour and disability is a potentially controversial topic due to the commonplace role of jokes with disability as the punchline (Cumberbatch and Negrine, 2022). When considering sibling experiences of learning disabilities in an everyday context it is inevitable that joking and humour will come up, and this is something that, as a researcher, must be approached with careful consideration. This section will explore humour, sibling relationships and disability in the hope to lay the groundwork for a comprehensive analysis of participant accounts that allows space for 'shared family humour styles' to come through (Everts, 2003).

The joy that humour can bring is something that is reflected in the family sociology literature with humour seen as a key part of children's social lives (Bergen, 2006). The relationality of siblinghood is reflected in this literature with children's understandings of what is funny often being influenced by their family. An example of this is found in Paine et al's (2019) research where it is argued 'siblings' shared experiences and knowledge of family life appeared to form a basis for co-constructed, reciprocal humorous exchanges' (ibid: 347). Similarly, Whalen, Doyle and Pexman (2019) argue that children's understanding of sarcasm and irony is often stronger amongst family members and people they know well. This literature shows how humour between siblings is something that is expected and, in many cases, encouraged. Further it can be seen to have wider implications such as managing conflicts (Campbell et al, 2008) and maintaining 'family social health' (Brooks et al, 1999). Carter and Davies (2024) refer to 'family humour practices' as integral to 'how families build and maintain valued relationships' (ibid: 14). Considering family display, Finch (2007) speaks of narrative and stories as potential 'tools' in display both within families and to outside audiences. The connection between humour and family stories (Everts, 2003) offers an understanding of humour as something that can contribute to family display.

When read alongside Punch's (2008) reflections on the backstage nature of sibling relationships it is clear how sibling humour could push boundaries and potentially move into more murky spaces. Punch argues that backstage relationships are characterised by 'a joking manner and openness of expression' (ibid: 336). This relaxed 'openness of expression' can see joking that moves to more sinister territory at points:

> *'Teasing lies on a perilous boundary between aggression and play and can increase intimacy and integrate members into groups or through subtle changes of form become a vehicle of victimisation and ostracism'* (Keltner et al, 1998: 1244).

This is echoed in Lampert and Ervin-Tripp's (2006) reflections on teasing between friends where they argue 'teasing is only possible in a group whose members know each other well enough otherwise, it could be perceived as an insult' (ibid: 55). For the authors teasing, when done between a close group, can be a sign of a strong relationship. Returning to Davies' (2015a) emotional tightrope we see how humour sits within this, with intimacy and integration on one side and victimisation and ostracism on the other. Whilst acknowledging the joy humour can bring to families it is important to recognise the potential for tensions and difficulties to arise from it. Harwood (2010) notes that in some cases sibling teasing can be more sinister than it might initially appear. Further, humour can be used to exert power or control over social status, with humour being a means by which 'out groups' are created (Billig, 2005; Carter, 2019). Sibling humour therefore can be seen to reflect Punch's (2008) argument of siblinghood as a 'dynamic relationship which can switch almost simultaneously between being a positive and negative experience' (ibid: 342).

Shifting the focus to disability, it can be said that humour and disability is a potentially controversial topic. This is due to disabled people being the 'butt' of jokes in a number of areas such as film, TV, stand-up and socially (Cumberbatch and Negrine, 2022). Reflecting on this, Reid, Stoughton and Smith (2006) differentiate between 'disabling humour' and 'disability humour'. Disabling humour is seen as that which is 'denigrating' and could be considered to be ‘punching down’, whereas disability humour is that which ‘centres disability or is offered by disabled persons’ (ibid, 631). Seeing humour as a part of the way we construct our identities, Shakespeare (1999) notes the potential for disability humour to make non-disabled people feel ‘at ease’. They argue that impairment can be ‘overwhelming’ for strangers and therefore ‘the disabled person must find a way of acknowledging the difference, showing that it is not important and that the interaction can now progress’ (ibid: 50). Whilst this framing of using humour to make non-disabled people feel comfortable appears conformist, the sentiment has been revisited in work that explores the more radical potential of disability humour. An example of this is Anesi’s (2018) research into disability activism in Samoa, which explored the role of humour in engaging people in debates around disability. Anesi argues that humour allows more difficult discussion points to be explored without people feeling too uncomfortable to engage. For Smedema, Ebener and Grist-Gordon (2012), disability humour has the potential to shift how people feel about disability in a positive sense. They argue there is a crip element to disability humour viewing it as ‘a means for comedians with disability [sic] to ‘come out’ through autobiographical counternarratives that redefine the meaning of disability, promoting disability as a valid social identity’ (ibid: 1433). There are echoes here of McRuer’s (2006) notion of ‘coming out crip’ with disability being celebrated as a positive ‘valid social identity’.

This idea of humour unlocking a ‘valid social identity’ highlights the politics of who is considered to have ‘sense of humour’ and, more pressingly, who is not. Bertilsdotter Rosqvist’s (2012) work on the common perception of autistic adults as ‘humourless’ highlights how this narrative is steeped in understandings of autism as ‘inhuman’ with humour being seen as a ‘universal human ability’ (Lyons and Fitzgerld, 2004). Bertilsdotter Rosqvist’s (2012) challenges this by exploring counter-narratives which highlight the role of humour in ‘constructing a sense of community and belonging among autistic people’ (ibid:

245). In their systematic review of humour and people with learning disabilities, Chadwick and Platt (2018) note how discussions are often framed around comprehension. This brings with it the implicit assumption that people with learning disabilities do not ‘know’ why something is funny. In both instances these understandings are unfounded, however the notion of humour as a ‘universal human ability’ echoes the notion of ‘ideal type’ (Wendell, 1989). Within this, those who are seen as humourless or unable to ‘comprehend’ humour are somewhat ‘less desirable’, and to take it further ‘less human’, than the humour-full majority. The politics of these narratives becomes clear when read alongside previously discussed ideas of ‘neo-liberal ableism’ (Goodley, 2014) and the pursuit of the ‘normal’ (Campbell, 2009).

With regards to the role of humour in sibling relationships where there is a disabled sibling, there are questions around whether the non-disabled sibling can partake in disability humour. Alongside definitions of disability humour, Reid, Stoughton and Smith (2006) discuss the concept of ‘insider jokes’ where disabled people joke about disability. Insider jokes can serve a number of purposes including the previously discussed identity management (Smedema, Ebener and Grist-Gordon, 2012) and ‘crip humour’ with Reid, Stoughton and Smith (2006) arguing the jokes work to ‘provide a bond for members of disability culture’ (ibid: 635). The idea of insider humour brings with it questions around who is considered an insider, or a ‘member of disability culture’. Drawing on the previously mentioned discussions of ‘disability by association’ (Burke, 2010; Scavarda, 2023) we see potential for family members to take part in disability humour due to their shared lived experience. Considering the sibling literature discussed earlier, Lampert and Ervin-Tripp’s (2006) distinction between teasing and insults raises a point of interest regarding disability humour. They note that teasing is something that requires all parties to know each other ‘well enough’ as without this context it can cross into more abusive territory. Taken alongside Punch’s (2008) reflections on the backstage nature of sibling relationships which can have ‘a joking manner and openness of expression’ (ibid: 336) it is easy to see how ‘disability humour’ between siblings could occur. Further, sibling humour is often presented as ‘co-constructed’ and ‘reciprocal’ (Paine et al 2019). Through this, there is potential even for humour that in other spaces might be offensive or controversial to take on a different meaning when it is ‘teasing’ between two close siblings. Of course, the other side of this reflection is one of humour that does cross into ‘disabling’ and this is something that must be considered especially when read alongside literature on sibling abuse (Kiselica and Morrill-Richards, 2007) and further the power and privilege often attached to humour and determining ‘what’s funny’ (Carter, 2019).

Considering home as ‘comfortable’

Understanding proximity as a key tenant of many sibling relationships (Edwards et al, 2006; Punch, 2008) we see the role of the home and more generally navigating ‘space’ as important in how sibling relationships are enacted and experienced. Within disability studies, the role of home for disabled people has been a point of much discussion bringing with it questions around inclusion. ‘Space’ along with the home are concepts that have been explored widely in sociology (Massey, 1994; Gieryn, 2000; Frehse, 2021) and recognising the limitations of this thesis I will be focusing specifically on discussions of ‘family home’, which will then lead into reflections on sibling conflict and sharing space with particular focus on learning disability.

Key to this thesis is the role of home in how siblings negotiate their relationships, with this being a central space in which sibling relationships are enacted (Smart, 2007; Punch, 2008). For Easthope (2004) ‘homes are ‘places’ that hold considerable social, psychological and emotive meanings for individuals and groups’ (ibid: 135) and for this reason we have to be cautious of presenting a ‘rigid’ definition. Massey (1994) offers an understanding of ‘place’ as something we ‘actively make’. In thinking about the home as a ‘place’ we make, Coccia (2024) understands it as a ‘moral reality’ alongside the material structure in which we reside. Building on this they argue that the home is a site that is relational, in which we create and maintain relationships. Smart (2007) explores this understanding stating home is ‘part of the way people experience and make their relationships’ (ibid: 165). Massey (1994) similarly argues ‘the singularity of any individual place is formed in part out of the specificity of the interactions which occur at that location’ (Massey, 1994: 167). Boccagni and Kusenbach (2020) refer to the home as a site of ‘normalcy’, touching on the notion of home as ‘comfortable’. For Mallet (2004) the home can be a space of relaxation and security, with there being a chance to move away from the rules of outside spaces. This sentiment is one that is seen often in literature (Chapman and Hockey, 1999), with the home presented as a space distinct from wider society that ‘can offer a time and place to be free from the expectations, risks and uncertainties that come to define social spaces’ (Burch, 2024: 969). Stehlik (2017) notes how definitions of the home often centre around its opposition to the outside, to what it is not. What these definitions point to, is an understanding of home as relational, a space we make that moves past the material structure in which we live (Webber, 2023). It is important to note, and will be discussed in more detail in the following section, how this is not a fixed space that fits this expectation consistently. For example Lowe and DeVerteuil (2022) note how the home can also be a site of insecurity and discomfort.

Taking these understanding of the home and viewing them through a disability studies lens, Imrie (2004) argues that commonplace notions of what makes a ‘home’ often do not give thought to disability. They argue ‘disabled people often experience the home as a series of ‘disembodied spaces’, or places that are designed in ways that are rarely attentive to their psychological and bodily needs and functions’ (ibid: 26). Dyck et al (2005) use the example of care in the home often bringing with it a blurring of the privacy that is seen to be inherent with having your own space. Similarly, Annison (2000) acknowledges the importance of home in how we maintain our social identity, arguing however that this is often overlooked for people with learning disabilities. O'Brien (1994) refers to the role of a 'sense of place' as important to how we make sense of our lives, again noting how this is often not considered for people with learning disabilities. For Hall (2010) the question of belonging is often what is overlooked in policy around housing for people with learning disabilities, they argue this can only be achieved through the creation of 'spaces of inclusion'. Alongside these considerations of how home is made, research has also highlighted the question of choice in where you live and how people with learning disabilities are often not afforded this (Bigby and Fyffe, 2009; Vehmas and Mietola, 2021). These arguments make clear how we must be cautious around notions of what the home 'is' and that of course, these normative understandings will not apply for everyone.

Whilst we must acknowledge how home is not always a site of comfort and safety for disabled people, it can for some also be a 'space for refuge; a space that is not governed by the strict rules and regulations of social encounters' (Burch, 2024: 969). Cheshire et al (2021) argue that compared to the unreliable outside, the home can be a secure space for disabled people echoing wider conceptualisations as discussed above. Considering relational understandings, and the importance of a space that is 'secure' we can begin to consider how home can be a place in which inclusion is central (Rapp and Ginsburg, 2011), understanding inclusion as linked to a sense of belonging in making a home (Hall, 2010). Boccagni and Kusenbach's (2020) placement of the home as a place of 'normalcy', and this bringing with it a sense of comfort, offers further potential to this. If we take a more fluid approach to the word 'normal', such as that which Thomas (2024) evokes around parenting a disabled child, we can begin to see an understanding of this 'normal' that is rooted in inclusion. The relational context of the home alongside this feeling of 'normalcy' tied to the space sees potential for the home to be distinct from wider cultural and social expectations. Returning to Grue's (2021) reflections on home as a space we can create and therefore pursue inclusion through, we see further how this 'normalcy' of the home can be one where inclusion is the 'normal' (Rapp, 1999). This is of course not something that comes without question, and in many instances the home is not like this, with many factors playing a role in how a home is 'made'. This said, these understandings point to the potential for home to become a space of inclusion for disabled people and their families.

Conflict and sharing space

When thinking about sibling conflict, the home can be seen as a key space where this can occur, with the close proximity contributing to potential disagreements (Punch, 2008). Davies' (2015a) concept of the 'emotional tightrope' reminds us of the contradictions that make up a sibling relationship. These contradictions are apparent in the role of care, humour, conflict and closeness and lead to a state of 'conflictual closeness' (Winther et al, 2015: 58). For Davies (2023) these contradictions highlight the importance of 'contextual understandings of sibling relationships' (ibid: 47), with the interactions of siblings being firmly rooted in their families, practices and more. Sibling conflict and rivalry is of particular interest in wider society. Edwards et al (2006) note the prominence of chapters on sibling conflict in parenting books and Davies (2023) reflects on the high number of articles on the topic and references in popular culture. This interest in sibling conflict also sits alongside an acceptance of it:

> *'Sibling relationships are unique in the general societal agreement, at least in the west, that conflict, even physical violence, can be a day-to-day part of a 'normal' sibling relationship'* (Davies, 2023: 79).

Through exploring this acceptance of sibling conflict, including physical altercations, through a disability studies lens some questions are raised about who is allowed the privilege of a ‘normal’ sibling relationship.

Sibling conflict is often understood as a part of growing up (Edwards et al, 2006), with potentially aggressive or difficult interactions between siblings being seen as expected. Davies (2023) refers to a ‘co-existence of annoyance and care’ (ibid: 54) whilst Allan (1996) describes a ‘complex interplay of co-operation and conflict’ (ibid: 64). Reflecting on their research, Sherman et al (2006) note ‘in our sample, some sibling relationships were still characterised by relatively high levels of conflict. However, such conflict was accompanied by relatively high levels of warmth in affect-intense relationships' (ibid:161). These contradictory emotions capture what Gulløv et al (2015: 511) term the ‘ambiguous emotional practices’ that everyday sibling interactions are made up of. This ambiguity manifests in participants' reflections on more conflictual interaction between them and their siblings with Gulløv et al (2015) reflecting ‘even when troublesome incidents are retold, in most cases we register a tone of close connection and inseparability’ (ibid:81). The previously discussed examples of teasing, and sibling humour more widely, highlight the ‘contradictory’ nature of sibling interaction. Tensions can arise in situations where one sibling feels they are joking or jokes that were agreed to be funny by both parties can take on a different meaning when used in a different context. Even a ‘troublesome’ incident or joke can be transformed over time into a funny family story that everyone, even the person on the receiving end, can laugh about (Everts, 2003).

For Edwards et al (2006), sibling conflict is seen as an outcome of many of the factors that are often associated with a ‘good’ childhood, which the authors describe as:

> *a separate phase of life; a time of freedom from worries and responsibilities, of spontaneity and happiness, and of cognitive and emotional development in preparation for adulthood* (ibid: 78)

They go on to draw on Elias' (1994) reflections to note how this understanding of a 'good' childhood features space in which tension and conflict could develop. It is interesting to note this reference to 'cognitive and emotional development' as a factor of a 'good' childhood and the implications this has regarding 'ideal types' and Goodey's (2016) reflections of intelligence as meaning 'better'. This understanding brings us back to Punch's (2008) locating of siblinghood in the 'backstage'. They argue this is a space where 'rage and irritation need not be suppressed, whilst politeness and toleration can be neglected' (ibid: 336). This builds on Dunn's (1984) reflections on sibling relationships as 'emotional, intense, uninhibited … steeped in an understanding of how this person behaves and what will affect him' (ibid: 141) and as characterised by a 'devastating lack of inhibition' (ibid: 11). This comfort that can be found in the backstage, and the home more widely (Boccagni and Kusenbach, 2020), brings with it a space in which boundaries can be pushed and where there is potential for conflict (Sanders, 2004).

These notions of tension and annoyance being part of everyday sibling interaction are found throughout research about people with learning disabilities' sibling relationships. In their work exploring the experiences of sisters of autistic young people, Pavlopoulou and Dimitriou (2019) note the ups and downs of the participant's reflections and how frustrations alongside closeness are common emotions. Lardieri et al (2000) describe rivalry and conflict as 'expected'. They argue there are not noticeable differences in this regard between relationships where a sibling has learning disabilities and those where both siblings are non-disabled. Stalkers and Connors (2010) similarly refer to a 'healthy degree of irritation and rivalry' (ibid: 225) between their participants and their siblings with learning disabilities. This acceptance of conflict as expected echoes the reflections within wider family sociology as outlined previously.

Whilst being a core component of many sibling relationships, it can be easy to dismiss serious sibling bullying or abuse as an almost expected part of childhood (Gelles,1997). Meyers (2017) calls for a clearer distinction between sibling conflict and sibling abuse, highlighting the difficulties that can arise in supporting families due to the lack of definition. As noted earlier, sibling teasing occupies a space in which boundaries can be unclear. Whilst not all sibling teasing, or conflict, will be abusive it is important to acknowledge this as an often overlooked occurrence in discussions of sibling relationships. Kiselica and Morrill-Richards (2007) reflect on this stating 'families and society dismiss abuse among brothers and sisters as normal sibling rivalry' (ibid: 157). There is a difficult tension here between the nuance and complexity of sibling relationships informed by a backstage setting amongst other aspects and the serious problem of sibling abuse. This is furthered in Kettrey and Emery's (2006) research which finds that in some cases people overlook abuse they have experienced from siblings when discussing their childhoods. From a disability perspective, it is important to recognise the potential for this to move into disabling spaces. As with the discussions around humour there is a historical context here around joking about disability with teasing potentially moving into more challenging territory (Reid, Stoughton and Smith, 2006). As was the case in the humour discussions, we see how potentially a sibling relationship could be a context in which conflict moves into more difficult spaces without being inherently 'problematic'. This said, the pervasive nature of hate crimes in the UK must be noted, with family members being responsible in some cases (Thomas, 2011; Burch, 2024). Whilst this thesis is not specifically focused on sibling abuse, and the limitations of the work prevent this being fully unpacked, these examples make clear the importance of keeping in mind its covert nature.

The factors that make sibling relationships complex and nuanced (Davies, 2023), such as the centrality of emotion alongside the amount of time siblings often spend together involuntarily, can be seen to contribute to sibling conflict (Gelles, 1997). McIntosh and Punch (2009) note the role of age in sibling conflict, arguing it is a factor in negotiations with threats and bartering often being used by older siblings to get what they want. Recognising this, they go on to note the subversion of birth order hierarchies by younger siblings. They offer the example of a younger sibling in their study threatening to tell on an older sibling in order to get something from them. The role of age in sibling relationships is further touched upon in the next section. These examples reinforce the backstage nature of siblinghood (Punch, 2008), with conflict arising often around the sharing of space and possessions, something Punch notes in her participants' reflections on conflict with their siblings:

> *'The children themselves suggested reasons for their antagonistic behaviour towards siblings which included their shared history, the permanence of the sibling bond, their lack of privacy and control of space in the home and the obligation of living together'* (ibid: 337)

It is clear from this quote the role of shared space in the navigating of sibling relationships and emotions. This is a theme that comes up in the wider literature, with both sharing a room and sharing possessions being a potential catalyst for conflict between siblings. Palludan and Winther (2017) explore the emphasis children place on having their own room and what it means to them. They note how their participants recount fighting over sharing a room, or in some cases over which room they want, with having one's own space argued to be a place for children to ‘spill’ into with their things and their own rules. The authors highlight the power having your own space can provide, referring to the process of ‘homing oneself’ (Winther, 2009). It is this process that allows children to ‘reinforce their position and thus change the social dynamics [in families]; for instance they can decide which of their siblings they will allow to enter and when’ (Palludan and Winther, 2017: 40). They draw on Douglas’ (1991) placement of fairness at the centre of households emphasising its importance amongst both parents and children. This extends to allocation of bedrooms, with an expectation from all parties that this will be done fairly and on a relational basis. This notion of fairness, from parents to siblings, is a recurring theme in sibling literature with perceived fairness being linked to sibling closeness in later life (Van Volkom, Machiz and Reich, 2011).

This section has highlighted the complex tensions that conflict within sibling relationships can bring. There is a consensus within wider literature around conflict being almost expected with proximity and closeness being offered as an explanation for this (Edwards et al, 2006; Punch, 2008). This brings with it some other considerations around sibling abuse going unnoticed. Further, from a disability perspective these tensions are potentially clearer with concerns around disablist discourses important to note. This said, conflict is of course a part of relationships where one sibling has learning disabilities (Lardieri et al, 2000; Pavlopoulou and Dimitriou, 2019) and this should not be deemed disablism in all instances. Instead, the wider literature provides an approach to understanding conflict within the context of siblinghood, offering a means to apply this to disability and siblinghood in a manner that recognises the realities of ‘living alongside’ one another (Davies, 2023).

Care: A siblinghood and disability reading

When considering Hayley Davies’ (2015a) concept of the ‘emotional tightrope’, the more loving side touches on themes of sibling care and closeness. There are a number of ways this ‘care and closeness’ can manifest itself, such as giving advice (Aaltonen, 2016), looking after (Morrow, 2008) and ‘just being there’ (Brownlie, 2014, Davies, 2023). These examples highlight the unique role of siblings, with research capturing their place in care relationships as often distinct from that of a parent, or wider family members. Once again, Punch’s (2008) notion of ‘backstage’ sibling relationships is reflected in the research on closeness and care. Often characterised by an ‘easy, relaxed atmosphere’ (ibid: 335) and ‘familiarity’ (Dunn and Kendrick, 1982), the uniqueness of sibling relationships extends, and troubles, care interactions. Of course, acknowledging the under-theorisation of disability in family sociology, there are normative assumptions of both siblinghood and care in these examples. This section will explore the role of care and closeness between siblings by unpacking literature from both family sociology and disability studies. The points of contention that can arise in this process will also be discussed. It is important to note that ‘care’ is a wide-reaching area of scholarship, and within the limitations of this thesis it is not possible to cover all aspects. Recognising this, the discussions of care here are driven by mainly sibling literature alongside some disability studies scholarship.

Care and closeness can be seen as central to many sibling relationships, with siblings being a source of intimacy and support for one another (Gillies and Lucey, 2006). This is often rooted in everyday practices and occurrences, with Davies (2023) drawing on Brownlie’s (2014) notion of ‘just being there’ and the comfort this can bring in their reflections on sibling care. Smart (2007) argues emotion is required for this relational care to be effective, enabling everyday actions to become ‘interaction laden with meaning' (ibid: 60). Considering everyday acts of care, Heath et al (2010) reflect on the important role siblings can play in young people’s educational decision making, arguing that they often have a positive impact on how siblings view education. Furthermore, Aaltonen (2016) notes how siblings can ‘cut through’ the diplomacy that parents may prefer and provide more honest information regarding future planning, even if delivered in a more ‘blunt way’ (ibid: 7). This ‘insider information’ (Holland, 2008: 120) is an example of social capital being exchanged between siblings in a manner that is more effective than that offered by parents (James and Prout, 1997). It can also be seen to reflect the ‘lateral nature’ of sibling relationships. Davies (2015b) argues these relationships can be seen as ‘lateral in the sense that siblings are often of the same generation and experience more readily comparable education systems, job markets and cultural signifiers than, say, children and their parents’ (ibid: 687). Further, the ‘backstage’ nature of sibling relationships (Punch, 2008) creates a space in which this ‘blunter’ form of interaction can occur, with the relaxed and more informal setting allowing for this. These examples present an aspect of sibling care that builds on the discussion around humour and conflict, here this proximity sees siblings having each other’s backs through their honesty.

Alongside the closeness and support that comes through honesty, care can manifest itself in a number of ways in sibling relationships. For example emotional, such as offering support in difficult times (Gass, Jenkins and Dunn, 2007) or the previously mentioned ‘being there’ (Brownlie, 2014; Davies 2023). Sibling care can also be experienced in more ‘active’ ways with Brannen et al (2000) referring to siblings as ‘active co-participants in care within their families’ (ibid: 195). Davies (2023) provides the example of older siblings looking out for their younger siblings outside of the home, specifically at a school holiday club. A similar example is siblings, often older, looking after or ‘babysitting’ their younger siblings when their parents are out (Morrow, 2008). Edwards et al (2006) reflect on the role of birth order in care between siblings:

> *‘Most of the sisters and brothers talked about 'looking after each other', whatever their position in the siblings' order. Nonetheless, many understood caring as a sibling practice that was integrally related to practices shaped by their predetermined*

> *position in the sibling birth order hierarchy, and as involving issues of power and authority'* (Edwards et al, 2006: 68).

It is important to note the gendered nature of care roles in families, with responsibilities often falling on women (Read and Wuest, 2007; Webster, 2018; Kenway, 2023). Regarding this, Mauthner (2005) refers to a sense of 'obligation' often experienced by sisters around stepping up with regards to care activities within families. For Edwards et al (2005) this extends to outside of the home, with expectations of calling home and returning after leaving placed on sisters more than brothers. Returning to Edwards et al's (2006) care reflections, it must also be acknowledged that sibling birth order does not lead to responsibility in all cases and sibling care can be more personal in many instances. This is something that will be discussed more further into this section.

The role of sibling care can shift when read through a critical disability studies lens, with the care roles and expectations placed on siblings potentially changing the way the relationship is experienced (Levante et al, 2025). Echoing Brownlie's (2014) reflection on 'just being there', Hayden and Hastings (2022) state 'siblings are able to offer friendship and support where elsewhere in society, many disabled people continue to face discrimination and exclusion' (ibid: 6). By placing their reflection within the context of neo-liberal ableism, Hayden and Hastings (2022) acknowledge the politics of everyday care in allowing disabled people to feel included. Cebula et al (2025) touch on this with reference to 'sibling warmth'. They note how in their interviews with people with learning disabilities and their siblings there is this 'warmth' that is 'expressed in an embedded manner' (ibid: 508). They give examples of recognition of each other's interests and appreciation of each other's knowledge and strengths to capture how both siblings care through 'being there'. The authors make clear this is reciprocal, addressing how people with learning disabilities provide care for their non-disabled siblings, both through this warmth but also in more active ways. This is important to acknowledge when considering the commonplace overlooking of care provided by people with learning disabilities (Ward, 2011; Ward, 2015; Truesdale et al, 2021). For Edwards and Loughnane (2024), making clear the care roles of disabled people works to pushback against ‘constructions of disabled people as passive care receivers’ (ibid: 597). They argue these presentations work to further present disabled people as outsiders, drawing on Thompson’s (2022) reflection that ‘hegemonic understandings of who is a care receiver, and who within that category are then ‘deserving’ care subjects, are situated within problematic social hierarchies of power’ (ibid: 1136).

In many cases, siblings of disabled people can be expected to take on responsibility for care. For example, taking on a more active role in physical care (Arnold, Heller and Kramer, 2012), and sometimes through advocacy for access to services and support (Kramer at al, 2013). An example of this can be seen in Pavlopoulou et al’s (2022) research into school experiences of siblings of autistic people. They argue expectations are placed on siblings to take a role in their brother or sister’s support in school, be that through communicating their needs or helping them with adjusting to new settings. Whilst the complexities of siblinghood and education have been discussed in family sociology (Davies, 2019), this reflection on expectations placed on siblings to actively help at school takes this care role further. It is important here to acknowledge and challenge the dominant narrative around ‘care as a burden’ regarding sibling experiences of disability. Gibbons and Gibbons (2016) argue ‘much of the research on care between non-disabled siblings and disabled siblings focuses primarily on the provision of care as a burden’ (ibid: 828). Through this presentation, the pathological understandings of disability that are central to a neo-liberal ableist society are reinforced. Goodley’s (2014) reflection ‘a system that wants ‘young and strong’ workers is always haunted by disability’ (ibid, 2014) is particularly pertinent here, with burden reinforcing narratives contributing to this. Gibbons and Gibbons (2016) go on to challenge pathological narratives, referencing feminist disability philosopher Wendell (1996) who calls for more recognition of our interdependence in the pursuit of real inclusion in society. As mentioned previously, the literature around reciprocal care helps to further this recognition of interdependence and offers generative understandings of sibling care that avoid narratives of burden (Ward, 2015; Truesdale et al, 2021; Boland and Guerin, 2022). Returning to Pavlopolou et al’s (2022) reflections on school, the authors state that the siblings interviewed found these expectations frustrating but did not call for separate schooling, instead they argued for more support for siblings of people with learning disabilities.

Questions around support for siblings of people with learning disabilities is a common theme in the literature (Knox and Bigby, 2007; Leane, 2019; Tozer et al, 2013). This differs from care specifically, however, is often framed around siblings taking over care once parents grow older. Leane (2024) notes this, arguing there is little support available for this process leading to siblings feeling ‘overwhelmed’. Tozer and Atkin (2015) echo this, calling for more value placed on siblings in care decisions stating:

> *Recognising, valuing and supporting siblings, in a way that establishes productive and fulfilling family relationships for all parties should, therefore, be a keystone to progress in social care* (ibid: 350).

These examples highlight the misplaced, and politically loaded nature of using a term like ‘burden’ when referring to sibling care, with the implication being one that reinforces deficit narratives around sibling experiences of disability. The language of ‘burden’ places the fault with the disabled person, whereas these examples touch on a want of siblings to provide support whilst wider structural factors, such as school or care services, fall short (Moran-Morby et al 2024).

Whilst conscious of highlighting care as a burden, it is important to explore these care expectations critically without reinforcing problematic narratives. Meltzer's (2017) paper unpacking the relational implications of care between siblings provides an example of this. Challenging normative understandings of disability, Meltzer questions the application of the phrase 'young carers' when discussing siblings of disabled people. Drawing on interview data, the author reflects that some siblings 'do not see themselves this way, precisely because it has complex implications for their sibling relationships' (ibid: 1024). This is seen in how participants discuss their care roles, preferring to say 'giving help' rather than 'care'. Cebula et al (2025) similarly note how siblings interviewed in their research referred to 'looking out for' their sibling. This sentiment is echoed in Pavlopoulou and Dimitriou's (2019) reflections on how sisters of disabled people frame care. They stated that their participants often preferred words such as 'help' and 'look after' as opposed to 'care specific' language. This active rejection of the label is seen to some siblings as a way of preserving their relationship with their brother or sister. They call for researchers to be careful of framing 'helpful relations between siblings, in which sisters seem to feel comfortable'... 'as non-normative caring tasks' (ibid: 10).

In both of their research, Meltzer (2017) and Pavlopoulou and Dimitriou (2019) refer to participants having certain care actions they are not willing to do as they feel it would shift their sibling relationship. This reflection implies for some people there is a limit to what constitutes 'expected' care and highlights a need to critically examine how we understand wider sibling care through a disability lens. Similarly, Dellve et al (2000) refer to 'harmonising dilemmas' in their research. By this, they mean the tension that can occur between wanting to support your sibling whilst also feeling that you have no choice about it. Leane (2019) builds on this reflecting on the potentially conflicting emotions around sibling care and disability, also acknowledging the role of neo-liberal austerity politics in the production of this situation. Returning to Goodley's (2014) reflection on a neo-liberal society's rejection of those that are not 'able bodied and minded', it is clear how this is more than an individual or family 'issue'. This harmonising dilemma can be seen to arise directly from a system that enforces individuality at the cost of inclusion. This is shown by the expected increase in family care over the coming years (Hourigan et al, 2017).

Alongside reflections on how siblings of people with learning disabilities feel about care, it is important to acknowledge the views of the disabled person also and how they feel about the label 'young carer' being ascribed to their sibling. In their work on intimacy and disability, Liddiard (2018) explored the role of care in relationships between partners. Arguing that receiving care is an 'emotionally difficult' thing, Liddiard notes how some participants preferred not to receive intimate care from their partners as it could change the feeling of the relationship. This viewpoint can be applied in the case of sibling care with Spagnuolo et al (2025) noting how the current expectation that siblings take over care when parents grow older means disabled people are often left without choice in their care provisions. By reframing these care discussions through a more holistic view of the sibling relationship an important question is raised: do people want their family, or siblings more specifically, to be providing intimate care and what implications does this have for their family relationships? This thinking reflects more widely the important omission of disabled people's voices in research around disability and siblinghood (Kovshoff et al, 2017; Richardson and Jordan, 2017).

Conclusion

By engaging with family sociology through a critical disability studies lens new understandings of siblinghood and learning disability can be generated. This literature review has brought together key theories and concepts from these areas to provide a foundation on which to begin to answer the research questions of the thesis. In doing this, the project will contribute to scholarship through the pursuit of counter-narratives that challenge dominant understandings of both learning disability and siblinghood. Further, this work will add to the small, but growing, body of literature that takes a more critical approach to understanding this topic (For example Richardson and Jordan, 2017; Meltzer, 2018; Moran-Morby et al 2024).

This chapter has covered many different areas and concepts in recognition of the exploratory nature of the research questions and narrative methodology being used. This ‘wide’ focus allowed for an overview of both critical disability studies and crip theory, touching on the notion of the ‘ideal type’. This was followed by a discussion of the social and cultural models of disability which led into a section on the theorising of learning disability. This theoretical lens established, the chapter then began to explore siblinghood and the key concepts that family sociology offers to this thesis. This consisted of an outline of what makes siblinghood ‘complex and unique’ (Davies, 2023) in which ideas around the backstage nature of sibling relationships (Punch, 2008) and family practice and display (Morgan, 1997 and Finch, 2007) were explored. Next, a short overview of everyday sociology was offered in acknowledgement of the firmly everyday nature of sibling relationships. This focus was then applied to disability, with discussions of parenting and public interactions. To finish, the chapter then explored siblinghood in the everyday using the examples of humour, home, conflict and care with consideration of the questions disability can raise in these contexts.

The following chapter will present the research approach of this study, outlining how the theory and concepts introduced in this chapter inform the thesis as a whole.

Chapter 3: Methodology

Introduction

This thesis aims to engage with and explore the experiences of siblings of people with learning disabilities, with a focus on how they make sense of their childhood experiences and conceptualise disability and siblinghood. To do this, a narrative approach is taken using semi-structured narrative interviews that incorporate the creative methods of photo elicitation and timeline mapping. Through this approach, participant stories are generated which are then presented through narrative thematic analysis alongside narrative portraits.

With these aims in mind, this chapter sets out the research approach and the considerations this brought. This will begin with the methodology of the thesis, focusing on narrative research and what it can offer understandings of disability. Following this counter-narratives will be discussed, looking at the potential of this approach for generating new understandings of learning disability and 'narrative repair' (Nelson, 2001). This leads into an explanation of the research design, centred around Rosenthal's (2007) narrative interview framework with the addition of timeline mapping and photo elicitation. Here, I introduce the project advisory board and its role within the study and present the three key takeaways from the meeting. Next, the sampling and recruitment is discussed with consideration given to the decision of allowing participants to 'self-define' as fitting the sampling the frame. This is followed by the ethical considerations raised in the project and how these were navigated. Then reflections on the data collection are presented, drawing on extracts from my research diary. Next the analytical approach is made clear, narrative thematic analysis, along with discussion of the role of narrative portraits in the work. The chapter concludes with reflections on my positionality. Drawing on Kleinsasser's (2000) understanding of reflective practice as creating 'physical evidence of personal and theoretical tracks through a created text, evidencing the researcher’s deep learning and unlearning’ (ibid: 156), I aim to be reflexive throughout the chapter. This is done through offering justification for decisions I have taken and engaging with their outcomes critically.

Methodology

This thesis sets out to answer three research questions, these are:

> How do young adult siblings (aged 18-32) of people with learning disabilities make sense of their childhood experiences of family life?
>
> How do siblings of people with learning disabilities conceptualise disability, family and sibling relationships?
>
> In what ways might counter-narratives of siblings problematise dominant pathological models of disability in families?

These questions are concerned with young people’s experiences of growing up with a sibling with learning disabilities. As outlined in the previous chapter this is informed from a critical disability studies perspective, with the methodological approach reflecting this ontology. Acknowledging the theoretical openness offered by critical disability studies (Goodley, 2014), a number of understandings of disability were presented in the literature review, with a driving force being how learning disability is constructed socially. This makes clear the importance of speaking to lived experiences in order to address the aims of this thesis, something that Goodley et al (2019) note as an essential aspect of critical disability studies scholarship. As part of this, I used an advisory board in the early stages of the fieldwork. This was in recognition of the work's focus on the experiences of non-disabled siblings, with the advisory board offering insight from self-advocates. This research design section discusses this in more detail. Further, the thesis aims to challenge dominant majoritarian narratives around disability and siblinghood, with the third research question speaking specifically of the potential of counter-narratives. To address this, a narrative approach enables the capturing and exploration of how participants narrate and make sense of their experiences. The nuance and depth this offers allows the countering of more dominant understandings of disability through the centring of participant stories. This stance, alongside the research question's focus, led to the thesis taking a narrative approach to collecting data.

The research questions are concerned with how siblings make sense of their childhoods, understand disability and siblinghood, and the counter-narrative potential of their accounts. Narrative inquiry enables the exploration of lived experiences and through this counter-narratives can be generated (Clandinin, 2006). Narratives can be described in a number of ways, Gee (2005) provides a series of names such as "folk theories", "frames", "scripts", "mental models", "cultural models", "discourse models", "social models" and "figured worlds" (ibid: 89). Frank (2010) argues that narratives are stories and researchers should embrace this and refer to narrative research as stories. Thavakugathasalingam and Schwind (2022) build on this, arguing stories and storytelling are central to how we create meaning. Echoing this sentiment, Hoffman (1993) argues stories give structure and meaning to our lives. These ideas are summarised by Garland-Thomson (2007) who states 'narratives do cultural work. They frame our understandings of raw, unorganised experience giving it coherent meaning and make it accessible to us through story' (ibid: 122). Garland-Thomson is writing from a disability studies perspective and makes clear how narratives of disability shape understandings. Within the research focus, attention is given to the everyday, with everyday routines and occurrences playing a role in the construction of marginalised identities socially (Back, 2015; Ghisleni, 2017). Considering the second research question, how participants conceptualise disability, siblinghood and family will come through in their narratives and further give insight into cultural understandings of these topics.

For a narrative to be effective it has to be understood by the audience (Wells, 2011). Sparkes and Smith (2011) argue this requires following ‘conventions of reportage’ and drawing on ‘socially sanctioned viewpoints’ to avoid being misunderstood. Bruner (2004) echoes this noting that narratives must ‘mesh’ with wider cultural stories in order to be effective. Understanding narrative as significant culturally whilst also reinforcing socially sanctioned viewpoints, we begin to see how it plays an important role in contributing to the ‘generalised and culturally established canon’ (Medved and Brockmeier, 2008: 469). Returning to Sparkes and Smith (2011), the act of ‘stimulating narrative imaginations’ achieves ‘solidarity and bond with others empathetically as fellow human beings’ (ibid: 369). This importance of narrative in how we make meaning and further achieve solidarity has clear implications within disability studies, with narrative disability research pointing to the role of dominant narratives in how disability is understood. For example, Grue’s (2016) exploration of inspiration porn highlights the prevalence of narratives of overcoming disability within popular culture.

Focusing on learning disability, Jarret’s (2020) research explores how people with learning disabilities have been understood historically in the UK, drawing links between disablism and racism in the construction of empire. Mann (2019) highlights how concerns in the media around MMR vaccinations and autism were rooted in deficit narratives, reinforcing problematic medicalised understandings. Bogdan and Talyor’s (1982; 1987; 1989) work centres the narratives of people with learning disabilities and their families, exploring understandings of learning disability and the insight this offers into culture’s conceptions of human difference. Looking specifically at siblinghood, Edery and Harvey (2025) explore the narratives of adult siblings of autistic people arguing ‘previous conceptions of ‘outcomes’ and the ‘normative’ standards against which sibling relationships with an autistic sibling are understood require revision’ (ibid: 21). These examples highlight the role of culturally available narratives of disability, with there being a clear need for more research that challenges these dominant understandings (Smith and Sparkes, 2008). The role of counter-narratives in narrative disability studies research will be explored in the next section.

The pursuit of an understanding of our lives through narrative inquiry can raise some concerns around validity, particularly regarding the notion of stories as data. These concerns are rooted in questions of authenticity as captured by Polkinghorne (2007) who argues ‘the language description given by participants of their experienced meaning is not a mirrored reflection of this meaning’ (ibid: 480). Spence (1982) argues that narrative research is concerned with ‘narrative truth’, with Kalekin-Fishman (2016) taking this further placing the focus on ‘lived truths’. They refer to these as the ‘stories that people live by’ (ibid: 154) with these stories being ‘key to understanding how people create society’ (ibid: 153). These examples point to narrative inquiry being interested in ‘interpretation’. For Lieblich et al (1998), it is this interpretation that is central to the method and when read alongside Garland-Thomson’s (2007) reflection on narrative helping us to make sense of events the role of interpretation is made clear. Here we see how the question of validity cannot be interested in an ‘objective truth', as Rodriguez-Dorans (2022) outlines narratives ‘do not intend to present accurate realities, they are interpretations that aim to reflect people’s narrated experiences’ (ibid: 80). Indeed Frank (2013) similarly argues ‘the truth of stories is not only what was experienced, but equally what becomes experience in the telling and its reception’ (ibid: 20). With regards to the aims of this thesis, the research questions centre around participants’ sense making, be that of how they understand their childhoods, or disability and siblinghood more widely. Therefore, these can be seen as questions of interpretation in which a narrative approach provides the opportunity to understand the lived experiences of participants.

Counter-narratives

The thesis aims to generate and explore the potential of counter-narratives in understanding learning disability and siblinghood. This is the focus of the third research question and further informed by the ontological and epistemological approach of the work. As discussed in the introduction and chapter 2, this thesis is informed by Meltzer's (2018) reflection on sibling disability research as often focusing on what relationships 'are not'. Through making counter-narrative a central aspect of the methodology of this project, participant relationships will be given the space to be understood for what they are. Counter-narratives challenge majoritarian narratives through showcasing different perspectives (Klinge, Carlson and Kahle, 2020). Existing in contrast with dominant discourses, they centre lived experiences, often from marginalised perspectives (Delgado, 1984; Walker, Mitchell and Dlouhy, 2020). For Andrews et al (2004) counter-narratives are 'stories that lie in tension with the ones that we are socialised to expect'' (ibid: 97). Considering stories 'we are socialised to expect' with regards to this thesis, we are brought to dominant understandings of siblinghood and disability framed around non-disabled sibling outcomes (Meltzer and Kramer, 2016).

Lueg, Bager and Lundholt (2020) build on Andrews et al's (2004) argument, noting the importance of counter-narratives when researching marginalised communities. In their pedagogical reflections, hooks (1994) notes the importance of curriculums that embrace counter-narratives arguing they become sites of resistance. They cite Mohanty's (1989) reflection 'resistance lies in self-conscious engagement with dominant, normative discourses and representations and in the active creation of oppositional analytic and cultural spaces' (ibid: 185). Originating in critical race theory (Solórzano and Yosso, 2002), this emancipatory potential of the approach has resulted in its application more widely in other areas of research such as queer scholarship (Helmer, 2016), and feminist theory (Hemmings, 2005). Vaccaro's (2010) research into inclusive family narratives raises the activist potential of 'living your counter-narrative'. Their reflections on queer multi-parent families reinforce the importance of counter-narratives in the pursuit of inclusion as they allow for the telling of 'invisible stories' (ibid: 426).

With specific focus on this research, counter-narratives provide an opportunity to challenge dominant understandings of disability. This thesis sets out to disrupt the deficit stories 'we are socialised to expect' (Andrews et al, 2004: 97) through a focus on the everyday to explore new counter understandings. Looking at previous counter-narrative disability research offers insight into how this can be achieved. For example, Ronksley-Pavia and Pendergast (2020) use counter-narratives to challenge dominant understandings of disability and 'giftedness' in school environments. They argue 'teachers embraced dominant narratives; considering giftedness as high achievement and disability as low achievement, and frequently possessed very limited understanding of both' (ibid: 252). In actuality they found these categories to intersect often, highlighting the risk majoritarian narratives pose to understandings of disability. For Leaning and Adderley (2015) this leads to what they term 'problem saturated narratives' about disabled people. Further, counter-narratives have been used to challenge medicalised discourses around disability. Fischer and Goodley (2007) explore the narratives used by mothers of disabled children noting how medical understandings are often rejected in favour of, what they term, 'challenging narratives' and the 'philosophy of the present and becoming'. Challenging narratives embrace the social model through questioning ideas around 'progression' and 'goals', whilst 'philosophy of the present and becoming' narratives see parents finding a kind of comfort in the lack of certainty and embracing their child as they are in the present.

Landsman (2003) explores the role majoritarian narratives play in how parents ‘emplot’ the lives of their children following diagnosis, highlighting their central role in the navigation of disability. This argument is enhanced in the work of disability studies scholar Garland-Thomson (2007):

> *‘Both our bodies and stories we tell about them are shaped to conform to a standard model of human form and function that is called normal in medical-scientific discourse, average in consumer capitalism and ordinary in colloquial parlance’* (ibid: 114)

Through this understanding we can begin to see how promoting counter-narratives which challenge these understandings of ‘bodies and stories’ becomes a radical act in itself. Furthermore, in their research on disabled artists Harter et al (2006) emphasise the role narratives play in shaping public perceptions around disability, arguing counter-narratives can be a key tool in shifting understandings. This stance echoes Nelson's (2001) reflections on how identities are constituted and subsequently damaged, with counter-narratives presented as a tool in the pursuit of ‘narrative-repair’. Through this lens counter-stories work to resist oppressive identities, replacing them with more representative ones (Nelson, 1995). Drawing on Bal’s (1985) concept of ‘focalisation’, Nelson (2001) encourages us to explore the relationships between the ‘presented elements’ and the perspective it is being presented through. They argue that counter-stories are important as they are stories of self-definition, as opposed to oppressive stories that come from majoritarian perspectives.

Informed by this understanding, this thesis challenges dominant medical discourses around learning disability and siblinghood through allowing siblings to define their own experiences.

It can be argued that through focusing on counter-narratives there is a risk of creating a binary in which the nuance of lived experiences is lost in favour of a ‘bad’ majority narrative being challenged by a ‘good’ counter-narrative (Müller and Frandsen, 2021). Acknowledging this, the everyday focus of this thesis will look to draw out counter-stories that capture the ups and downs of growing up with a sibling with learning disabilities. An everyday focus can be generative in itself as it situates disability away from highly medicalised spaces and understandings (Connor, 2006), instead allowing for more holistic readings that prioritise people’s lived experiences (Walker, Mitchell and Dlouhy, 2020).

Alongside the counter-narratives that can be found throughout disability studies, crip theory provides a space for ‘crip narratives’ which offer a celebratory focus. McRuer (2006) calls for ‘counter-representations’ that challenge the notion of the ‘ideal type’. These ‘counter-representations’ can be seen as a form of counter-narrative. Furthermore, examples that challenge dominant medical discourses around disability can be understood as ‘crip-narratives’ through their presentation of ‘counter-representations’ of disability. Alongside those previously discussed, Shrodes’ (2023) research into ‘storying disability’ highlights the role disability narratives have in rejecting notions of ‘getting over disability’. Shrodes builds on Kafer’s (2013) reflection ‘to put it bluntly, I, we, need to imagine crip futures because disabled people are continually being written out of the future, rendered as the sign of the future no one wants’ (Kafer, 2013: 46). Abrams and Abes (2021) use a narrative approach to celebrate ‘crip health rebels’. Drawing on Kafer’s (2017) understanding of ‘health rebels’ as those who pushback against ableist understandings of what it means to be ‘healthy’, their understanding of ‘crip health rebels’ challenges ableist understandings. This is done through ‘radical self-love as resistance of compulsory able-bodiedness’ (Abrams and Abes, 2021: 269).

These discussions echo the previously mentioned work of Garland-Thomson (2007), with their call for ‘life affirming narratives’ clearly linked to crip ideas around allowing disability to exist without the added expectation of pity, sympathy or an inspirational overcoming story. In their exploration of sexual surveillance amongst people with learning disabilities, Feely (2016) draws on Deleuze and Guattari’s (1987) notion of ‘deterritorialization’ to note how ‘regulation is resisted, norms are subverted, and new sexual possibilities emerge’ (Feely, 2016: 735). In doing this, Feely invites the reader to rethink sexuality and learning disability in a manner that can be seen as crip. Similarly, Levy and Young (2020) ‘crip social care’ through reimagining an approach which sees collaboration as central, where it is not ‘doctor’s know best’ and instead recognises individuals as knowing what is best for them. These examples point to the importance of research that rejects dominant narratives, especially regarding marginalised experiences.

Shuster and Westbrook (2022) refer to a ‘joy deficit’ in social science research, arguing that as we often focus on social harms this becomes the lens through which marginalised groups can come to be understood. They call for more research that acknowledges joy and other more positive experiences to challenge these commonplace deficit narratives. The lack of joy in disability studies is something that has been raised (Sunderland et al, 2009) and can be linked to counter-narratives and crip narratives, with the celebratory nature of crip theory offering a clear path to joyful understandings of disability. The thesis aims to build on this, offering space for joy where appropriate and addressing the third research question in the process. This approach further ensures sibling stories are explored with a focus on what ‘they are’ as opposed to what they ‘are not’ (Meltzer, 2018).

This section has outlined the methodology of the thesis, making clear how the narrative approach is driven by the research aims and the theoretical grounding of the work. The next section explains the research design, building on this foundation to explore how the research was carried out.

Research design

Recognising the research focus on childhood, a narrative approach offers the opportunity to centre participants' everyday lived experience of growing up with a sibling with learning disabilities. To do this, 14 narrative interviews were conducted with siblings of people with learning disabilities aged 18-32, these featured the creative methods of timeline mapping and photo elicitation. This section outlines how the research was conducted, building on the methodology discussion to highlight the choices made.

The research approach draws on Rosenthal's (2007) narrative interview framework, alongside the creative methods of timeline mapping and photo elicitation. As will be discussed in more detail in the following section, the creative methods acted to support this framework with participants drawing on their timelines often in the initial section of the interview and their photos at different points to encourage discussion. This framework saw the interview split into two sections, the first being the 'period of main narration' in which the participant is asked to provide a 'long biographical narration' (ibid: 52). The aim here is to have little researcher input, allowing participants to discuss their childhood in a manner that covers what they feel is important. As one of the research aims is around how participants made sense of their childhood, it felt important to allow this space where they could drive the interview. This section varied from around 30 minutes to an hour. It is important to note that this does ask a lot of the participants, and how this went in practice will be discussed further into the chapter. The second section follows a more conventional semi-structured interview approach with the interviewer asking follow up questions based on what the participants have spoken about alongside some pre-prepared questions that cover the research focus.

This section’s length was impacted by the period of main narration, often being around 20 to 40 minutes depending on whether the participant had already addressed the pre-prepared questions. These were things such as ‘what was breakfast time like in your house growing up?’ and ‘what did you do on weekends?’. These questions were deliberately open-ended and worked to ensure that the participants spoke of their everyday lives, as this is also a central aim of the thesis.

Due to the potentially sensitive nature of the research, alongside the recognition of the design asking a lot of participants, it felt important to adopt a flexible approach. This was informed by Budworth’s (2023) work around research with disabled and chronically ill people, which calls for researchers to be flexible in recognition of the complexity of participants' lives. Whilst my participants were not disabled and chronically ill people, the centring of care in the research approach is one that felt appropriate and helped to ensure a comfortable environment was created. This was also inspired by Branelly and Barnes’ (2022) notion of ‘researching with care’. They call for ’being attentive to specific contexts and of working out how to do care that ‘fits’ the relational circumstances in which we live and work’ (ibid: 77). In practice this meant ensuring I worked to participant schedules, and preferred locations. This saw most of the interviews take place online. Returning to the research design, being flexible also required working with what those taking part found most comfortable such as adapting the approach if a participant did not prepare a timeline or was concerned about the period of main narration as a difficult task. This is revisited further into this chapter. Overall the research approach worked well, with participants and myself feeling comfortable and the data generated being effective in answering my research questions.

Creative methods

As part of the interviews participants were asked to bring along a timeline of their childhood and some family photos. The rationale for this came from wanting to allow participants to bring something they have pre-prepared away from the researcher to refer to during the interview. Considering the research questions, it was important to focus on how participants ‘make sense’ of their childhood experiences and therefore the choice to let them lead part of their interviews felt important. Creative methods have the potential to be generative to discussion and are a means, even if only slight, to challenge the power dynamics of interview spaces (Mannay, 2010). Further, it should be noted that the interview approach of the project relied on participants talking at length with little input from the researcher in terms of prompts or questions. Having these items to refer to was one way to ensure that this was a less daunting task as they could draw on their timeline or photos when considering what to discuss. Timeline mapping aligns clearly with the narrative nature of the interviews (Sheridan et al, 2011), allowing participants to present a ‘clear course of events’ for discussion (Kolar et al, 2015). From this, they can speak to the meaning of these ‘key events’, providing detail as to why they were chosen (Leung, 2010). Further, having something to refer to can be a source of comfort when discussing more difficult topics or experiences (Mason and Davies, 2009). O’Brien and Charura (2024) refer to object elicitation as a ‘compassionate’ research approach for discussing more difficult topics. In practice these creative methods served mostly as prompts as opposed to driving the discussion, with participants often referring to them in moments where they were unsure of what to say next. This will be revisited further into the chapter.

Advisory board

During the process of conducting my fieldwork I used an advisory board made up of self-advocates and siblings to discuss how the project was coming together and gather some early feedback on the work. As discussed previously, this was informed by my methodology with it being important to ensure people with learning disabilities were involved in the project. The advisory board met midway through the second year of the project in an online meeting to discuss how the research was developing. At this point, I was roughly halfway through my fieldwork and was able to offer some early findings to the group. In attendance were two self-advocates and their support worker from the charity My Life My Choice and Saba Salman the trustee of the charity Sibs. The self-advocates and their support worker were paid for their attendance. Due to scheduling conflicts I had a separate discussion with a member with extensive experience working with people with learning disabilities. The session consisted of a short presentation in which I offered some reflections from participants and how these linked to my wider thinking for the research. Throughout there were opportunities for those taking part to contribute their thoughts. Drawing on participatory methods literature, I tried to ensure the session was accessible for all who took part (Walmsley, J.,1997; Mikulak, M. et al., 2022).

The attendees offered a series of thoughtful reflections on the research. The three key ones being: considering ageing, accessible findings summaries, and word choices and nuance. The first key takeaway was a discussion on how participants reflected on their relationships as they aged. Focus group attendees were particularly interested in later life, which is unfortunately outside of the scope of this project. However attendees noted the importance of not presenting family ties as static, and that even within childhood these change and develop. This thinking informed how I chose to write about and present my data, ensuring that attention was given to this where possible. The second consideration was regarding findings summaries. One of the self-advocates reflected on other research they had been involved in and how they found the summaries circulated to those who took part had been inaccessible. This is something I have taken on board and intend to address when bringing together a summary of findings for participants and the advisory board at the end of the project. The final takeaway was around word choice, particularly the evocative nature of certain terms. This stemmed from discussions around care and responsibility, with the attendees noting that they found the word ‘responsibility’ did not capture their experiences. One attendee in particular reflected that family care was just something you do, not a responsibility. I sat with this for a while, considering how my participants had at points used the word responsibility. In the end I chose to stick with participants' own word choices, however as part of the ‘commitment to the case’ (Riessman, 2008; Frank, 2010) in narrative thematic research I tried to ensure these discussions were nuanced and enough context is offered to ensure clarity for the reader.

Sampling and recruitment

Participants were sought who were 18-30 years old and who by self-definition had a sibling with learning disabilities. This age bracket was chosen with the aim of capturing stories from ‘young adults’. During the sampling I was contacted by someone who was 32 years old, I chose to extend the sampling frame to include them meaning the participants ranged from 18-32. The sample was recruited using purposeful sampling drawing on my own networks alongside social media. This was done with the aim of gathering ‘information rich’ participants (Palinkas et al, 2013), in acknowledgment of the sampling frames alignment being one of ‘intrinsic interest’ (Henry, 2009) on account of the more ‘niche’ requirement. The sampling was done through 'x’ to begin, where I circulated the recruitment poster (Appendix 1) alongside a short video clip explaining the project and what taking part would consist of. This was in recognition of the potential that social media sampling can offer in reaching more ‘niche’ groups (Wasilewski et al, 2018). The video was provided to ensure accessibility in the sampling process. The recruitment poster was also circulated in the volunteer newsletter of a charity where I used to work, the charity works with people with learning disabilities and their volunteer list featured many siblings. Respondents were provided with the information sheet

(Appendix 3) and ethics form (Appendix 4) and encouraged to ask for clarification if they had any questions. Both forms also had easy read versions which were made available to participants if needed.

Whilst my initial avenues for sampling proved somewhat effective, the majority of the sample were white middle-class siblings. In my latter recruitment phases I tried to reach out more widely to gain a more diverse sample, particularly with note to gender as in the first wave the majority of my respondents were women. I contacted Oxfordshire Family Support Network (OFSN), a charity that supports families of people with learning disabilities, running a number of groups regarding things such as accessing support, money management, care and much more. Alongside this, snowball sampling was conducted with a specific focus on brothers. This was successful in recruiting more men to the study, however, as will be discussed in the next section the sample was not as diverse as I hoped for. In recognition of the risk of 'over-estimating' participant interest (Green and Vandall-Walker, 2016) my aim was to gain 8-12 participants. The recruitment brought back more responses than expected, with 25 people showing initial interest. Due to the nature of the topic I was keen to, within reason, try to accommodate everyone who responded. I found that following initial interest there was a drop off in those who wanted to take part, this was a combination of some not replying to emails or changes in plans. In the end I conducted 14 interviews which lasted between one and a half and two hours. Whilst not a large sample, I am confident that the data provided is enough to carry out comprehensive analysis (Hennink and Kaiser, 2022).

Throughout this process I tried to ensure the participants full control of their involvement, adopting an indirect approach in which they were left to make first contact (Buckle, Dwyer and Jackson, 2010). Whilst it is important to be cautious when categorising all research around learning disability as sensitive (Snipstad, 2022), adopting sensitive ethical approaches in practice hopefully allowed more comfort to participants. The choice to allow self-definition with regards to the sampling frame is in recognition of the aim to move away from pathologising narratives around learning disability in research. By allowing participants to decide themselves if they fit the sampling frame, and by not limiting the category to certain diagnoses or labels, the research avoids medicalising. There is a risk to this approach, with ‘imposter participants’ becoming more of a focus especially in online interview settings. In the recruitment phase I drew on the advice offered from Santinele Martino et al (2024) in their reflexive work on recruitment post-pandemic and spotting ‘imposters’. Using a critical disability studies perspective they note how ‘disabled people so often have to “prove” their disability and, yeah, we can’t reproduce that’ (ibid: 1297). It is also important to note that I was not offering any incentive to take part in my research, so the risk of imposter participants was likely lowered by this factor.

The participants

The sample consists of 14 siblings of people with learning disabilities aged 18-32. Here short introductions to each participant will be provided touching on what they do now, something they enjoyed growing up and who their siblings are. More specific demographic information is available in the Appendices (Appendix 2).

Zara, 23

Zara is training to be a therapist. Growing up Zara enjoyed camping holidays and taking day trips to the local town. She grew up in the south of England with three siblings. She is the youngest, with a brother, Jake, and two sisters, Jenny and Mia.

Hannah, 27

Hannah is an occupational therapist. She grew up in the south of England and is the middle child of 3 with an older sister, Anna, and younger brother, Harvey. Growing up Hannah enjoyed swimming and movie nights with her siblings.

Emily, 26

Emily is a student. She is the oldest of 3, she has a younger sister, Claire, and brother, Adam. They grew up in a northern town in the UK. Growing up Emily enjoyed BBQ's and playing on her trampoline with her siblings and family friends.

Ellie, 30

Ellie is an academic. Growing up Ellie enjoyed family holidays, particularly going to the beach. She is the youngest of 4, with 3 older brothers, James, Erik and Harry. They grew up in the south of England.

Oscar, 22

Oscar is a graduate who is living at home taking a year off after university. Growing up Oscar enjoyed making water slides in his garden with his siblings. He is the oldest of 4 with two brothers, Liam and Owen, and a sister, Jane. Oscar's brother Owen passed away in 2021. The family lives in the south of England.

Eva, 22

Eva is a master's student currently studying in Amsterdam. She is the oldest of 4 with 3 younger brothers, Tim, David and George. They grew up in the south of England. Growing up Eva and her siblings liked playing in the garden and had a lot of pets.

Martha, 24

Martha is a social worker who works with young people. Growing up Martha enjoyed dancing and sailing. She has two older brothers, John and Guy. They grew up in the South of England.

Zack, 28

Zack is a teacher currently based in China, he grew up in a northern city with an older brother, Josh, and a younger sister, Beth. Growing up Zack and his siblings loved playing the Nintendo Wii, particularly Wii bowling.

Alex, 22

Alex recently graduated from university and is currently looking for jobs. He has an older sister, Lola. They grew up in the midlands. Growing up Alex liked playing football with his friends and swimming.

Susan, 19

Susan is a student studying Law at university. Growing up Susan enjoyed walking and disco’s on family holidays. She is the youngest of 3, with an older brother, Peter, and sister, Gemma. They grew up in the South of England.

Dina, 22

Dina is a geography student currently studying abroad. She is the middle child, with an older sister, Tyler, and a younger brother, Samuel. They grew up in the south of England. Growing up Dina liked reading and doing arts and crafts.

Kerry, 19

Kerry is doing an apprenticeship in engineering. She is the oldest of two, with a younger brother called Jack. They grew up in the south of England. Growing up Kerry enjoyed camping and walking.

Scott, 32

Scott works in the public sector. Growing up Scott liked sports, particularly swimming in which he competed. He has an older brother, Dean. They grew up in the south east of England.

Faye, 29

Faye is a student. She grew up in the south with her mum and two older brothers, Luke and Sami. She also has half siblings that were born after she left home. Growing up Faye enjoyed reading and watching movies with her siblings.

Whilst these short descriptions do not offer much in the way of the participants' stories, the aim was to give an introduction to who took part in the study with the findings chapters offering more insight into their narratives. 10 of the participants identified as women, with 4 identifying as men. All participants grew up in the UK. The majority of those who took part identified as ‘white British’, with one participant identifying as ‘white European’ and one participant identifying as ‘mixed and black Caribbean’. Most of the participants were middle-class and their family relationships differed, with detail of both of these available in the appendices (Appendix 2). While concerted efforts were made to recruit inclusively, using links with local organisations, time constraints meant this did not work out as hoped. The homogeneity of the sample is a limitation of the study. This brings with it questions around the narratives that are being centred in this thesis and further the counter-narratives that remain hidden (Solórzano and Yosso, 2002). This is a discussion I return to in chapter 7.

Ethical considerations

This project received ethical approval from the University of Sheffield research ethics committee. A central consideration was the potential for the work to bring up distressing experiences for participants. Whilst the project aims to challenge deficit narratives and provide more holistic accounts of siblinghood, it was still likely that some more difficult experiences would feature within the narratives. Particularly as the age range of the sampling frame meant many of the participants' childhoods occurred during a time where austerity was being pursued by the coalition and conservative governments. There has been much written into the implications this branch of politics had on disabled people, and their families (Oliver, 2013; Goodley, 2014; Ryan, 2020), so it was expected that people who took part would have felt these policies. Following the procedures outlined in the university ethics guidance, participants were aware they could stop at any point, be that for a break or to finish the interview. Alongside this, if necessary participants would be directed to the charity Sibs who support siblings of disabled people. In practice this was not something that felt appropriate in the interview settings with participants seemingly feeling comfortable discussing topics without needing a break or to withdraw. Alongside the considerations for participants' comfort, it was important to ensure that I, as the researcher, was ok to undertake the project. This was something that was discussed in depth with my supervisors, with precautions put in place such as only having one interview a day and ensuring I had free time after interviews if needed. In practice I found the interview process to be manageable, but having these plans in place contributed to my own comfort during the process.

During the fieldwork I had to submit two amendments to my ethics application to address unexpected things that arose. The first of these focused on making easy-read versions of the information sheet and consent form. This was due to being contacted by a parent of two people with learning disabilities who felt one of their children would be interested in taking part. I wanted to ensure that these forms were given ethical approval as the initial versions had been. In the end they chose not to partake in the project, but having the forms was useful as it was something I could offer other respondents if they wanted them. Further, I was able to use these easy-read forms in my advisory board work which helped summarise the project to a wide audience. The second ethics amendment was regarding the recording feature of google meet in online interviews. I was using google meet as it is university approved and has a built-in record feature that puts the recording straight into my password protected google drive, in line with my data management plan. In my consent form I had specified to my participants that I would record the audio in interviews and that once transcribed the interview would be deleted. I realised that the video also automatically records, and it is not possible to record the audio only without asking participants to turn their video off. I felt that the nature of the interviews meant that having the video on, where participants were happy to, was essential to creating a comfortable environment (de Villiers et al, 2022). I reflected on this with my supervisors and we came to the decision to submit an ethics amendment to change the consent form to make it clear that video would be recorded also. As with the audio, this was deleted as soon as transcription was completed and participants were made aware at the start of the interview about this. In each of the online interviews participants chose to have their cameras on.

Alongside obtaining ethical approval, were the more relational ethical practices that are essential to ensure the participant is comfortable and in many cases require going beyond procedural ethics (Guillemin and Gillam, 2004). Whilst, as discussed above, the focus of the project brought with it potential for more difficult discussions there was also scope for more positive reflections and participants took great pleasure in recounting these childhood experiences. This meant in practice the format and focus brought with it a sense of comfort for those taking part. Further there were instances where participants felt their narratives were important, and were aware more widely of majoritarian narratives around learning disabilities in a UK context. As will be unpacked in the findings chapters, this was seen in discussions of care, love, joy, politics, fun and more where participants were keen to explicitly make the case for the personhood of their siblings. My own positionality played a central role in the interview environment. Whilst I had noted on the recruitment poster that I had family experience of learning disability, I did not explicitly mention this initially. However in most of the interviews there was a moment where the participant would ask me or I would ‘give it away’ through a reaction. In these instances I noticed how this changed the mood in the interview, with there being a sense of a more relaxed environment following this disclosure, something that I feel contributed to the data I was able to gather (Roberts, 2014). My positionality is something I will unpack in more detail further into this chapter.

Due to the intensive nature of narrative methods it felt important to ensure the participants were keen to take part, something that the non-direct approach helped with. This was particularly relevant with regards to Oscar, who responded to the call for participants showing an interest in the research. Due to the networks I am part of on ‘x’, I was familiar with Oscar and knew that his brother had passed away a couple of years ago. I was conscious of this and whilst I did not want to disregard Oscar’s sibling experiences, I also did not want to pressure him into taking part in any way. Through discussions with my supervisors we agreed to leave it with Oscar giving him the information sheet and not following up. This was in recognition of the potential of ‘vulnerability’ to be over-ascribed to people, with Dyregrov (2004) arguing that bereaved individuals can decide for themselves if they would like to take part in research. After a couple of weeks he got back to me expressing interest in partaking. During the interview I also made sure to create a comfortable space in which Oscar knew he could stop at any point and offered breaks throughout. Upon reflection Oscar noted that whilst not an ‘easy’ experience he felt glad to have taken part in the research:

> *‘it’s not the easiest thing to talk about but then it’s also kind of nice. I mean you say it like I don't talk about it* [childhood] *that much right, it's so far removed from most people’s understanding of reality right that I think it's a pretty hard thing for most people [to discuss]’* (Oscar)

This aligns with wider research around bereavement, with the space interviews can provide being described as ‘empowering’ (Moss and Moss, 2012) and having positive impacts (Buckle, Dwyer and Jackson, 2010). Of course in practice, the process was less smooth than this implies, and there were moments where I likely offered more breaks than was entirely appropriate. This said, Oscar’s appreciation of the interview reflects how the approach worked.

To show thanks for taking part, participants will be sent an accessible summary of findings at the end of the project. To preserve anonymity this will not include any photographs or timelines and instead will focus on the main takeaways of the project. Whilst I recognise this is a small gesture, those who took part expressed great interest in this and I am hopeful they will be happy with the end results. This will also be distributed to the members of the advisory board and shared online.

Reflecting on the data collection

In this section I reflect on the research process, drawing on extracts from my research diary. A key consideration was the follow up questions, with the period of main narration varying in how much was covered between participants. This variation was captured in my research diary:

> *Interview 3- I think the more 'mundane' questions are useful as they get participants to think about their childhoods in an everyday sense. The questions are often following very interesting and 'moment' based recollections in the first section so the space to step back and just think about 'tea time' or 'after-school' is welcome I think.*
>
> *Interview 9- The questions were slightly less useful here, but mainly just because the participant went into a lot of detail throughout. Similarly to other interviews, the post timeline question section was a little bit less effective but I do think they work in digging into the everyday a bit more and painting a picture of family life.*

As is made clear in the extracts, these more 'mundane' questions were effective in drawing out discussions of the everyday, however they did not feel as fruitful as the initial participant reflections. These questions were designed in recognition of the difficulty of talking for an extended period of time, and I wanted to be sure I had some questions ready in case participants did not take to the 'period of main narration'. In most interviews participants seemed to enjoy the format and these more mundane questions felt slightly out of place. I chose to still ask them though as they often elicited some everyday stories of family life that further spoke to my research aims. For some, the first section was quite short, or required some general prompts. This was particularly the case for two participants who did not bring timelines with them. In these instances, I encouraged them to discuss their childhoods around key events such as school or holidays in order to focus this section towards a narration of childhood over time. This was something I reflected on in my research diary following the second interview I conducted:

> *The participant had not prepared any of the creative methods side of the interview. This can be seen as a result of both me not mentioning it explicitly in the emails (something to do from now on) and they said they skim read the information sheet. Initially this made it quite difficult to get started, however once we moved to a more narrative semi-structured interview the participant started to open up more and it was a really good interview. I still feel the timeline and photos would have added to the overall discussion though.*

As mentioned, I proceeded to ensure I was more explicit in the emails about the creative elements of the interview and what would be expected of those who took part, as opposed to just having the information sheet specify this. Doing this helped to ensure that the other 12 interviews followed the research approach appropriately.

A further challenge that occurred during the data collection was ensuring participants spoke about themselves, and not solely their siblings. Participants often assumed that as I was interested in the childhood experiences of siblings of people with learning disabilities that I wanted to hear solely about things that happened involving their siblings. In some ways this is expected, however the research focus is on the experiences of the participants. In the interviews it could be hard to ensure participants spoke about themselves, with questions about their childhoods being met with answers about their siblings. This was something I reflected on in my research diary:

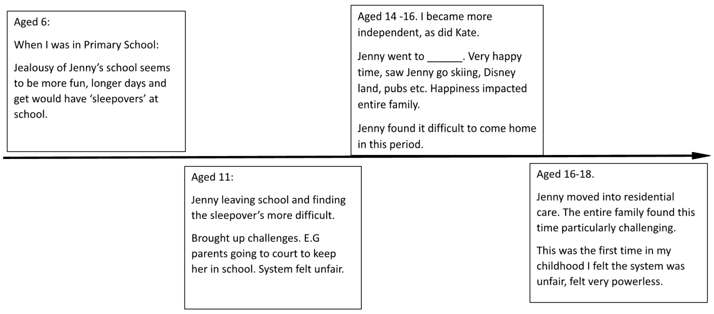
> *Interview 4- I think there were points where it was hard to ensure the participant spoke about themselves and not just their sibling. This is a wider problem that stems from the focus, as people arrive assuming I only want to hear about their sibling.*
>
> *Interview 8- Their narrative was very clear and they were really open to questions. Maybe framed through their sibling, this said they came through also quite well.*
>
> *Interview 13- I thought there was a good balance of the participant speaking about themself which was really nice, although initially I think they found this part slightly odd in a 'why would you care what I was doing' way.*

As mentioned in the diary, this felt like a problem that arose as a result of the research focus, and there was a level of discussion about their sibling that was to be expected and even encouraged in the work to some extent. In the early parts of field work, there were more occasions where the participant did not come through as strongly. As the interviews continued I tried to be more explicit in my questions to ensure that they still spoke about themselves. This aligns with the reflection in the extract regarding interview 13 with the solution being one of allowing participants to speak freely about what they felt was important and to ensure I was careful to ask questions about their experiences specifically.

Timeline mapping

Participants were given little guidance regarding their timelines. They were asked to bring a 'timeline of their childhood'. This was with the aim to give them the chance to attend the interview with something pre-prepared away from the researcher (Basnet et al, 2020). There was a wide mix in what participants brought along to discuss. The examples here, all anonymised, highlight the different ways participants decided to engage with the brief:

Fig. 1: Examples of participant timelines



Aged 6:

When I was in Primary School:

Jealousy of Jenny's school seems to be more fun, longer days and get would have 'sleepovers' at school.

Aged 11:

Jenny leaving school and finding the sleepover's more difficult.

Brought up challenges. E.G parents going to court to keep her in school. System felt unfair.

Aged 14 -16. I became more independent, as did Kate.

Jenny went to ______. Very happy time, saw Jenny go skiing, Disney land, pubs etc. Happiness impacted entire family.

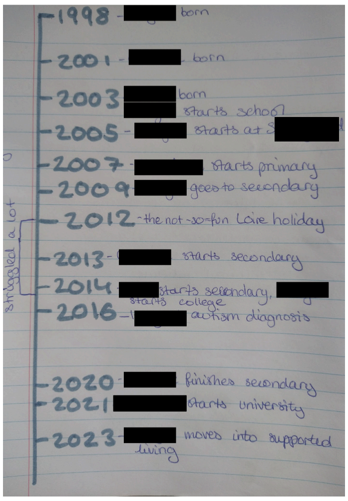
Jenny found it difficult to come home in this period.

Aged 16-18.

Jenny moved into residential care. The entire family found this time particularly challenging.

This was the first time in my childhood I felt the system was unfair, felt very powerless.

Photo redacted due to personal data



1998 - [redacted] born

2001 - [redacted] born

2003 [redacted] born

[redacted] starts school

2005 - [redacted] starts at S[redacted]

2007 - [redacted] starts primary

2009 [redacted] goes to secondary

2012 - the not-so-fun Loire holiday

2013 - [redacted] starts secondary

2014 [redacted] starts secondary, [redacted]

starts college

2016 - [redacted] autism diagnosis

2020 - [redacted] finishes secondary

2021 [redacted] starts university

2023 - [redacted] moves into supported living

struggled a lot

As the examples show, the timelines varied considerably in format, materials and detail. Alongside this were some participants who did not create a timeline but attended the interview with key dates in mind to discuss, without explicitly having had written them out. For three participants, they had either checked with their parents about key dates or planned to and would let me know, so some dates were provided as more rough estimates than definite timings. This was an interesting insight into participants' memories of their childhood and was expected, especially in the case of younger childhood. In these earlier instances, events were either major life moments such as siblings being born, or family stories that they felt were important even if they could not really remember them. By giving the chance to shape the interview through choosing what to focus on, Basnet et al (2023) argue timeline mapping allows 'the participants an opportunity to be in charge of their stories' (ibid: 6). This can be seen to contribute to how the interview is experienced, with the approach potentially helping with sensitive topics through participants having more control over their narratives (Pell et al, 2020). In some instances timelines jumped quite far, with participants feeling as though nothing of note had happened over certain time periods. This was seen in Emily's timeline, as discussed:

> *'I went to a school anyway, and this is where my timeline jumps literally through 2008 to 2014 because, I think this is just because I was a teenager and I was off doing my own thing'* (Emily)

This reflection is in itself interesting, and highlights what participants expect to be important to the research project. This was something that could then be discussed in the second part of the interview, allowing for areas of the timelines that were less detailed to be explained. Some participants provided more detailed examples with photos built-in meaning they would discuss both the photos and the timelines together during the first phase. These more detailed examples featured sections that split away from the year, with one participant having a section dedicated to the Nintendo Wii games console for example or another participant framing their timeline around medications their sibling was taking at certain points. Due to the focus on 'big events' that is expected from putting together a timeline of childhood, the more everyday discussions tended to be during the second phase of the interview. Here, the questions allowed a chance to dig deeper into more mundane aspects of siblinghood.

Photo elicitation

Where the timelines were in each interview a prompt to lead discussion, the photos were used in different ways by participants. In some cases, the photos acted similarly to timelines, they were used to elicit memories and draw on when unsure of what to discuss next. In other instances participants had sought out specific pictures that captured events with their being a sense that the photos added depth to that story. Drawing on Kuhn's (2002) reflections on family photographs, it is important to recognise the role of photos in the 'production of memories about our own lives' (ibid: 152). For Kuhn this link between photographs and memory is tied to personal narratives, they argue 'telling and retelling their memories is one of the strategies people use not only to make sense of the world, but to create their own world and to give themselves and others like them a place, a place of some dignity and worth, within it' (ibid: 166). Rowsell (2025) builds on this, arguing that photos offer the potential to understand 'participants- their care, their stories, their familial compositions- in deeper ways' (ibid: 224). These arguments have clear implications for narrative repair, with ideas of 'dignity and worth' and a 'deeper' understanding of participants offering counter-narrative potential. Kuhn (2002) notes that family photos are often taken in happier times, a sentiment evoked by Emily during her interview:

> '*And I don't know if that's a guilty thing, if you just take pictures at your happiest times kind of thing'* (Emily)

This is an important point to note and ties to Emily's reflection regarding skipping sections of her timeline. As the photos were part of a wider research approach there was not a large risk of overlooking experiences due to solely focusing on positive photos. Further, returning to arguments around creating a comfortable research environment (Mason and Davies, 2009), in many cases the photos participants brought in were of fun memories allowing for reflection on joyful moments during the interview.

One practical consideration that was brought up through the photo elicitation was access to family photos. Most of the participants had moved away from their family homes which meant accessing older pictures was not always easy. This saw many either asking parents to send over photos or mostly bringing photos of the later years of childhood as these were ones they had on their phones or had taken themselves. The result of this was the photos being engaged with to differing degrees across interviews. For those who chose not to bring along so many pictures, or struggled to acquire them, the photos were often something I would ask about resulting in short descriptions of the events they showed. For other participants, there was an aim to bring along photos that covered their whole narrative, with photos from across their childhoods being presented. One participant framed their timeline around photographs, with each section featuring a number of pictures. In this case, the photos framed their period of main narration as they were part of the content of the timeline and central to their narrative.

The difference in how participants drew on the photos had implications for the analysis, with photos not taking as central a role as I initially assumed. Instead they were approached more as interview aids, helping in moments where participants had less to say. In instances where photos were more explicitly drawn upon, these are included in the analysis where permission has been given. In all interviews the photos worked well to encourage discussion, with participants clearly enjoying the memories they evoked. Further, as I had access to them I could also ask questions about them in the second part of the interview with this often being a good starting point for questions around everyday occurrences that were captured in the images. This echoes McLaughlin and Coleman-Fountain’s (2019) reflections on visual methods as having the potential to provide insight into ‘social dynamics of valuing, pitying, othering, celebrating and stigmatising. They both open up such dynamics to consideration, as well as replicating them in the materials they produce’ (ibid: 378). Within these photos were often examples of family inclusion, with birthday parties or family holidays capturing the everyday of learning disability. This saw the photos leading to interesting reflections from participants on their everyday lives that may not have been evoked without the visual prompt.

Analytical approach

Narrative thematic analysis (Riessman, 2008) was carried out placing emphasis on both the content of the interview and, where relevant, to capture the narratives as a whole. With the focus of the thesis on childhood experiences, the choice of analysis stems from a recognition of the temporal elements of siblinghood and how it changes over time (Davies, 2023). Alongside this, the research questions explore both narrative and thematic elements such as how siblings conceptualise disability and make sense of their childhoods. In presenting my findings I centre each chapter around a research question. The themes that address the question are explored with attention given to narrative throughout. To achieve this, narrative portraits were created to offer further insights into participants' stories and to sit with a narrative in a longer form at different points throughout the work. The portraits are created around the themes being discussed in a chapter, drawing on a narrative where that theme was particularly relevant (Rodriguez-Doran, 2022).

The narrative thematic analysis was informed by the work of Riessman (2008), which offers a framework that sees the researcher ‘keep a story ‘intact’ by theorising from the case rather than from component themes (categories) across cases’ (ibid: 53). Smith (2017) builds on this, offering the description:

> *‘The purpose is to identify central themes (i.e. patterns) and relationships among these within one specific form of discourse; that is, stories. In other words, the focus on themes in stories, rather than all or any talk, is what distinguishes a narrative thematic analysis from other analyses’* (ibid: 391)

These examples capture the focus on both the narrative story and the thematic content. Riessman (2008) further extends this, placing the aim as ‘theorising across a number of cases by identifying common thematic elements across research participants’...’while also preserving narrative features’ (ibid: 74). Ray et al (2025) similarly understand the analytical approach as concerned with ‘focusing on entire narratives instead of their individual parts’ (ibid: 322). Through these examples, we can understand the aim of narrative thematic analysis as to recognise the central themes within a narrative, and to where possible present the data with narrative contextualisation. To do this, the analysis was approached with a series of key principles in mind informed by previous examples of narrative thematic analysis and the ethical and ontological considerations of this work.

The ‘commitment to the case’ (Frank, 2010) was a central principle of the analysis. This was in recognition of the nuance and ambiguity of sibling relationships (Edwards et al, 2006; Davies, 2023) meaning participant accounts would require contextualisation to ensure where possible an authentic representation was presented. For example, in chapter 6 humour is discussed as a central theme across participants' stories. These sections include reflections around teasing and sibling banter that could be read in certain situations as problematic. It is essential that context is given that makes sure participants' family humour is not misrepresented. The second key principle was to pause with certain words, allowing time to define them within participant understandings whilst also engaging with wider literature. This was particularly relevant for research question two, which is concerned with how participants conceptualise learning disability and family. There were times where participants' word choices did not align with my own personal politics around disability. Recognising this, I wanted to still ensure narratives were authentically represented, therefore participant word choices were left in. The dilemmas this raised are discussed in more detail further into this section. The final key principle of the narrative thematic analysis was to ‘sit’ with cases to ensure narrative engagement consistently throughout the analysis. This is due to the chapters being framed around the key themes of participant stories, with the analysis seeing themes being engaged with across cases (Riessman, 2008). To do this, narrative portraits are incorporated into the chapters. These were created using participants’ words and centred around themes that were key in their narratives (Rodríguez-Dorans, 2022). This further ensures that attention is given to the mundane in participant stories, recognising this as a central concern in understanding sibling and family relationships (Punch, 2008; Morgan, 2011).

With these principles in mind, the narrative thematic analysis was carried out. This was done in two ‘phases’ which informed each other. Whilst this description offers these two phases as distinct, it is important to note the ‘messiness’ of qualitative research (Law, 2004). In practice this was slightly more ‘blurry’ than the steps suggest. Notably the process of writing and theorising with the data played a role in conducting the narrative thematic analysis. This process of ‘working’ with the data influenced how the narrative portraits and themes came together. With this in mind, the first phases of the analysis saw each transcript coded thematically to explore the central themes. This followed Braun and Clarke’s (2006) approach to coding beginning with ‘familiarising yourself with your data’ (ibid, 87). Part of this was done through transcribing the data myself, a process that can be seen as a good entry into generating potential early themes (Riessman, 1993). From there, inductive codes were created through the reading and rereading of the data (Braun and Clarke, 2006; Gioia, Corley, and Hamilton, 2013). The codes varied across each narrative, with some cross over that allowed for themes across the dataset that were effective. For example, codes such as ‘doing siblinghood’, ‘conflict’ and ‘sharing space’ were brought together into the theme ‘Siblinghood at Home’. Where ‘conflict’ was not necessarily central in all participant narratives, ‘sharing space’ may have featured heavily instead. Therefore the themes work to speak to what was important in participants’ narratives, alongside the research aims and questions (Braun and Clarke, 2006). The other themes were ‘Care’, ‘Wider family and outside the home’, ‘Navigating disability’, ‘Humour’, and ‘Self Reflection’. In their narrative thematic analysis, Green et al (2015) refer to the ‘main ideas’ of participant stories. This sentiment was central to identifying themes within the data, with the aim of ensuring the ‘main ideas’ of the narratives informed the analysis. These themes shape the findings chapters which address each research question individually using data from the relevant themes.

Following this, the transcripts were then read with specific narrative focus in mind. Notes were made around the key aspects of participant stories, which were then developed into short narrative reflections on each participant, examples of which can be found in the appendices (Appendix 6). The narrative reflections focused on the approach outlined by Rodriguez-Dorans (2022) which builds on the Labovian framework (Labov and Waletzky, 1997) for narrative inquiry with some additional steps included to focus the coding on portraiture. This sees the data read with a focus on characters, orientation in time, complicating action, result and evaluation, small stories, special narrative features and the abstract. Of particular note to this research project were the more thematic elements of this coding, with special narrative features and the abstract being the main focus. Both of these draw heavily on the themes of the narrative, allowing portraits to be constructed around the themes that were central to the participant’s story whilst also giving insight into their experiences as a whole (Wells, 2011). This was informed by the first ‘phase’ of analysis with the ‘main ideas’ (Green et al, 2015) of the narratives being used to shape the portraits that were created (Rodríguez-Dorans and Jacobs, 2020). Alongside this, narrative attention was given to the context and how participants placed themselves within their stories.

Considering the portraits specifically, these were created as part of the analysis providing extracts of participants' narratives in their own words. Rodríguez-Dorans (2022) makes a distinction between the ‘self that experiences and the self that narrates’ (ibid: 11) acknowledging the questions around validity in narrative research. However as the project is concerned with how siblings of people with learning disabilities make sense of their childhood experiences this is less of a pressing issue as the ‘self that narrates’ is who this project is concerned with. Rodríguez-Dorans goes on to define the self that narrates as ‘one that tries to make sense of the experience and creates a story’ (ibid: 12). Vaccaro (2010) argues narrative analysis offers the opportunity to ‘holistically explore a person’s identity, relationships, and emotions, all within a larger cultural and social context’ (ibid: 427). The narrative portraits build on this to help us understand further how participants navigate disability. By incorporating the participant's own words the portraits prioritise their language choices and give a sense of how disability and siblinghood featured throughout their interviews. Culturally, there are interesting implications here with regards to ‘conventions of reportage’ (Sparkes and Smith, 2011) and stories ‘meshing’ (Bruner, 2004). For our stories to make sense they have to be understood, and how participants choose to draw on cultural understandings of disability in their own narratives help to further answer the research questions.

Alongside the methodological implications of these narrative portraits, there are political ones. Smyth and McInerney (2013) refer to narrative portraits as a form of advocacy ethnography. They argue portraits allow space for participant voices to be put at the forefront of the research process, which brings with it a chance to challenge the power imbalance between researcher and participant (Rodríguez-Dorans, 2022). Returning to Nelson's (2001) notion of ‘narrative-repair’, portraiture enables this by centring of voices often under-represented in certain contexts (Rodríguez-Dorans, 2022). Through presenting narrative portraits of the experiences of siblings of people with learning disabilities the nuance of sibling relationships is allowed to come through, challenging deficit narratives in favour of more human, holistic ones.

One of the key challenges that arose in both phases of the narrative thematic analysis was with regards to navigating discussions that in some form could be seen to uphold developmentalist and ableist narratives of learning disability without misrepresenting the intention of participants. This was particularly the case in chapter 5, in which participants' references to learning disability were explored. In some cases these definitions could be seen as problematic, with ideas of ‘normal’ and mental age being drawn upon when describing siblings. These descriptions do not align more widely with critical disability studies and my own personal disability politics, which brings with it a question of the role of the researcher in these moments. This is something that Back and Solomos (1993) address in their reflections around doing research into racism, in which they raise the important question of whether not challenging these viewpoints means you are ‘legitimating these ideas through your silence’ (ibid: 189). Building on this there is also a question of whether through not raising a challenge during the interview and then proceeding to criticise these stances in the thesis, I am unfairly presenting my participants. This was something I did not want to do as within their wider narratives participants were strong advocates of their siblings, with their stories being full of love and care, and to imply ableism would feel unfair.

Recognising the importance of remaining reflexive throughout the analysis (Mauthner and Doucet, 2003) I was conscious of my own positionality here and the potential of my insider outsider status influencing how I saw this. My positionality will be unpacked further in the latter part of this chapter, however it is important here to note the role it played in this element of the analysis. Otter (2024) argues that holding an ‘insider’ status in research can lead to nuance being missed in some of the work, with this being a result of almost taking for granted certain points of view and therefore not engaging critically with them. This was something that I think aligns with my initial reaction to these moments in participant narratives. It was not until I went away and began to do more reading around this subject, and read again the transcripts, that I began to view these instances slightly differently. Through discussion with my supervisors a decision was made to ‘sit with’ these contradictions, which informed the second principle of the narrative thematic analysis. This approach draws from Chadwick’s (2021) reflections on the ‘politics of discomfort’. They place discomfort as an entry point for theorising and call for researchers to ‘work with discomfort instead of trying to smooth over or ‘iron out’ that which does not make easy or comfortable sense’ (ibid: 569). In practice this sees chapter 5 explore these descriptions and not avoid pointing out potentially problematic language choices. However, this is done so in a manner that attempts to contextualise these within wider narratives as to try to ensure fair representation of the participants. In their work on narrative portraits, Rodríguez-Dorans (2022) argues the method:

> *‘seeks to understand and recognise people’s expertise in their own lives. Therefore, it is crucial to also look for those instances of the text in which participants define in*

> *their own terms what those key concepts mean for them and use those parameters to analyse the data accordingly'* (ibid: 33).

This is of course relevant for the portraits in the work, but it can also be applied more widely to participant narratives. In this work I chose to understand these descriptions in the contexts of the participants' wider stories. This means whilst I do note potential ableist or developmentalist language, I also accept that participants may not be well versed in the debates of the disability studies field and try to provide context where possible to ensure they are fairly represented.

Positionality

In discussing positionality in this thesis, I have chosen to split the section into two. The first part explores more conventional positionality discussions around how my role as a researcher is likely to influence the project and approach taken. The second part aims to situate my work within wider debates in disability studies around *who should be doing disability research?*

Positionality plays a central role in how we conduct research, as highlighted by Braun and Clarke (2022):

> *'We are all deeply embedded in our values and experiences"..."Who you are and what you bring to the research shapes and informs your research, inevitably, through what you do and don't notice, and what you take for granted.'* (ibid: 14)

Through this we see the centrality of positionality to the research process, and the importance of reflexivity throughout (Fine, 1992). For Alcoff (1991) researchers must engage with the question of where they are ‘speaking from’. My experiences growing up with an autistic sibling with learning disabilities are important to acknowledge for the role it has played in this work. My passion for the research comes from my experiences, which extend also to work and campaigning within the area. This ‘closeness’ to the topic brings with it a number of considerations. For Kittay (2009) insider experiences create an ‘inextricable relationship between the personal, the value of the political and the philosophical’ (ibid: 606). Similarly, Mears (2013) argues a personal connection to research can contribute to it feeling more ‘authentic’. This is of course valuable in a number of ways, of particular note was the role my positionality played during the field work. Whilst I mentioned family experience on my recruitment materials, there were moments during interviews where it was more explicitly addressed. This could be in the participant asking me about it, or in moments of agreement or acknowledgment that made clear my experiences. This had an impact on the interview, often seeing participants become more comfortable in the space. As reflected on in my research diary:

> *Interview 3-Similarly to the first two a definite expectation/ comfort in the knowledge that I have lived experiences. I also feel like the stories people share are very interesting. They show what they think I am interested in and they maybe skim over certain things because of this.*
>
> *Interview 4- Felt as though the participant was grateful when I mentioned I had lived experience, they almost seemed to relax a little also. Knowing when to share this information can be slightly tough, but this felt more natural with my reflections being invited in a couple of spots and the participant seeming to enjoy the validation of another person with a similar experience.*

> *Interview 11- The participant grew up in the same city I did and whilst we did not know each other some of the places they mentioned I was familiar with, I felt this helped to relax the participant and led to them opening up more as I was able to ask questions about these things in ways that seemed to work well.*

These extracts capture how I felt my positionality benefitted the interview space, with participants feeling comfortable opening up more as there was an understanding between us. This is reflected in wider research, with it having been argued that personal experience can contribute to comfort in more sensitive research discussions (Bell, 2005*)*. Alongside this, these extracts also highlight the potential shortcomings, with the note of concern about participants skimming over topics due to assuming I am familiar with what they mean. Roberts (2014) highlights this as a potential risk of 'insider' research making clear the importance of asking participants to elaborate on topics that they may have 'skimmed' over. Further, as discussed in the analysis section of this chapter, the 'insider' identity that in some ways I hold brings with it potential to miss nuance, or take for granted aspects of participants' stories (Otter, 2024). Adu-Ampong and Adams (2020) critique the binary nature of 'insider outsider' that can occur, noting how no two experiences are the same and therefore it can be problematic to view oneself as a complete 'insider'. My experiences in a white middle-class family in the south of England will not be universal, and it is important to be reflexive as to avoid the danger that the 'findings will be overshadowed by the enclosed, self-contained world of common understanding' (Mannay, 2010: 94). Drawing on this I was conscious of the risk of viewing oneself as an insider, with the addition of an advisory board one of the ways I worked to mitigate this. I tried to remain reflexive throughout the research process, engaging with the data critically whilst recognising how my experiences influenced how I approached it. The advisory board helped to achieve this, ensuring that people with learning disabilities, and their family members were able to have input in the project as it was coming together.

The second aspect of the positionality is the wider debates within disability studies around '*who should be doing disability research?*'. As captured by the mantra 'Nothing About Us Without Us' (Charlton, 1998), the role of non-disabled researchers within the field of disability studies has long been a topic of discussion. A central aspect of these debates is the importance of positionality, with concerns around disabled people being reduced to a 'topic of study' (Lester and Nusbaum, 2018) leading to calls for more reflexive research. For Stone and Preistley (1996) there is a need for an understanding in which non-disabled researchers' 'knowledge' has a place within disability studies alongside the lived 'expertise' of 'knowers'. They call for the acceptance of non-disabled researchers whilst acknowledging disabled voices must be central to the field.

Ryan and Runswick-Cole (2008) raise the question of the place of mothers within disability studies arguing:

> *'As non-disabled academics who research in the field of disability and who both have disabled children we occupy a position of liminality; we are neither disabled nor non-disabled'* (ibid: 199)

This reflection ties into discussions of 'courtesy stigma' (Goffman, 1990) and 'disability by association' (Burke, 2010; Scavarda, 2023). Courtesy stigma refers to people associated with someone who experiences stigma, experiencing it alongside them. Disability by association builds on this, with both Burke (2010) and Scavarda (2023) arguing siblings of disabled people experience stigma when out in public with their family on account of society's response to disability. Whilst my own work is exploring the experiences of siblings of people with learning disabilities, and my positionality as a sibling could be read as 'enough' explanation for carrying out this research, as the work is concerned with learning disability more widely it feels important to acknowledge these debates. For this reason I felt it was necessary to share my positionality. This said, I am also conscious of the debates around the expectation to share within qualitative research (Paechter, 1996) and the potential position this can put researchers in. Gani and Khan (2024) argue the ‘obsession’ with confessional positionality statements is a ‘hangover’ of the logic of reason and objectivity, a logic Mohamed (2024) argues reinforces the notion of the ‘ideal researcher’ ‘as someone who remains unaffected’ (ibid: 5). Further, Pillow (2003) problematises understandings of positionality as ‘confession’ or ‘catharsis’ arguing this can lead to researchers seeing confession as a means to avoid critically engaging with where they are ‘speaking from’ (Alcoff, 1991; Dean et al, 2018). Whilst the urge to share in disability studies spaces is rooted more in risks of marginalising disabled voices, these examples raise important concerns around ‘confessional’ positionality statements. It is for this reason that whilst I have disclosed my sibling experience, I have deliberately not gone into more detail in favour of recognising that this should not be something we expect of researchers, especially as this can be an expectation levelled more at PhD students (Paechter, 1996). I am conscious of the role of my experiences within the analysis of the data and whilst I am not disclosing further this is not to say I have not engaged in the ‘difficult conversations’ Ktenidis (2024) argues are central to being reflexive about one’s positionality. This is something that I have committed to, and hope comes through in the thesis.

Conclusion

This chapter has outlined the research approach of this thesis along with the wider considerations around positionality and ethics that the project requires. The approach consisted of semi-structured narrative interviews which included timeline mapping and photo elicitation. The analysis follows a narrative thematic framework (Riessman, 2008) with the data presented through extracts and also narrative portraits. This approach was designed with the research questions in mind but also paid special attention to the comfort of participants throughout the process. Reflexivity was key to the project, with the questions and challenges that arose during the work being documented throughout this chapter. The following section of the thesis outlines the findings generated through the research, with each research question being addressed in a specific chapter.

Chapter 4: How do young adult siblings of people with learning disabilities make sense of their childhood experiences of family life?

Introduction

In reflecting on their childhoods, participants reinforced understandings of siblinghood as nuanced and complex (Davies, 2023), offering insight into the mundane everyday family practices that make up being a sibling (Morgan, 2011). This chapter addresses the first research question: *How do young adult siblings (aged 18-32) of people with learning disabilities make sense of their childhood experiences of family life?* In considering this question, the everyday experiences of participants will be explored, unpacking how siblings of people with learning disabilities retrospectively understand their childhoods. To do this participants narratives are analysed drawing on theories from both critical disability studies and family sociology as outlined in the literature review.

This chapter is split into three sections: 'Siblinghood at home’, ‘Sibling care, or looking after’ and ‘Wider family and outside the home’. ‘Siblinghood at home’ focuses on how siblings negotiate the home, looking at communal space, sharing material objects and sharing bedrooms. ‘Sibling care, or looking after’ explores participants’ relationships with the term ‘young carer’ drawing on Meltzer’s (2017) critique of how the label is attributed to siblings without question. This is followed by discussions around responsibility and how siblings see this changing as they grow older. This section concludes with reflections on the gendered nature of care and how this manifested in participant narratives. ‘Wider family and outside the home’ explores family support networks, the role of ‘formal’ care for families and experiences out in public.

Siblinghood at home

Participants reinforced the understanding of home as a key setting for enacting sibling relationships (Punch, 2008; Davies, 2019). ‘Home’ is a theoretically loaded term; this chapter draws on sociological understandings of home as ‘relational’ (Massey, 1994; Smart, 2007) alongside critical disability studies readings of home as a potential space of inclusion (Rapp and Ginsburg, 2011). Through this lens, reflections on the experience of ‘living alongside’ (Davies, 2023) one's siblings and what it means to be a sibling will be discussed. This section will touch on participant reflections on communal spaces, the role of private space in their daily life, and sharing things with their siblings.

Communal space

Central to participant narratives was the negotiation of communal space, understood as distinct from more private spaces like bedrooms with examples such as kitchens or living rooms being commonly discussed. These shared spaces were often where participants spent time with their siblings carrying out the ‘unremarkable events’ that make up family practices (Morgan, 2011: 6). Considering these everyday ‘unremarkable events’, participants spoke to the importance of dinner time practices in families (Smart, 2007; D’Angelo and Moreno, 2019) whilst also offering insight into how these can be reimagined through a critical disability lens. Eva, who was the oldest of four, reflected on how dinner time changed over her childhood:

> *Now it's very much, and when we were a bit older, quite chatty, like relatively long dinner times, all talking to each other. When we were younger it was probably more*

> *eating quicker to get back to what we were doing. When it was just the four of us we wanted to go back and play outside or something* (Eva)

Eva’s reflection touches on how dinnertime has shifted from a means to an end, being able to play outside, to something her and her siblings came to enjoy as a social event. Eva went on to talk about family rules around dinner time:

> *I think we could get down when we were finished, but we had to be finished and we had to sign, that was the thing I remember really clearly, we had to sign like ‘thank you for my dinner, please can I get down?’ and I remember we got to be able to do that bit so quick, like we could sign ‘can I get down? Thank you for my dinner’ speedy.* (Eva)

The family practice of finishing food before leaving the table is cripped (McRuer, 2006; Kafer, 2021) through the introduction of having to sign asking to get down. The reflection ‘we got to be able to do that bit so quick’, whilst humorous, also highlights how her parents saw an opportunity for family practices around dinner time to become a space where they could develop this skill. This in turn sees their family practices become more inclusive. Eva’s parents then took this further, introducing ‘signing only mealtimes’:

> *There were times like when we really trying to learn where my parents would make us have signing only mealtimes and things that I remember finding pretty annoying, I was like ‘I just want to have this conversation’ and they were like ‘sign it’.* (Eva)

This extract can be seen as an example of centring inclusion in their family. This practice Eva found annoying, later going on to note how her brother can understand speech but uses sign language to communicate. At the time, it felt over the top to have to sign at dinner. However, Eva enjoyed showing her signing skills in the interview noting how she still remembers how to sign ‘thank you for my dinner, can I get down?’ in two different types of sign language highlighting the effectiveness of her parents' approach. This story can be seen as an affirmative reading of family dinnertime with the notion of ‘dinnertime stories’ (Fiese and Marjinsky, 1999) being extended in a manner that is accessible to everyone in the family. Considering family display here (Finch, 2007), the inclusive choices at dinner work as display within the family. Eva, her parents and her siblings all work to ensure the mealtime is inclusive for everyone and further learn skills that will extend this inclusivity to other areas of their daily life, displaying to each other that this is an important part of enacting family. The crip element of this reinforces Walsh et al’s (2020) argument on the potential of family display to ‘broaden hegemonic norms around family’ (ibid: 356). Similarly, the everyday nature of this as a dinner time practice reflects Rapp and Ginsburg’s (2011) notion of the ‘reverberations’ that come with having a disabled child. Here, inclusion becomes central to their everyday life through these mundane family practices such as sign only mealtimes.

The expectation of sitting down together and eating as a family was a common occurrence for many of the participants:

> *We’d sit at the kitchen table and we each had our own chair and we'd eat together and no phones and all of that.* (Susan)

> *Yeah, always, we've always eaten dinner, family at the table with our own seats and stuff like that. If I sat in Beth’s seat she would not be happy she’d be telling me to get out.* (Zack)

These examples echo middle-class conventions around dinnertime, with people sitting in ‘their chairs’ and added rules such as no phones (D’Angelo and Moreno, 2019). Whilst these reflections show mundane everyday family practices (Morgan, 2011), other examples pointed to how dinnertime might look different in some families. Dina is the middle child of three, and reflected on dinnertime in her narrative:

> *Sometimes dinner could be quite stressful if she* [Dina’s sister]*, if my mum was trying to get her to eat anything else like baby food or anything, but she wouldn't eat it so then that wouldn't be very nice and, but yeah usually she was okay and that was fine usually it was just me and my brother talking about what we did at school and then my mum and my dad helping her eat and that was fine.* (Dina)

Dina’s reflections touch on an everyday sense of sharing space and ‘being there’. Davies (2023) draws on Brownlie’s (2014) everyday understanding of care and support in their reflections on siblings just existing together or ‘being there’. Dina and her brother chatting whilst her sister eats dinner with the help of a parent reflects a negotiation of disability with Dina’s finishing comment ‘and that was fine’ highlighting the everyday-ness of this ‘non-normative’ practice. The reflection on the potential stress of dinnertime was echoed by Scott who noted:

> *… if he* [Scott’s Brother] *was in a shit mood and he was like stressed and angry it would be like not a fun experience to have dinner because he would be like stressed out and banging things or hitting himself like often I feel like because that’s the environment where it’s like this slight forced thing of ‘no we’re all gonna sit down together now’, not that that made him stressful but it was like otherwise if he was in a*

> *shit mood I'd be like well I'm not gonna be around that and I just wouldn't be near him.* (Scott)

Smart (2007) notes the importance of dinner time practices in families, drawing on DeVault's (1991) understanding of feeding the family as central to producing family. They argue the process of sitting down for meals can be one of the only times family members come together. Scott's reflection highlights a challenging side to this, with the more 'forced' nature of dinnertime creating a situation that Scott cannot just leave. This links to Punch's (2008) arguments around sibling proximity and potentially conflictual interactions. Scott's own approach to dealing with his brother's bad mood is not possible due to being forced into close proximity for the duration of dinnertime. Throughout Scott's narrative there were reflections around how he felt as though his parents did a lot to ensure he was able to be independent which meant he rarely felt as though he could not do things on account of his brother. This example highlights how, due to the work his parents did, he often was able to just go and find his own space if his brother was annoying him. Dina similarly discussed conflict with her sister and how she went about managing those situations:

> *I think I learned quite quickly that if you didn't leave Tyler alone she would probably slap you or something so, not because she was wanting to hit you just she wanted to be left alone so I quite quickly learned that if she said no you just left it and moved on.* (Dina)

Whilst not justifying her sister's 'hitting', the extract does see Dina rationalise the outburst. Where family sociology discusses sibling conflict it is often with regards to disagreements that stem from arguments or in some cases play fighting that has gone askew (Mason, 2018). Previous work around disability and sibling conflict has commonly focused on the disabled person and framed the struggles of their sibling to live with them (Benderix and Sivberg, 2007). Whilst Dina and Scott's accounts of tense situations highlight potentially aggressive and physical behaviour, they also show the care taken to try to navigate these interactions. Further effort is made to recognise the intentions of the actions, with both choosing to remove themselves to resolve potential conflict. This understanding is something that will be returned in a later section of the thesis.

When considering communal space in his house, Scott reflected on how his brother did not always respect his bedroom as a private space:

> *That was his favourite room because it got warm and sunny so he would just go up there a lot of the time so yeah quite often he'll take himself off and he'll, he doesn't like follow you around he's quite happy being on his own and stuff within the house but he'll just walk in.* (Scott)

Scott's brother's actions disrupt the expectation around privacy in your own room (Landon et al, 2022). The reflection places this as part of how his brother navigates the whole house, with Scott's bedroom functioning in a similar way to other communal spaces. This gives insight into the everyday of Scott's childhood, with this being a commonplace occurrence that he was used to. Lincoln (2015) argues that young people's use of their bedrooms can represent wider politics of the household. This sense of potentially 'non-normative' practices as everyday and mundane is revisited in chapter 5. For Faye, there was a period of her childhood where her bedroom was the living room also, as she was quite young when this was the case it was not something she expressed too much bother about. However she did reflect on the comfort having her own space later on brought with it:

> *I think it felt significant. I think there's an element of like you have a bedroom you have a space you get to like choose the colour*. (Faye)

This notion of having your own ‘space’ is reflected in the literature around bedrooms and siblinghood. Palludan and Winther (2017) note how a bedroom can bring with it a sense of control that is often missing in more communal spaces, a sentiment Faye echoes in the significance of being able to choose the colour of the room. The role of bedrooms in participant narratives, and how experiences of personal space varied, will be explored in the next section.

Sharing bedrooms

Alongside discussions of communal space, participants reflected on the role of their bedroom in how they navigated the house. The space a bedroom can afford young people is very valuable, with it offering potential for privacy that is not possible in other areas of the house (McNamee, 1999). The living arrangements of the participants varied, with some having their own bedrooms and others sharing with siblings. For Dina, her bedroom provided a space where she could be on her own, particularly after school:

> *I would usually go upstairs and do my own thing, I could do my homework in my room or I would go and watch TV by myself or read books by myself.* (Dina)

Dina’s experience reflects Lincoln’s (2015) arguments around the roles of private spaces in young people’s lives. Within Dina’s wider narrative was reference to how her sister’s favourite room was the kitchen which connected to the living room. This meant Dina could not always use the living room as she wanted, noting for example that the noise of the games console her family had would often bother her sister. When this is considered with the quote, the importance of having your own space for Dina becomes clearer. Where in communal rooms she had to be aware of how she used the space, in her own room this was not a concern. For participants who shared bedrooms with their siblings the dynamic shifted, with some challenges arising as a result of wider expectations of what a bedroom ‘should be’. Hannah’s portrait offers insight into how this dynamic was explored throughout her narrative. For context, Hannah is the middle child and shared her bedroom with her older sister:

Hannah’s Narrative Portrait: ‘I maybe never saw it as my space. It was shared space and it was just for going to bed’

I remember we always shared a bedroom, well until she moved out when I was 18 we shared a bedroom so that was quite challenging. I think it is that being a teenager is difficult anyway, and then we're sharing a bedroom and she was quite emotional. She's also got hydrocephalus so like her emotion and her learning disability alongside that… I'll say she could be very emotional. She went to a special school, but it was too far away from my house for her to go every day so she went to a boarding school Monday to Friday, she would only come home for the weekend. I was then used to having the bedroom to myself in the week and then she’d come home and we’d be sharing again and I guess that wasn't a time where we were close either. I think it probably could have gone one of two ways, it either could’ve made us closer because we had that more limited time together, but I think with us it just yeah. Because she's in a wheelchair she couldn't go upstairs to our room without going on the stairlift which requires someone else so we never really spent time in our room and, I was thinking about this the other day, people must have gone home from school and sat in their room but we never did that we would always sit in the lounge together and watch TV and eat biscuits and stuff. I think it's because I maybe never saw it as my space. It was a shared space and it was just for going to bed. I very rarely would go up and sit on my bed and read a book or whatever. If I did any of that I would do it downstairs which is interesting actually and whether subconsciously I was like maybe it's *because she’s… I don't know if that's why but we just didn't really spend time in our rooms like we just would always sit around together.*

Bedtime was stressful. I think just not having your own space and not having my own room was really difficult and obviously I'd be there while she was getting dressed into her pyjamas but she didn't really have a problem with that but I think that it’s not relaxing either. So always the bedtime for me, if I ever think about that aspect of my childhood, it just makes me think of like having a knot in my chest, feeling like het up and I think that's also because she would get put to bed and then I would go and have my shower or whatever but she was almost going to sleep by the time I was then ready. I felt like I was just sneaking around and yeah not having any alone time and also she used to make this really, she used to make this horrible noise in her sleep and it used to wind me up so I used to throw my teddies on my bed at her face so that they would hit her and she'd stop making the noise, which is obviously annoying for her as well. So yeah, definitely normal, I feel like if she wasn't disabled I would also have done that yeah and then she moved out when I was 18, so that was, yeah, that was good.

Hannah’s narrative touches on a number of aspects of sharing a room. The overarching point is one of not feeling as though it is your own space, and as the portrait continues we see examples of how this feeling manifests. Once again, there is a sense of ‘conflictual closeness’ (Winther et al, 2015) throughout the whole narrative with the proximity of both the bedroom and also the communal spaces creating feelings that at times led to physical altercations. Reflecting on these moments, Hannah is keen to make clear she would still have done that if her sister ‘wasn’t disabled’ [sic] highlighting wider social expectations around conflict and learning disability. The choice to justify this action as something that comes under ‘sibling conflict’ reflects understandings of sibling conflict as a common occurrence, if not almost expected (Mason, 2018). From a disability perspective this is potentially more controversial, with violence towards disabled people a common occurrence (Khalifeh et al, 2013). Here we see Hannah's sister's identity of disabled person clashing with the identity of being a sibling creating a situation where Hannah feels the need to ensure that

I, the researcher, understand this conflict was just sibling conflict and not something more sinister. Considering this example alongside the notion of sibling relationships as backstage (Punch, 2008), Hannah's justification is an interesting example of a backstage action being brought into the more front-stage environment of an interview. Her choice to justify it can be seen to highlight a concern over the interaction being potentially misunderstood by the audience.

Hannah's comment on other people going up to their rooms after school can be read as a reflection on how her experience differed from what she may have expected. This understanding of your bedroom not really feeling like your own space was also expressed by Emily who stated:

> *My bedroom was very much for going to bed and I think it's probably why I spent so much time at like my friends on a weekend because they had their own room and when we'd closed the door no one would really come in, we could just sit and not even do anything in particular we could just hang out.* (Emily)

Both Hannah and Emily's feelings reflect Palludan and Winther's (2017) findings around how siblings who share rooms feel about the potential of having their own room. Their participants contrast their own experiences with that of friends or other people they knew, feeling as though a space of their own would have been really useful. This links to expectations, a theme which is explored in detail in chapter 5.

The experience of having to sneak around your room once your sibling had been put to bed was shared also by Zara, however she reflects more positively on the fun she had with her sister after her parents had left:

> *Jenny gets given medication which helps her to sleep and I was playing around with her, maybe my parents are aware, oh well, but it was a really positive, it was brilliant, it was so fun you got to read, you got to play and Jenny had a bed that went up to the ceiling, don't know why that design was there, but I would like put us both up and then like jump off.* (Zara)

Zara's account is both crip and affirmative through the repurposing of medical equipment into something they could both play with (McRuer, 2006; Kafai, 2021). We see the backstage setting and close proximity providing the potential to reimagine overtly medical equipment in favour of something more fun, this is particularly pertinent in the comment about not knowing why the equipment had that feature. Zara's story does not speak to the reason for having the bed, instead she was interested in the fun it could provide for her and Jenny. Further, the privacy of a bedroom, as away from parents even if shared, allowed for this fun to take place. Whilst Zara is unsure if her parents knew, this joyful experience is a result of sharing a bedroom and would not occur in a situation where the siblings had their own rooms.

Sharing things: What to watch on the TV

Alongside the role of bedrooms and communal space in the home, participants reflected on sharing things with their siblings, both communal objects and personal items. The key thing discussed across the interviews was the television. Often situated in the living room, the TV featured as a key site of sibling interaction after school or on the weekend with contention arising at times around what to watch. Some participants described a similarity in interests and relative harmony around television choice:

> *She definitely likes more trashy TV than I do. But yeah, I think as kids we generally watched similar things. I can't remember us really having arguments about what we would watch or anything like that.* (Hannah)

> *There's a list of movies where I feel like, I could almost say word for word the entire movie now, like do you know the original Matilda with Danny Devito that's huge in our house, Beth loves that so pretty much that whole movie we could do any sketch from that pretty near perfect I think.* (Zack)

These reflections point to lateral relationships, with siblings often close in age and therefore having similar cultural reference points and interests (Davies, 2023). It is also important to note the joy in Zack's reflection, with the extract providing insight into how they had fun growing up. The role of joy in participant narratives will be returned to in chapter 6. Some participants recognised that the expected 'growing out' of certain TV was not shared by their sibling which meant over time they were not into the same programmes. Hannah for example stated 'as kids we generally watched similar things', while Martha described how her brother:

> *… just stayed watching like the Tweenies, Dora the Explorer, stuff like that.* (Martha)

These reflections touch on Niedbalski (2024) and Nguyen et al's (2024) research into the roles siblings of people with learning disabilities take on over time, often moving from playmate to potentially more support focused roles throughout childhood. Whilst they note how these roles are fluid and change over the life course, the growing out of certain TV programmes can be seen as a small example of how sibling interests can impact how they carry out their daily lives. The notion of 'kids TV' brings with it developmental narratives around what someone 'should' be watching at certain ages. It is important to acknowledge participants were not passing judgement on their sibling's interests, instead noting how they did not enjoy those programmes and therefore it was harder to find something to watch together. For other participants the choice of programme did not pose a huge issue, instead they struggled with their sibling's watching habits:

> *It's very frustrating that he knew everything so well, his memory was amazing, but obviously nothing was watched in a linear order and that was the kind of frustrating thing like ok he's put on, I don't know, Rapunzel or something, that's fine I can get behind Rapunzel I can do that, but then you watch scene 1 and then you watch scene 20 and then you watch scene 9 and it's just like if I'm going to sit here and watch it please at least let it play.* (Oscar)

Oscar's frustrations build on the difficulty of sharing the television, moving past the choice of what to watch and instead taking issue with how his brother chooses to watch movies. Within the reflection is an admiration of his brother's memory going on to explain how his brother would often recite lines from movies just before the character said them on screen. This admiration is directly tied to Oscar's frustration echoing Hayley Davies' (2015a) emotional tightrope with admiration and frustration occurring simultaneously. For Zara, her sister's TV choices were coupled with the fact she got preference on what to watch:

> *Jenny is obsessed with Eastenders so most of the time, Jenny's got trump card on the TV, so we would all be sat watching Eastenders constantly and that's still a thing now.* (Zara)

When asked about her sister's 'trump card' Zara went on to explain:

> *My honest opinion is the kick-off from Jenny is the worst. I think that obviously we could all go do something else… yes maybe it was because you know I could always just go, I didn't feel like that at the time cause I wanted to be there as well… I also did, when my parents left the room I would trump the tele choice.* (Zara)

Zara’s conflicted around why her sister got the trump card, initially noting how her ‘kick-offs’ were the worst of the four siblings. This is followed by a reflection around how the other siblings could all just go and do something else whereas Zara’s sister uses a wheelchair which impacted where she could access in the house. Zara’s comment that she did not feel like she could leave touches on the ‘involuntary nature’ of sibships (Gelles, 1997) and the reality of ‘living alongside’ one another (Davies, 2023), with Zara wanting to be in front of the TV even if what was on did not interest her. The additional note of Zara trumping Jenny’s choice once her parents left gives insight into how siblings negotiate shared space and touches on Winther et al’s (2015) concept of conflictual closeness.

Zara’s narrative also explores fairness, with perceived parental fairness something that is often important to siblings (Gozu and Newman, 2020). Jenny’s ‘trump card’ over the TV did not make sense to Zara when she was younger so she chose to put on what she wanted once her parents were not in the room. When read alongside the discussions Scott and Dina offered around physical conflict with their sibling, Zara’s reflections highlight how wider social expectations around disability do not mean siblings will not question behaviour or actively challenge it when they felt parents were being unfair. Where Scott and Dina showed understanding and chose to remove themselves from situations, Zara wanted to be there and further was happy to ignore her sister’s TV choice in favour of her own interests. Here we get insight into the power dynamics within Zara’s family, with potential birth order hierarchies (Edwards et al, 2006) and wider ‘trump cards’ ignored by Zara as they did not seem ‘fair’. This ambivalence further highlights the everyday reality of living alongside siblings (Gulløv et al, 2015; Davies, 2023).

Some participants touched on how their siblings might break communal things and the implications this had on their use of the space:

> *… he'll break things when he's happy as well, he's just very, he's six foot three and all of that so he'll just go about like one time I asked him to turn the light on, he turns the light on, I turn around the light switch is broken, like smashed I’m like what has happened there but yeah, he's hard, tough on houses.* (Kerry)

For Kerry, things being broken was presented as just a part of daily life. There was a sense of everyday-ness in the occurrence, seen in the remark ‘he’s hard, tough on houses’. When asked about her family's response to things being broken and more widely the resources they had available, Kerry said:

> *I think there was savings in certain aspects where because we weren't on really expensive holidays or anything like that because we weren't able to do those things so savings in that sense but those savings probably went then towards breakages.* (Kerry)

Kerry notes how her family was able to replace things, but felt this was almost a result of the fact they did not go on ‘really expensive holidays’ on account of her brother’s support needs. This ties into wider discussions around resources available to families and how this impacts the experiences of the siblings interviewed. For Susan, things being broken could not always be replaced:

> *I remember him breaking a microwave and us never having a microwave again because he will probably break it anyway and yeah I did notice the way that if things were broken they'd either be put out or replaced.* (Susan)

Here, Susan's experience of communal space is directly impacted by her brother breaking things and her family not always being able to replace them. This directly contrasted with participants whose families were differently positioned in terms of resources and financial capital and therefore things being broken posed less of an issue. In the examples of sharing, and particularly how siblings were often understanding when things were taken or broken, we begin to see the everyday care participants spoke of. A key part of this everyday care centred around an acceptance and understanding that echoes the conceptualisation of 'being there' (Brownlie, 2014; Davies, 2023). The next section explores this sibling care in more detail.

Sibling care, or 'looking after'

All the siblings interviewed referred to some form of 'care' between them and their siblings, with the home being a key site for this. However in many cases they rejected 'care' labels in favour of a more everyday understanding of support. As discussed in chapter 2, when approached through a critical disability studies lens, commonplace understandings of sibling care are disrupted and we are invited to reimagine how we view care and co-dependence. Participants highlighted this through their understanding of care, and what it meant for them and their siblings. This section will explore this focusing on 'Being a young carer', 'Responsibility and looking to the future' and 'Gendered care practices'. Throughout these sections how siblings understood 'care' will be unpacked.

Being a ‘young carer’

Many of the participants had attended some form of young carer group during their childhood. However, their reactions to this varied quite considerably. For Kerry, being a young carer, and attending young carer meetings, provided much needed support:

> *Yeah so I was recognised as a young carer by my GP. So at your GP you can be recognised as a carer’ … ‘it just means for getting flu jabs and stuff as well they know that I'm associated with that but it's also flagged on my records so school always knew that I was a carer and all of that.* (Kerry)

Kerry was the only participant who mentioned being recognised as a young carer by their GP and further went on to discuss how they enjoyed the young carer activities on offer in their local area but wished there had been more. These reflections align with the arguments of Fives et al (2013) around the importance of the term young carer for ensuring people have access to support, with the GP registration being useful for Kerry growing up. Alongside this, Kerry’s pride in being a young carer reflects Smyth et al’s (2011) research around the significance the term can hold for young people. They note potential benefits such as ‘recognition and validation, acknowledgement of responsibilities, peer support, an explanatory label, and accessing support’ (ibid: 150). For others there was less of an emphasis on being a young carer with the label not aligning with how they understood their sibling relationship. However, the commonplace use of the phrase saw it still playing a role in their lives. For example, a number of participants had been encouraged to attend young carer groups by their parents but had not really enjoyed it once there, as shown by Alex:

> *There was one instance where she's* [my mum] *signed me up for a carers* [group]' … '*which I completely, as a kid I completely rejected, I don't want it because I'd have to go on Saturdays, go to this thing and I didn't know anyone so I was like no.* (Alex)

Alex went on to explain that he did not enjoy the social aspect and had initially attended under the assumption that the group would help him become a better carer for his sister. Meltzer (2017) argues that a label of young carer can have relational implications and that often siblings do not see themselves as 'young carers' with the label being something attributed to them by others. For Alex, his mum had signed him up and he himself had 'completely rejected' it. This said, Alex's interest in a group that would help him become better at care highlights support that he would have benefitted from that could be tied to an understanding of himself as a 'young carer'. For some participants there was a feeling of almost confusion around why they were attending the group:

> *They'd be like you are a young carer like you, your brother is a serious situation and you should, but I was never really a young carer, my parents were very good to make sure that I was not the one caring for him like I'm looking after him and no one else is kind of way which is something I thought that was happening to the other kids instead of me, I was very fortunate.* (Susan)

> *I almost felt like, because you had people there whose parents had cancer and stuff like that, and I almost felt like I shouldn't have been there because I was like mine's not really bad it's not a negative kind of care sort of young carer thing. So I almost felt like I didn't really belong there.* (Martha)

For both Susan and Martha there was a sense that their situations did not warrant being seen as a young carer, and therefore it was strange for them to be attending the group at their school. Susan's quote specifically raises an important point about the role of parents in the care expectations placed on siblings, with Susan noting how she was fortunate that she did not have to be the only one caring for her brother. This was in contrast to others who attended the group who she felt took on a larger share of the 'caring', highlighting how sibling care experiences will vary between families. Both quotes align with Meltzer's (2017) reflections around the tendency to ascribe a young carer label to people without asking them nor recognising the nuanced and complex understandings of support, affiliation, connection associated with being a sibling. Similarly, these examples echo Pavlopoulou and Dimitriou's (2019) finding that siblings of people with learning disabilities often do not see 'care' actions as 'care' instead referring to things such as 'helping out'. Scott offered a similar sentiment when asked if he considers himself a 'carer':

> *No, no, I will when my parents have died but I don't now because they do it all.* (Scott)

When asked to expand on this, he explained:

> *I don't see myself as a carer and I've never seen myself as a carer like I never saw myself as a young carer because I didn't do, I did do stuff but I never felt like I was doing stuff so no.* (Scott)

For Scott he did not do enough to warrant being seen as a carer, however he did feel as though this will change when he is older as he will take over his brother's care, something that will be revisited in the next section. Scott's narrative further reinforces the role of parents in how siblings experience care roles, and the privilege associated with not feeling expectations to care (Kuo, 2014). Alongside this, Scott's feeling that he did 'do stuff' but it did not feel like 'doing stuff' aligns with the arguments of Meltzer (2017) and Pavlopoulou and Dimitriou (2019) and with Susan and Martha's feelings around not belonging to the group as their situations were not 'bad' [sic] enough. This was shown in wider reflections from participants in how their 'care' manifested, for example Oscar's reflections on helping with his brother's medications:

> *Yeah, I don't know. I wasn't giving it as a kid and stuff, but you know I mean, it's just normalised, it's just like another thing it's like getting a cup of tea or something it's always on the side of 'oh can you get us epilem, where's epilem' or something, but I think it was normalised.* (Oscar)

Oscar's feelings touch on his experience of living with a sibling with learning disabilities and the mundane family practices that come with that (Morgan, 2011). The normality of grabbing epilepsy medication shows it just become another part of daily life with Oscar's narrative depathologising an overtly medical act (Connors and Stalker, 2007). Through this, expectations around constructing disabled people as 'dependant' (Morris, 1993) are challenged in favour of contextualising the act of care as something mundane and everyday. This discussion of 'alternative norms' is revisited in detail in chapter 5. Building on this, Zara's reflections around taking her sister out for the day provide an affirmative reimagining of sibling care:

> *When I started looking after Jenny in the summer holidays where we would just go shopping, go to the cinema' … 'if Jenny and I could get dropped off somewhere, because you don't want to be with your parents when you're teenagers, and that was*

> *really fun and that was that was much more like chaotic but I just, yeah you are limited obviously it was down to like shopping, movies and like movie days but was amazing I loved it.* (Zara)

Zara's narrative around 'looking after' her sister is presented more so as teenagers hanging out without their parents, with their being clear reference to how both the sisters enjoyed the days out. This reflects more widely arguments around the co-dependent nature of sibling care (Mauldin and Saxena, 2018), with both siblings enjoying each other's company and their time together. Within the narrative sit interesting reflections around how disability can disrupt sibling birth order hierarchies, with Zara being Jenny's younger sister but referring to 'looking after' Jenny (Edwards et al, 2006; Morrow, 2008). Further, the specific reference to 'looking after' reiterates Meltzer's (2017) stories of siblings rejecting care labels. On this, Pavlopoulou and Dimitriou (2019) call for researchers to be conscious of framing 'helpful relations between siblings, in which sisters seem to feel comfortable'... 'as non-normative caring tasks' (ibid: 10). Whilst 'looking after' speaks to the care Zara is engaging in, the word choice is more everyday. Further, the additional reflections around fun centre the closeness in their sibling relationship (Gillies and Lucey, 2006) and the importance of 'being there' (Brownlie, 2014; Davies, 2023). Hayden and Hastings (2022) argue 'being there' is even more important when your sibling is often excluded from social events. Recognising this, Zara's account of 'looking after' her sister holds within it a radical rejection of understandings of 'care as burden' (Gibbons and Gibbons, 2016), in favour of a reading of care that allows joy to be central.

Responsibility and looking to the future

Whilst participants differed on their views towards the label of young carer, most of them felt a sense of responsibility towards their siblings and parents, both in helping out during childhood and looking towards the future. With regards to daily life, these reflections were similar to those discussed in the previous section:

> *It was like if Mum and Dad are really busy doing other stuff in the mornings and stuff like I'd help Guy, make sure he brushes his teeth, had a shower, gets dressed because he still struggles with like doing buttons and stuff on the shirts. So I just kind of help him where I could with that and yeah, taking him places if Mum and Dad can't do it or stuff like that.* (Martha)

This clearly ties into the discussions around everyday care or 'looking after', the difference here being the recognition that they were not just supporting their sibling, but also their parents. This example reinforces Arnold, Heller and Kramer's (2012) argument that some siblings of disabled people can be expected to take on more responsibility and a more active role with regards to care. Kramer et al (2013) note how this expectation often extends to advocacy and working to help access support services. This was reflected in participants' views on the future and how they felt about this both as children and then now. For Alex there was a recognition that he would be the one to look after his sister in the future, a responsibility he felt was tied to him being an adult now:

> *I feel like we've got closer recently because you understand that obviously when my mum and dad go I'm going to be the main carer for Lola so it's gone from obviously being like a teenager going out to now I'm an adult and I need to start.* (Alex)

Alex’s reflection touches on the relational implications of care for siblings of disabled people (Meltzer, 2017), with him seeing his role as Lola’s main carer as signalling a significant change in his life and in their relationship. Alex presented this as a distinct change from how he felt when he was younger. This notion of his role changing over time reinforces Niedbalski’s (2024) research around siblings of people with learning disabilities moving into more explicit care roles as they grow older. Further Alex cites two reasons for this, the main one being because he loves his sister and the second being to make his parents proud. These reasons reflect the closeness of Alex’s family and the love that is central to their relationships, reinforcing understandings of support and intimacy as central in sibling care (Gillies and Lucey, 2006). Scott was the oldest participant in the research at 32, for him the reality of taking over his brother’s care was more immediate:

> *… now is more the sort of background knowledge that there’s this thing that you're gonna be responsible, not thing but like the situation you're gonna be responsible for and what it means for my own life choices and things I want to do.* (Scott)

When asked about whether this was something he has always felt, Scott responded:

> *No, and I think that’s a lot down to my parents like doing the work and not, like on a day-to-day basis, being like I have a load of responsibility to this person because I just didn’t.* (Scott)

The extracts capture how Scott’s feelings around his care responsibilities have changed as he’s grown older. This is a theme that can be seen in wider sibling literature around the negotiation of relationships over the life course and how they change over time (Connolly et al, 2016). Further into his narrative Scott mentioned that this was something he had discussed with partners also. Scott's concerns about his life moving forwards highlight the negotiation of responsibility, and how far it extends within families, reflecting Vanhoutteghem et al's (2014) work around experiences of siblings in law living with a disabled family member. Alongside this, research points towards siblings of disabled people taking over care as they age (Heller and Arnold, 2010). For Avieli et al (2019) this is characterised by a sense of calling or love that is often met with positive reaction, a sentiment shown in Alex's reflections above. In contrast, Scott feels frustrated about this, showing concern over how this experience will be:

> *I feel like a good 50% of the conversation* [with my parents] *is talking about the latest shit with my brother, not him but like his care and things that are going wrong and things they're having to sort out and things that aren't going well and reasons why he's stressed out or his health and those kind of things and that's, a lot of that is a case of shit support rather than him as a person but yeah.* (Scott)

Scott's comments reflect a 'harmonising dilemma' (Dellve et al, 2000), understood as tension between the love and closeness you feel for your siblings meaning you want to support them and the reality of this and the lack of choice you feel you have. This is shown in how Scott is conscious of stressing that these frustrations are 'a case of shit support' as opposed to due to his brother specifically. A similar argument is made by Hwang and Charnley (2010) regarding how siblings of people with learning disabilities experience expectations of care placed on them as both positive and negative. For Leane (2019) these conflicting emotions around sibling care and disability are a direct outcome of a neo-liberal ableist system which places emphasis on individuals and as a result relies increasingly on family care. Scott finished his interview with an honest reflection on this discussion, and his childhood more widely, stating:

> *…there's loads of nuance to it but like it was also shit, not shit for me I had a lovely childhood and loved it and had lots of really nice things and I don't think my parents would say this but it was also shit and I think really in their heart of hearts and maybe in mine if you could change and not have a brother who was autistic I probably would without being harsh on him, he's lovely and I wouldn't change him it's all theoretical but I'm pretty sure I would swap him for a non-autistic brother because of the like ongoing stress and issue and stuff that it causes but that can be the case while at the same time it was really lovely.* (Scott)

Reflecting on his current care responsibilities, and his childhood, Scott captures the 'ambivalence' and complexity of siblinghood (Punch, 2008; Davies 2023). However his reflections take this further unpacking the experience of growing up with a disabled sibling within an austerity context (Leane, 2019). These feelings echo Spagnuolo et al's (2025) reflections around the lack of choice in taking over care that often occurs for siblings. They make clear that this also extends to disabled people who are rarely considered in these discussions either. Scott speaks to the urgent need for better support for people with learning disabilities and their families, a theme that is commonplace in literature on this topic (Conway and Meyer, 2008; Leane, 2024). Further, this has clear implications for Scott and his brother's relationship, reinforcing the importance of support that enables 'productive and fulfilling family relationships for all parties' (Tozer and Atkin, 2015: 350).

Gendered care

Participant narratives reinforced understandings of women being expected to undertake more care roles in families (Read and Wuest, 2007; Kenway, 2023; Travers et al, 2020). Dina's narrative portrait offers insight into these gendered care expectations and how she reflected on these throughout her childhood. Dina is the middle child of three, with an older sister and younger brother:

Dina's Narrative Portrait: 'I think what annoyed me more was that my brother would never think to do that'

I always knew that if we were gonna do something that I would have to help Tyler and I would have to help Samuel do things, that's my brother. If we would go to the park and if my parents weren't helping Tyler then I would be like 'Tyler let's go and do this' or something, she's not bothered about things if you're not doing something so we used to like run around gardens and stuff and she's a really good runner so I would have to hold her hand to make sure that she knew where she was going but that was always quite fun because she could run quite quickly, I liked it, a lot more me than my brother he was never so interested. I think maybe because he was just the youngest it just didn't occur to him, equally I'm a bit more of a social child than my brother, I wanted somebody else to play with so if you don't want to play I'd go and find my sister.

It was pretty good for the most part, I didn't really do anything when I was little there was nothing I had to do like if I didn't want to play with Tyler then my parents would be right there, they would be watching anyway so if something happened or if I was like 'yeah I want to go and do my own thing' they'd be like 'that's fine, Tyler will stay with us' and it was never assumed that I had to do anything. I used to want to do quite a lot so I would help if we went to family events and there was lots of aunts and uncles or extended family and I wasn't so interested in talking to people then I would help Tyler and sometimes that frustrated me because I felt like I couldn't do my own thing but I think had I said to *my parents like I just want to go and sit by myself or talk to people they would have been like 'yeah of course that's fine'. I think what annoyed me more was that my brother would never think to do that so it would just be me who would do it so he was just like off doing his own thing by himself, of course he was… so yeah, sometimes I think he had quite a different experience of the whole thing to me because he wasn't so, I don't know if he was as aware or not really, but he just wasn't so engaged with Tyler when we were growing up and so when it did go to a point where my parents were like 'could you be at home?', when I was about 15 my mum started saying things like 'could you be at home for when Tyler gets home in the taxi because I'll be out but you just have to sit with her for 20 minutes and then I'll be home' or 'could you just be in the house for 20 minutes because I'm going out and your dad's gonna get home in a bit' and that sort of thing, he wouldn't do as much of that and then when I got to about 17, 18, 'would you like to look after Tyler this evening we'll pay you like a proper babysitter and we'll go out and are you happy to do that' like I could put her to bed and stuff like that. But to this day I don't think my brother could do that, I don't think he knows how to do it and he just wasn't as interested. I think I wanted to be part of it, I wanted to know what was going on from quite a young age as well, so yeah. We talked about some things but not a lot of things. I think it's weird because when we have talked about things we've had quite different like memories of what it was like which is interesting.*

Dina's narrative portrait outlines how she would 'help' Tyler and how her brother did not do this. Within these reflections is an understanding of familial care as everyone's responsibility (Leane, 2019), not just their parents. This meant that her brother's disinterest in helping out caused friction between the siblings. The portrait reiterates Mauthner's (2005) findings around the responsibility often placed on sisters to step up more than brothers. There is a clear shift in how care manifests as the narrative continues, with more physical 'active' support being taken on by Dina and a greater responsibility attached to this as shown through her parents offering to pay her for the work. Once again, this reinforces understandings of sibling care changing over the life course (Barnes, 2012; Tozer and Atkin, 2015). There is also a sense throughout the narrative of responsibility leading to more responsibility (Morrow, 2008), with Dina specifically being asked to take on more care as she gets older as opposed to her brother who was ‘not very interested’ from the start. When read alongside literature around the gendered nature of care (Webster, 2018; Wikle et al, 2018) this risks becoming a self-fulfilling situation in which there is already a larger expectation that Dina supports her sister. This leads to more responsibility being placed on her due to her being ‘good’ at it and taking on more of a role initially.

Kelada et al (2022) argue that taking a more active role in sibling care can lead to closer relationships and understandings between siblings, this can be seen in Dina’s account of the conversation between herself and her brother where he does not remember as much as she does. Dina is keen to stress that she was more interested in supporting her sister then her brother was. Once again, there is a sense of the complexities of sibling relationships (Davies, 2023) with care practices and responsibilities in family being the result of a number of factors, both structural and more interpersonal. Through this, wider gendered care expectations are experienced alongside more everyday, mundane, realities of family life. Similarly to Dina’s brother, Oscar expressed not taking as active a role in his brother’s care and the implications this had on his sister:

> *… basically once I started becoming a teenager and going out and stuff and having more of a social life, I was enjoy doing all that work but I did also have the very strong conviction that this shouldn't define my life and I should still be able to go out and stuff and consequently my sister picked up a lot more of that slack and also she was a girl and she's very close to Owen and stuff.* (Oscar)

This want for independence was similarly shown by Scott in the previous section. In seeking this independence, Oscar’s sister ended up taking on more responsibility, something he partly attributes to her gender. Within the wider narrative this reflection was one of understanding of the unfair-ness of this, however offering this as a reason does provide an insight into how these gender-based care practices can reproduce themselves (Erevelles, 2011). Similarly, the reflection reinforces Edwards et al's (2005) argument regarding the expectations placed on women to be at home. Whilst their research is exploring when siblings leave home, the sentiment applies here and finds that whilst brothers are expected and almost encouraged to go out and seek independence, sisters are expected to call home and return home more often. Oscar's justification of wanting independence and to not be defined by his brother partly relies on his sister being at home and stepping in where he previously had. Whilst the examples outlined up to this point have mostly centred around home, the next part of the chapter explores how siblings reflected on experience outside of home, and with people who were not immediate family.

Wider family and outside the home

Within their narratives of childhood, participants would speak of experiences with those outside of their immediate family, and how these interactions, whether positive or more challenging, were an important part of their everyday growing up. This section explores participants' reflections on these experiences through three sub themes of 'Family support networks', ''Formal' care networks' and 'Navigating society'. It is important to note that the narratives are situated within the austerity politics that have characterised social care in the UK since 2010, with this being the backdrop for the majority of the experiences they spoke of.

Family support networks

Participants spoke of the importance of having trusted family and friends who could offer support for them and their families. Under the policy of austerity there have been huge changes to care policy in the UK with disabled people being one of the core groups targeted (Runswick-Cole et al, 2016; Ryan, 2020). This has led to a rise in informal care which, whilst mostly undertaken by immediate family members (Hourigan et al, 2017; Lee et al, 2024), also includes wider family and friends (Broese van Groenou and De Boer, 2016). Throughout participant narratives informal care networks were referenced and discussed highlighting their important role in family life. This manifested in a number of ways, for example Emily and her siblings would go and stay with their grandparents in the holidays:

> *I loved being at my nana and grandad's because my grandad's really strict, he's not strict in the sense that he'd shout at you but he's got an aura you just know not to misbehave and so when she was at their house, she was always really good and so going to their house is respite for me because she wouldn't pull my hair and she wouldn't shout at me.* (Emily)

Emily's reflection on staying at her grandparents is interesting as it references commonplace understandings of grandparents as strict (Peterson et al, 2019), however this is reimagined as a positive thing for Emily as it meant her sister was well behaved and there was less conflict. The change in setting, away from the relaxed and backstage home (Punch, 2008), could also be seen to play a role in their being less conflict. Dina similarly noted the support her grandparents gave, telling a story about a two-week holiday that changed once her grandparents joined them:

> *I remember hating that holiday just the whole time wanting to go home and not having fun at all and yeah she didn't have very much fun and that meant that the whole holiday was kind of like what can we do to make sure the Tyler's feeling okay, and then it wasn't very exciting and then we were a week there and then' … 'my grandparents joined us and I think almost, I don't know whether it was that she felt so much better that they were there or because there were suddenly two more people with another car but the holiday just got a lot better and we could suddenly do lots more things.* (Dina)

Dina's reflections show similarities with Emily's, especially the notion that maybe the holiday improved as her sister 'felt so much better that they were there'. Where this is not a case of 'aura' leading to a better holiday, Dina's account does point towards her grandparents' helping to create a more positive atmosphere. Alongside this, Dina does note that their arrival also meant they had two cars and could do more things. These reasons echo arguments around how grandparents' informal care manifests in emotional and more hands-on practical ways (Koslowski, 2009). Whilst these examples show wider family stepping up and providing needed informal care for all siblings, Kerry's narrative included reflections on more difficult family situations:

> *I know with my mum's parents, it's very much an aspect of if they had Jack, they wouldn't have kept him he would have immediately been put into care or something like that so my mum's mum, she's a bit of piece of work like she doesn't understand why we like him, let alone love him. I think she can understand why we would love him as a family member, but I don't think she understands that we sacrifice a lot and we do a lot because we want to'… 'and she just doesn't understand that and she's*

> *never interacted or made any effort to and that definitely really bugs me because it's not difficult, or from my perspective is not difficult to interact with him.* (Kerry)

There is a conflict within Kerry's narrative between what she expects from family and the reality of her wider family's feelings towards her brother. Gillis (1996) argues that tension can arise between what we feel our family should be like, and the reality of their actions. The extract reflects Lee and Gardner's (2010) findings that how grandparents treat one sibling impacts how other siblings feel about them. Kerry's narrative takes this further with her wider family's non-engagement being rooted in ableism and this impacting her feelings also. The contrast between the wider families reaction and Kerry's closeness with her brother give insight into ableism in families as well as reinforcing the importance of 'being there' when you have a disabled sibling (Brownlie, 2014; Hayden and Hastings, 2022). On the former, Kerry argues that her grandmother has not made the effort and therefore her feelings stem from cultural understandings of learning disability. When read alongside arguments around family as a potential space of inclusion (Stainton and Besser,1998; Thomas, 2024) these reflections encourage caution in how we define family, reinforcing more fluid approaches (Silva and Smart, 1999; Mason and Tipper, 2008) as not all families bring the same inclusion. Kerry contrasted this with her immediate family, who she noted work hard to ensure an inclusive home environment. For Emily, friends played a central role in informal support throughout her childhood. Her portrait highlights the importance she placed on these relationships throughout her narrative. Emily is the middle child of three, with an older sister and younger brother:

Emily’s Narrative Portrait: ‘My mum and dad used to joke that if Claire doesn't like you there's something seriously wrong’

My family were quite social, it is the summers that stick in my mind like on a weekend there would just be people around, whether we were at their house or they were at ours. My dad and my mum have got a lot of the same friends, my mum and dad met because my mum’s brother is my dad’s best friend so like they’ve kind of all grown up with the same friends and, like I say, they all had kids at the same time and when Claire was born we actually called them the A-team and I remember it got really chaotic once the A-team came along because there were like three babies. I actually have a picture from, it's their baptism and I couldn't find an earlier picture of all of us together, but the people sort of surrounding us are my mum and dad's best friends, I was never on my own because all of these people had kids at the same time.

Fig. 2: Photo of Emily’s family and friends at a christening

Photo redacted due to personal data

I have really brilliant friends and I've always been really lucky that the friends I've had are really good friends. So I met Katie when I was four and we're still friends, there was Sarah and when I met Sarah, she had a two-year-old sister and obviously it's not the same thing, but I think she was kind of attuned to listen to people's developing speech and things like that so she never really struggled and so I don't think I've ever had anybody who was difficult to get along with my sister. In fact, my mum and dad used to joke that if Claire doesn't like you there's something seriously wrong because she's such a yes *person like she's always been the more the merrier kind of thing and I think it was probably more of a me thing than them thing but when I was sort of like 17-18, maybe even a little bit younger and going to parties and stuff and if she'd hang around while we were trying to get ready and I'd be like 'Claire get out it's so uncool don't follow me around' whereas they'd always be like 'no, no, she's fine she can stay', they've always been really good, really accommodating with her and Rachel her mum loves to bake and so she would put on like a cream tea afternoon and she would always be like 'please bring your sister' and I think she quite liked having me and my sister around because Claire is super feminine, the idea of watching sports and stuff like that is just offensive in her world and so I think yeah, she's always settled in quite nicely with everybody.*

Emily's narrative portrait reflects the central role friends have played in her family life. The support provided by these friends constitutes 'being there' (Brownlie, 2014) with the portrait highlighting a number of instances of people 'getting it'. When read alongside Mallett and Runswick-Cole's (2014) reflections on the mundanity of being asked about impairment, having people around who just 'get it' and understand your sibling becomes really important. This was seen in Oscar's narrative, where he reflected on dinner time during a holiday he went on with a family who had a child with learning disabilities:

> *We'll be sat around the big dinner table and he'll be signing and speaking, telling a story and everyone will wait the extra two, three minutes it takes to understand that sentence no one's hurrying it along or anything and yeah I really love that. I think it's really cool.* (Oscar)

Whilst Oscar is discussing a friend's family, his love of this interaction reflects Emily's feeling around people who 'get it'. The comment 'no one's hurrying it along or anything' holds within it an understanding of the importance of this moment. For Oscar there is comfort in being in an inclusive environment like this that is tied to his own experience as a sibling of someone with learning disabilities and his recognition that this is often not the case. The story speaks to the potential for siblings to offer a generative insight into what inclusion can look like for people with learning disabilities. A similar sentiment could be found in Zack's narrative:

> *That birthday night was good. Me and Beth went down to the pub together and some friends that I have that know Beth came out and I can remember thinking that they were really good with her in the pub that night and we were kind of just like chatting and doing whatever.* (Zack)

Similarly to Oscar, Zack took comfort in the fact his friends 'were really good' with Beth pointing to the potential for this space to not be inclusive. There are echoes of Kerry's reflection that it is not that hard to engage with her brother. Just the act of chatting and 'doing whatever' was enough for Zack to feel like his sister was included, with the fact he brought this up highlighting how important this was (Hayden and Hastings, 2022). Within these reflections are comments about society and the general attitudes to including people with learning disabilities. For both Oscar and Zack these were exceptions and not the rule when it came to people interacting with their siblings, something that will be revisited in the final section of this chapter. Zack's decision to bring Beth down to the pub along with his friends reflects wider research on the role siblings can play in fostering social inclusion for people with learning disabilities (Boland and Guerin, 2022; Castelino, 2024).

In some cases, more informal support from friends was translated into more formal settings with families who had more control over their child's care opting to hire sibling's friends to do PA work:

> *There's a thing like the council will pay for a carer for Beth so we're allowed to employ whoever, it's basically whoever my mum wanted it to be' … 'that was best job in the world for my friends'...'especially my closest friends who lived nearby and have got to know Beth quite well and basically got paid to go to the cinema with her or go to the theatre and do things that they enjoy, chilling out with somebody that they like and they get paid for it.* (Zack)

Zack's comments point to inclusive understandings of care and the joy care can bring (Gibbons and Gibbons, 2016). They also reinforce understandings of informal care as 'easier' than more formal routes (Robinson et al, 2016) as shown by the family choosing to employ Zack's friends. Moving informal care into a more formal space can bring some challenges, as shown in Dina's narrative:

> *One of my friends started working for my mum and helped look after Tyler' … 'she would take Tyler for a walk and then they would have a snack and do a puzzle and it would be like four hours in an afternoon and that's what they would do and Tyler loved it because it was a special Tyler time and she got to do like what she wanted to do but if I came in and chatted too long to my friend she would get upset and start making like upset noises or something like that because she was like this is supposed to be my time, like you need to leave so I'd have to run into the kitchen and be like, hi, bye and then not say anything.* (Dina)

Here the shift to a more formal role for Dina's friend brought with it some challenges for how Dina and her sister negotiated their relationships with this friend. The move to formal care brought with it expectations around the friend being there for Tyler specifically. The understanding they come to highlights the importance of this time to Tyler and Dina's recognition of this. This willingness to adapt reflects an understanding of Tyler's needs reinforcing the importance of care and closeness in sibling relationships (Arnold, Heller and Kramer, 2012; Davies, 2015a). Alongside informal care networks and the important roles played by family and friends, participants referenced interactions their family had with more formal care networks. These reflections will be explored in the following section.

Formal care networks

Where the reflections on family support networks were, for the most part, characterised by people that 'get it', discussions of more formal care networks raised some difficulties. Participants made clear the stresses and frustrations of poor care, echoing wider arguments on the importance of good support for the whole family (Conway and Meyer, 2008; Tozer and Atkin, 2015). This was shown in Hannah's reflections around a tribunal her parents had attended regarding her sister's schooling:

> *I think I was just aware that my parents were really stressed about it. They were having to pay for reports from private speech therapists and physios and stuff like that to build the case for why she needed to go to that school and stuff. So I think I just remember that being a bit of a stressful time, but also probably I didn't really understand what was like going on, I knew the word tribunal but I didn't really know what that meant.* (Hannah)

Hannah's account reflects wider politics in the UK around treatment of disabled people and their families which can be linked to austerity measures (Ryan, 2020). For Hannah this manifests in her parents having to fight at tribunal creating stress for the whole family. The comments 'I knew the word tribunal but I didn't really know what that meant' highlights how these moments existed within their home, with Hannah being too young to know what it was but still being impacted by the stress of it. Participants also noted how they felt frustrated by the work their parents were having to do in trying to gain support for their sibling:

> *These specialists think they can just do what they want with him but we are his family and we know him best kind of thing and I'll always be mad at people who belittle my mum and dad's voice and don't listen to them.* (Susan)

> *I personally think that my parents do too much and I think they should, and it's hard because I'm not there and I don't see how shit the carers are that he's been provided elsewhere but I think they do an awful lot and they have him for quite a lot of time in the week and stuff and I personally wouldn't do that.* (Scott)

Parents not being listened to by professionals is well researched (Lundeby and Tøssebro, 2008; Ryan and Runswick-Cole, 2009), however Susan and Scott's reflections build on this highlighting the wider impacts on siblings in families where this is happening. Their comments point to the impacts of structural ableism and the pressure it puts on families of people with learning disabilities. On this, Robinson et al (2016) note how these experiences lead to further stress for parents, with these reflections once again touching on how this spreads to siblings and other family members. This is perhaps best captured in Scott's feelings around the carers his brother has, his language reflects an understanding of why his parents do so much and also point towards the state of social care in the UK currently (Ryan, 2020; Moran-Morby et al 2024). When read alongside Scott's earlier feelings about taking over his brother's care, his reflection that his parents do too much coupled with the other option of terrible carers make it easy to understand why he has such concerns over his role moving forwards. It is important to note that some participants did reference examples of formal support that had been positive for them and their families:

> *… the next part I've got there is about the Down's Syndrome Support Group'...'I imagine that that group was a big help to my mum and I don't really know what they offered or things like that but my experience of it was just going every now and then to these kind of like play day kind of things' … 'I was quite happy to be there and then yeah just a bunch of other kids with Down's syndrome and then, you know get to know them, some of the siblings were there as well so there'd be like people my age who were also there with their siblings and stuff so talking to some of those people and things like that so that was always quite fun* (Zack)

Zack's experience at this support group was really important to him, with there being a section of his timeline dedicated to it. Zack outlines the support group as an inclusive space that was fun, a big help to his mum and also a place where he met more people with Down's syndrome and their siblings. His account highlights the importance of more formal support structures when done right (Lefley 1997; Siklos and Kerns 2006) as well as providing an outline for an alternative kind of support to the more intense young carer groups discussed earlier. Oscar similarly reflected on an after-school club that his brother would attend:

> *He started getting support from the local authority from this after-school club which is actually where I've been working recently and all my siblings work which has been really nice and that was a huge part of our life I mean the woman that still runs it was amazing I mean the level of support they could give was just huge and my life is littered through people like this and certain teachers you just can't, when you have a*

> *sibling or someone with those complex needs you can't just function without people like that they are completely integral to your life.* (Oscar)

It is clear from this extract how important good support is for siblings, further building on research that has called for this (Tozer and Atkin, 2015; Leane, 2024). Oscar notes how his life is ‘littered through with people like this’, touching on both formal and informal support networks and the importance of these both working in tandem. Further, the fact that Oscar and his siblings had all worked for this club as they got older reflects how good experiences of support lead to people with lived experience choosing to get involved themselves (Taylor and Shivers, 2011). This was shown in participant narratives with a number of them having volunteered or worked in learning disability services at some point.

Navigating society

A central part of navigating society for many of the participants was the experience of being out in public with their siblings, and how members of the public reacted to their family. These reflections echoed wider literature around stigma and disability in public (Petalas et al, 2009; Schmid, 2024). There was a mix of more explicit interaction and then more passive staring, with both forms being a source of frustration for participants throughout their childhoods. Hannah recounted a story of shopping with her sister:

> *Me and her walked around to our local shop. That was like, I don't know, I think we must have been, she must have been 12 and I was 11, 10 or 11 and a woman came up and was like ‘what happened to you’ or something like that and it was a grown-up like a grown woman. I remember being rageful, feeling full of like absolute rage and just wanting to get away from her.* (Hannah)

Hannah’s story is one that is common, as argued by Mallet and Runswick-Cole (2014) who state ‘being asked about impairment is a mundane and everyday experience for disabled people and their families’ (ibid: 125). Whilst mundane and commonplace, Hannah’s reaction highlights the inappropriateness of this interaction and how these experiences extend to family members as well as disabled people. This echoes Petalas et al (2009) research around the work that siblings have to do in order to deal with ignorant members of the public. Kerry expressed a similar experience with other children’s parents in the park:

> *I remember a lot of situations with that, there'd be a lot of things where parents would be upset with Jack because he wasn't behaving how they thought and then their children would imitate his behaviour and I remember because he couldn't talk so they would be shouting at him and I'd be like ‘he doesn't know what you're on about’, I remember a lot of those situations when I was younger.* (Kerry)

Where Hannah’s experience is almost framed as someone being inquisitive, Kerry’s was of parents telling off her brother for his behaviour. Whilst these are different the outcome is similar with the feeling of frustration and anger being universal amongst the siblings. Kerry’s experience specifically is a sort of extreme example of what Ryan (2010) refers to as ‘surveillance’ through which people make it known to parents when they feel their child is misbehaving. Kerry’s story highlights how this extends to siblings, creating stress and frustration (Moyson and Roeyers, 2012). This also touches on discussions around ‘invisible disabilities’ as shown in Blum’s (2015) work on parenting. They argue parents of children with ‘invisible disabilities’ are seen as less ‘legitimate’ than those of children with ‘visible’ disabilities. Thomas (2024) argues that this can lead to assumptions of ‘bad behaviour’ from other parents. Kerry’s story applies this to siblings, with her support for Jack reinforcing

Nguyen et al’s (2024) argument that siblings often having to advocate for people with learning disabilities’ personhoods. Kerry’s advocacy echoes Jones’ (2019) stories of sibling activism in public encounters, something that is revisited in chapter 6.

Alongside those more active interactions participants noted the experience of staring when out with their siblings, this is something that is commonplace in literature around disability and negotiating public spaces (Garland-Thomson, 2005b; Eisenhauer, 2007; Schmid, 2024). The experience of people staring at their sibling bothered participants, with Dina explaining in detail what it was about staring that she found so frustrating:

> *I don't know I guess it kind of feels that you are becoming public entertainment or something like everybody, like because somebody's making a lot of noise it’s suddenly okay for everybody to kind of, not necessarily enjoy watching you, but they're allowed to keep watching you for a long time’...‘the gawking and prolonged staring, it feels like, even if you're in a public space it feels like you should be entitled to some form of privacy and everybody doesn't need to be staring at exactly what they're doing while you're doing it and yeah, and I think it also annoys me because it feels like people don't have compassion for Tyler like it feels like they think that she's different and because she's different they can do whatever they want, they could just stare at her and she wouldn't notice and she wouldn't care but I don't think that anybody could know if she cares or not.* (Dina)

Dina’s reflection makes clear how staring is experienced by siblings of people with learning disabilities, with this being described as ‘becoming public entertainment’. When read alongside discussions of ‘disability by association’ (Burke, 2010; Scavarda, 2023) you can see how siblings can experience ableism alongside people with learning disabilities in public spaces. This is both through being aware of the staring happening or, in Dina's case, feeling as though they are being stared at themselves. Like the previously explored literature around parents out in public, these moments extend to the whole family and impact how they navigate spaces. Considering Finch's (2007) family display as about showing people 'this is my family and it works' (ibid: 70), Dina's feelings around being allowed public privacy highlights the potential consequences of one's family display not being convincing. Furthermore, the extract shows how 'successful' family display is often tied to normative understandings and presentations (Walsh et al, 2020). Landsman (2009) argues that when parents advocate for their children with learning disabilities in public they are also making a case for their family more widely, both Dina and Kerry's reflections point to this with these difficult public interactions impacting them considerably. Dina goes on to place the staring as an indicator of how people feel about her sister, stating 'p*eople don't have compassion for Tyler like it feels like they think that she's different and because she's different they can do whatever they want*'. This echoes Grue's (2021) reflections on staring as situating one within 'a narrative that has already been written and that is told by others' (ibid: 48). We see in Dina's account how this extends to siblings, highlighting the material impacts of deficit narratives on the everyday lives of disabled people and their families.

Barr and Mcleod (2010) argue families create ways to manage these public interactions. Within their narratives, a number of participants noted their resistance to staring and how they would push back against people who stared at them or their siblings. This can be seen in Scott's reflection:

> *To be honest with you, if someone stares at my brother I'll just stare really like aggressively back, not aggressively but like it's really rude to stare at anyone doing anything.* (Scott)

Like Scott, Dina also chose to stare back. These examples point towards siblings reclaiming staring as a form of resistance against people staring at their family. Martha took her response slightly further, noting how she ‘saw red’:

> *Martha: If we were out in public like going shopping and people were staring at him or you could quickly tell if they were talking about him that used to really wind me up, yeah. I used to see red, I still do.*
>
> *Researcher: what would happen if you saw red?*
>
> *Martha: Well mum would just be like stare back at them, make them feel uncomfortable for staring at Guy but I'd have to purposely make a loud comment.*

These reactions to staring in public reflect frustrations and care from siblings of people with learning disabilities. Where the backstage nature of home saw conflict and ambivalence, participants often noted that when out in public there was a sense of unity in recognition of a non-inclusive society. This reinforces Kittay’s (2001) argument that ‘connections with family members are often the only shield against the slings and arrows of an uncaring society’ (ibid: 571). The choice to stare back or purposely make a loud comment shows the participants looking out for their siblings, standing up for them and challenging ableism in the process (Eisenhauer, 2007). Within this are echoes of Ktenidis’ (2022) findings around systemic violence and bullying in school. They reflect on the role of friends in challenging this, arguing this brings with it a sense of community building and care. Dina, Scott and Martha’s choice to challenge those that stared at their sibling echoes this sense of care.

Conclusion

Throughout this chapter, participants disrupt commonplace expectations around disability and siblinghood, rejecting deficit narratives in favour of stories of nuance and complexity that are rooted in the everyday. This understanding builds on wider family sociology concepts around the backstage nature of siblinghood (Punch, 2008) and the emotional tightrope (Davies, 2015a). Alongside this, participant accounts offered new understandings of siblinghood and disability that further the theoretical lens of this study. This chapter has sat with familial and relational sibling stories, recognising how these insights can contribute to new understandings of learning disability in families across a number of settings and practices. For example, reflections on siblinghood in the home, disruptive understandings of privacy and navigating public spaces were presented along with the challenges these stories potentially raise for more normative understandings. This chapter has touched on a number of areas of family life starting with sharing space in the home. Participant reflections raised discussion around inclusive family practises alongside more frustrating moments that reinforced understandings of siblinghood as nuanced and complex (Davies, 2023). Furthermore, new understandings of siblinghood were offered through a disability lens, with reflections around roles changing over time, disruptive discussions of privacy and the depathologising of medical equipment.

The next section of the chapter explored care and how siblings of people with learning disabilities understand their childhood care roles. Participants echoed Meltzer’s (2017) questioning of the label young carer, with some rejecting it in favour of phrases such as ‘helping out’ or ‘looking after’. This was with an understanding of the work their parents had put in to ensure they did not see themselves as carers, with reference to how this would change as they got older. These reflections brought with them concerns around independence and navigating a broken social care system. This section finished with an exploration of the gendered nature of care, with narratives reflecting wider research that sees care roles fall disproportionately on women (Read and Wuest, 2007; Kenway, 2023). Throughout the section there were moments of affirmative readings of sibling care, with participants taking joy in their experiences and the closeness they brought, rejecting understandings of ‘care as a burden’ (Gibbons and Gibbons, 2016).

The final section of the chapter explored the role of wider family and outside the home. Informal support networks such as family and friends who ‘get it’ played a central role in a number of narratives, in contrast to more difficult and frustrating experiences accessing formal care (Robinson et al, 2016). Within these stories was an understanding of the work parents had to undertake to access an ableist system, with participants being appreciative of the good support their families received both in formal and informal settings. The section concluded with a discussion on staring and how this impacted participants. The stories pointed to wider research on the impact of staring and contributed to understandings of ‘disability by association’ (Burke, 2010; Scavarda, 2023). Alongside these more difficult moments were stories of resistance further reinforcing the role siblings can play in challenging ableist practices. These disruptive stories centred the closeness participants felt to their siblings.

Throughout this chapter participants gave insight into how they understand disability and siblinghood. Whilst this is a thread throughout the analysis, the following chapter will focus specifically on how siblings conceptualise disability and siblinghood, allowing space for their understandings and the tensions they bring to be explored.

Chapter 5: How do siblings of people with learning disabilities conceptualise disability, family and sibling relationships?

Introduction

Throughout their narratives participants discussed disability and siblinghood in a number of ways. Of particular note was the role of the term ‘normal’ which participants both drew on to explain their experiences and actively rejected at different points in their narratives. This chapter addresses the second research question: *How do siblings of people with learning disabilities conceptualise disability, family and sibling relationships?* This will be achieved by exploring how participants spoke of disability and siblinghood and where this discussion appeared within their narratives. How participants chose to discuss disability, or pass by it, holds within it interesting reflections around the mundane realities of learning disability in families. Alongside this, how cultural understandings of siblinghood were drawn on and negotiated within narratives offers insight into lived experiences of being a sibling.

The first section of this chapter explores the role of the term ‘normal’ in narratives, engaging with the notion of normal and how it plays out in sibling relationships. This draws upon Goodey’s (2016) concept of ‘alternative norms’ to recognise how participants’ reject understandings of their experiences as abnormal in favour of placing them as normal to them and their families. This leads into a section exploring how participants drew on commonplace understandings of disability, or the ‘normal abnormal’ (Mallett and Runswick-Cole, 2016). Normal abnormal refers to wider expectations of how disabled people should be, with Mallet and Runswick-Cole highlighting the potential implications of not aligning with these understandings. Following this, examples of how disability was discussed in passing will be unpacked, focusing on the everyday realities of living with a sibling with learning disabilities. Next, more overt reflections exploring things such as references to mental age and impairment labels will be considered. The subsequent section explores the role of expectations in sibling narratives, focusing on how wider understandings of siblinghood aligned with or were challenged by participants' experiences. The way that these feelings were negotiated is then discussed with a focus on the role of wider family and friends. Finally, the chapter concludes with a discussion of being 'known' as someone's sibling and how these 'sticky' identities (Smart, 2007; Davies, 2019) were played out in school and in the local community for participants. Throughout the chapter, I refer to 'hegemonic normal', this is used to capture the socially accepted ways of being that could be described culturally as 'normal' and how participants echoed or challenged these.

The role of 'normal' in participant narratives

Throughout their narratives, participants used the word normal in discussions of family life, siblinghood, and disability. This was broadly in two ways. The first referring to a hegemonic understanding of normal, with participants noting how their experiences echoed or differed from this. In these cases, participants acknowledged a 'normal' way of doing things and used this to discuss their own experiences (Löfgren-Mårtenson, 2013). Whilst this could be seen as problematic, with participants desiring normal in their family lives, these examples are considered within participants' wider narratives to ensure their experiences are presented with context. This contextualisation allows for the nuance of their stories to come through in a manner that avoids falling into deficit understandings of learning disability and siblinghood.

At other times, normal was used in a fluid sense to speak to the everydayness of their experiences. In these instances we see how siblinghood can offer generative approaches to learning disability through this understanding of normal as something that is different for everyone and speaks to one's own everyday family experiences (Rapp and Ginsburg, 2011).

This aligns with the notion of family practices and the ‘unremarkable’ everyday events that make up family life (Morgan, 2011). To explore this, Goodey’s (2016) distinction between ‘alternative norms’ and ‘abnormality’ is drawn upon, with participants placing their experiences in the former category. ‘Alternative norms’ allows for a recognition of the diversity of lived experiences, without creating a category of ‘abnormal’ that stands in contrast to an imagined hegemonic normal. For Thomas (2021) this alignment with normal reflects a wider commitment to resisting being understood as abnormal and the potential othering that this can bring for families (Burke, 2010; Scavarda, 2023). In their discussions participants often moved between these two understandings of normal, at times even evoking both simultaneously. Where this presentation could potentially be seen as contradictory, participants’ wider narratives offer potential to sit with this alongside considerations of the nuances and complexities of sibling relationships (Davies, 2023)

Considering the former first, participants used the term normal when discussing their childhoods to note how their experiences aligned with what they perceived to be ‘normal’ childhood experiences in a hegemonic sense. This was shown in Zara’s description of a photo of a camping holiday:

Fig. 3: Photo of Zara’s family camping trip

Photo redacted due to personal data

> *… We went swimming and for dinners together a lot, just everything you would expect for a normal kind of camping holiday* (Zara).

In this extract Zara draws on wider discourses of normal with reference to a 'normal kind of camping holiday'. For Thomas (2021) 'recognising that disability can, for parents, coexist with normative notions of 'the good life'' (ibid: 455) is a disruptive act that challenges deficit understandings of disability and family. The extract extends this understanding to siblings, the family holiday reflections evoke normative notions of 'the good life' with Zara keen to point out how her family was able to go on a 'normal kind of camping holiday'. Within this is a tension around the importance of questioning what normal means whilst also recognising that for many disabled people and their families 'fitting in' is something desired (Kittay, 2006). Thomas' (2021) argument provides an understanding of this which is disruptive in nature, allowing scope for normative ideas to be drawn upon in potentially generative ways. This was echoed in Emily's narrative:

> *On a Friday or a Saturday if my mum wasn't there, she was at work, I would always help to get my sister ready in the morning. Just because like I said, I didn't want her to feel embarrassed about her hair and it's such a small thing in hindsight being like I didn't want to have ugly hair but I think in hindsight, there's enough things that people could sort of, like mean spirited people could make fun of her because she dribbles or she can only wear Converse and you know kids at school if they're not cool or in fashion at the minute it's that thing where somebody could take the mick out of her and I think I've always felt quite protective of that if I could mitigate anything to sort of make her, I don't like the word normal, but to feel like everybody else feels.* (Emily)

In Emily’s reflection we see how she struggled with the word normal whilst simultaneously feeling a need to help her sister ‘fit in’. This touches on an interesting point regarding the risks of moving away from what is seen as ‘normal’ especially in a school setting, a topic which Ktenidis (2022) highlights in the school experiences of young people with dwarfism. Emily’s personal feelings towards the word normal struggle to align with the reality of a non-inclusive school system. Writing on the desired non-normativity of youth, Slater (2016) argues non-conformity is something that requires privilege to be exhibited without question stating ‘the (sometimes) expected abnormality of youth can only be safely played out by the most normative and privileged of people’ (ibid: 16). Emily’s reflections can be understood as a desire for her sister to fit in that is not rooted in desiring normal but more so from a place of care and concern for how others will treat her.

Where more affirmative understandings of disability, otherwise reinforced in this project, push for a celebration of standing out (McRuer, 2006) or being a ‘misfit’ (Garland-Thomson, 2011), Emily raises an important concern around the lived reality of this in a school setting that is not inclusive. Whilst this could be read as a non-disabled family member pushing normativity on their sibling with learning disabilities, this reading would overlook the love and care of Emily’s actions and the want for her sister to not be made fun of. Hayden and Hasting’s (2022) discussion of sibling care builds on this, they argue ‘siblings are able to offer friendship and support where elsewhere in society, many disabled people continue to face discrimination and exclusion’ (ibid: 6). Through this reading, Emily's choice to try to help Claire ‘fit in’ plays on her recognition of this wider risk of discrimination and exclusion. Emily’s reflection, along with the others in this chapter, point towards the nuances of the term normal and how participants were both aware of its potentially problematic connotations whilst also feeling it was important to draw upon and evoke at different points.

Emily’s feelings were echoed by Alex, who similarly mentioned in passing how he did not like the word normal, when asked to discuss this he said:

> *It's one of those things like what is normal again, what is normal and it's not so much that I hate people saying it’ … ‘but I hate myself for saying it, I feel like I'm offending someone you know what I mean, rather than people, again I wouldn't get offended by it, in fact I say it myself’ … ‘it's just me being maybe a bit that I shouldn't say it, say if I was around Lola’s mates and I said it I would maybe expect someone to say ‘but what do you mean by normal’ do you know what I mean’…’it's one of those words where it sounds bad, I go to say it but yeah I almost feel guilty for saying it.* (Alex)

Alex touches on wider discussions and understandings of the word normal, noting how his sister’s friends might call him up on using it. These feelings reflect the arguments within critical disability studies that critique understandings of normal as a ‘non-identity’. McRuer (2006) states normal exists in relation to the positioning of disability as ‘deviant’, with Löfgren-Mårtenson (2013) noting the role of this understanding in situating normal as a flexible non-identity. Here, Alex’s sister’s friends echo this by challenging him on using it in this manner, with the question ‘what do you mean by normal’ channelling this discussion. Alex’s reflection on how he says it whilst also recognising it sounds bad holds within it a nuance around how he negotiates his own life and the different spaces he occupies offering distinction between those in which he may be challenged and others where he is unlikely to be called out for this. This reflects the potential for siblings to learn from each other and the impact disability can have on this, which will be returned to in the next chapter.

Many of the participants, including Alex, also referred to normal in a more fluid sense in their narratives. This ‘alternative normal’ relates to personal experience and how what is normal is dependent on your own lived experiences:

> *…growing up with disabled sister it's weird how because it's so many years it grows to be like a normality, you wouldn't know what it’d be like any different, absolutely what it'd be like without, so you can’t, it's kind of like normality for you so I can't really comment, obviously I haven't got an experience where I haven't had a disabled sister so it's hard to comment on that.* (Alex)

Within Alex’s statement is a sense that his experiences were both ‘not normal’, understood here in a hegemonic sense, but also normal for him. This echoes Goodey’s (2016) distinction between alternative norms and abnormality, with Goodey inviting us to rethink normal and recognise the fluidity of the term. For Alex the everyday nature of his experiences see them become part of the practices that make up his family life (Morgan, 2011), which brings with it a sense of normal. Thomas’ (2021) reflections of the ‘crip’ nature of disability existing alongside ideas of the ‘good life’ offer the potential to further this. Participants evoke the ‘good life’ by presenting their daily lives as their normal, cripping understandings of learning disability and family in the everyday. This sees them place their experiences as ‘alternative norms’, refusing understandings of ‘abnormal’ lives and the ‘othering’ that people with learning disabilities and their families often face (Burke 2010; Scavarda, 2023). This was seen in Hannah’s narrative, where she was explicit about how her situation growing up was ‘not normal’, in a hegemonic sense, whilst also being normal for her and her family:

> *Do you know what I used to be very against ‘people are normal and people are not normal’ and saying that because that's not too true, everyone's normal but I think it's*

> *okay, our situation was not normal and her life is not normal because the majority of people don't have a life like hers and didn't have a childhood like hers, but yeah, yeah, I think I was aware that it wasn't what other people did but it was normal in our family and it was normal to us and so it didn't feel, it didn't feel like 'oh god what an awful tragedy'. It was just different.* (Hannah)

Hannah's understanding of normal is rooted in what the majority of people experience, situating her family's experiences as outside of this and therefore 'not normal'. Hannah goes on to then acknowledge that this does not mean that their experiences should be understood in a tragic sense, rejecting a deficit understanding in favour of one that acknowledges difference without problematising it. There is a clear sense once again of the fluidity of the term normal as used by participants, with Hannah simultaneously evoking a hegemonic normal and also her own alternative normal. This fluidity, combined with the rejection of a deficit understanding, highlights a lived experience of disability in which difference is not 'an awful tragedy', it is just a mundane part of Hannah's everyday life. This was similarly echoed in Oscar's discussion on having ambulances come to his house growing up:

> *I was the eldest right so through this early part of this life I did a lot and I kind of enjoyed the responsibility and stuff but yeah, regularly, at like seven or eight, calling ambulances and waiting outside and telling them what's going on was kind of very normal.* (Oscar)

The action of calling and then directing ambulances was something that became normal for Oscar due to how common it was for this to be the case. Similarly to Oscar's discussion of epilepsy medication addressed in the previous chapter, there is a sense in the quote of the everyday-ness of disability in his family. Where for many having to call and direct an ambulance at a young age would be a big moment, it was just a part of life for Oscar, one that he noted brought some enjoyment through the responsibility. Rapp and Ginsburg (2011) refer to 'reverberations' in how new norms are created for families of people with learning disabilities. They argue these potentially 'non-normative' moments become normal for families and become established as family practices. This is similar to the dinnertime stories presented in the previous chapter, with participants presenting family dinnertime practices that whilst non-hegemonic, were normal for them. Alongside this, Oscar draws on cultural narratives of siblinghood evoking a sense of birth order hierarchies through his understanding of this being his role as the eldest. Oscar built on the experience of this at different points in his narrative:

> *…it's so cool like the lengths you go to to kind of care and look after people so I just really loved all that stuff like I'm actually really gutted I lost them but I used to collect you know when paramedics come and they transcribe all their notes and they give you a copy I used to have hundreds of them so I kind of liked and I found interesting I thought it was kind of cool you know the kind of extra measures I don't know you can have had to go to for all of the things Owen required.* (Oscar)

> *For my year six soapbox, everyone had to do a little presentation about something whatever, most people did football, my 10-year-old self gave a 15-minute presentation about complex epilepsy and rescue meds and stuff. My year leavers book asked what do you want to be when you're 30, everyone's like footballer or ballet dancer, I would say paediatric heli-med trauma surgeon or something, so yeah, it was just normal I mean you don't know anything else.* (Oscar)

The first example reiterates the previous chapter’s discussion of the importance of good care, and how it impacts families. Oscar clearly gained a lot from his experience with paramedics feeling a strong sense of respect and also interest in their work. The ability to enjoy those experiences could be seen to be tied to the everyday-ness of them, enabling these more positive reflections. Once again, Goodey’s (2016) notion of alternative norms as opposed to abnormal is evoked in Oscar’s consistent reiteration of these experiences as normal. This is particularly apparent in the second quote in which Oscar contrasts his aspirations with those of his peers stating how they were still normal to him. This highlights how even if we take an understanding of normal as fluid and individual, wider cultural understandings of what normal is still feature heavily in how we understand the world. Kerry expressed a similar sentiment of the everyday-ness of medical experiences and how this led to different understandings to her peers:

> *When I was in nursery, and I read this in one of my reports of what Kerry did today, and apparently one of my peers, so another like three, four-year-old, had asked why my brother wore a hat, so the epilepsy helmet, when we were both at the same nursery and apparently I went into quite some depth and when I was reading it with my parents, my dad was like so basically you explained in harrowing detail but it didn't bother me and it was completely normal* (Kerry)

This reflection touches on a number of interesting areas, first the story of a peer asking about Kerry's brother’s hat which reinforces the mundanity of being asked about impairment (Mallett and Runswick-Cole, 2014). Going on to answer this question in detail, Kerry disrupts expectations around what children should be discussing and have knowledge of, as is captured in the report of what Kerry did that day placing it as something out of the ordinary. Kerry’s understanding was simultaneously ‘completely normal’ to her whilst being non-normative within the nursery setting reiterating the fluidity of definition alongside the understanding of wider cultural discourses of what is considered normal. In both Kerry and Oscar’s examples there is almost a sense of pride associated with this disruption of expectations and by extension of their personal sense of normal in contrast. Kerry’s use of humour captures this, centring the absurdity of the story (Morreall, 2009). As with Oscar and the epilepsy medication, Kerry’s narrative sees the depathologisation of an overtly medicalised act, something she unpacked further:

> *… again I think I was kind of too young for it to really bother me and doctors and hospitals are already so normal to me’ … ‘hospitals and everything, just always felt very normal I had quite a lot of knowledge about that even though I didn't know my ABC's probably at that point, but I could identify seizures and stuff.* (Kerry)

Kerry reiterates the everyday-ness of these medicalised settings noting how maybe her young age played a role in it not being something that bothered her. Like Alex there is a sense here of not necessarily having a point of comparison further reinforcing the fluidity of what is a ‘normal everyday experience’. Alongside this, the quote holds within it reflections on responsibility and care from Kerry’s perspective. As was the case with Oscar, Kerry learnt to identify seizures quickly as it was important and that was something that came as a result of the everyday-ness of these hospital visits and being around doctors as well as her brother’s seizures. In this regard, the action became a mundane practice that was part of Kerry’s family life (Morgan, 2011). The next section explores how the narratives of ‘normal abnormal’ featured within narratives, giving further insight into how participants conceptualise disability.

Narratives of ‘normal abnormal’

Alongside drawing on the term normal in discussion of their daily lives, some participants also drew on cultural understandings of disability when discussing their sibling. Mallett and Runswick-Cole (2016) refer to the ‘normal abnormal’ to describe how even if disability is placed outside of the hegemonic normal within that placement there is still a ‘normal’ attached to impairment labels, often rooted in medicalised understandings. This was shown in Scott’s description of his brother:

> *I don’t know the right terminology but he's like very autistic like I’ve not met anyone that’s like more autistic than him I don’t think, I don’t know. It was very obvious from an early age like he got diagnosed very early so I don’t know if I remember there being a time when it wasn’t.* (Scott)

This response came from a question around whether Scott has always known his brother has learning disabilities with Scott’s answer drawing on cultural understandings of autism to convey an idea of his brother as ‘very autistic’. Through a critical autism studies lens this definition does not offer much, autism is not something that has a ‘biomarker’ and therefore the diagnosis process is rooted in social understandings meaning the term is applied to a very diverse group of people (Woods, 2023). This said, Scott’s description is reliant on cultural narratives of autism, and the interviewer’s knowledge of this, to describe his brother. These are narratives that can be seen as medicalised and shaped by ‘psychological and psychiatric discourses’ (Runswick-Cole and Goodley, 2023). Susan drew on a similar narrative when describing her brother:

> *I mean, he's very outwardly, sounds weird to say outwardly autistic that's a weird saying but yeah, I never spoke to my parents about it, it was always just a thing that was right in front of my face.* (Susan)

For Susan there was an understanding that this description was 'weird' reflecting some discomfort in this. Considering the normal abnormal (Mallett and Runswick-Cole, 2016), both Susan and Scott evoke 'normal' narratives of autism to describe their siblings. Faye looked to these understandings of autism when describing her brother, however she focused on how her brother did not align with them:

> *… my brother isn't a genius who has bad social skills which I think was, I think my whole family have learned about autism via Luke and then that becomes our kind of internal marker of it and actually thinking of autism as a spectrum' … 'I remember like making friends at uni who had autism and my mum would know and she'd be like are they allowed to drive she would think well they must be like Luke and so it's kind of like I know how my family sees autism but then I also think the rest of the world see autism, as I don't know, Sheldon Cooper type.* (Faye)

The distinction between how Faye's family sees autism and then how others do is used to ensure that when describing Luke, Faye does not misrepresent him through the researcher associating the term autism with certain characteristics. The extract references 'Sheldon Cooper' the Big Bang Theory character touching on more pop-culture understandings of autism commonplace in the media (Matthews, 2019). Zack similarly rejected cultural narratives of Down's syndrome throughout his interview, as highlighted in his portrait. For context, Zack is the middle child of three:

Zack’s narrative portrait: ‘I think they always think that people with Down’s syndrome love to hug everybody or run up to everybody and be cuddling and stuff like that, that’s definitely not Beth’

I’d describe Beth's personality, it's always been kind of, she loves being the centre of attention but she never demands it. She’s not, some stereotypes people have for people with Down’s syndrome, I think they always think that people with Down’s syndrome love to hug everybody or run up to everybody and be cuddling and stuff like that, that’s definitely not Beth, she's quite introverted I think for somebody with Down’s syndrome. My mum has taken her to the hospital a few times to have checks and things and I think that she is on the autism spectrum I think, it's very very light, I think I mean I don't really know too much about that and I think that's, that was more important for my mum to sort of understand I think and so I don't really know too much about that. So Beth isn't the big hugging, shouting, super excitable she's a lot more chilled out and laid back which I think actually makes her quite popular at school and things like that I think that's kind of helped her out a lot, for people liking her and she might take a while to warm up to people a little bit but yeah I was just saying that because I could see that the contrasting personalities with some people that come around our house sometimes and this other girl, she was very physical, she loved to fight so me and my brother quite liked it we'd be play fighting on the bed kind of thing and things like that but then I think Beth could get a bit sick of it sometimes and want everybody to get out or whatever.

I think in terms of the stereotypes, I probably didn’t know what stereotypes of people with Down’s syndrome were but I knew other people with Down’s syndrome like the boy in my class for example and like, so then with Beth yeah I guess like yeah I think I knew because she had, I knew she had the disability I think I was just happy that people liked her. I didn’t know that Beth wasn’t so much against the stereotypes maybe until I was in secondary school and I get more of an impression of what people thought about people with Down’s syndrome but because she was a little bit more reserved. You get to realise that with everybody with Down’s syndrome, just because they have Down’s syndrome doesn’t mean they will fit into the same personality type, you know everybody that I've met with Down’s syndrome is a little bit different. There are definitely some similarities there, usually in the *sense of humour is always quite similar but again, that's human beings, sense of humour is pretty similar with most people but yes, everybody's got different personalities and then also that some people have, not just different personalities but different capabilities as well is a big thing, this is something that I feel a little bit more awkward about today where like just the other day I saw a really cool video it was an American girl with Down's syndrome and it was 'just because I got Down's syndrome doesn't mean I can't do this' and then she does the thing and 'you think I can't do this blah blah blah' and that's really cool and I'm like it's really ace and it's really good but there is always a little bit of a thing of like, I guess it's more that I feel for my mum a little bit where Beth won't be able to do those things, Beth doesn't have that capability.*

Throughout the portrait there is an 'urge to know impairment' built upon cultural understandings of disability (Mallett and Runswick-Cole, 2016) perhaps best seen in Zack's musings around whether Beth is autistic. This thinking is rooted in how Beth does not align with stereotypical narratives of Down's syndrome leading Zack and his mum to speculate that she may be autistic. Mallett and Runswick-Cole (2016) recount a similar situation in which a participant expressed concerns about their daughter not being the 'happy smiling person with Down's syndrome' who dominates cultural understanding. They argue that labels bring with them a hope for certainty through the promise of 'a 'normal' version of abnormality' (ibid: 114). Further, the participant thinking that her daughter may be autistic works to 'neutralise the dangers of the abnormal Down's syndrome by introducing another 'category of existence' and hoping the overlap would provide the punctual explanation and unified order' (ibid: 114).

As the narrative portrait continues we see how cultural narratives of Down's syndrome, and attempts to disrupt these, can be frustrating for Zack due to his feeling that they do not represent his sister. Zack deconstructs stereotypical assumptions with a care and consideration that echoes Goodey's (2016) notion of difference as something to be celebrated, citing Beth’s laid back-ness as a key factor in her popularity. However he also notes how he feels frustrated with more disruptive discussions of Down’s syndrome as he does not feel his sister is represented in these arguments. This highlights the potential dangers of not fitting into the ‘normal’ of an ‘abnormal’ category and the potential for more disruptive work to leave people behind in the pursuit of assimilation. The urge to know impairment was echoed by participants, for example Eva:

> *I remember being a certain age and asking my mum like ‘why has he got special needs?’ like ‘what's he got?’ basically, which was always a bit harder to know because he doesn't have autism or Down’s syndrome or something like he has a chromosomal abnormality, so it's, I mean obviously lots of other people have chromosome abnormalities, but they all manifest differently so he's kind of the only one who's got exactly the combination of things that he's got.* (Eva)

Within Eva’s reflection is a medicalised interest in knowing impairment as captured by the ‘what’s he got’ question. Her brother’s impairment label does not evoke a well-known narrative as she feels autism and Down’s syndrome do and therefore she did not get the answer she was hoping for from the discussion with her mum. This reflects how common understandings of specific impairments are medicalised (Mallett and Runswick-Cole, 2016). This is interesting when read alongside Zack’s narrative portrait which challenges this notion of an impairment label of Down’s syndrome bringing with it explanation. Oscar similarly explained how his brother did not have an impairment label taking pride in his unique-ness:

> *So yeah, we tried everything but there was really no rhyme or reason and he never had an actual diagnosis, Dravet syndrome is a particular type of epilepsy and later on we thought whether it's this kind of sodium channel mutation all of which came back*

> *negative. So, his epilepsy was really up there with kind of some of the most unique epilepsy you can get in the world which you know, I always thought was pretty cool.* (Oscar)

Oscar's account both reflects the 'urge to know impairment' but also crips this through the celebration of a lack of answer. Further, Oscar's pride works to reject the pursuit of the 'normal abnormal' instead inviting us to embrace the non-hegemonic through celebrating it as 'cool'.

Discussing disability in the everyday

Alongside participants discussions of normal, were examples of aspects of their daily life that could be seen to be linked to their sibling having learning disabilities but were not explicitly unpacked in their narrative. Within these moments we can see the everyday of learning disability in families. This was shown in participants talking about schooling growing up, for example the recurring notion of their sibling getting a taxi to school:

> *Yeah, we got up on a similar time frame. Tim would always have to go earliest because his school was furthest away and he would go in a taxi but the same taxi every day* [it] *was like a school car I guess.* (Eva)

> *Yeah, I think it was like you just, mum and dad would get Guy sorted and then he'd get picked up by taxi and I'd kind of just get ready on my own and John would as well* (Martha).

> *When I think of mornings before school my brother's not there I don't remember it. Oh no, no I do when he used to get, when he used to go to a school that he needed quite a long taxi to go to he'd leave quite early I think he might even have left before I was properly up basically and I think like any morning before school with kids it was basically like a manic rush to like try and get shit ready and my brother won't rush, like he just doesn't.* (Scott)

In each of these examples, and for many other participants, we see their sibling with learning disabilities being the only one of the kids that gets a taxi to school. The idea of getting a taxi to school is common for kids who attend non-mainstream schooling with the taxi picking up a number of kids in the area hence there being certain timings that have to be met. In these cases their siblings always left earliest, which meant for Martha and Scott in particular they were not there when they were getting ready for school. The fact that this was not linked explicitly to disability by participants reflects the mundane reality of this occurrence and how it was experienced by them, as one less person in the house. For Emily, her sister was there along with her brother in the morning which similarly echoed the rush Scott referred to:

> *My sister is a really early riser but I remember me and my mum would just get up and get on with things but my dad and my sister would like sing and it would drive me and my mum insane, we'd be like 'can you just hurry up and get on with things, can you just feed her' and I remember my mum would always be like 'this is not what the mornings are for'. So it was always a bit rushed but I think that's just symptomatic of having 3 kids and like trying to get everyone to work and school on time. We used to watch Bear in the Big Blue House every morning and my sister, I'd sit in silence and them two would be like really annoying and if I'm honest I don't remember where my brother was in those mornings, I don't know if my mum fed him separately, I don't*

> *know if they used to like tag team and my dad would feed my sister, I honestly don't remember. I think my dad and my sister just stand out because they would like sing and dance and stuff like that and I'd be like 'oh my god'.* (Emily)

This story of the morning before school focuses mostly on frustrations around Emily's dad and sister singing and doing things that Emily and her mum found annoying. At other points in the interview Emily talked about how her sister had a feeding tube and had to be fed by her parents at different times in the day. In this story Emily chooses not to draw on this or make it explicit, instead her sister needing to be fed is a mundane aspect of her everyday, placed to the side of the narrative. This echoes Morgan's (2011) placement of family practices as 'unremarkable events' of daily life. Once again there is a sense of the everyday reality of 'living alongside' (Davies, 2023) a disabled sibling with the feeding becoming just another mundane action, an 'alternative norm' of Emily's family life (Goodey, 2016). This was the case at other points in Emily's narrative, for example what she chose to focus on when discussing how she and her siblings were parented and how this links to her own understanding of disability:

> *They had to treat her differently for obvious reasons in specific ways, but if she was naughty she was in trouble the same way that me and Adam were or if she was good she was praised in the same way, she was treated really similarly to us and so I think I didn't really think about her disabilities until I was much older and once she became more verbal. I've always been able to understand her really clearly and it's only when people that don't maybe see her as much try to speak to her and I realised that she might be a bit difficult to understand. Whereas I understand her intonations and what she means when she says certain things and God since she started talking she doesn't stop.* (Emily)

Emily’s reference to disability works to make clear that her sister was, for the most part, treated the same as her and her brother. Even in the reflection on how there were some instances where Claire was treated differently, for Emily the main thing was that she got in trouble the same way and was praised the same way. This reiterates the importance of fairness to siblings, a theme that is commonplace in literature around siblinghood (Heath, 2018). Further, this is then linked to how Emily understood disability growing up, with the main reflection being that she did not really consider it until she was older and began to realise that others might struggle to understand her sister. Interestingly this is then brushed over with Emily making a joke about how much she talks. This understanding of her sister touches on the closeness and love that can make up sibling relationships and can also be seen as an outcome of ‘living alongside’ (Davies, 2023) with Emily not noticing her sister’s speech until others who are less used to it struggle to understand her. As explored in the previous chapter, this story speaks to Walsh et al’s (2020) argument around the role of the audience in family display. For Emily what could be seen as a successful display within her family shifts when introduced to an outside audience who struggle to understand Claire. This reflects discussions from the literature review around home as a space of inclusion, with Hall’s (2010) notion of a sense of belonging which is tied to inclusion being seen here. We also see an understanding of home as ‘comfortable’ (Boccagni and Kusenbach, 2020) and relational (Smart, 2007) with Emily and her family all working to create an inclusive space.

Similarly to Emily, Zara’s reflection on her sister’s school was framed around her experience of the place as opposed to the fact it was a non-mainstream school:

> *I was so jealous of her primary school, she was like living it up like we went on holiday to her school in summertime because it was so fun there like, I don't know*

> *why they just allowed it, they opened up for parents cause obviously they've got everything adapted for disabled children and the rooms are massive which meant I could come as well and other siblings came along as well and it was, oh my goodness, it was so fun like we, it would just be like me and my mum, Jenny and then all the other parents with their siblings and it was just like amazing you would be, it's probably really bad, but would be playing on all of the equipment like swinging along because like we are all used to it because we've all got it at home but it's just way better at the school.* (Zara)

Zara notes that the school is adapted for disabled children but aside from that the focus of this extract is the joy and fun they had visiting the school in the summer. Like Emily the focus here is on her experiences of this school as opposed to the reason her sister was attending. This story is also affirmative both in the excitement Zara expresses in discussing the school and in the joyful reimagining of medical equipment as objects that kids could play on. When asked about not attending the same school as her sister Zara explained that this was not something she found unusual as all her siblings attended different schools to her:

> *So everyone was at different schools, my oldest two siblings were the same school, Jenny's different and I went to different the reason that we weren't at the same school as my two older ones is because they are quite a lot older than me and the catchment area changed so I couldn't get there so actually, I actually, it's so interesting you brought it up because I never thought about it, because everyone went to different schools.* (Zara)

This reflection reinforces the fluidity of normal for different people and families (Goodey, 2016). For Zara as all her siblings were at different schools it did not feel like a big deal that her sister attended a separate school and further the fact that this was a non-mainstream school did not even cross her mind. This was just a mundane reality of her childhood as opposed to a factor that meant that Jenny was experiencing something different to her siblings. Returning to the focus on how disability was discussed in passing within sibling narratives, Ellie's discussion of what she would do with her brother in the summer touches on disability whilst the focus is on fun:

> *We have a trampoline. We used to have a trampoline because I think it was part of his fun government funding that we could get a trampoline. So we played on the trampoline for ages every summer and we played on our bikes a lot as well.* (Ellie)

The mention of government funding is linked to her brother's learning disability but again the focus for her is the fun of the trampoline and the role that played in their childhood. The funding is presented as a side note on how it was acquired as opposed to the central part of the narrative, instead the focus is the joy of the trampoline and their everyday experience of 'living alongside' (Davies, 2023) one another and playing together. Where the focus here is on passing references to disability, the next section explores where participants were more overt in their discussions.

Overt disability discussions

When introducing their sibling, participants often provided impairment labels as part of their descriptions:

> *So Claire was born in 2003 and then I was six in the following February. So there's almost six years between us. She was born with Cerebral Palsy. My mum's*

> *pregnancy was pretty much smooth sailing and then my sister was starved of oxygen when my mum was in labour and then she was in intensive care for, I'm a bit iffy about this, but I think it was five to six weeks* (Emily).

> *I was born in April 2005, I have an older sister who's born in 96 and my eldest brother 98 is called Peter and he was diagnosed with autism in I think around 2001, he was non-verbal and he stims.* (Susan)

> *Yeah so, I was born in September 1999 and then, 18 months later Tim, who is my brother with special needs, he was born so we are only 18 months apart.* (Eva)

These examples, particularly the first two, draw on medicalised understandings of disability. This is particularly interesting when we consider Emily's quote here with her discussion of fairness from earlier in this chapter. Whilst Emily drew on more medicalised understandings in introducing Claire, further into her narrative, disability was mostly mentioned in passing which can be seen to give some insight into the reality of 'living alongside' (Davies, 2023) a sibling with learning disabilities. Emily's concerns around fairness took precedence over overt discussions of disability as the narrative progressed.

It is important to recognise the nature of the interview likely contributing to a feeling of needing to justify why they are taking part. Participants were recruited based on the sampling criteria of having a sibling with learning disabilities and therefore the choice to begin their narrative with an explanation of their sibling's impairment label is to be expected. Stalkers and Connor's (2010) research highlights a similar situation in which the siblings they interviewed would be quite overt in providing an impairment label for their siblings however in practice this did not lead to participants viewing their siblings as 'different from them in any significant way' (ibid: 224). This is particularly apparent in Eva's introduction, with the explanation being added almost in passing as she ran through all her siblings. What can be seen to hold more interesting reflections about how siblings negotiate disability are the moments where participants attribute things to their sibling's impairment or cite it as a source of difference between them. This was shown in references to age and sibling development, for example Martha's feeling about her older brother:

> *Guy's like a younger sibling. He's not really like an older sibling because he's got the mental age of a seven-year-old so yeah, I kind of grew up being an older sibling to him but being seven years younger, so strange.* (Martha)

Martha's comment can be seen to draw on ableist development narratives around mental age and intellect (Walkerdine, 1993; Gabriel, 2021). This reading is important to consider, however attention should be given to the wider reflections in Martha's narrative of the closeness of her and Guy. Further, Martha's comments reiterate understandings of mental age reflected in wider cultural narratives of learning disability. Kittay (2001) touches on this discussing the difficulty of describing her daughter:

> *When asked about my daughter, I want to tell people that she is a beautiful, loving, joyful young woman. But then I need to tell them what she cannot be, given her profound cognitive limitations, her cerebral palsy, and her seizure disorders. When people ask how old my daughter is I always hesitate, wondering whether to give her chronological age and speak of her as a lovely and intense thirty-year-old woman, or to speak of the age that reflects her level of functioning and her total dependence. The positive set of responses is truer to who she is. Her limitations describe the face she shows to those who don't know her, but they also convey the ways she cannot*

> *make her own way in the world. Knowing her capabilities, one gets a glimpse into the richness of her life and the remarkable quality of her very being.* (Kittay, 2001: 559)

Kittay’s explanation offers an alternative reading of the reference to mental age urging the listener to understand it alongside a multitude of aspects of someone’s personality. Other participants evoked age in similar ways often referring to how they were similar to their sibling when they were younger and how this changed as they grew up:

> *… when you’re kids I feel like it's not as noticeable and then maybe as we were getting old and she wasn't behaving in the ways that, and I can't like pinpoint a specific age, but actually thinking about it as a child, like a younger child, I don't remember thinking that her behaviour or anything like that was abnormal or like probably because developmentally we were probably more closely aligned and then as we got older, yeah.* (Hannah)

> *… when you're a child like it's very hard to almost distinguish because kids obviously can't speak correctly and stuff like that so it's hard to, she was almost like, I hate the word saying normal, but almost like a normal child when she was growing up’ … ‘but as for this age in this photo I didn't know she had had a disability whatsoever.* (Alex)

Like the previous examples, age is evoked here as a means of understanding their sibling, but also to unpack their childhood closeness. Within these two quotes are quite explicit developmental narratives around growing up and ‘developing’ with the use of normal and abnormal across both reinforcing this. The interest in age brings with it a discussion of the role of time in sibling relationships with Davies (2023) arguing that ‘different facets of temporality profoundly affect siblingship’ (ibid: 140). This could be seen also in the importance of the future in participant narratives, as discussed in the previous chapter. To make this argument Davies draws on May's (2019) concept of temporal scripts which 'set out social norms that describe how we 'should' grow up and grow older' (ibid: 87). The examples laid out in this section touch on these temporal scripts, with the participants drawing on how their siblings did not meet these 'expected milestones'. Davies (2023) notes the pervasive role of these scripts in everyday life, arguing that when they are not met there can be strong emotional reactions from those who feel they are missing out. Within this is a reflection on the role of expectations in how we understand siblinghood. This is explored in the next section, which unpacks how participants conceptualised siblinghood in their stories.

Expectations of siblinghood

Considering the scope of the research question, the following sections explore how participants conceptualised siblinghood. This is of course linked to their understanding of learning disability, with the prior discussion around normal informing participant expectations of their own relationships. Participant's reflections on expectations of siblinghood echoed Davies' (2023) argument that we live with the idea of siblinghood as well as our siblings. This was seen in Dina's comments about being younger than their sister and not having the older sister experience they would have liked growing up:

> *… that was definitely period of my life where I think, it was probably when I was in secondary school' … 'and meeting people who had older siblings and being like oh wow, like older siblings who could tell them things about what it's like to do things or older sisters who could tell you about what it's like to be a teenage girl and things I was so jealous of and so I really wanted and I spent a while imagining what it would be like if Tyler could tell me things and like what would she say and things like that.* (Dina)

> *… it was weird I always wondered what it would have been like to not be the first sibling to do everything like if she'd gone to the same school she would have been the first one to do GCSE’s, the first one to go on school trips and things like that but I was like yeah it was me so, that was, yeah different I guess.* (Dina)

Dina’s feelings about what an older sister should do were informed by normative understandings of siblinghood, with Dina imagining what having an older sister who fit that narrative would have been like. Within this we see again the importance of temporality in sibling relationships with these expectations being rooted in temporal moments such as GCSEs and school trips. Where older siblings can provide invaluable insight in these moments (Aaltonen, 2015), for Dina this was not something her older sister offered, at least in the context of schooling. In the next chapter how participants learnt from their siblings will be explored in more detail. Punch (2005) notes how birth order hierarchies are often negotiated in sibling relationships and this is seen in Dina’s narrative through her taking on the role of first one to do GCSEs and other things. Hannah expressed similar feelings about having an older sister that did not attend the same school:

> *… so one of my best friends from school, her sister is a similar age there's a similar age gap and obviously they went to school together. I think I found that hard when I was younger, I still find that hard now, but less hard. But yeah other people have their sibling there, especially an older sibling that they could go at break time or something like they would talk to them and it was kind of cool like ‘ooo lets go talk to her older sister that's so cool’. But yeah not having that and I think I said normal didn't I? I said that's what normal siblings do or something.* (Hannah)

Like Dina, Hannah's expectation comes from seeing friends and peers interacting with their older siblings and wanting something like that. Hannah also explicitly refers to this as 'what normal siblings do', touching on the previous discussions of normal and further reinforcing the idea of 'temporal scripts' (May, 2019) as central to normative constructions of getting older and siblinghood. For both Dina and Hannah they compare their experience of having an older sister with these expectations and, as touched on by Davies (2023), feel strong emotional reactions to not having this experience. Interestingly, for Eva there was a similar feeling of wanting an older sibling even though she was the oldest:

> *I mean for a while when I was little I wanted a sister, apparently when my mum was pregnant with my youngest brother, I said… she knew he was going to be a boy and I said no has to be a girl I want a sister, my mum was like sorry it's definitely a boy and apparently I replied fine if he has to be a boy can he at least be older than me? Because I was bored of younger brothers I wanted something different.* (Eva)

Eva's comment is different to Dina and Hannah's, however the outcome of wanting an older sibling is the same. The idealisation of the older sibling as a role model is one that has been questioned (Punch, 2005), however in all these instances there is this imagined older sibling who was important in how participants made sense of their lives. Returning to Dina, in her reflections she mentioned imagining what it would be like if Tyler was like these other people's siblings. This sentiment was echoed by Ellie in her discussion of her brother's disability and her other non-disabled brothers:

> *… I guess maybe around seven or before seven, so quite young and I was thinking so I was aware of it because I was thinking 'if he didn't have this disability then what would he be like?' and I was thinking of that in relation to my other brothers who were*

> *even more annoying or not more, like my oldest brother was in this really cool phase and I thought god if Harry didn't have this disability he would also be this really like more annoying cool person that I did, I guess that I wouldn't recognise because it wouldn't be him but also I kind of registered that maybe I don't want that because yeah, at that point as I know I like him as he is and we could have fun or we could play together at that age.* (Ellie)

This quote touches on a number of things. Firstly, there is something crip about the celebration of difference here (Goodey, 2016), with Ellie enjoying her brother because he was not fussed about being a ‘cool person’ which can be read to have connotations of fitting in and conforming more widely to normative expectations of ‘cool’ (Garland-Thomson, 2011). Instead Ellie has a really good relationship with Harry because he is not like her other brothers and is more fun for it. Alongside this is an interesting reflection around the question of what Ellie’s brother would be like if he did not have learning disabilities, one that echoes Dina’s question earlier in the chapter and Scott’s in the previous chapter[1]. There is a sense of curiosity to this angle, particularly from Ellie, with the conclusion noting that it is a central part of who he is and therefore she would not change him as she likes him as he is, once again reinforcing the celebration of learning disability. When considered alongside Meltzer’s (2018) argument that sibling disability research often focuses on what the relationship is not and therefore is ‘found wanting or damaged in comparison’ (ibid: 1228), Ellie’s story sees her focus on what their relationship is, positioning it as more fun than her relationships with her other brothers. Alex, whilst acknowledging more difficult moments, similarly offered a more nuanced approach to understanding siblinghood:

---

[1] When discussing his responsibility and the future Scott stated ‘*if you could change and not have a brother who was autistic I probably would without being harsh on him, he’s lovely and I wouldn’t change him it’s all theoretical but I’m pretty sure I would swap him for a non-autistic brother because of the like ongoing stress and issues*’

> *I just think to myself everyone has got something that happens in their life so it's not that 'oh like why'd you have to' it's more that everyone's got stuff and the fact that this is my thing, this is the card that we've been dealt and I always say to myself with Lola, which my cousin said to me, the good times are amazing with Lola because when she's happy it's not like, I would say 50% of the time she's happy, 50% of the time she's not, the good times are really good and the bad times can be really bad but it's the fact that the good times are that good you almost and obviously she's your sister so you almost think of it, but yeah that's how I'd say that I wouldn't be almost jealous of other people's situation because I know what other people can go through.* (Alex)

Alex did recognise that there were more difficult points in his childhood, however he rejected the notion that his life would be better if his sister did not have learning disabilities. Alex's reflection on 'the good times' and 'the bad times' reinforce the notion of the emotional tightrope (Davies, 2015a) touching on the complex range of emotions that can make up sibling relationships. This, alongside the discussion of other people's experiences, sees Alex reject normative expectations and acknowledge that in most cases siblinghood does not map onto these in the way that we sometimes expect. Davies (2023) refers to the contradictions of siblinghood when addressing this, noting how we often believe that siblinghood follows rules, as expressed in the normative expectations, when in reality this is often not the case. As shown in the discussion around 'yearned for' older siblings earlier in this chapter, these rules are rooted in 'gender, age and birth order positions as well as being culturally and ethnically contextual' (ibid: 114). In their narratives, participants echoed research around more fluid definitions of family (Edwards et al, 2005; Mason and Tipper, 2008) citing the importance of friends, cousins and other figures growing up. For some participants these were rooted in their expectations of siblinghood, for example returning to Dina who sought the yearned for ‘older sister’ in family friends:

> *I think when I wanted an older sister, I always wanted a big older sister who was like five years older than me and had kind of done everything, we did have a family friend, family friends, who we used to hang out with a lot when we were literally, used to live opposite us and then we both moved and they lived kind of around the corner and she was five years older than me and her younger brother was three years older than me and I think I kind of wanted like to see her as an older sister but then after, kind of after they left Primary School, we didn't see them as much, they used to come over a lot and things but then it kind of stopped happening, we just grew up and move on but yeah.* (Dina)

Dina’s comments touch on the possibility to reimagine family, echoing Mason and Tipper’s (2008) work around how young people are often creative with how they define family. When read alongside their previously discussed reflections it is clear how growing up Dina felt as though she was ‘missing out’ on having an older sister who fit her expectations and offered advice. This theme was continued by other participants, with cousins often being cited as ‘like siblings’ as shown by Alex:

> *I always say my cousins because obviously with Lola you've not had the childhood of again running about and stuff like that my cousins, I even admit to them and I have one cousin who's an only child who's a year older and me and him look at each other like we're brothers we look literally identical and he's grown up as the only child so he hasn't had a brother, he hasn't got any I think I might even be his only cousin to be fair and I've said to him before that yeah, I look at you as almost like my older brother*

> *and he said I look at you like you're my younger brother' … 'So yeah, that's what I would say, I wouldn't say jealous of it whatsoever but I'd say maybe you do subconsciously almost gravitate more towards your cousins as you don't get that from your obviously direct sibling.* (Alex)

Within this reflection is once again the role of expectation and almost the idealisation of siblinghood, with being 'like a brother' presented by Alex as meaning more than a cousin or a friend. The added note of how they even look alike reinforces the role of resemblance in how people understand kinship (Mason, 2018). Further, this is then placed as the result of not getting that kind of feeling from his sister. It is important to note here that more widely in Alex's narrative, as with the other participants, was a deep sense of love for their sibling so this is not a case of wishing they were different but more a reflection on how these expectations manifest and how sibling relationships are viewed culturally. Scott also pointed to a similar relationship both he and his brother had with their cousins, again touching on this being partly due to the relationship he had with his own brother:

> *I've got three cousins who I'm really close to and probably would describe my relationship with them like siblings which I think particularly given that my own like immediate sibling, didn't have the same kind of relationship with him as I think you would do so typically they almost sort of like filled that hole of having that kind of relationship and I think they probably, they definitely would describe their relationship to me like siblings and they probably describe their relationship with my brother Dean similar to a sibling although they have some distance and stuff like that but like very close like look after him, take him out places and stuff now.* (Scott)

For Scott his cousins were a really important part of growing up and still are key figures in his life. Within his reflection, Scott goes on to note the role his cousins play in his brother's life being like siblings also. When read alongside the discussions around wider family support in the previous chapter we know this is not always the case and we also know how important this support is for everyone when it is done well. This invites us to look at Scott's account as touching on the role of expectations around what a sibling 'should' be like but also as an account of care and support from wider family. Scott's choice to justify the sibling feeling with examples such as looking after and taking Dean 'out places' reinforces this notion and evokes a sense that, for Scott, being a sibling is about these almost mundane examples of care. Later on in the narrative Scott spoke about family humour and noted that sometimes he felt his cousins found situations funnier than he did:

> *I think my cousins find a lot of it more funny than me which is interesting, it may be because they're not around it as much so some of the stuff he may do was a bit more novel whereas I'm just like oh yeah that's just what he does' … 'like yeah it sounds quite funny but like I think they find some of that stuff way funnier and maybe they're in a nice position where they're close enough to Dean that they can laugh at it but like it's also still quite novel and like I think they find it funnier than I do in a way, I don't know.* (Scott)

Scott does offer some explanation for why his cousins may find certain things funnier and again reading this within his wider narrative it is important to reiterate how he made clear he has a really strong relationship with his cousins and that they were central figures in his childhood. Recognising this, the extract, along with the previous one, touches on something about siblinghood and the reality of 'living alongside' (Davies, 2023) that brings a very specific relationship and sense of intimacy. Scott simultaneously outlined how his cousins are ‘like siblings’ and noted a time he felt they found something funny on account of there being enough distance for them to find it novel. Implicit in this reflection is that Scott’s cousins do not live with his family and therefore only see them at certain times and cannot be said to ‘live alongside’ them in the sense outlined by Davies (2023). There is a certain level of intimacy that this setting and relationship brings, that has been discussed throughout this thesis, that Scott attributes to not necessarily finding things as funny as his cousins. The role of humour in the participant narratives will be discussed in more detail in the next chapter, but it is interesting that Scott alludes to this quite fixed difference between siblings and cousins that is rooted in this proximity and closeness. This further reinforces understandings of siblinghood as unique and touches on the idea that whilst being socially constructed there is something that resonates with people about what being a sibling means and how that is different from other relationships. This is also made clear in how the participants were evoking siblinghood to almost elevate their cousins to a closer relationship. For a number of participants, this living alongside brought with it a sense of being known as a sibling. The next section explores how participants reflected on this experience.

Stickiness and known-ness in sibling relationships

Many participants reflected on how their sibling was a known figure in the local community. This was particularly apparent in narratives where the participants attended the same school as their sibling. For Zack, this led to him being known as ‘Beth’s brother’:

> *… she was quite popular and she had a group of friends. People liked to play with her and that's where I became known as Beth's brother definitely, other children in school would be asking me are you Beth’s brother? She's almost like the celebrity of the school.* (Zack)

This narrative extract highlights the popularity of Zack's sister and how this played into how he was known at school. Davies (2019) builds on Smart's (2007) concept of stickiness to explore how sibling ties are hard to shake and often in school settings having a sibling who is 'known' can have implications for how you are received. This can have positive and negative implications for young people and their own sense of identity, when asked to elaborate on this Zack stated:

> *Being in Beth's shadow, no honestly I, no it was just funny I think it was good I was happy that people liked Beth I think like it didn't really bother me that much, I knew at the time that, I felt like a lot of people were saying 'your Beth's brother', a lot of people were saying that sentence a lot but yeah I don't even really, it was never a negative feeling basically in fact one of my closest friends now who was in my class at the time we still talk about it like a kid coming up to me who was in Beth's class and like Beth having Down's syndrome her speech is ok, it's not amazing in terms of clarity, he came up to me and my friend and he was asking if I was [mispronounced name], are you [mispronounced name] and I was like 'what are you talking about', 'Beth's brother?' And I was like oh right yes, but yeah so no I was always happy with being Beth's brother I think that was great yeah.* (Zack)

The initial comment of 'being in Beth's shadow' was delivered as a joke with Zack going on to explain how he found it funny and actually enjoyed the experience overall. Davies (2019) argues having an older sibling who attends your school can lead to expectations being placed on students by teachers and peers. In this case Beth is younger, disrupting expectations around how this occurs. Within Zack's comments is also a sense of pride around his sister fitting in, even if it comes with the caveat of being approached in the playground and asked if you're Beth’s brother. More widely in his narrative Zack spoke very highly of his sister’s personality and attributed this to her popularity at their school, with this example being wrapped up in a sense of love and closeness between the two siblings. As discussed earlier in this chapter, Emily had concerns around her little sister starting school due to ‘mean spirited people’, however in practice it was the opposite:

> *When she was at Primary School nothing ever really happened and very quickly, even though I was older, it was, you know how most younger kids would be like ‘you’re Emily's little sister?’ It became ‘oh your Claire's big sister?’ She was like the school celeb and everyone was kind to her there.* (Emily)

As with Zack, despite being older Emily became defined by her younger sister who she felt reached almost celebrity status within the school. Emily’s reflection is rooted in cultural expectations around birth order in sibling relationships as discussed in the previous section, with her being aware that often it is the younger sibling who is ‘defined’ by their relation to the older one (Davies, 2019). Again, there was a recognition of this as a good thing with Emily specifically noting how people were kind to her, a reflection that holds within it an understanding of how this may not always be the case in school settings (Walton, 2011). Alongside the happiness that their sibling was being included, Emily also noted that being ‘Claire’s sister’ came with the benefit of being her playground assistant:

> *She came to my primary school and my mum and dad sent her to mainstream for I think about four or five years and I got to be her playground assistant type thing and I got to choose a friend every day who I could walk around with my sister with and I thought that was the best job in the world and then everyone wanted to be my friend*

> *because we got this special job at playtime and we were allowed on the other playground where we were much bigger than everybody else.* (Emily)

This reflection touches on the issue of people being expected to help support their siblings when at school, something Pavlopoulou et al (2022) notes can impact the education of young people. This argument points to the problematic nature of expecting siblings to support in school as they are there to do their own work. Where Pavlopoulou et al (2022) findings place this as something that bothers young people, Emily's account challenges this as a solely problematic occurrence with there being a sense of joy and excitement attached to the role. It is important to note this role was one that was during breaktime and that brought with it a fun element of play. More widely in her narrative Emily did not mention any support she was expected to provide that impacted other aspects of her school experience. For Scott, he chose to not attend the school that his brother attended:

> *…I think like* [I] *just wanted to be my own person and sort of make my own way and not being known as like 'oh your Dean's brother' and I don't know if I would have felt that if I'd have had a sibling that didn't have learning disabilities like I know friends and people it's like you come to school and your siblings have been before and it's like 'oh your so and so's brother' and you kind of want to pave your own way but in a more extreme way because you'd got this association with someone else and that maybe feels more significant when that someone else is like is someone who is in the unit.* (Scott)

Whilst Scott recognised that being known as 'so and so's' sibling is a common occurrence when attending the same school, he felt there was maybe more significance to this as his brother attended 'the unit'. The unit was a specialised area of the school for people with learning disabilities and this factor was a concern for Scott. When read alongside Scott's desire for paving his own way that is apparent throughout his narrative, it can be seen how having a sibling who might stand out in school settings can create concern over being able to be your own person in that same space. The experience of having a sibling who was ‘known’ extended outside of the school setting, with participants noting how this was a common occurrence in the local community as shown in Ellie’s narrative portrait. Ellie is the youngest of four with three older brothers:

Narrative Portrait Ellie: ‘I think you’re just looking for people that know you’

It was a relatively small town but he was just such a big character in it so I think I knew from a young age that he was fine in the spotlight and I was happy to just shrink into the shadows so I did that immediately I feel and then, so yeah, he would just be, like people know his name but he's looking for it as well he's like ‘hi’. I mean when we went into town the other day he was literally just staring at everyone going as we walked past, it’s like ‘I think you're just looking for people that know you’ like just to say hi which is fine but I was like what do you want to do like you're just walking through and yeah so they'd just say hi and just talk to him, they know his name and he generally knows something about them maybe not their name but where they're from or what they're doing or where they work or things like that so you have a good chat whereas I think I just was more than happy to not. I didn't really want that attention but I think I was okay that it was going to him because he liked it. I do think when I was younger I was more embarrassed, I think that's why I was more likely to be like shy-er because I was more embarrassed and then became more shy.

For his 18th birthday he wore his new Phil ‘the Power’ Taylor, the darts player, shirt. We've got a local pub and David who runs the pub knows us and Harry and he's a bit of, so Harry's a little bit of a celebrity in the town anyway, because he's quite well known and he loves that. So we used the hall in the pub and we got a DJ and I remember mum organised a limo for us, which was so exciting. I think Harry loved that as well and when we got there, I think the fire brigade came out as well because at *that point they knew, they knew him as well because he's really quite well known and he's been to see the fire station quite a lot. So they know I think we had a specific fireman, I can't remember his name. He was quite good at coming to see us. Yeah, so they came and then, yeah invited everyone to this massive party.*

Fig. 4: Photo of Ellie's family at her brother's birthday party

Photo redacted due to personal data

Ellie's portrait tells of how well known her brother is in the local area and even if she teases him for it at times there is a sense of love and closeness in the extract. Ellie places herself in relation to her brother's popularity, noting how she preferred not to be so outgoing. This choice to define herself in relation to her brother reinforces arguments around siblinghood and identity, with siblinghood seen as a key factor in how people make sense of themselves and how others receive them (Jenkins, 2004; Edwards et al, 2006). The idea of her brother being a 'big character' can be seen to challenge questions of 'fitting in' and learning disability. Where people with learning disabilities are often excluded (Yates et al, 2008; Goodey, 2016), Harry instead actively engages in the community enjoying his local celebrity status. The narrative portrait finishes with the story of Harry's 18th birthday and how different people in the local community came together to help put on the party. This story reiterates Harry's 'known-ness' and, more importantly, gives an example of inclusion in practice and what that means for people with learning disabilities and also their families. Ellie speaks of the excitement of the limo and how the fireman was ‘quite good at coming to see us’ with these examples highlighting both the fun of the day but also her appreciation of Harry’s involvement in the local community. Eva expressed a similar sentiment in her discussion of going around the local shops with her brother:

> *… he's like everybody's favourite person and very memorable like we’ll go into the village or something at home and everyone will be like ‘Hi Tim’ and I’m like ‘I've lived here this whole time as well and no one remembers me’. He's just always going in and to shops and things and chatting to people and stuff like I went to the post office with him last weekend or something and the post office was shut and the lady was like ‘it's fine Tim I’ll open it for you’ kind of thing like just amazing.* (Eva)

Eva’s story makes clear how her brother is well known in the local community. Like Ellie there is also a sense of love and closeness captured in the reflection ‘he’s like everybody’s favourite person’. We get the same feeling of inclusion that came through in the narrative portrait with Tim clearly a part of the local community and this being something that is appreciated by Eva. In these examples the potential frustrations that could come with being known as someone's sibling, as outlined by Scott, are offset by an appreciation of their sibling being an active part of the local community with participants making clear the importance of this. Kittay (2001) argues ‘connections with family members are often the only shield against the slings and arrows of an uncaring society’ (ibid: 571). When this is considered alongside the discussions from chapter 4 regarding navigating society these examples can be seen to extend this argument. The participants' appreciation can be seen to be linked to being aware of an often ‘uncaring society’, with the inclusion being discussed here taking on a greater meaning because of this.

Conclusion

This chapter has sat with the tensions around how siblings of people with learning disabilities conceptualise disability and siblinghood. On account of the research's focus, disability and siblinghood were central to most of the participant narratives, with these being presented in a number of different ways throughout. The contradictory nature of sibling relationships (Davies, 2015a) was reflected in how participants conceptualised disability throughout their narratives. Discussions varied from overt references to disability that could be seen as medicalised to nuanced reflections on the everyday of learning disability in families. Throughout, participant narratives were rooted in care for their siblings, and their families, with even more potentially difficult reflections often being situated alongside stories of joy and closeness.

This chapter began with a discussion around the role of the term 'normal' in narratives and how participants drew on the word when discussing their childhood and their siblings. This was split into two sections, with the first exploring how participants evoked 'normal', in a hegemonic sense, in their narratives and how their lives were similar or differed from this. The second unpacked more fluid discussions, with participants reinforcing the everydayness of their experiences and how even non-normative interactions became normal within their family. Within this was a discussion of the 'normal abnormal' (Mallett and Runswick-Cole, 2016) and how siblings evoked or rejected normative ideas of disability in relation to their experiences. Following this, how disability was addressed both in passing and more overtly was discussed. Participants offered insight into the everyday reality of disability through their reflections on things like taking taxis to attend different schools. The more overt reflections touched on defining disability with regards to impairment labels and references to mental age. Throughout these sections were tensions around how participants simultaneously evoked hegemonic understandings of normal whilst also rejecting them. These contradictions reflect the reality of their lived experience, with the closeness and sometimes more frustrating aspects of siblinghood providing the space to discuss learning disability in the everyday.

The next part of the chapter saw how normative expectations played a role in how participants understood their own sibling relationships. Here the discussions focused on the role birth order played in how participants felt about their older siblings, and how the yearned for normative older sibling experience manifested for them in their childhoods. This was followed by reflections around the role of wider family and friends in how participants mitigated for these perceived missed experiences, echoing the discussions of family support networks in chapter 4. The chapter finished with a discussion of being known as someone's sibling in school and in the local community and how participants reflected on this with a love and appreciation for their sibling being included.

In this chapter, and the one before, stories that challenge dominant narratives around siblinghood and learning disability have featured heavily. The next chapter will focus on the counter-narrative nature of participants' stories, looking at the radical potential of siblinghood to centre the human in discussions of the everyday and disability.

Chapter 6: In what ways might counter-narratives of siblings problematise dominant pathological models of disability in families?

Introduction

Within their narratives participants actively rejected deficit understandings of siblinghood and learning disability, with joy playing a key role in their reflections. This chapter addresses the research question: *In what ways might counter-narratives of siblings problematise dominant pathological models of disability in families?* This is done by exploring how participants disrupted problematic understandings, drawing specifically on the use of humour in narratives and how participants felt their experiences had influenced them. Returning to Meltzer's (2018) reflections around presentations of siblinghood and disability as often defined by 'what they are not' (ibid: 1228) this chapter centres participants' accounts of 'what they are'.

Joy played an important role in participants' stories, with deficit understandings being challenged in favour of more nuanced readings that recognise the humanity of their siblings throughout. Humour was one of the core ways this was achieved with participants reflecting on funny stories of childhood as well as humour in more difficult times. Throughout their narratives, the deliberate nature of their siblings' jokes was made clear, even if it was to make fun of them. This sees narratives of 'lack' of humour (Bertilsdotter Rosqvist, 2012) or questions of comprehension of jokes (Chadwick and Platt, 2018) that can often arise in research around learning disability being rejected. Alongside these discussions, the chapter considers how participants' experiences as a sibling of someone with learning disabilities have influenced them. These reflections are rooted in closeness and also in social justice and allyship. Here, ideas around sibling outcomes are challenged with participants reflecting on how they feel they are 'better' people for these experiences.

Defining joy and humour

Throughout this chapter, both joy and humour are referred to and whilst these are hard to define, a ‘working definition’ of both will be provided in order to be transparent about meaning when used. Regarding joy, this chapter draws on Arnett’s (2023) understanding of joy ‘as an intense, temporary feeling of elation combined with an appraisal of right relation between ourselves and the world, a sense that there is an ideal fit between ourselves and the world around us at that moment’ (ibid: 1). This definition speaks to joy as both an individual and social emotion, with the more social aspects being of particular note in this chapter. Considering a ‘working definition’ of humour, the discussions in this chapter are centred around how participants presented stories, and where they found humour. This leaves the definition with the participants, and what they either say was funny or presented in a humorous way. This does not mean that there is not scope to engage critically with this humour, as outlined in the literature review the relationship between disability and comedy is potentially controversial (Cumberbatch and Negrine, 2022). This said, humorous stories will be contextualised narratively in order to, where possible, ensure participant accounts are represented authentically (Frank, 2013; Rodriguez-Dorans, 2022). This chapter is influenced by Shuster and Westbrook’s (2022) discussion of ‘joy deficit’ in social science research. They argue that there is a tendency to focus on social harms with this contributing to deficit understandings of marginalised experiences. They call for more research that acknowledges how ‘studying joy offers opportunities for advancing a more nuanced approach to how marginalised people live and experience social life’ (ibid: 806). The notion of a ‘joy deficit’ can be applied to disability studies (Sunderland et al, 2009), with the deficit narratives challenged throughout this thesis pointing to the importance of counter-narratives that centre joy.

Humour as a source of joy

Throughout their narratives participants drew on humour to reflect joyful moments or capture the fun of their childhoods. In doing this, deficit understandings were rejected with a focus instead on more nuanced readings that recognise joy as a central part of childhood. These funny moments had become family stories, and participants took great pleasure in retelling them, for example Emily's account of her sister's birthday:

> *And then her 13th birthday felt huge for us because she was 13 and we never really thought that would happen and we had a huge party' … 'she danced for literally the entire day and then couldn't walk for about three days and still to this day she's like 'I'm never doing that again'. She still feels sorry for herself that she danced that much that then she couldn't walk.* (Emily)

The story came after reflections on health complications Emily's sister had experienced growing up, with the party being presented as a particularly big moment. The humorous anecdote that follows works to reinforce the fun of the party, with Emily finding the notion of dancing so much you cannot walk to be particularly funny. Considering discussions in the previous chapters around how participants navigated disability in their narratives, this story also speaks to where disability arose in Emily's narrative. In this instance, the story is prefaced with discussion of health complications but Emily chooses to discuss the humour of the party also, presenting a nuanced picture of her childhood and rejecting a solely deficit understanding in the process. Everts (2003) argues that it is often the humorous stories that become 'family stories' that we return to again and again. This was seen in Zack's narrative, with the photos he chose to bring along being ones he, and his family, found funny:

Fig. 5: Photo of Beth on holiday

Photo redacted due to personal data

> *The next one is one of our family favourite pictures of Beth where I think she was saying she didn't want to do anymore cycling, even though she wasn't cycling she was in the chair on the back. I think she got sick of it and then like we sort of turn around and we are like 'hang on, where's she gone?', she's just put herself on the chair like that, arms across the chest, head straight on just looks so funny but yeah, she must have been, I don't know how old she was there but dead young.* (Zack)

Zack is explicit here that this is a family favourite picture. Further the photo itself adds another aspect to the family story, with there being a record of the comedic event that can be returned to and enjoyed by everyone. Kuhn (2002) argues, similarly to family stories, that family photos are often shaped around happy or fun events as you are less likely to take a photo in more difficult moments. This instance is interesting as the photo's comedy comes from Beth's frustration. This brings with it considerations around family teasing, something that will be returned to further in this chapter. Zack also brought along another photo he enjoyed partly because of the humour of it:

Fig. 6 Photo of Zack and Beth at a gig

Photo redacted due to personal data

> *In the middle of my A-levels we went to go and see Katy Perry together so that was a good one' … 'the picture of me and her at the gig cause she wore a full Katy Perry outfit, so we went together on the train, it were quite far away and I had to get her outfit on her on the train' … 'so she's got like a big pink wig, a massive cotton candy big dress thing on, like an ice cream cone or something, it's a huge extravagant dress basically and I had to get her all set up in it and I was there in a black band t-shirt or something like that so it looks like polar opposites, but it were mint so I've got a picture of the two of us sat in the chairs for that, it's a great picture we have. But yeah so we've got the Katy Perry gig, that was in the middle of my A-Levels so that was like my little break in the middle of it.* (Zack)

The humour here is drawn from the disconnect between Beth's very exciting outfit and Zack's more toned down one with the two together creating a funny scene. Alongside the humour of this, Zack's context also gives insight into the closeness between him and his sister and touches on sibling care. Zack took time out of his A-levels to go and watch the gig with his sister, helping her with her costume on the train. Interestingly, Zack refers to this as 'his little break', echoing Pavlopoulou and Dimitriou's (2019) notion of siblings rejecting care labels. Zack was keen to stress that it was also really fun for him, something that comes through in the photo with them both looking happy. The sense of fun, alongside humour, in family stories was shown in Dina's account of getting into trouble with her grandparents:

> *One year me and my brother played a practical joke on my grandparents and then we weren't allowed to come at the same time as my sister, it was like me and my brother and my sister separately because they thought we were too much trouble altogether' … 'it was because my granny had asked us to look after Tyler and we thought it would be funny, they used to have bed and breakfast guests, and we thought it would be funny if we jump scared all the bed and breakfast guests with my sister but they didn't think that was very funny so we couldn't all go together.* (Dina)

For Dina, the humour comes from the silly-ness of the story and the fun that the three siblings had, even if the end outcome was them getting in trouble. Like Zack's gig story, there is a nod towards care here with Dina and her brother being asked to look after their sister by their grandparents. This role is what gives them the space to do the 'scaring' that leads to them getting in trouble. As Dina recounted the story she was laughing about the idea of the three of them being too much trouble together, highlighting how this did feel a little overboard. Once again, this was a story that Dina's family found funny and told a number of times, with the humorous element being central to this memory. Dina does start the story with a note that this was a prank by her and her brother, raising a question of her sister's role in it. This brings with it an important consideration of whether they were laughing at their sister or with her, a distinction that would raise questions around power and humour (Carter, 2019). However as Tyler took part in the scaring of guests it feels as though this was likely a joint effort. Alex touched on this argument in his discussion of funny moments with his sister:

> *When Lola gets really happy it's like that times ten, when she's singing, she's belly laughing and stuff like that she comes out with some funny stuff and it is hilarious. The whole family will literally be laughing and singing with her. They're the good times and even like funny stuff I know it's obviously disability, obviously you shouldn't laugh at it but some of the stuff, she goes, basically she has this thing again like an infant doesn't like going to sleep so says she goes 'not bed' so she doesn't like it but then we've been wheeling her around a Sainsburys and when she says it quick, when she says it quick she goes 'knobhead' at everything so she's got people, she would be shouting knobhead at people which it's honestly hilarious obviously you shouldn't laugh at it but it's funny stuff like that it's almost like it's, and some of the stuff she does, like again you shouldn't laugh at it but obviously you gotta find some stuff funny you know what I mean it is good but then yeah we have amazing times with Lola to be fair and a lot of them, like I said is the stuff that you remember so yeah.* (Alex)

This extract touches on a number of aspects of family humour. Similarly to the previously discussed example, Alex notes how these funny moments are the ones you remember and further there is a similar sense of love and closeness in the description of the family singing and laughing together. Of particular interest is how as the story develops Alex acknowledges the potential of this humour to be seen as problematic due to his sister having learning disabilities and this meaning that people might think they should not laugh about it. The reflections are rooted in an understanding of the potentially controversial nature of humour around disability, with jokes about disabled people often being offensive and problematic in wider social and cultural environments (Cumberbatch and Negrine, 2022). Reid, Stoughton and Smith (2006) call for a distinction between ‘disabling humour’ and ‘disability humour’. Disabling humour, they argue, is that which is ‘denigrating’ and the latter that which ‘centres disability or is offered by disabled persons’ (ibid: 631). Within this is a question around who can carry out ‘disability humour’ and whether, drawing on understandings of ‘disability by association’ (Burke, 2010) and the ‘backstage nature of sibling relationships’ (Punch, 2008), it can be argued that siblings can offer jokes about disability that are not disabling. Further, in their discussions of family stories, Smart (2007) argues that comedic stories are rooted in ‘affection and sense of connectedness’ (ibid: 94). This offers an approach to understanding these stories that recognises the narrative context, and the closeness, that creates an environment where these jokes can be made. We see this in Alex’s reflections, with his awareness of the potential for the joke to be understood as problematic being mitigated by it being ‘family humour’ and being wrapped up in the love and closeness he feels for Lola. This does bring with it some considerations around power, and the role of humour in creating ‘in groups’ (Carter, 2019). However, as with Dina’s extract it is important to read Alex’s comments within his wider narrative, one that spoke to an inclusive home environment which Lola was very much a part of. Martha told a similar story:

> *Martha: So if we're playing Pictionary, because we do that every year that's like a tradition, he'll either team up with my uncle or it would be like my dad and it would just be like you say draw this and he’ll draw something completely different so you’ll be like ‘it's a cabbage’, he’ll be like ‘yeah, that's it. Well done’ and it’ll be like it wasn’t a cabbage but that would be what Guy draws so you just do, like you just guess what he's drawn, really and he’ll just be pleased that someone's guessed it.*
>
> *Researcher: Is it fun?*

> *Martha: Yeah, it's funny, we all have a giggle, it's good.*
>
> *Researcher: does he join in with the laughter when things like that are happening and you're all going like this is really funny, is he finding it funny that everyone's finding it funny?*
>
> *Martha: Yeah. Yeah, he laughs a lot even at things he shouldn’t.*

Martha’s story touches on her family practices around Christmas. Part of the humour comes from her brother playing the game in an unconventional way, disregarding the rules and drawing what he likes. Like Alex, the comedy is from the potential misunderstanding and therefore could be read as a form of disabling humour. This reading however would overlook the fun of the story in which Guy is very much a part of the joking as shown in his joining in with the laughter. The final comment from Martha points to the fun of the act of laughter, which can be distinguished from understanding or context. Whilst Martha is noting how her brother laughs even if he does not ‘get’ the joke, laughing is something in itself that brings closeness and joy (Scott et al, 2014), often referred to as ‘contagious’. This allows recognition of the benefits of family humour, without the necessity of the joke being something everyone understands. Instead the laughter itself is enjoyed by Guy and he is very much a part of the act of group laughing. Once again we see the ‘affection’ and ‘sense of connectedness’ (Smart, 2007: 94) that family humour can bring. Further the whole story can be read as the family adapting to Guy’s approach and ensuring that he is included in the game, even if he plays it in a different way, showing an understanding that works to create an inclusive space for the whole family. Where Martha and Alex commented on whether their siblings understood certain jokes, Oscar’s narrative portrait offers an alternative reading of his brother’s humour that presents it as subversive and deliberate. Oscar grew up in the

South of England and is the oldest of four, his brother Owen passed away when Oscar was 21. His portrait makes clear his brother’s sense of humour and how Oscar reflected on this throughout his narrative:

Oscar’s narrative portrait: ‘A lot of these kids don't quite get the credit they deserve in terms of they know what they're doing, they know they're taking the piss’.

He really was just amazing, he was so funny and he was really really cute and yeah like he loved people, he loved doing things his own way and yeah, he really cared about people a lot right. He loved doing stuff with my dad like mowing the lawn, he loved doing those kind of like household chores. I mean my dad, you know those big hedge trimmers and stuff, my dad was trimming the hedges and then you’d come out and go and see what's going on, Owen's there with a massive ‘vrrrrr’ like ‘oh my gosh fucking hell’, stuff like that. He was just so funny, like in Blockbusters, and he was such a romantic really, him serenading the girls that worked in blockbusters and stuff is a particular highlight and it's just funny and all this stuff comes back in like kind of vague fragments but you know just kind of like in-jokes and stuff you know we love taking the piss out my mum for being a lazy driver he would always say because she only had two pedals in her car because she drove an automatic and things like that or you know when one time when we were on holiday by the coast in a hotel there's a kind of old grandma who's a bit kind of posh and uppity and stuff and Owen's climbing on the seats and stuff and she's saying ‘don't do that what are you doing’ and all of that and I don't know whether he told her to shut up or something and she says ‘I'm watching you’ and she was so unexpectant for him to just turn around and your just there like ‘yeah, you tell her son’.

There was this one time at school they'd kind of restrained him on a sofa and there was like two or three staff that had been there and they're kind of like holding him for a while and stuff and I think things were kind of settling down and some other staff member came up and said to the staff members who had been kind of like dealing with Owen like ‘oh do you want a cup of tea’ or something and him having been having a meltdown then you know he looked up from the sofa and said ‘yes’, you *know 'milk two sugars please'. All that stuff I just find really funny. But yeah, I mean the kind of hard and sad thing is so much of this stuff is just kind of so mundane and day-to-day but the day-to-day existence was kind of just so funny and unique. It's just that somewhat lack of filter but it was enough filter and perception to, I think a lot of these kids don't quite get the credit they deserve in terms of they know what they're doing, they know they're taking the piss and yeah, it's just so funny yeah, I mean, I really just think just in general it's just such a beautiful way to see the world and such a beautiful different way to see the world that is so refreshing from you know everyone else sometimes.*

The narrative portrait captures the love Oscar feels for his brother and also touches on a number of different elements of their family humour. One central aspect to the portrait is the recurring everyday-ness of the humour with Oscar noting the mundane day-to-day being particularly funny. This is seen in the examples of the back garden and the car as being places for family in-jokes and general funny events. This is a similar setting to the stories explored in this chapter so far, with there being a sense amongst participants of the humour of their everyday lives. There is a clear counter-narrative element in the everyday nature of this joy, with stories being rooted in wider narratives that were instilled with a sense of love for their siblings. Alongside the more everyday humour is the story of his brother being restrained at school, whilst the subject matter here is difficult, Oscar takes pride in his brother's comedic response. There is something crip about this story with his brother using the joke almost as an act of resistance. Further, this can also be understood as an example of humour being used for relief in more difficult times (Carter and Davis, 2024), with both Owen's joke and Oscar's appreciation finding joy in a distressing situation. These two readings will be returned to in the latter parts of the chapter.

The final reflection in the portrait shows Oscar arguing that people with learning disabilities can be overlooked when being funny, with their being an assumption it is not deliberate. This is a theme that comes through in literature, with discussions of learning disability and humour often being raised alongside questions of comprehension (See Chadwick and Platt, 2018 for an overview of this). In their research around narratives of ‘lack of humour’ and autism, Bertilsdotter Rosqvist (2012) questions understandings of humour as a ‘universal human ability’ (Lyons and Fitzgerld, 2004). Challenging both the narrative of being ‘humourless’ and the notion of ‘universal human ability’ they highlight the implications of being viewed as ‘lacking humour’. The idea that ‘they know they’re taking the piss’ is Oscar choosing to make sure his brother is recognised for his humour and make clear it is not perceived as accidental. When read with Alex’s concerns around being seen to laugh at disability, Oscar’s reading offers an understanding that is rooted in subversive humour. This argument is then drawn out into a wider point that centres the humanity of his brother as well as people with learning disabilities more widely with Oscar placing this approach to life as ‘beautiful’ and ‘refreshing’. This addition brings the narrative into a crip space, echoing Goodey’s (2016) understanding of difference as something to be celebrated as opposed to viewed as a problem. Returning to the everyday-ness of family humour, Emily jokingly reflected on her sister’s facetime habits:

> *Claire got a phone, she got a hand-me-down phone so that we could FaceTime, so I think that was quite a nice thing actually in a lot of ways that FaceTime had become a thing by the time I'd moved out and stuff so we could always stay in contact and to be honest that's why at the very beginning I said I was put in my phone on do not disturb because she's got absolutely zero boundaries and she rings me about 10 times a day until I answer.* (Emily)

This story is rooted in the everyday and taps into that mundanity that Oscar touched on in his narrative portrait. Whilst this was a discussion on how they stayed in touch after Emily moved out, it developed into a humorous reflection about her sister ringing all the time. The final sentence of the extract is particularly interesting, with Emily referring to Claire having ‘zero boundaries’. Where Emily could have strayed towards disabling language she instead draws on more commonplace discourses of ‘zero boundaries’. Goodley (2001) argues people with learning disabilities often have actions ascribed to impairment, even when this is not the case. Here, Emily actively refuses to move into a discussion of impairment effects and instead her reflection is rooted in everyday discourses. Further, in a later paper Goodley and Runswick-Cole (2012) outline their concern ‘that the quirky quality, creativity and personhoods of disabled children are merely understood as signs, symptoms and signifiers of pathology’ (ibid: 64). More widely in her narrative, Emily draws on humour in discussing various topics. She placed this as a wider family thing, noting how they are all quite funny. This shared family humour style (Everts, 2003) will be revisited later on in the chapter as it was something that the family drew upon in more difficult times. Zack similarly had a humorous approach to how he told stories, this was seen in his discussions of playing Wii bowling with his sister:

> *The best one-on- one time that I have with Beth is playing Wii sports together and like that’s like our thing that we can do you know and like we have a bit of fun, it feels nice because we are in a separate room from mum and dad you know, it feels kind of normal like hanging out kind of thing and she’s, oh man she’s amazing at it as well’ … ‘she has this technique with the controller right where she, she has such grace she kind of gets her hand down and flicks it up to the side, the same hand motion and she’ll be like stern her face will have no expression and she’ll flick it up to the side and the ball does the most, the maddest like swerve so she can set up her shot beforehand she goes right to the edge of the lane as far as you can go and she does this swerve and honestly 9 times out of 10 it’s a strike, like every time.* (Zack)

The reflections on Beth's skill at Wii bowling is comedic in its delivery, with Zack taking his time to explain in depth how good his sister is at the game. This humour is also tied up with a sense of admiration for his sister, with Zack clearly impressed by how effective the technique is. Alongside these more comedic aspects, the extract makes clear how important this one-on-one time is with his sister, with Wii bowling being something they still return to now years later. This adds to the joy in the story, with the act of playing the game together being something that is fun for both of them. Zack really valued their time away from parents, noting how it felt like 'normal' hanging out. Whilst this touches on the debates of the previous chapter, in this instance Zack went on to explain how he can find chatting to his sister trickier when his parents are in the room:

> *Beth will happily stay quiet if she doesn't have to speak and we are always wanting her to speak and if I, if I like facetime them now and something like that and I start talking to Beth, I try to ask her a question and she'll be really quiet and my mum and dad will fill in for her and they'll speak over her and that bugs me a bit because I feel like it's not helping her with her speech but it's also not helping mine and her connection which is maybe why I talk about the Nintendo Wii so much because that's me and her in a different room, the door is closed, it's just me and, it's an opportunity for me and her to actually spend time together where there's not really that many other opportunities to do that.* (Zack)

For context Zack now lives abroad meaning that video call has become his main method of communication with his family. This adds depth to his story of Wii bowling, alongside being fun and humorous it is also part of how he keeps his connection with his sister and has been since they were kids. Humour and fun being central to closeness was also evoked by participants who noted how making their sibling laugh was something they enjoyed. This was seen in Zara’s reflections on spending time with her sister in their bedroom after she had been put to bed:

> *Bless her Jenny’s all cuddled up and I start like chatting away and playing so it was really fun to have someone there. Also someone who would like listen to my stories I'm making up and my whole like ambition was to make Jenny laugh. I thought I was like a comedian or something I don’t know what came over me but like it was a really amazing experience.* (Zara)

For Zara, trying to make her sister laugh and just generally playing together in their room is a memory that is very important to her. This was something that came up multiple times in her narrative, as seen in the discussion in chapter 4. Scott et al (2014) argue there is a sense of joy attached to the act of making someone else laugh and this is very apparent in how Zara reflects on this. This interaction is one that further reiterates the idea of everyday humour that has been apparent throughout this section. Sharing a room created a space in which Zara could try to make her sister laugh, with this being rooted firmly in the mundane everyday humour of ‘living alongside’ one another (Davies, 2023). Kerry offered a similar reflection:

> *I feel very special about it, but I think If you're right in front of his face, he's a big, intensive interaction I don't remember when we were really young but I think I would just, if you pull faces at him and all of that and so it was more in that than being able to do role play or kind of verbal communication, it was kind of pulling faces and doing silly things and he’ll kind of laugh at you.* (Kerry)

Smart's (2007) reflection that humorous family stories are often 'imbued with affection and a sense of connectedness' (ibid: 94) is evoked here by Kerry. The comment that this was 'very special' can be seen to reiterate how this humorous interaction was central to their feeling of closeness in how it enabled them to interact and engage in a way she now really appreciates. This closeness that arose in participant examples of family humour can be seen to have led to some potentially more conflictual situations in which siblings gave examples of jokes that could be seen as teasing or 'banter'.

Sibling teasing

Teasing is often presented as a central part of sibling relationships (Edwards et al, 2006). Lampert and Ervin-Tripp (2006) argue 'teasing is only possible in a group whose members know each other well enough otherwise it could be perceived as an insult' (ibid: 55). This is something that has been contested, with some arguing sibling teasing can be more sinister than presented (Harwood, 2010). Whilst acknowledging this, Lampert and Ervin-Tripp's (2006) understanding places closeness as a core component of 'teasing' something which was echoed by participants in their reflections. This took a number of forms, for example Martha's discussion of phone calls with her brother:

> *When he rings me now it's like I answer the phone I'm like, 'hi Guy'. He's like 'guess what I did today', so now I've started going 'hi Martha, how are you?' and then he's like 'hi Martha, guess what I did' and I'm like 'no, how are you Guy?' and he's like 'hi Martha, how are you?' And then he'd be like 'guess what I did' and then I already know and I tell him and I'm like 'ha'*
>
> *'...'*

> *Researcher: How long are the phone calls?*
>
> *Martha: like two minutes Yeah*
>
> *Researcher: Does he hang up or do you?*
>
> *Martha: He hangs up, he gets bored. Yeah, he said his bit he's like 'see ya I got to go now'. It's like you rang me but whatever.*

Martha's approach to phone calls with her brother reinforces understandings of teasing as requiring closeness (Lampert and Ervin-Tripp, 2006). Her response draws on knowledge of her brother, with there being a sense of 'getting one over' on him by spoiling his chance to tell her what he did that day. This teasing also touches on Guy not sticking to normative conversation orders with Martha doing this partly because she feels not asking her how she is at the start of the conversation is slightly rude. Whilst Martha felt justified in her teasing, Hannah described teasing her sister without a direct reason:

> *I would definitely wind her up. Yeah. yeah, when I was feeling like I say spiky you know when you're just feeling annoyed and yeah, yeah, I'd definitely wind her up. I'm trying to think, would she ever do it? No, she'd not, not deliberately. Which is almost more annoying in a way because it's like you don't even know you're doing it but she would never do anything like nasty whereas, I think as a child, I definitely did things that were not nice in the same way that other siblings do and stuff.* (Hannah)

The idea of feeling ‘spiky’ and therefore choosing to tease your siblings can be seen as an example of the 'ambiguous emotional practices' (Gulløv et al, 2015: 511) that can be commonplace in sibling interactions. Hannah’s comments point to her feeling ‘spiky’ and ‘annoyed’ and choosing to make fun of her sister as a result of that. She juxtaposes this with her sister who she does not believe would do things to annoy her deliberately. Whilst Hannah was aware that she was teasing for no reason in particular, she did note that this was the same as other siblings do. As was unpacked in the previous chapter, we see the role of expectations of siblinghood here, with Hannah drawing on wider narratives of what being a sibling is like to justify the teasing. Where Hannah felt her sister did not deliberately do annoying things, Ellie noted how she and her brothers would all enjoy teasing each other even if she did feel she was targeted most:

> *I remember just having such a chip on my shoulder like everyone is ganging up on me and we were outside on the patio area so I know exactly where. Erik, so James had obviously teased Erik and then he teased me and it really got to me’ … ‘There's those really weird quite wordy* [jokes]*, they trip you up like no I can’t believe I fell for it again so I then I could do that to Harry but he, I remember him teasing me with the you can't eat Yorkies because it's not for girls and that literally was the most, I've never been so upset in my life. I couldn't believe it and then for me and Harry we weren't allowed to do the ‘that's naughty’* [gestures sign]. *I mean that’s bad* [gestures thumbs down]*, you could say that you're bad but naughty is like almost swearing at each other. We took that, or me, maybe it was just me, I took that, I was offended so much about being signed that you're naughty. I was like I can't believe you would say that about me over the dining room table and mum was like that’s enough this is getting too far.* (Ellie)

This example reflects Keltner et al’s (1998) placement of teasing on ‘a perilous boundary between aggression and play [that] can increase intimacy and integrate members into groups or through subtle changes of form become a vehicle of victimisation and ostracism’ (ibid:1244). The initial story touches on sibling birth orders, and Ellie’s attempt to disrupt this. Further there is a gendered element to this story, with Harry using a joke about Yorkie chocolate bars to make fun of the only sister in the group. In this instance the teasing is simultaneously uniting the brothers whilst singling Ellie out. Ellie then goes on to focus on how she and Harry specifically would tease each other using sign language. This story is an interesting example of inclusion in the home that can be read as crip through how it disrupts expectations around more normative sibling teasing. The story of the ‘that’s naughty’ sign having to be banned due to the teasing being too much is humorous whilst also showing the home as a potential site of inclusion (Rapp and Ginsburg, 2011). Ellie and her brother use sign language to ensure they both understand what is being said, even if the intended outcome is to make fun of each other. Zara expressed a similar sentiment regarding shouting matches with her sister:

> *‘I shared a room with her [Jenny] up until about 15 years old and it was a nightmare like we would argue so much but upon reflection, how awful Jenny can't really argue back with me, she was just like shouting at me and I’m shouting back, it was so funny’* (Zara, 24)

This reflection sat within wider discussions of sharing a room, in which Zara outlined both more positive and more challenging elements of this experience. In this instance we see that the frustrations would sometimes manifest in arguments that consisted solely of shouting, something Zara finds funny on account of the ridiculousness of it. Punch (2008) argues that the ‘backstage’ setting of sibling relationships can lead to frustrations and outbursts, something we see in the extract. Zara’s comment that her ‘sister can’t really argue back’ is interesting as she then goes on to discuss how they would still have a shouting match. This comes from an intimate understanding between the siblings of how to get their point across with, once again, the example cripping sibling conflict. Whilst Jenny may not have been verbalising her frustrations, the siblings were still able to engage in arguments and express themselves in a way they both understood, with Zara jokingly referring to the situation as a ‘nightmare’. For Eva, there was a sense of teasing being a part of what makes her family ‘funny’:

> *I'd say we're all quite funny, we have quite funny, like we have quite joke-y conversations and are always kind of taking the piss out of each other, it's hard to say something at a mealtime without someone making fun of you basically, so there is quite a lot of that going on and, yeah, I'd say we are quite a funny family but then yeah, so Tim's kind of part of that too and he just comes up with just absolutely hilarious sentences in sign language and stuff and I don't know how to describe it really but I think everyone finds him funny as well especially family friends who we know quite well and things like, they’ll always be laughing and joking as well.* (Eva)

The extract aligns with the distinction between teasing and insult outlined by Lampert and Ervin-Tripp (2006), with Eva seeing their joking as a sign of how close they are as a family. Similarly to Ellie and Zara, we see a cripping of sibling humour through the use of sign language from Tim. When asked to elaborate on this Eva added that he would use facial expressions alongside the signing to add to the humour. The story ends with a note on how everyone finds Tim funny and how family friends join in with the joking. This reflection, alongside Eva’s wider narrative, reinforces understanding of home as a potential site of inclusion (Rapp and Ginsburg, 2011), with teasing a central aspect to this. As discussed in chapter 4, Eva’s family had ‘sign only mealtimes’ and had to sign to get down from the dinner table. These family practices play a central role in facilitating this ‘shared family humour style’ (Everts, 2003), with all members of the family joining in with the joking around. Zack similarly reflected on his families shared humour style, placing Beth as the funniest:

> *I think everybody is a bit funny. But Beth is just hilarious’ … ‘the most genius thing she did like as a kid I had this weird habit right where I kept fidgeting with my hands and what it would be was like if I'm thinking about something cool or exciting I get into my own world and I start doing like this with my hands, I start kind of shaking them about and stuff and so I, mum always used to tell me off big time whenever I was doing* [it]*’ … ‘I was always really paranoid then about doing it but I just couldn't stop doing it and then just completely unprovoked one day I remember Beth is going like ‘hey Zack oooooo’, and she starts doing it like right up into my face and everybody else is there, everybody just bursts out laughing like where has she got that thought of taking the mick out of me for doing that and she'll have been young then.* (Zack)

This story captures Zack’s family humour style with their being a sense, similarly to Eva, that teasing is part of how they like to engage with each other and that it brings closeness and joy. Beth is drawing on an intimate understanding of her brother to make fun of him. This reflects Paine et al’s (2019) argument that ‘siblings’ shared experiences and knowledge of family life appeared to form a basis for co-constructed, reciprocal humorous exchanges’ (ibid: 347). Returning to the discussion around deliberate humour, both Eva and Zack make clear that their siblings are deliberate in their teasing, echoing Oscar’s feelings about giving credit to people with learning disabilities for their humour. Alongside the comedy of Zack’s reflection is also a sense of admiration for Beth and how funny she is, with the joke being described as ‘genius’. Zack went on to give an example of how he and his brother would also make fun of Beth for her reactions to being asked to do things:

> *… like it's time to get a shower, ‘urghhhhhh’, so these reactions big reactions to things and we all find really funny and stuff like that so yeah, I don't know it's hard to put, there was one where she got into this habit of saying this phrase, she kept saying ‘nah that’s rubbish, put it in the bin’ so kept saying that it’s like ‘do you want to go for a walk Beth?’, ‘nah it’s rubbish put it in the bin’ and things like that, she kept saying it all the time for everything and then Josh said to her at one point he was like ‘Beth should I put you in the bin?’ and she went ‘nah it’s rubbish put in the bin, no, no, no’ but yeah, things like that, it feels like no matter what she comes out with or anything like that we find it funny and then she finds it funny and then we're all just laughing about everything.* (Zack)

Zack’s account of him and his brother teasing Beth for her ‘big reactions’ is rooted in the everyday, with this an outcome of ‘living alongside’ (Davies, 2023) creating a knowledge of one another that the brothers can draw on to tease their sister. When read together these two examples from Zack’s narrative highlight the role of humour in their closeness as a family, with their being a sense of joy attached to the teasing. In both instances Zack refers to everyone laughing, even those on the receiving end of the jokes. Brooks et al (1999) refer to humour as a central part of maintaining ‘family social health’ and this comes through in Zack’s narrative where this teasing is clearly something that everyone in the family enjoys. Kerry similarly spoke of being teased by her brother:

> *… he remembered a few months ago that when I was younger I was really scared of balloons, he seemed to remember that so he chased me around the house with a*

> *balloon in one hand and screwdriver in the other screaming bang at me yeah, he likes teasing a lot, you can't tell him if you don't like spiders because he's obsessed with spiders and he will pick them up and throw them at you if he knows that you're scared of them.* (Kerry).

Once again, this interaction is rooted in intimate understandings of each other, with Kerry’s brother Jack drawing on knowledge of her to make his teasing more effective. Like Hannah’s reflection on feeling ‘spiky’ there is a sense in these examples that Jack is taking enjoyment from the act of making his sister uncomfortable. Further the note that he enjoys teasing once again highlights Oscar’s point around giving people credit for their jokes, this is very much a deliberate choice from Jack and gets the outcome he desires. Kerry went on to explain how she would also tease him:

> *… he doesn't get away with much with me, he generally, the idea is pushing him towards independence, he will never be able to live independently, but being able to put his own shoes on and putting his socks on, getting dressed, getting his own plate and cutlery out, he doesn't want to do any of that though and my parents will kind of let him get away with it a little bit more, but he, if I ask him to get a plate out he’ll say ‘I’m not strong enough, I’m not strong enough’ I’m like what are you talking about, I just saw you break a light switch with your hand, you're definitely strong enough and so I'll tease him and say that. Other people from an outsider perspective, me calling my disabled brother pathetic probably seems a little bit not necessarily correct, but it's just, I’ll tease him in that way because it's things that I know that he's perfectly capable of doing and he understands it's a little silly game but I'll tease him on those things, I'm like do it yourself mate, do it yourself and he'll groan and moan at me but* [it’s] *funny.* (Kerry)

The teasing is situated in their daily interactions, with Kerry arguing this is partly driven by a want for him to do more. She goes on to note how this may look from an outside perspective drawing on taboos around humour and disability. This reflection points to an awareness of disablism more widely. Similarly to Emily's statement that she 'hates the word normal' from chapter 5, Kerry is conscious of potentially problematic language and wants to ensure what she means is not misrepresented. The idea of calling your disabled brother pathetic could be read as disabling, however in this case Kerry is very clear this is not a question of disability. Further, we see that her brother is actively encouraging the joking with them both seeing it as a 'silly little game'. This links to the question of who can engage in 'disability humour' (Reid, Stoughton and Smith, 2006), with Kerry's justification making a case for sibling closeness and understanding creating a space in which disability can be played with for humorous outcomes. Scott was very upfront on his ability to find things funny that may be problematic from others:

> *I think we find it quite funny, you're in some way a privileged position, without being mean, that like if you've got your brother who's like that you can like laugh about stuff that you're not able* [to] *because otherwise it's quite offensive so yeah some of the stuff he does is quite funny.* (Scott)

This reasoning aligns with the literature around 'disability by association' (Burke, 2010, Scavarda, 2023), with Scott arguing that his relationship to his brother gives him the ability to find certain things funny without their being a more problematic element to this. Considering Reid, Stoughton and Smith's (2006) definition of 'disability humour' as that which 'centres disability or is offered by disabled persons' (ibid: 631), Scott's understanding is one which makes a case for this category to be extended to include siblings and other family members.

This comes from a place of feeling as though he has a certain ‘in’ that allows him to partake in potentially more taboo humour. Scott’s reflection about his cousins in the previous chapter shows that he considers this to be a privilege afforded to immediate family only[2]. Throughout this section there has been a sense of siblings feeling more comfortable joking about things. These instances point to an understanding from participants that their relationship with their sibling, and their own experience ‘living alongside’ someone with learning disabilities, means they are able to joke around in this way. ‘Disability humour’ is further understood by Reid, Stoughton and Smith (2006) as providing ‘a bond for members of disability culture’ (ibid: 635). This was captured in Zara’s reflection around teasing amongst her siblings:

> *We really are protective so like obviously you can have like jokes between and like make fun of each other, Jenny’s involved in that. Anyone else gets involved, it's like ‘how dare you, like that's awful’.* (Zara)

Like Scott, Zara creates a clear distinction between those that can make fun of her sister and those who cannot. This echoes the definition of teasing presented by Lampert and Ervin-Tripp (2006) with there being a difference for Zara between teasing and insult that is rooted in an understanding of each other. This caring element of the humour is furthered through the notion of all the siblings being protective of each other, with Zara using their jokes almost as evidence of their closeness and tying it to their protectiveness. When considered alongside the reflections on staring from chapter 4, we see a sense of unity between siblings when outside of the home even if they would make fun of each other within their families. Once again, we see participants placing themselves within ‘disability humour’ (Reid, Stoughton and Smith, 2006), with Zara furthering the understanding of humour as

---

[2] Scott noted that whilst his cousins were ‘like siblings’ he did sometimes find it frustrating when they found things his brother did funny, especially if he did not.

‘providing a bond’ (ibid: 635). For Faye, there was an enjoyment in having friends that would join in on family humour:

> *I have really light-hearted friends who are just, like just really un-fussed and I think sometimes you meet people who are like I don't care and maybe will be annoyed at my brother, but in a very jokey way so another thing he’ll do is obsessively clear things away, he'll watch you eat anyway but the moment your plate is clean he'll take it and he'll put it away and some people will kind of be like oh you know ‘nice to have a helpful man’ or something like that others will be like ‘oh my gosh chill’ and kind of joke with him where as there are some people who would be like I feel nervous, I feel like I'm being watched but I think, yeah, in secondary school a lot my friends were just really ready to laugh’ … ‘I think you can see that in my mum, it’s kind of like you can be annoyed at my brother or you can just do something really weird to match his energy and de-escalate and so one will be like my brother's really ticklish on his belly and my mum will kind of threaten to go near his belly and he’ll like back off and I think it just helps to like have people who are like yeah this is weird or these behaviours are not that nice but oh well.* (Faye)

This discussion was in relation to having friends over to the house and Faye’s brother potentially doing something that people might find unusual. Where Scott and Zara had quite a clear distinction of who could make fun of their sibling, Faye enjoyed the fact her school friends would match his energy arguing it was more effective in managing certain moments. Here the shared family humour style (Everts, 2003) is extended to friends in a manner that is particularly affirmative. Speaking on family practices and humour, Carter and Davies (2024) note ‘shared humour relies on shared knowledge, including shared appreciation of what counts as transgressive or incongruous within group norms’ (ibid: 4). This is seen in Faye’s reflection and ties back to the discussion in chapter 4 around the importance of people that ‘get it’ for families of people with learning disabilities. Alongside the benefit Faye feels of her friends joining in, there is also a sense in the story of inclusion and community with Faye’s friends showing love and care to her brother, and her, through their joking. Carter and Davies’ (2024) draw on Kuiper's (2009) understanding of shared humour as having the potential to strengthen ‘closeness, solidarity and trust’ (ibid: 231). Further, Hedin et al (2012) speak of humour as promoting inclusivity through creating ‘warmth’ between individuals. Faye’s story speaks to this affirmative potential, contrasting her school friends with others who would come to the house and not share this approach or understand the family practices around humour. Faye’s family were quite happy to joke about disability or around the subject, with Faye recounting a story of her brother Sami teasing her about her brother Luke ‘not really’ being non-verbal:

> *I think there is probably an unspoken and sometimes spoken dynamic of Sami and Luke being full siblings and I'm not and that can just be and it’s also they're both boys, they're a similar age but Sami would say things like ‘oh Luke can speak he just only speaks to me’.* (Faye)

This example is interesting as you have two non-disabled siblings joking with each other about their sibling with learning disabilities. This can be read problematically especially when considering the role of humour in constructing ‘out groups’ (Carter, 2019), and this is something that should be considered. Understanding that, there is a narrative context to this joke, in which Faye’s family closeness, love and support was clear. Also this was a joke that Sami told Faye when he was around 10 and she was around 8. Throughout this chapter, and the thesis, we have seen examples of the everyday-ness of learning disability, understood through mundane family practices (Morgan, 2011), and the potential this has for humour.

Through this reading you can make a case for Sami drawing on an aspect of their everyday to tease his sister, something that when their age is taken into consideration is hard to frame as overtly disablist. Further, to Faye there was a sense that this joke was rooted in Sami and Luke being ‘full siblings’ as well as brothers. This brings with it a number of aspects of how this joke was received that touch on gender, sibling birth order hierarchies and kinship understandings with Sami drawing on all of these to imply that he is closer to Luke than Faye and tease her for it. There was a sense in Faye’s narrative that this was something she finds funny even calling back to it later on when discussing her brother’s carers:

> *He basically went missing for a few hours and it was just because the woman was like, ‘I couldn't stop him. I can't stop him from walking off’. Wow, that's terrible so we found Luke and he was in McDonald's with his normal order, which I think supports the theory that he does speak.* (Faye)

Whilst the situation was serious and difficult for Faye and her family, the callback joke around her brother’s McDonald’s order plays a narrative role of both keeping the discussion ‘light’ and also reinforcing Faye’s understanding of Sami’s joke as funny. At a different point in her narrative, Faye referred to a family joke about an experience at the local lido:

> *We went to the local Lido and my mum really does milk it so there was a huge queue and she was like ‘we've got a disabled person in our party can we get through blah blah blah’ and they're like ‘okay come on come to the front’ so we walked past this really long line and there were a few grunts and mum was like ‘but we've got a disabled person’ and this mum was like ‘what disabled’ and it's still like running* [joke] *in my family like ‘what disabled’ because it was like all of you can walk and you're walking past us why.* (Faye)

This story supports Evert’s (2003) argument that the funny stories are often the ones that remain and become family stories. The humour here stems mainly from the reaction of the member of the public, with the joke poking fun at their ignorance. Sherry (2004) notes the crip potential to ‘use humour and parody as political tools’ (769). Faye’s family humour evokes this, reinforcing their closeness whilst also pushing back against a less understanding member of the public. Alongside this, Faye stated ‘my mum really does milk it’ in relation to the queue jumping. Due to the more humorous nature of Faye’s discussions and her comfortable approach to joking about disability I asked whether she would tease her mum about ‘milking it’:

> *Probably not. I think she sees it as more like a criticism like I'll be like ‘oh we really don't need to’ and I don’t think she can take that, I think she will just see it as an attack in the way other people would.* (Faye)

This understanding tells us that Faye’s humour is rooted in an understanding of what she feels she can or should joke about. Where she and her brother Sam are quite open in their comedy, Faye recognises that certain joking would be upsetting for her mum. This has been a common theme in a lot of the examples, where participants rarely made reference to deliberately upsetting their siblings or family more widely. In most cases joking and humour were used in a way that reflected Lampert and Ervin-Tripp’s (2006) understanding of teasing as distinct from insult. These examples point to an everyday-ness of family humour with participants and their siblings partaking in fun and deliberate humour that brought joy to them growing up. Participants engaged with disability in ways that were radical and actively saw their relationships and closeness as allowing them to make jokes that otherwise might be slightly problematic. This act can be seen to resist deficit understandings of siblinghood and learning disability through the centring of joy. The next section explores this resistance more overtly, looking at how participants would use humour to manage more difficult situations.

Humour in challenging situations

Alongside their reflections on humour as a source of joy and teasing, participants placed humour as something that was useful in more challenging situations. Discussing her brother occasionally coming to her school and other students asking questions, Ellie reflected:

> *I saw him so I waved and then my classmates were like 'why are you waving at that boy' I was like 'oh that's my brother' and then there was a few questions, which is fair enough, sort of saying 'what's wrong with them?' or 'why is he like that?' and I already had my answer so I must have had conversations with mum, I had my answer like 'oh he's got this disability and it means that even though he's fourteen he acts like six' or something like that 'his reading and writing* [is] *as if six' and for example, 'he still watches CBeebies' and then I'd joke 'so do I' and people would be like yeah there's some good stuff.* (Ellie)

Ellie's answer draws on the discussion in chapter 5 around mental age, evoking Kittay's (2001) reflections on describing her daughter to people who do not know her. We also see again the mundanity of being asked about impairment (Mallett and Runswick-Cole, 2014). Where the first part of the response attempts to answer the questions from other students, the second part sees Ellie almost simultaneously resist normative understandings of what age you should be watching CBeebies. The joke serves two purposes in this respect, firstly it lightens the mood when discussing a topic that, particularly for kids, could feel quite weighted. It also, and for this section more relevantly, is a way for Ellie to stand with her brother in a setting in which not ‘fitting in’ can have big consequences. This choice is then supported by her peers joining in and agreeing that CBeebies is still good to watch even at an older age. This echoes Liddiard’s (2018) discussion of humour in their work on disability and intimate relationships. They note how humour can be a tool used to navigate more ‘awkward’ interactions. Whilst Liddiard is not speaking to family relationships, we see here an example of this in how Ellie draws on humour in a potentially difficult moment. Zara discussed how her family used humour when visiting places that were not wheelchair accessible:

> *We went to a national trust property and there was stairs everywhere and we were making light of it but like we're just taking photos of Jenny at the top of stairs everywhere and I will send them to you afterwards cause they are quite funny because she's just laughing, she can't get anywhere like she’s just stuck in like different places, like it's so hard to navigate and I think perhaps that was like, it was funny as like siblings at the time but like, it was you have to laugh like otherwise you’d just be annoyed.* (Zara)

This story highlights Zara’s family’s frustration, whilst also seeing comedy used in a resistive way. Alongside this there is a sense of her family coming together through humour during a more challenging time. Roaldsen et al (2015) notes how this can be used as a way to address more difficult situations, with Zara’s family choosing to lean into humour as opposed to the other option of ‘being annoyed’. In their research around disability activism in Samoa, Anesi (2018) notes the potential of comedy in disability activism as a means of disrupting ‘systems of normalcy’. Considering this, these photos can be understood as funny acts of resistance that make clear the inaccessibility of the national trust property. There is a situation in which this extract could potentially be read more negatively around siblings laughing at their sister. It should be noted that the wider narrative context, alongside the explicit reference to Jenny finding it funny, points towards this being a story of all the siblings laughing together. The final comments around laughing as opposed to being annoyed was something arose in a few participant narratives at different points, for example:

> *Yeah, it is kind of like if you don't laugh you cry.* (Martha)

> *I feel like if you don't laugh you'll cry won't you.* (Alex)

Within these reflections was often a sense of ‘shared family humour style’ (Everts, 2003), with humour being a choice from families and something that brought them together in difficult times. This can be read in some ways as a form of ‘coping’, a theme that arises in literature around challenging times (Wanzer et al, 2005) and specifically regarding disability and family (Rieger and McGrail, 2013). However the coping narrative can be seen to overlook the more everyday nature of some of these occurrences. A second reading could be one of navigating challenges, with the families choosing humour as the means to do this but not distracting from it (Carroll, 2016). This was seen in Emily’s discussion of her sister’s time in intensive care after being born, with Emily recounting a family story of a comment she made about her sister not coming home:

> *My dad told me about it years later that they decorated the bedroom for her and we were stood in the bedroom and I was like, ‘what was the point in having a baby if you can't even bring her home?’ and my dad laughed about it because he was like we were going through this really awful thing, but actually having a five-year-old who could cut through everything was quite funny.* (Emily)

Even if Emily's comment was not meant to be comedic at the time, her dad's reaction and the further retelling of this as a family story reflects the potential for humour to 'cut through' more difficult times and provide some relief (Roaldsen et al, 2015). Emily went on to reflect on this, touching on the importance of joy even in difficult times:

> *I think there's always been those kind of light-hearted moments within our family and no matter what happens we've always been able to find a joke in it.* (Emily)

Emily's feelings about her family's ability to find a joke in difficult situations highlights the importance of nuance in how we understand how families navigate challenges. Carter and Davies (2024) point to humour as part of family practices, particularly in how families choose to engage with more difficult topics. Emily's stories point to this, with the whole family being a part of the process of 'finding a joke' in these events. Within this reflection is a sense of refusal to let a situation be read in a purely negative light. Susan reflected in her narrative on her brother being in different residential care settings throughout her childhood. In their research about this topic, Jacobs and MacMahon (2016) note how the siblings they interviewed expressed concern for maintaining their relationship with their sibling. This was something that was clearly very difficult for Susan's family, however like Emily there was still a lot of humour in these stories with her brother's personality coming through very clearly. This was seen in Susan's reflection about her brother being 'cheeky':

> *We always go for birthdays that's one thing that's important and one way he's funny with that is we'll get him to sing Happy Birthday and he'll always say the name wrong like he'll say another name and we'll laugh and that will go on for a while until he says the right name which sometimes he just doesn't do, he finds it funny like he sees that as that's something he shouldn't do so does it.*

> *Researcher: Does he like making people laugh?*
>
> *Susan: I think so yeah, he's cheeky that's a word for him.*

The quote captures the humour her brother likes to use, noting how he enjoys making people laugh. Returning to the earlier discussions, we see here examples of the deliberate humour that Oscar was referring to. Furthermore Susan’s description of her brother as cheeky is both slightly teasing and also gives a sense of closeness. Later in the interview Susan reflected on a funny family story of her sister and partner visiting her brother:

> *They went to visit him, they drove a couple hours to see him and he was lying in bed and they bought him food and he grabbed the packet of crisps, he didn't say hi, grabbed the packet of crisps, grabbed the drink, turned back in bed and said ‘bye-bye now’ and they had to leave like they drove all that way just to give him that drink but they laugh about it and they don't think it was a waste, they enjoyed it you know.* (Susan)

This story reinforces the closeness Susan and her sister feel with their understanding for their brother coming through. Whilst the wider context was difficult, and Susan’s sister and partner did not have the visit they hoped, the family still finds humour in the story. The potential of this story to reflect her brother’s isolation in a residential care setting should not be overlooked (Cumella and Lyons, 2018). Recognising this, it is important to note that Susan told the story as an example of the ‘cheeky’ side of her brother which comes through even in this difficult situation. Susan’s stories point to the necessity of counter-narrative for families navigating challenging experiences, the humour works to highlight her brother’s personality and allows his character to come through. This ensures that the family's experiences are not viewed solely through a deficit lens, instead offering a nuanced understanding of the everyday mundane realities of difficult family situations. Where the participants in this section have chosen humour as a means to navigate challenging moments, with most reflections pointing to joy and closeness as a result of this, Hannah felt conflicted on her family's use of humour in more difficult times. This was something she unpacked in an extensive section of her narrative, which is offered here in full to ensure the nuance of her reflections are clear:

> *I feel like that is the only way sometimes to, you can't take stuff too seriously and I think it was definitely as a family a big coping mechanism for all of us. Yeah. I think being able to make light of difficult situations, even for my sister being able to be like 'this is fine whatever it was, this is fine' and just laugh. Yeah, which I think can have a negative side to it as well, but I don't know how people who don't laugh at hard situations that they find themselves* [having to] *cope with because I just think you can't be serious like you just can't be serious because yeah.* (Hannah)

When asked to discuss this further Hannah added:

> *I guess not always having your feelings about a situation validated because it's like laughter and the acknowledgment I think my parents are a lot better at this now but when we were younger, I think because everything was so stressful, lots of health stuff with my sister and things, I think that keeping going and you kind of have to sometimes, not give airtime to more difficult situations, but I think that definitely meant as a child sometimes I didn't feel like, obviously I did not consciously think this as a child but as an adult looking back like it might have been helpful sometimes for*

> *someone to be like this is a really difficult situation and I think that happened probably more as I got older anyway, into later teen years and stuff but yeah, I think that almost if your… especially as a child if something feels scary or stressful or something and then it's being brushed off then you kind of don't know where you stand in terms of 'am I meant to find this stressful, am I being, am I just being, am I being silly if I'm finding this particularly stressful?'. So yeah, I think that is the negative side of it, but I guess I would 100% prefer humour to be the kind of mechanism rather than just taking everything really seriously all the time.* (Hannah)

Hannah makes clear the importance of not overlooking difficult situations or choosing humour without acknowledgement of challenges. Unlike Emily and Susan, Hannah views the humour explicitly as a coping mechanism and raises concerns around how this meant her feelings were understood and received at times in her childhood. This presents a potential shortcoming of her family's humour practices, with Hannah feeling frustrated that humour was always their go to in difficult situations. Where narratives of coping can present this response in a binary light, Carter and Davies (2024) offer a nuanced approach noting how the habits of family humour practices can be hard to shake, even if it is not a humour that works for everyone. Here we also see how family humour is not immune from wider considerations of power in its construction. Whilst Hannah is understanding of why her parents often went for humour, her feelings of frustration highlight how this 'family practice' is not necessarily one that everyone was unified on (Morgan, 2011).

Interestingly, Hannah notes at the end of she would still prefer humour to seriousness if there was only one option. This outlook is nuanced and reflects mixed feelings about how her family dealt with challenging times. It is important to reflect on this as it raises concern around acknowledging more difficult situations in participant narratives and ensuring that whilst there can be humour and joy in these moments, there is also going to be more challenging emotions that are still as valid. This does not mean that Hannah's reflection is reinforcing deficit understandings of disability and siblinghood, instead the nuance and complexity Davies (2023) places as central to sibling relationships comes through. The humour gives insight into the closeness that was shown in other aspects of participant narratives. For example, participants reflected on how growing up with a sibling with learning disabilities has impacted them in a number of important ways as will be explored in the next section.

Reflections on the self

Participants challenged deficit understandings of siblinghood and learning disability through their reflections about themselves, and the influence their siblings had on them growing up. Their stories generated counter-narratives that spoke to their experiences as siblings of people with learning disabilities, highlighting the generative potential of disability in how we engage with the world (Kafer, 2013; Goodley, 2023). This was seen in discussions about personal qualities they viewed as influenced by growing up with their siblings. Further, a number of participants expressed a strong sense of justice with regards to social causes, with their allyship and advocacy coming from these childhood experiences. For many participants there was a sense that their experiences have made them a 'better' person, and this being something that they are proud of. This was seen in Kerry's reflection on her patience and sense of perspective:

> *I think that I haven't really had many crisis situations like external to my family but yeah I would say so, my patience definitely, it's definitely been kind of noticed at work, I can stick at doing one thing until it's done and doing like tiny little adjustments and*

> *things that other people, they have to do 15 minutes and walk away from it and I could do a full day. I'm more like people have to prise me away from it because I'm like no I will get there. I'll be very patient in that sense. I don't know necessarily how I react in different crisis situations, but I think generally yeah, I would probably be fairly calm. I have more of a scale of what's really bad and what's not, so there's things where I'm like that's not that bad, there's far worse things actually, so this is fine.* (Kerry)

For Kerry the more difficult moments growing up have given her perspective on dealing with different situations in her life. This is an interesting reflection as this perspective, and further her sense of patience, is something that Kerry was happy she now has even if it is the result of challenging times. Hannah noted her sense of calmness if plans changed:

> *I feel like that is one of my greatest strengths now if a plan does not work out, I'm just like never mind it's fine and I think yeah, that's definitely from my childhood just being, me being annoyed because we can't do something because she's doing this or whatever 'cause that will just cause another element of stress for my parents but I don't think I thought about it that consciously I think it was just like innate like 'that's not helpful right now'.* (Hannah)

We see the sense of pride that Hannah has for her ability to deal with change. Interestingly, whilst Hannah is noting how her parents may have to spend more time with her sister, a common theme in sibling disability literature (Hanvey et al, 2022), her appreciation for this part of herself rejects ideas of this being a problem for her. Where in this instance Hannah was hyper-aware of not making a situation more difficult for her mum and dad, she does not lean into a deficit understanding of her experiences, instead choosing to acknowledge how this has made her a better person. Alex similarly touched on the idea of parent time, challenging ideas around sibling frustrations:

> *I almost at a very young age kind of, maybe that's down to my subconsciously thought ‘oh well Lola kind of needs to’, she almost gets different treatments to me but I almost understood it, I think the age of understanding it was quite young for me, I know some people may have grown up and still maybe have that problem, I don't know, but me I kind of gauge oh Lola’s going to get a bit of special treatment obviously I'm not going to get that which I completely understood probably at the age of maybe eight, maybe nine, so it's quite young and that followed throughout going into secondary school obviously Lola needs to be looked after, I was never jealous whatsoever about obviously the attention she got, my mum always ask me that saying ‘did you not feel like we put a lot of attention on you?’ and I just obviously yeah, I mean that she was always gonna get a lot more attention to me, but I really didn't care at all I was doing my own thing and it's never really crossed me and it's never really, I feel like if I would have been jealous or something I would have shown signs but literally unfazed, I kind of just did my own thing.* (Alex)

Alex actively rejects dominant narratives around parent time and learning disability, noting how he was ‘literally unfazed’. In wider literature, the argument is often that having a sibling with learning disabilities leads to situations in which parents have less time for their non-disabled children (See Ladieri et al, 2000 and Hanvey et al, 2022 for examples). Whilst Alex does not refute this, he offers a narrative that can be seen to be rooted in the everyday care discussed in chapter 4. Where his mum was particularly concerned about this, something that came up multiple times in the interview, Alex’s reflections make clear his understanding that Lola might get some special treatment and that this did not bother him.

This echoes Kerry's sense of perspective and was something that Alex felt he benefited from when he got to university and had to deal with stressful situations:

> *I would say a lot more understanding of stuff so you would be a lot more say if someone's going crazy and they've just had a breakup a lot of people would be like that doesn't justify you doing that, me I'd be a lot more understanding obviously with a disabled sister you have to be understanding that's one of the things, you can't get annoyed at her for stuff that she can't really control. So yeah I'd say it would be definitely, it helped my understanding skills and empathising with people and yeah, I think that's probably one of the skills that almost subconsciously has been embedded in me, which I don't realise until when you actually reflect back on it that that's happened.* (Alex)

Like Kerry, Alex attributes his sense of perspective to his childhood experiences growing up with a sibling with learning disabilities. It is essential to note the wider context of austerity and structural ableism that impacted all the participants in their childhoods, with this likely being a factor in Alex's sense of perspective. This is built upon with Alex further adding that he feels he has a strong sense of understanding of others as well. The examples so far are counter-narrative in how they offer an alternative reading to potentially difficult parts of childhood. Where we could see these as stories of parents that did not have time for their non-disabled children and plans being changed to satisfy the sibling with learning disabilities, the participants offer a sense of understanding rooted in love for their siblings. The pride in how they have learnt from these experiences enables an alternative, counter reading. Throughout his narrative Scott spoke about how his experiences have shaped him, reflecting on his own self awareness and understanding as is outlined in his portrait. For context, Scott has one older brother called Dean:

Scott's Narrative Portrait: 'I think I'm very self-aware in a nice, in a really nice way and I think empathetic and aware of other people and other people's situations'.

I think in some instances, in some situations I'm incredibly accommodating and understanding and probably a lot nicer towards, not that people aren't nice towards people with learning disabilities, and sometimes I'm a bit like I've got so little patience here because I've dealt with this for so long you know what I mean like I slightly can't be bothered to engage with you like whatever it's better to just like not engage because you know you're gonna get stuck in this really annoying conversation and I feel like maybe you're more able to take that approach, again kind of the closeness of being able to laugh at my brother, like maybe you can also afford to be harsher and I would say in a nice way treat them more like a normal person. It's like if you have a normal person and you're like I find that person really boring or I find them annoying you just won't chat to them you don't feel duty bound to do it and it's almost like not patronising. I think in general I'm very compromising and I'd say one of my favourite traits about myself is because of growing up with him and growing up in a situation where you have to be accommodating and compromising and just really chill and not kick off about things and be fine and you know yeah it's nice and so I think, I don't think that's necessarily just my nature I think that's from being in that environment.

At the risk of like going on about how great I am, I think the traits of mine that I really like that I can put down at least in part to that, I think I'm very self-aware in a nice, in a really nice way and I think empathetic and aware of other people and other people's situations and lots of people are but I feel like I am, about that one of the other ones which is maybe slightly odd which I think is really nice is a bit of like the autistic not being embarrassed, not having the capacity to be in embarrassed about what people think about you so just not giving a shit about what people think and I think a lot of people worry way too much about what other people are thinking about them or like worried that everyone's... Like no one cares, like on the whole no one does and I think being in a situation where someone has zero of that worry they literally like they don't have it, they just don't, they're just not embarrassed about something and maybe part of this is being forced to be in situations and being like it's fine and I *think I've got that, quite a lot of that and I think that's really nice and I think it saves a lot of anxiety and worry that lot of people have about like constant worry and having to portray an image and that kind of stuff and being worried about being perceived in a certain way and I don't think I have a lot of that which is really nice.*

Scott's portrait touches on a number of interesting reflections about how he views himself and how this relates to his experiences growing up. Like many of the participants, Scott sees himself as understanding of other people however he views this slightly differently through his feelings around how he treats people with learning disabilities. Scott refers back to his point about being able to laugh at certain things due to his experiences, in this case he feels more comfortable potentially not engaging with people just because they have learning disabilities. This is quite an unusual reflection in that it is slightly taboo, however when read alongside the ideas of 'disability by association' (Burke, 2010; Scavarda, 2023) that have featured throughout this thesis, and particularly in Scott's narrative, there is sense of this being for Scott a sign of his comfortableness around disability. This is reinforced in him arguing that this is an example of treating people equally and further noting how he feels that to do something different would potentially be patronising.

As the portrait continues Scott discussed other aspects of himself that he feels are particularly 'nice', touching on empathy and 'not being embarrassed'. The former is something that arose in other participant narratives, as seen in previous examples. This echoes wider research which has explored self-perception, showing that siblings of people with learning disabilities often take pride in aspects of their personalities they attribute to their childhood experiences (Wolff et al; 2024; Shenoy et al, 2025). The embarrassment point is interesting as Scott places this as an 'autistic trait', drawing on stereotypical understandings of autism in the process. This framing, and the reference to 'normal people' in the portrait, is potentially problematic, however the discussion in the previous chapter allows for some debate around this. The wider point of learning this from his brother and it being something he really likes about himself is quite radical. As mentioned earlier, discussions of parent time often point to an understanding of siblinghood and learning disability that is centred around the parents (Ladieri et al, 2000 and Hanvey et al, 2022). Scott's reflection, along with most of the participant narratives in the study, places his relationship with his sibling as something independent of that with their parents. In doing so, questions of parent time can be seen as misplaced on account of the participants viewing being a sibling as distinct and joyful in itself. Scott's feelings about his lack of embarrassment and further the benefits this has in his life put forward a narrative of more lateral sibling teaching that allows for both brothers to learn from each other as distinct from discussions of parent time and sibling outcomes. Martha similarly reflected on how her sense of understanding came from her experiences growing up:

> *It's made me more understanding of other people and what they go through and I'm quite an open person as well, which I think is quite good like I'd happily just open up to people which, I actually don't know if that's good. But It's like kids at school, when you get the 'weird kids' other people don't want to be friends with I'd always kind of relate to them a little bit and I remember when I was a kid, there was this one person who couldn't tie their shoelaces for a while and I used to just help him because that's what I used to do with Guy and you got all these other kids walking past and there's me still trying to learn to tie up shoes, but I'm still trying to help.* (Martha)

In the example, Martha attributes her openness and understanding to having grown up with a brother with learning disabilities. The example of supporting someone to tie their shoes points to an understanding of inclusion and what that looks like in practice, with Martha drawing a direct link between this and helping her brother. The way these traits are discussed is very everyday and matter of fact, however they come together to create a picture of inclusion. The importance of fitting in at school has arisen throughout the analysis sections of this thesis and when read with this in mind, Martha’s actions take on even more significance. Hannah echoed this sentiment in her reflections:

> *I feel the positives of having her as my sister are like I just think you have more…. especially when I was at school, I just felt like I have more, I guess, maybe more mature which maybe isn't a good thing when you're little but I don't know more like empathy. Like, you know, if there was someone who was maybe a bit weird at school or something like that.* (Hannah)

In both examples the participants refer to having more empathy for people at school who were ‘weird’. As with Martha, whilst the language choice is potentially problematic, the wider context highlights Hannah as someone who is aware of the potential implications of not fitting in at school. For Faye, there was a frustration around people not giving certain students the ‘time of day’ that echoed the feelings of both Martha and Hannah:

> *…it was interesting because we had maybe two students who had additional needs in my year, by which I mean very clearly, in a class specifically for it and it was interesting because at our school prom I took loads of pictures I brought like a proper camera and I remember uploading them and there was a picture of this girl who was disabled dancing and having a good time and people love reacted, they really liked it and I was like it’s so interesting that you're like ‘wow she's having a good time, she looks great’ and in school you never made fun of her but you didn't necessarily warm to her or give her the time of day.* (Faye)

Faye’s story points to the more explicit allyship and activism that siblings touched on during their narratives and their frustrations with people not being inclusive more widely. In their discussion of siblings of disabled people’s stories of activism, Jones (2019) outlines a number of examples of small-scale acts of resistance that come from this sort of frustration at a lack of inclusion. Interestingly, in all three of these examples the participant’s inclusive choices are rooted in more mundane everyday things like being ‘warm’ or helping someone to tie their shoes. These acts are directly linked to their childhood experiences and seem to almost come naturally to the participants, with there being a sense of retrospective understanding in their narrative as they are looking back at the actions with a more critical eye. Nishida (2016) draws a link between experiences of ableism and activist practices, referring to ‘politicisation’. This sense of social justice as driven by lived experience came up in a number of interviews, for example Oscar reflected on his personal politics as directly linked to his experiences as a sibling:

> *I mean my politics and I think this kind of thing I've been saying about a balance of needs and stuff. The Marx slogan' … '"from each according to their abilities to each according to their needs". I think really kind of encapsulates what I think about stuff and that's transcended from even the levels of funding like his school or stuff was, it's a million over or maybe a hundred thousand pounds a year or something huge sums of money but like that was what was required and then that's translated all the way down to individual stuff of how long it takes someone to say a sentence like you know ok yeah you just have to wait and you've got to listen.* (Oscar)

Throughout his narrative, Oscar returned to this understanding, as shaped by the Marx[3] quote he mentions. This was the crux of his personal politics, with the latter part of the quote

---

[3] The quote “from each according to their abilities to each according to their needs” is from Marx’s (1933) *Critique of the Gotha Programme*.

encapsulating this from the larger, more structural issue of school support to the everyday choice of allowing more time if someone needs it. He is explicit in how this links to his own upbringing, making clear that this is a central part of how he understands the world. Once again, inclusion is key to this with the example being rooted in ensuring that everyone gets to be heard and is given the time they need to get their point across. Sauer and Lalvani (2017) argue that family members of disabled people often become activists and advocates through their experiences, noting a commitment to questioning deficit narratives and ‘the underlying societal structures that contribute to them’ (ibid: 52). Oscar’s reflections move between the structural and the individual, making clear how he feels about disability and politics more widely. Discussing activism in families, Runswick-Cole et al (2022) note disability’s disruptive nature in generating new understandings and alternative ways to view the world. Oscar’s politics is influenced by his sibling experience which has given him insight into ways of thinking about how things should be. This sentiment was echoed in Hannah’s narrative:

> *I just think you are aware that people's lives are not straightforward and also people, people deserve help. Can you tell I'm not a Tory and it has hundred percent has shaped my politics because you just know that people deserve help from the state and they deserve, and everyone's lives are of equal value. I think that's one thing like that just doesn’t, I just feel like the current climate it doesn't really seem to be a thing that people feel that everyone’s lives are of equal value and value isn't like to do with how productive people are and what they put back into society’ … ‘People's lives are just inherently valuable and not because of how hard they can work because some people like my sister are not going to be able to work really hard and does that mean her life is not, because she can't ‘give back to society’ in the ways that people, in a monetary sense.* (Hannah)

Hannah’s feelings about her personal politics echo Oscar’s, with their experiences as siblings clearly impacting them. Once again, we get a sense of lived experience as ‘politicising’ (Nishida, 2016). This extract in particular touches on a number of disability studies arguments such as challenging the notion of the ‘neo-liberal able-bodied citizen’ (Goodley, 2014) and critiquing finding value in life through a capitalist conceptualisation of ‘productivity’ (Wendell, 1989; Berlant, 2007). Hannah explicitly refers to her sister in how she challenges these individualising and pathologising ideas, making a case for her personhood in the process that is distinct from neo-liberal understandings of human value. Rapp and Ginsburg (2001) reflect on the potential of family experience to politicise arguing:

> *‘the way that family members articulate changing experiences and awareness of disability in the domain of kinship not only provides a model for the body politic as a whole, but also helps to constitute a broader understanding of citizenship in which disability rights are understood as civil rights’* (ibid: 545)

Hannah’s call for rethinking how we understand the human echoes this. Further, her comments challenge deficit understandings of people with learning disabilities through making a case for human value that is rooted in love and care, a stance that echoes Goodley’s (2023) argument for centring the human in how we understand learning disability.

Conclusion

This chapter has focused on how participants rejected dominant pathological models of disability in families. This was done through the centring of joy in many of the narratives, which brought with it a nuanced understanding of sibling experience that allowed for counter-narratives to emerge. This chapter used the example of humour as the main focus, exploring how humour featured in participant’s stories and worked to centre the humanity of their siblings. This was addressed in a number of ways, firstly as a source of joy with family stories often being those that were humorous and retold for this reason. Then, sibling teasing was explored, with participants highlighting the closeness and love that teasing often requires. Further, commonplace narratives around ‘lack of humour’ and comprehension were rejected in favour of examples of deliberate joking and teasing from their siblings. Humour as resistance was then discussed to finish this section, with stories of participants and their families using humour to navigate more difficult times. These examples pointed to the importance of nuanced understandings of sibling experiences and acknowledged the potential of joy even in challenging times. The stories worked to address what can be seen as a ‘joy deficit’ in sibling research (Sunderland et al, 2009; Shuster and Westbrook, 2022). This echoes Thomas’ (2024) argument that ‘parents revolt against dominant conceptions of parenting a disabled child as a source of despair, fear, and no future’ (ibid: 2). This was seen from a sibling perspective in my interviews, with participants actively rejecting deficit understandings of their experiences.

The chapter finished with reflections from participants about their personalities and how they felt their experiences had shaped them as people. Participants noted traits they felt proud of that they saw as linked to their experiences, for example their sense of understanding and patience. Alongside this, they discussed their views of social justice and allyship reflecting on how their experiences have shaped their politics both at a government and more personal day-to-day level. These examples push back against ideas of sibling outcomes with stories centring the positive influences their siblings have had on their lives. The following chapter outlines the conclusions of the thesis. This is done through revisiting the research questions, discussing the contributions and outlining the potential limitations of the study.

Chapter 7: Conclusion

Introduction

This thesis set out to explore the childhood experiences of siblings of people with learning disabilities. The narratives generated in this work present the everyday of siblinghood and disability, with participants reinforcing notions of closeness and frustration that are often expected of having a sibling (Punch, 2008; Davies, 2015a). Throughout their stories participants refused to simply reproduce deficit understandings of learning disability and siblinghood, instead providing nuanced accounts of 'living alongside' (Davies 2023). These counter-narratives were at times crip, with siblings offering radical celebratory understandings of their childhoods. Further, we saw the generative potential of siblinghood in presenting new understandings of learning disability, with the closeness and proximity of the relationship seeing participants reflecting on their experiences with humour and care alongside, in places, frustrations. Throughout all of these moments participants centred the human in their stories (Goodley, 2023), speaking to the personhood of their siblings and making clear how important these relationships are for the whole family and in local communities.

This chapter begins with an overview of the study, focusing on how the research was conducted. Next, the research questions are addressed, with each corresponding to an analysis chapter providing a summary of the findings in the process. Here, how the analysis furthered understandings of learning disability and siblinghood is made clear. Following this, the contributions are outlined looking at both family sociology and critical disability studies. Then the recommendations for research and practice are outlined, offering possible applications for the framework developed in this study. This leads into limitations, with the potential shortcomings of the project made clear. To finish, the thesis concludes with some final reflections which situate the work within the current context of disability politics in the UK and recognise where the findings can provide some hope moving forwards.

Summary of study

This project drew on concepts from family sociology through a critical disability studies lens in order to explore learning disability and siblinghood, with the central aim of challenging commonplace deficit narratives that often arise in research around this topic. The literature review addressed both of these areas of scholarship, initially separately. Discussions of critical disability studies and theorising learning disability drew on key theorists in these areas (for example Garland-Thomson, 2007; Davis, 2008; Goodley, 2014; Goodey, 2016) and introduced crip theory as a counter-narrative approach to understanding disability (McRuer, 2006; Löfgren-Mårtenson, 2013; Kafer, 2021). Family sociology was then discussed, focusing on family practices and display (Finch, 2007; Morgan, 2011). Sociological understandings of siblinghood were unpacked, introducing the key theories and concepts that informed the analysis (for example Punch, 2008; Davies, 2015a; Davies, 2023). The second half of the literature review saw these two areas of scholarship brought together around four themes with the aim of exploring siblinghood and learning disability in the everyday. These themes were humour, home, conflict and care, with each being addressed using literature from family sociology and critical disability studies to begin to consider how siblinghood and disability is understood in research and how this thesis could build on these conceptualisations.

To facilitate this counter-narrative approach, the data were collected using narrative inquiry drawing on Rosenthal's (2007) narrative interview framework. 14 narrative interviews were conducted with siblings of people with learning disabilities aged 18-32. Participants were asked to bring along photos and a timeline from their childhood. As discussed in chapter 3, in practice these creative elements acted more as interview prompts than data in themselves, however some were included in analysis where participants directly referenced photos in their stories. Narrative thematic analysis was then conducted, with narrative portraits being produced as part of this process. The portraits offered insight into participant stories in their own words (Rodriguez-Dorans, 2022), allowing time to sit with themes in depth as they arose across participant narratives. These were presented at points within the analysis chapters to capture the nuance of siblinghood and authentically represent participant stories. The analysis chapters addressed each research question, which are discussed in the following section.

Addressing the Research Questions

This thesis set out to engage with three research questions which spoke to the experiences of siblings of people with learning disabilities across childhood, concerned specifically with the everyday. This allowed for the ups and downs of siblinghood to come through and discussion of how these experiences can inform understandings of disability and siblinghood more widely. The analysis was structured around these, with each chapter focusing on a specific research question. This section will address each question, providing a summary of the project's findings in the process.

How do young adult siblings (aged 18-32) of people with learning disabilities make sense of their childhood experiences of family life?

Chapter 4 explored this research question focusing on the everyday experiences of growing up with a sibling with learning disabilities. The discussion addressed three themes that arose during analysis: sharing space, sibling care, and wider family and outside the home.

Sharing space explores participant reflections on ‘living alongside’ (Davies, 2023) and navigating the home with their siblings and other family members. Here, participants’ family practices (Morgan, 2011) were unpacked with stories of siblinghood that echoed wider culturally available understandings around sharing a bedroom, playing together, conflict and dinner time. The analysis built on this, exploring how disability extended these understandings of everyday family practices. For example, in the discussion of dinnertime practices, one participant reflected on their parents instigating ‘sign only’ mealtimes to help everyone learn sign language. This story highlights the mundane everyday of siblinghood, whilst offering insight into inclusion that builds on Rapp and Ginsburg’s (2011) understanding of ‘reverberations’ within families of disabled children. This story, and others within the chapter, highlight the everyday of disability in families with participants reflecting Davies’ (2015a) conceptualisation of the ‘emotional tightrope’ of sibling relationships. Davies argues that siblings navigate both close and challenging emotions almost simultaneously attributing this partly to the proximity siblinghood often brings (Punch, 2008). This was seen in how participants spoke of sharing the television, with this being a point of contention for some. Reflections varied from shared interests with participants able to recite full scenes from movies even now, to one participant changing the channel once her parents left the room as she felt they always sided with her sister. These stories offered new understandings of the ‘backstage nature of sibling relationships’ (Punch, 2008), highlighting the everyday ups and downs of ‘living alongside’ (Davies, 2023) a sibling with learning disabilities.

Each participant reflected on care in some form within their narrative and this was explored through the theme 'sibling care or being looked after'. A key reflection of this section was around the word ‘care’ itself and the label ‘young carer’. Many of the participants rejected ‘care’ labels when presenting their own experiences, referring instead to ‘helping out’ and ‘doing stuff’, which extends arguments from wider research around sibling care and disability (Meltzer, 2017; Pavlopoulou and Dimitriou, 2019). Participants' stories of ‘helping out’ demonstrated the everyday of sibling care that offered depathologised understandings of things like supporting with medication or going out for the day. These moments furthered Pavlopoulou and Dimitriou’s (2019) argument around being mindful of presenting ‘helpful relations between siblings, in which sisters [siblings] seem to feel comfortable’... ‘as non-normative caring tasks’ (ibid: 10).

Alongside these reflections around care language, were discussions of feelings of responsibility and further how this looked moving forwards and growing older. This was tied to how participants understood themselves regarding care, with many participants seeing their ‘helping out’ as something that may become care as they grow older and take over from parents. Here the analysis reflected wider understandings of sibling care as changing over the life course, with siblings of people with learning disabilities often being expected to take over when parents get older or pass away (Barnes, 2012; Tozer and Atkin, 2015). This thesis has extended these arguments noting how feelings around this varied depending on participant age and family situations. For those who were towards the younger end of the sampling frame this was addressed in a more abstract sense, as something that would happen but not something that brought too much concern. For Scott, the oldest participant in the study, this was a far more realised consideration which brought with it greater concern and some frank reflections about his future. This said, it should be noted that in their discussions of responsibility and potential future care, participants were clear that this was a wider issue around poor support as opposed to something they attributed to their sibling. The importance of good support was explored in the final theme of this chapter, which will be considered later on in this section.

The theme of sibling care finished with reflections on the gendered nature of care practices within participant families. This echoed understandings of care often falling on women (Webster, 2018; Wikle et al, 2018), with participants speaking of these expectations and how they played out over their childhoods. The analysis explored this with reference to wider complexities of sibling relationships (Davies, 2023) recognising how participant care practices were influenced by both structural expectations around care and gender and also mundane everyday family practices. This was not solely presented as difficult, with some participants noting how this care could bring with it a closeness they value and felt with their sibling that did not extend to others in the family who took on less responsibility.

The final theme of this chapter, and section addressing this research question specifically, focuses on wider family and experiences outside the home. A key finding of this analysis was the impact of good support, and the role of wider family and friends in this. Participants spoke about informal support, specifically the importance of people that ‘get it’ when it comes to having a family member with learning disabilities. Examples were offered of grandparents that helped out on holidays, and friends that were particularly ‘good’ with participant’s siblings. This extended wider research around being asked about impairment (Mallett and Runswick-Cole, 2016), offering insight into the joy that being around those that ‘get it’ can bring. Participants also spoke of more formal support experiences, building on existing arguments about the importance of good support for the whole family (Conway and Meyer, 2008; Tozer and Atkin, 2015). Stories were offered of youth groups and other clubs that they had found useful growing up and how important this had been for them. These examples were contrasted with accounts of formal and informal support that was not as well received (Robinson et al, 2016), further making clear how important good support was to participants and their families.

This theme concluded with a discussion of navigating society, focusing on participant stories of public interactions. For the most part these were stories of difficult interactions, with members of the public asking inappropriate questions or staring at their siblings. Here, the research contributed to wider discussions of disability by association (Burke, 2010; Scavarda, 2023), with participants' experiences in public pointing to an understanding of siblinghood and disability that recognises how disablism can be experienced by wider family. Acknowledging this, the analysis took these discussions further, noting acts of resistance against this disabling behaviour, with participants reflecting on staring back or making deliberately loud comments to support their sibling and challenge the individual staring.

Across the chapter, participants framed their experiences in relation to their feelings as opposed to pointing to impairment effects or other discourses. In doing this, the chapter extended understandings of the everyday of siblinghood and learning disability, centring ‘living alongside’ and the challenges but also the joys this brings (Davies, 2023). How participants navigated disability within their narratives was the focus of the following research question.

How do siblings of people with learning disabilities conceptualise disability, family and sibling relationships?

This research question was discussed in chapter 5. How participants chose to address these topics gives insight into the everyday of disability in families and furthers understandings of siblinghood and learning disability.

The discussion of this chapter began with reflections around the term ‘normal’ within narratives. Participants spoke of normal in two main ways. Firstly, referring to a normal that evoked a hegemonic understanding, noting how their lives were similar or different to this. The second approach to normal was rooted in more fluid conceptualisations of the term, with participants speaking to their everyday experiences as ‘normal’ for them and their family. Regarding the former, these stories were situated within wider narratives allowing for careful analysis that avoided presenting these hegemonic discourses as inherently problematic standpoints from participants. Here the analysis drew on understandings of the nuance and complexity of siblinghood (Davies, 2023) to offer new ways to discuss ‘normal’. This was seen in Emily’s discussion of wanting her sister to ‘fit in’ at school, noting her concerns around ‘mean spirited people’. This could be read as a non-disabled sibling attempting to push ‘normal’ onto their sibling with learning disabilities, however this understanding would be ignoring Emily’s wider narrative and the care she feels for her sister. Instead this was understood as a recognition of the dangers of not fitting in, especially in a non-inclusive school system (Ktenidis, 2022; Slater, 2016). Through this analysis, Emily’s story can be seen to further understandings of ‘being there’ and the everyday support that siblings offer each other (Brownlie, 2014; Hayden and Hastings, 2022).

The second way participants evoked normal was in a more fluid sense, speaking to their families own sense of normal. Phrases such as ‘*it wasn’t what other people* [did] *but it was normal in our family*’ (Hannah) were commonplace in accounts. Within these moments, the analysis reflected Goodey’s (2016) distinction between alternative norms and abnormality, presenting their experiences within the former category. This was explored with a focus on the everyday-ness of the experiences and ‘living alongside’ (Davies, 2023) as discussed in the previous section. The stories were rooted in everyday life, the mundane events and practices that made up their childhoods and were normal to them, even if they were non-normative. In many ways these two definitions can be seen as contradictory with participants simultaneously evoking understandings of a hegemonic normal whilst also rejecting them. However, when approached narratively, the analysis presents the everydayness of siblinghood through this complexity, offering new insights into how siblings of people with learning disabilities conceptualise disability.

Further conceptualisations of disability came in the form of overt discussions and more everyday passing reflections. The overt discussions saw participants referencing disability, often through impairment labels. The everyday reflections were more concerned with how disability arose in participant narratives in passing, such as comments about a sibling attending a special school or going to certain youth clubs. The overt discussions in many cases drew on wider cultural understandings of different impairments, with participants noting how these narratives echoed, or differed from, their experiences. This reinforced Mallett and Runswick-Cole's (2016) conceptualisation of the normal abnormal with the siblings being aware of commonplace understandings of what having certain impairment labels 'should' mean. In some instances this could be seen as participants recognising the context of the interview and wanting to draw on wider cultural discourses in order to describe their sibling in a manner they hoped would make sense to the researcher, echoing Kittay's (2001) reflections on references to 'mental age'. Considering the more passing references, these reflected how disability arose in narratives without being a central focus. Throughout participant accounts would be discussions around attending different schools or their sibling being picked up in a taxi. These moments are linked to their sibling having learning disabilities, but this was not explicitly unpacked, instead these were presented as part of the everyday occurrences that made up childhood. The analysis found that participants' reinforced the nuance of learning disability and siblinghood through consistently conceptualising and reconceptualising learning disability, and ideas of normal, throughout their narratives.

The final findings of this research question relate to how participants understood siblinghood and family in their narratives. Throughout their stories participants spoke to widely understood expectations around siblinghood, noting where they felt their own relationships potentially did not align. These were in many cases tied to 'temporal scripts' (May, 2019) and ideas of how we should grow older. The analysis extended this through a critical disability studies lens recognising how participants who had older siblings with learning disabilities struggled with this, referencing frustrations around being the first to do GCSEs or go to university. Further, some participants presented crip arguments of having a sibling that did not align with these expectations being something to celebrate. This was seen in Ellie's reflection on her older brothers being annoying, and how her brother Harry did not annoy her partly because he did not try to be 'cool' like they did. How participants responded to these expectations varied, some cited cousins as being 'like siblings' drawing a link between this and things they felt they had missed out on, others referenced older friends or family friends who they felt they could learn from. This analysis reinforced arguments around the importance of siblinghood culturally and how these narratives influence how we understand our own relationships (May, 2019; Davies, 2023).

Considering 'stickiness' (Smart, 2007; Davies, 2019), participants spoke of their sibling being 'known' in the local community. Linked to expectations, the analysis offered new understandings of how this occurs, for example multiple participants noted how even though they were older, people would often come up to them and ask if they were 'so and so's' sibling. In most cases this was something that participants found funny, attributing their siblings popularity to their personality, providing an understanding that goes beyond impairment, something that will be revisited in the next section. For others this was something they found more difficult, wanting to avoid having their identity defined by their siblings. This aligns with wider sibling literature, reinforcing understandings of the difficulties that can arise in having siblings that are known well in the community and how this can impact how you are viewed (Davies, 2019). Within these stories of ‘know-ness’ were examples of how siblings were active members of their local communities, challenging the social exclusion that is often faced by people with learning disabilities (Yates et al, 2008; Goodey, 2016). In these moments, participants were happy for their siblings, enjoying these examples of everyday inclusion that extend beyond the home and immediate family. These stories, and others throughout the analysis were understood as counter–narratives to deficit understandings of siblinghood and disability, a theme which the final research questions addresses.

In what ways might counter-narratives of siblings problematise dominant pathological models of disability in families?

The final research question was the focus of chapter 6. In this, counter-narratives were centred through discussions of joy, humour and participant reflections about themselves. It is also important to recognise how counter-narratives featured throughout the other analysis chapters, as has been made clear where necessary. These counter-narratives stand in contrast to dominant pathological understandings of disability in family (Stoneman, 2005; Meltzer and Kramer, 2016; Meltzer, 2018).

Participants told joyful stories of their childhoods often centred around humour, both in the content of the stories and the delivery. The analysis drew on ‘family humour practices’ (Carter and Davies, 2024) and ‘shared family humour styles’ (Everts, 2003), recognising how funny stories often become family stories. These captured the fun of participants’ sibling relationships, touching on trips out, jokes, pranks and more. The analysis centred Arnett’s (2023) understanding of joy ‘as an intense, temporary feeling of elation combined with an appraisal of right relation between ourselves and the world, a sense that there is an ideal fit between ourselves and the world around us at that moment' (ibid: 1). Within these examples we saw the love that family humour can convey (Smart, 2007). There were also considerations of 'disability humour' as distinct from 'disabling humour' (Reid, Stoughton and Smith, 2006), with there being a question around whether siblings of people with learning disabilities can partake in the former. This was particularly the case in moments where participants raised questions around their sibling's understanding of their own humour. The findings presented examples that fit within 'disability humour' and further challenged wider discourses of lack of humour or comprehension that can be attributed to people with learning disabilities (Bertilsdotter Rosqvist, 2012). Whilst participants did, at times, speak to these narratives, more widely in their stories we saw their siblings actively partaking in family humour.

There were also interesting reflections around teasing between participants and their siblings. Teasing is often understood as a core part of sibling relationships, with a distinction drawn between this and insult that sees the former require a certain degree of closeness to be achieved (Lampert and Ervin-Tripp, 2006). Participants echoed this, speaking of teasing their siblings or being teased by them as a common occurrence taking joy in recounting these stories even if they were on the receiving end of the jokes. These reflections were analysed with consideration given to the discussions around comprehension that can arise in discussions of learning disability and humour; within these stories participants' siblings were presented as actively partaking in this and enjoying it. This was also the case in moments where participants spoke with admiration for their sibling's sense of humour. This choice ensured participants' siblings were recognised for their deliberate and subversive humour, rejecting deficit understandings in the process.

There were moments, of course, where this teasing was slightly more frustrating and the desire to annoy each other was not received well by either sibling. These reflections were understood with reference to the ‘living alongside’ that Davies (2023) refers to, with all parties drawing on their intimate knowledge of each other to find ways to annoy, joke and frustrate their siblings for fun. This was also seen in how participants justified some of the teasing; there were multiple references to the fact that it might not ‘look’ great to make fun of your sibling with learning disabilities but participants were quick to make clear how this was something they felt they could do on account of their close relationships. In most cases participants chose to draw on more everyday discourses as opposed to their sibling’s impairment in these moments of teasing. For example, Emily referred to her sister having ‘zero boundaries’ as she would constantly call her. Emily’s teasing spoke to her experience on the receiving end of these calls but did not try to pathologise this occurrence. Some of the stories offered alternative insights into inclusion in families, with Ellie for example noting how the ‘that’s naughty’ sign had to be banned in their house due to teasing. This story, amongst others, presents inclusive forms of communication and how even if the intention is to make fun of each other there was still a want to ensure everyone could partake in the interaction.

Participants spoke of the role of humour in navigating more difficult situations, with shared family humour practices (Carter and Davies, 2023) being described as a potential avenue by which to address challenging times. Whilst this could be seen as a form of ‘coping’ (Wanzer et al, 2005; Rieger and McGrail, 2013), the analysis understood this humour as a means of navigating and addressing challenges and not distracting from them (Carroll, 2016). Within the more difficult moments, humour was used as a way to reinforce their siblings’ personalities and centre their humanity at times where this could be at risk of being erased (Goodley, 2023). This was the case in Susan’s reflection of her brother's experiences in residential care settings, with Susan telling humorous family stories that she felt captured her brother’s ‘cheeky’ side even in these more difficult moments. This can be seen as a result of the approach of the study, with the commitment to identifying counter-narratives generating novel and affirmative understandings in participant stories. It should be noted that for some participants, their families’ choice to use humour in certain moments was not always appreciated. Similarly, Hannah stated that she felt her family may have used it too much in certain difficult times, however she did add that she prefers humour to seriousness if there was only one option. This highlights how whilst there was lots of fun and joy in participant narratives, there were also really difficult moments that reflect the reality of the austerity context in which the narratives were situated and the implications this has for people with learning disabilities and their families. Here the choice to recognise the wider structural factors ensured still participant stories were not presented solely through a deficit lens, allowing for readings that still moved away from pathologising narratives.

The final part of chapter 6 addresses the participants' reflections on the self. These were examples of how they felt their experiences as a sibling had influenced them, speaking to the generative potential of disability in how we engage with the world. There were numerous examples of things, such as patience, a sense of perspective, and feeling they were more understanding and kind for their experiences. Through these stories, the analysis challenged deficit narratives around parent time which can often arise in discussions of siblinghood and learning disability (Ladieri et al, 2000; Hanvey et al, 2022). Instead these examples saw participants celebrating how their experiences had shaped them and how much they appreciated this. This extended to politics, with multiple participants reflecting on how they felt society was not inclusive. This furthered research around activism in families (Rapp and Ginsburg, 2001; Runswick-Cole et al, 2022), with the focus on siblinghood offering novel contributions. As has been apparent throughout the project, these examples further saw participants centre their siblings' humanity making a case for human value that moves beyond economic output or ideas of ‘ideal bodies and minds’ (Wendell, 1989; Berlant, 2007; Goodley, 2023).

The analysis generated stories of siblinghood and disability that centred joy, with joking, teasing and even more frustrating moments presenting an understanding of people with learning disabilities as active members of their families. Participants refused to present their siblings through a deficit lens, offering nuanced accounts that made sure their sibling’s humanity was central. These counter-stories offer new understandings of family and disability that move away from dominant, pathological narratives.

Contributions

This thesis contributes to both critical disability studies and family sociology, offering a framework by which we can begin to explore siblinghood and disability in a manner that centres the human (Goodley, 2023) whilst allowing for the nuances of siblinghood to be apparent. This approach is influenced by Meltzer’s (2018) reflection:

> *‘Sibling disability research has traditionally defined the relationships between siblings where one has a disability by what they are not- that is, when compared to the normative view of relationships between siblings where neither have a disability, sibling relationships that include a person with a disability have traditionally been found wanting or damaged in comparison*’ (ibid: 1228).

Through focusing on participant narratives of their everyday experiences growing up with a sibling with learning disabilities this thesis refused to define the relationships by what they are not. In doing so, the findings present a nuanced understanding of siblinghood and disability that allows for challenges and frustrations to coexist with joy and love. This shows how family sociology can be elevated through engaging with learning disability as the nuance and complexity (Davies, 2023) of sibling relationships is made clear. This framework, combined with a critical disability studies lens, offers an understanding of siblinghood and learning disability that allows counter-narratives that reflect the everyday realities of siblinghood to come through. Further, Stoneman (2005) argues ‘conceptual models of families too often view children with disabilities as stressors rather than as family members’ (ibid: 347). Throughout this research participants offered stories that allowed their sibling to be annoying, frustrating or at times even aggressive but this was not met with discussions of outcomes or stressors. Instead, it was contextualised within wider narratives of childhood which highlight the realities of ‘living alongside’ siblings and the ups and downs this brings (Davies, 2023).

The narrative focus on everyday sibling experiences enabled the centring of human stories in the research (Goodley, 2023). Through this, the importance of everyday stories of learning disability and family life came through (Goodley et al, 2019), reflecting understandings of the setting as both mundane and extraordinary (Highmore, 2010). Connor (2006) notes how an everyday focus can be generative due to situating disability away from medicalised spaces. Participant accounts echoed this, making clear the humanity of their siblings and further the political potential of the everyday (Pink, 2012). For example in chapter 6, where participants spoke of how their experiences had politicised them (Nishida, 2016). We saw how they advocate for and support their siblings in their daily lives, something that research has shown to be necessary in an ableist society (Kittay, 2001; Hayden and Hastings, 2022). These mundane, everyday stories came together to offer essential counter-narratives that actively reject deficit understandings of siblinghood and learning disability. Further, recognising learning disability as a ‘discursively constructed object’ (Yates et al 2008: 53), the thesis generated reflections of learning disability and family life that were affirmative and novel. This builds on wider literature around the potential of everyday stories to offer new insights into marginalised experiences (Back, 2015; Ghisleni, 2017).

Considering critical disability studies, the work furthers understanding of learning disability through engaging with family sociology, speaking to Goodley's (2023) call for centring the human in discussions of learning disability. Goodley draws attention to 'being human as praxis', arguing:

> *'people with learning disabilities are being human in ways that challenge narrow forms of humanness that masquerade as the human per se'* (ibid: 172).

This work sits alongside this, with the stories presented being ones that further how we understand what being a sibling is and challenging 'narrow forms of humanness' more generally. Returning to the discussions of 'stressors', we see how the humanity of disabled people more widely can be overlooked in constructions of family and disability. The counter-narratives generated in this work allow for the humanity of people with learning disabilities, as siblings in their own right, to come through clearly. The joy and the humour alongside the self-reflections from participants show understandings of siblinghood and learning disability that are generative, presenting stories that are affirmative and centre the personhood of their siblings. The same can be said for more difficult stories, with discussions of annoying siblings and frustrations within the family speaking again to humanness and the reality of 'living alongside' one another (Davies, 2023).

A further contribution of this thesis within the critical disability studies space is in relation to disability by association (Burke, 2010; Scavarda, 2023) and more widely discussions around the role of family in understanding learning disability. This is of course a contentious area, with many debates (see for example Kittay, 1999 and Ryan and Runswick-Cole, 2008). This work speaks to the insight that can be gained from the perspectives of siblings of people with learning disabilities varying from difficult moments to more affirmative. Considering the former, participants spoke of being impacted by the ableism and disablism experienced by their sibling, and in some cases partaking in acts of resistance to offer support. Thinking more affirmatively, there were more generative stories in which we began to see how siblings of people with learning disabilities could provide insight into what inclusion looks like. A key example of this would be through the discussions of 'disability humour' (Reid, Stoughton and Smith, 2006). Participant accounts were full of humour, both in how narratives were delivered and also the content of the stories they chose to tell. This thesis chose to place these accounts within Reid, Stoughton and Smith's (2006) definition of 'disability humour', which is understood as that which 'centres disability or is offered by disabled persons' (ibid, 631), they go on to note how this can provide 'a bond for members of disability culture' (ibid: 635). Whilst their definition does not explicitly place siblings within this category, the notion of 'a disability culture' feels as though it could include siblings. Further, the humour within participant narratives was contextualised with stories of love and closeness and to call it 'disabling' would feel misplaced. Through this, the thesis has extended understandings of humour and disability in families, offering an affirmative approach to this topic that allows disability humour to be extended to siblings as part of wider family humour practices.

Considering the more generative aspects of this, Smedema, Ebener and Grist-Gordon (2012) argue that humour can provide 'counter-narratives that redefine the meaning of disability, promoting disability as a valid social identity' (ibid:1433). This was particularly pertinent in the deliberate, subversive humour that participants' siblings carried out. Where commonplace discourses around comprehension or 'lack' of humour can arise in discussions of learning disability (Bertilsdotter Rosqvist, 2012; Chadwick and Platt, 2018), the stories in this thesis highlighted how these narratives are misplaced. Participants recounted, with joy, how their sibling is an active part of their shared family humour practices (Carter and Davies, 2024), be that in telling funny jokes or sometimes taking the mick out of each other. In these instances these commonplace discourses were rejected, and in their place affirmative counter-narratives were generated that centred humour and joy.

The final contribution of the thesis is that of the application of crip theory to understandings of disability and siblinghood. Considering Meltzer's (2018) reflections on this field, as often opting to define relationships by what they are not, the crip approach of this thesis was key to rejecting this. Throughout there was a concerted effort to 'celebrate' participant stories with joy being a central theme of the work. In doing this it can be argued the thesis has demonstrated the many ways in which sibling relationships might be characterised as crip relationships. This ties into other contributions with this focus both centring the human in the work and also linking to ideas around humour and joy. This also extends the growing body of work that makes clear how crip theory can, and should, be applied to the experiences of people with learning disabilities (Löfgren-Mårtenson, 2013; Levy and Young; 2020; Kafer, 2021).

Recommendations for research

Alongside the theoretical contributions of this thesis, we must consider how the findings can be applied to further research. The framework provided in this study offers potential to explore siblinghood and disability in more depth. This section provides three examples of avenues for further research.

A recommendation for further research, and also a potential limitation of this study, is the need to bring the voices of people with learning disabilities into discussions of siblinghood. This is an argument that Richardson and Jordan (2017) have made, with research often being dominated by the viewpoints of non-disabled siblings. In terms of future research, through bringing together family sociology and critical disability studies this thesis has provided a framework for understanding siblinghood and disability that accounts for the ups and downs of living alongside one another (Davies, 2023). With this, there is generative potential to carry out research with people with learning disabilities about their sibling relationships. This ensures people with learning disabilities are allowed the chance to be siblings, something that can be seen as missing from work that focuses solely on non-disabled sibling accounts. Further, there is also potential to explore the joy of these relationships in this regard and generate more counter-narratives that centre people with learning disabilities' humanity (Goodley, 2023) and ensure that understandings of people as 'stressors' (Stoneman, 2005) are avoided.

The second recommendation comes from both the research and the advisory board. During the advisory board meeting the members noted how it would be interesting to see how sibling relationships developed over the life-course. Whilst this is something that research has explored (Knox and Bigby, 2007; Tozer et al, 2013; Dorsman et al, 2023), the framework outlined in this project could help develop this work to offer nuanced counter-narratives of siblinghood and disability over time. Further, participants spoke to this in a number of ways, for example Scott's concerns around taking over care from his parents or Zack noting how playing the Nintendo Wii is how Beth and he maintain their connection now he has moved away. As has been noted in wider sibling research, the relationship is often one of the longest people have in their lives and this brings with it the potential for navigating a number of life events and changes (Allan, 1979). Considering chapter 4 for example, these reflections on ‘living alongside’ (Davies, 2023) will likely be very different if siblings have moved away, and the relational implications of this would be an interesting and important addition to the counter-narratives generated in this thesis.

This also has policy implications, with the charity Sibs noting this as a core concern of adult siblings of disabled people (Sibs, 2025). Further, disabled people and parents have also expressed frustrations around care transitions in later life (Ward, 2011; 2015; Runswick-Cole et al, 2024). The analysis of this study has highlighted this as something that is important to siblings of people with learning disabilities, with the theoretical lens offering an opportunity to approach this in a manner that recognises the nuance of siblinghood. Where this was not the focus of the study, the potential to explore care transitions with attention given to sibling relationships could have implications for policy in this area. This framing enables an approach that recognises the love and closeness siblings may feel whilst also acknowledging frustrations and other emotions that make up these relationships (Davies, 2015a) and may influence feelings around care transitions.

The third recommendation is for more work exploring humour and learning disability. As this thesis has made clear there are commonplace narratives around learning disability that centre around ‘lack’ of humour or questions of ‘comprehension’ (Bertilsdotter Rosqvist, 2012; Chadwick and Platt, 2018). The stories in this thesis challenged this, instead offering narratives of deliberate, subversive comedy that was central to the joy of the sibling relationships. There is potential for this to be explored more in future research, with this offering an avenue through which affirmative understandings can be generated. Further, exploring this alongside the previous recommendation, it is important that this discussion engages with people with learning disabilities themselves. Whilst the humorous stories outlined in this work were contextualised and spoke to the participants' experiences as siblings specifically, the views of people with learning disabilities should be central to this. The potential of humour to generate affirmative understandings of learning disability in the everyday can be developed through opening up this discussion.

Limitations

As raised in the methodology chapter, a limitation of this study is in the lack of diversity in the participant sample. Whilst attempts were made to address this, through sending recruitment materials out more widely, this was not achieved within the time constraints of the project. Throughout the thesis are moments where participants referenced how their families had to fight with support services, with some explicitly referencing social capital and resources being helpful in these moments. Considering the context of austerity that acts as a backdrop to the childhoods of each participant who took part, it would have benefitted the project to have had a more diverse set of experiences regarding these services. The stories gathered do speak to a number of experiences, and the aim of the project is to explore everyday stories as opposed to provide a generalisable set of findings about siblinghood and disability. This said, in moments where we saw the impact of cuts and other austerity measures that can be seen to have targeted disabled people (Ryan, 2020) it would have been beneficial to explore this in more depth regarding the role social class and social capital play in navigating these systems.

A second limitation is more in the project's focus and how this impacts topics that were engaged with. The research set out to explore childhood experiences, and this is a wide-reaching focus that saw participants touch on a number of areas of interest that could have been projects on their own, such as care, home, humour and conceptualising disability. In practice this meant that many of these topics were addressed in passing where more detail could develop the analysis further into specific fields. The overview provided in this thesis is still relevant and the framework has the potential to be applied elsewhere to further understanding of siblinghood and learning disability. Recognising this, I still wanted to acknowledge that in places the work could be seen to move quickly through theories and concepts that have strong grounding in different disciplines and whilst I tried to acknowledge these areas appropriately, more time and space to address these may have furthered the analysis.

A third potential limitation can be seen methodologically, with the approach chosen for this work being reliant on participants attending the interviews with prepared timelines and photos. Whilst this was effective and I feel allowing participants the chance to bring something pre-prepared was generative (Mannay, 2010), there were instances where participants came unprepared and this did impact how the interviews unfolded. This was not a huge problem and these interviews could still be carried out with interesting data generated. However, in future research I would want to be clearer on what I ask from participants and consider more thoughtfully the potential time these activities could take. This was particularly the case with photo elicitation, where my sample frame of 18-32 years old meant many of the participants did not have easy access to photos from when they were young as they had moved away from their family home which weighted the photos provided towards latter parts of childhood. This was partly why I chose not to analyse the photos specifically and instead they were used more as interview aids to help participants engage with the narrative interview format. Overall I am happy with the data collected and feel privileged to have been allowed to explore this topic with my participants, but this is a consideration for how to approach this more thoughtfully in future work.

Final thoughts

The narratives generated in this work are situated within a context of austerity and cuts to services that targeted disabled people. Within the narratives were examples of poor support, tribunals and inadequate residential care settings. Over the course of writing this thesis the UK government has changed, however the political landscape for disabled people and their families remains the same. With the Labour government announcing cuts to PiP (Jayanetti, 2025) and recycling tired neo-liberal narratives about work and undeserved welfare (Harris, 2025), it is clear disabled people are not valued in the UK. This is captured in Goodley's (2023) provocation:

> 'That people with learning disabilities manage to exist in our communities is nothing short of astounding' (ibid: 172)

Goodley argues people with learning disabilities' humanity is under threat, calling for more scholarship that centres this. The stories generated in this research speak to the humanity of people with learning disabilities and their families. Thomas (2024) reflects that 'parents revolt against dominant conceptions of parenting a disabled child as a source of despair, fear, and no future' (ibid: 2). The same can be said for the siblings interviewed in this study, with participant narratives creating vivid portraits of themselves and their siblings as fun, annoying, cheeky, loving, frustrating, joyful, political and funny people. These are stories of community and support that go far beyond the narrow view of humanity the 'neo-liberal ableist citizen' (Goodley and Lawthom, 2019) offers.

Back (2021) argues one of our goals as social scientists is to recognise hope in troubling times, noting examples of this in the community response to the Grenfell tower fire. Whilst these are no doubt troubling times for people with learning disabilities and their families, and the anger this generates is important, this thesis highlights the everyday joy and love of growing up with a sibling with learning disabilities. The stories are littered with moments of solidarity and care, both within families and from local communities, something which feels essential at the moment. In recognition of this I wanted to finish the thesis by returning to a reflection from Oscar:

> *I think a lot of these kids don't quite get the credit they deserve in terms of they know what they're doing, they know they're taking the piss and yeah, it's just so funny. I mean, I really just think, just in general it's just such a beautiful way to see the world and such a beautiful different way to see the world that is so refreshing from, you know, everyone else sometimes.*

Bibliography

Aaltonen, S. (2016) ‘‘My mother thought upper secondary school was OK, but then my sibling said no’ - Young People's Perceptions of the Involvement of Parents and Siblings in their Future Choices’, *Sociological research online*, 21(1), pp. 65–76. doi:10.5153/sro.3850.

Abrams, E. J. and Abes, E. S. (2021) ‘'It's Finding Peace in My Body': Crip Theory to Understand Authenticity for a Queer, Disabled College Student’, *Journal of college student development*, 62(3), pp. 261–275. doi: 10.1353/csd.2021.0021.

Adu-Ampong, E.A. and Adams, E.A. (2020) ‘“But You Are Also Ghanaian, You Should Know”: Negotiating the Insider–Outsider Research Positionality in the Fieldwork Encounter’, *Qualitative inquiry*, 26(6), pp. 583–592. doi:10.1177/1077800419846532.

Alcoff, L. (1991). ‘The problem of speaking for others’, *Cultural Critique*, 20(20), pp. 5–32. https://doi.org/10.2307/1354221.

Ali, Z. Fazil, Q, Bywaters, P, Wallace, L and Singh, G. (2001) ‘Disability, Ethnicity and Childhood: A critical review of research’, *Disability & society*, 16(7), pp. 949–967. doi: 10.1080/09687590120097845.

Allan, G. (1979) *A sociology of friendship and kinship. London* (etc.): Allen and Unwin.

Altermark, N. (2017) *Citizenship inclusion and intellectual disability : biopolitics post-institutionalisation*. 1st. London: Routledge.

Andrews, M., Sclater, S. D., Squire, C., and Tamboukou, M. (2004) 'Narrative research', in Seale, C., Gobo, G., Gubrium, J.F. and Silverman, D. (eds.) *Qualitative Research Practice*. London: Sage pp. 99-112.

Anesi, J. (2018) ‘Laughing matters: humour as advocacy in education for the disabled’, *Disability & society*, 33(5), pp. 723–742. doi: 10.1080/09687599.2018.1453782.

Annison, J. E. (2000) ‘Towards a clearer understanding of the meaning of “home”’, *Journal of intellectual & developmental disability*, 25(4), pp. 251–262. doi: 10.1080/13668250020019566-1.

Arnett, J. J. (2023) ‘Joy: An integrative theory’, *The journal of positive psychology*, 18(1), pp. 1–14. doi: 10.1080/17439760.2022.2053878.

Arnold, C. K., Heller, T. and Kramer, J. (2012) ‘Support Needs of Siblings of People with Developmental Disabilities’, *Intellectual and developmental disabilities*, 50(5), pp. 373–382. doi:10.1352/1934-9556-50.5.373.

Asbjørnslett, M., Helseth, S. and Engelsrud, G. H. (2014) '"Being an ordinary kid" – demands of everyday life when labelled with disability', *Scandinavian journal of disability research : SJDR*, 16(4).

Avieli, H., Band-Winterstein, T. and Araten Bergman, T. (2019) 'Sibling Relationships Over the Life Course: Growing Up With a Disability', *Qualitative health research*, 29(12), pp. 1739–1750. doi: 10.1177/1049732319837228.

Avioli, P.S., (2012). 'Sibling relationships from midlife to old age', *Handbook of families and aging*, 17(8), pp.125-151.

Back, L. (2015) 'Why Everyday Life Matters: Class, Community and Making Life Livable', *Sociology* (Oxford), 49(5), pp. 820–836. doi:10.1177/0038038515589292.

Back, L. (2021) 'Hope's Work', *Antipode*, 53(1), pp. 3–20. Available at: https://doi.org/10.1111/anti.12644.

Back, L. and Solomos, J. (1993) 'Doing research, writing politics: the dilemmas of political intervention in research on racism', *Economy and Society* , 22(2): 178–99.

Bal, M. (1985) *Narratology : introduction to the theory of narrative*. Toronto ; University of Toronto Press.

Barnes, C. (1996), 'Theories of disability and the origins of the oppression of disabled people in western society', in Barton, L (ed.), *Disability and society: emerging issues and insights*, Harlow: Longman.

Barnes, C. and Mercer, G. (2004) 'Theorising and Researching Disability from a Social Model Perspective', in Barnes, C. and Mercer, G. (eds.) *Implementing the social model of disability: Theory and research*. Leeds: The Disability Press, pp. 1-17.

Barnes, M. (2012) 'An ethic of care and sibling care in older age', *Families, relationships and societies*, 1(1), pp. 7–23. doi: 10.1332/204674312X633135.

Barr, J. and McLeod, S. (2010) 'They never see how hard it is to be me: Siblings' observations of strangers, peers and family', *International journal of speech language pathology*, 12(2), pp. 162–171. doi: 10.3109/17549500903434133.

Basnet, N., Timmerman, M. C. and van der Linden, J. (2020) 'The Education-to-Work Transition of Young Rural–Urban Migrants in Kathmandu, Nepal', *Journal of Applied Youth Studies*, 3(4–5), pp. 331–344. doi: 10.1007/s43151-020-00027-z.

Basnet, N., Wouters, A. and Kusurkar, R. (2023) 'Timeline Mapping as a Methodological Approach to Study Transitions in Health Professions Education', *International journal of qualitative methods*, 22. doi: 10.1177/16094069221148868.

Bedford, V. H., and Avioli, P. S. (2012). ‘Siblings in middle and late adulthood’, In Blieszner, R. and Bedford, V. H. (eds.),*Handbook of families and aging* (2nd ed). Santa Barbara, CA: Praeger. pp. 125–153.

Bell, C. (2010), ‘Is disability studies actually white disability studies?’, in Davis, L. J. (ed), *The disability studies reader*. 3rd ed. (pp.402-410) London: Routledge.

Bell, J. (2005). *Doing your research project* (4th ed.). Maidenhead, England: Open University Press.

Benderix, Y. and Sivberg, B. (2007) ‘Siblings' Experiences of Having a Brother or Sister With Autism and Mental Retardation: A Case Study of 14 Siblings From Five Families’, *Journal of pediatric nursing*, 22(5), pp. 410–418. doi: 10.1016/j.pedn.2007.08.013.

Bergen, D. (2006) ‘Play as a context for humor development’, In Pronin Fromberg and Bergen, D. (eds.), *Play from birth to twelve*. New York, NY: Routledge, Taylor & Francis. pp. 141-155.

Berlant, L. (2007) ‘Slow Death (Sovereignty, Obesity, Lateral Agency)’, *Critical inquiry*, 33(4), pp. 754–780. doi:10.1086/521568.

Bertilsdotter Rosqvist, H. (2012) ‘The politics of joking: narratives of humour and joking among adults with Asperger's syndrome’, *Disability & society*, 27(2), pp. 235–247. doi:10.1080/09687599.2011.644933.

Bigby, C. and Fyffe, C. (2009) ‘Achieving their own lives: The implementation of individualised funding for people with intellectual disability’, *Proceedings of the third annual roundtable on intellectual disability policy*. Melbourne: La Trobe University.

Billig, M. (2005) *Laughter and Ridicule: Towards a Social Critique of Humour*. London: Sage.

Blum, L. (2015), *Raising generation Rx: mothering kids with invisible disabilities in an age of inequality*, New York: NYU Press.

Boccagni, P. and Kusenbach, M. (2020) ‘For a comparative sociology of home: Relationships, cultures, structures’, *Current sociology*, 68(5), pp. 595–606. doi: 10.1177/0011392120927776.

Bogdan, R. and Taylor, S.J. (1982) *Inside out : the social meaning of mental retardation*. 1st ed. Toronto, [Ontario]; University of Toronto Press. doi:10.3138/9781442632196.

Bogdan, R. and Taylor, S.J. (1987), ‘Toward a sociology of acceptance: the other side of the study of deviance’ *Social Policy*, 18(2), pp. 34-39.

Bogdan, R. and Taylor, S.J. (1989) ‘Relationships with Severely Disabled People: The Social Construction of Humanness’, *Social problems* (Berkeley, Calif.), 36(2), pp. 135–148. doi:10.1525/sp.1989.36.2.03a00030.

Boland, G. and Guerin, S. (2022) ‘Connecting locally: The role of adult siblings in supporting the social inclusion in neighbourhoods of adults with intellectual disability’, *British journal of learning disabilities*, 50(3), pp. 327–340. doi: 10.1111/bld.12404.

Brannelly, T. and Barnes, M. (2022) *Researching with care : applying feminist care ethics to research practice*. Bristol: Policy Press.

Brannen, J., Heptinstall, E. and Bhopal, K. (2000) *Connecting children : care and family life in later childhood*. (1st ed), London: RoutledgeFalmer.

Braun, V. and Clarke, V. (2006) ‘Using thematic analysis in psychology’, *Qualitative research in psychology*, 3(2), pp. 77–101. doi: 10.1191/1478088706qp063oa.

Braun, V. and Clarke, V. (2022) *Thematic analysis : a practical guide*. Los Angeles: SAGE.

Broese van Groenou, M. I. and De Boer, A. (2016) ‘Providing informal care in a changing society’, *European Journal of Ageing*, 13(3), pp. 271–279. doi: 10.1007/s10433-016-0370-7.

Brooks, N.A., Guthrie, D.W. and Gaylord, C.G. (1999) ‘Therapeutic humor in the family: An exploratory study’, Humor (Berlin, Germany), 12(2), pp. 151–160. Available at: https://doi.org/10.1515/humr.1999.12.2.151.

Brownlie, J. (2014) *Ordinary relationships : a sociological study of emotions, reflexivity and culture*. Hampshire, England ; New York, New York: Palgrave Macmillan.

Bruner, J. (2004) ‘Life as Narrative’, *Social research*, 71(3), pp. 691–710. doi: 10.1353/sor.2004.0045.

Buckle, J., Dwyer, S., and Jackson, M. (2010). ‘Qualitative bereavement research: incongruity between the perspectives of participants and research ethics boards’, *International Journal of Social Research Methodology,* 13(2),pp. 111-125.

Budworth, P. (2023) ‘Care, comfort, and capacity: The importance of being flexible in research with Disabled and chronically ill people’, *SSM. Qualitative research in health*, 4, p. 100352. doi: 10.1016/j.ssmqr.2023.100352.

Burch, L. (2024) ‘“I haven’t got anywhere safe”: disabled people’s experiences of hate and violence within the home’, *Social & cultural geography*, 25(6), pp. 967–984. doi: 10.1080/14649365.2023.2242325.

Burke, P. (2010) ‘Brothers and Sisters of Disabled Children: The Experience of Disability by Association’, *The British journal of social work*, 40(6), pp. 1681–1699. Doi: 10.1093/bjsw/bcp088.

Campbell, F. K. (2009) *Contours of ableism : the production of disability and abledness*. Basingstoke: Palgrave Macmillan.

Campbell, L., Martin, R.A. and Ward, J.R. (2008) ‘An observational study of humor use while resolving conflict in dating couples’, *Personal relationships*, 15(1), pp. 41–55. doi:10.1111/j.1475-6811.2007.00183.x.

Carroll, N. (2016), ‘The applied philosophy of humor’, In: Kaspar, L., Brownlee, K., and Coady, D. (eds.) *A Companion To Applied Philosophy*. Chichester: Wiley, pp. 527-538.

Carsten, J. (2003) *After Kinship.* Cambridge: Cambridge University Press.

Carter, A. (2019) ‘“Essex girls” in the comedy club: Stand-up, ridicule and “value struggles”’, *European journal of cultural studies*, 22(5–6), pp. 763–780. doi: 10.1177/1367549419861852.

Carter, A. and Davies, K. (2024) ‘Laughing through Brexit: Family humour practices, political troubles and everyday life’, *Current sociology*. doi: 10.1177/00113921241275684.

Castelino, A. (2024) ‘Supporting Families to Engage in Music Making with Preschool Children with Profound Intellectual and Multiple Disabilities at Home: An Interpretivist Multi-case Study’, *The Arts in Psychotherapy*, doi:10.1016/j.aip.2024.102200

Cebula, K., Gillooly, A., Coulthard, L. K. B., Riby, D. M., Hastings, R. P. (2025) ‘The experiences of children with Williams syndrome and their nondisabled siblings of their relationship’, *Family relations*, 74(1), pp. 500–518. doi: 10.1111/fare.13102.

Chadwick, R. (2021) ‘On the politics of discomfort’, *Feminist theory*, 22(4), pp. 556–574. doi: 10.1177/1464700120987379.

Chadwick, D. D. and Platt, T. (2018) ‘Investigating humor in social interaction in people with intellectual disabilities: A systematic review of the literature’, *Frontiers in psychology*, 9, pp. 1745–1745. doi: 10.3389/fpsyg.2018.01745.

Chan, J. K. H. and Zhang, Y. (2021) ‘Sharing Space: Urban Sharing, Sharing a Living Space, and Shared Social Spaces’, *Space and culture*, 24(1), pp. 157–169. doi: 10.1177/1206331218806160.

Chapman, T., and Hockey, J. (1999). The ideal home as it is imagined and as it is lived. In Chapman, T. and Hockey, J. (eds.), *Ideal homes? Social change and domestic life* (pp. 1–15). Routledge.

Chappell, A. L. (1997), ‘From normalisation to where?’, In Barton, L. and Oliver, M., *Disability studies: Past, Present and Future*. Leeds: The Disability Press: pp. 45-61.

Chappell, A.L., Goodley, D. and Lawthom, R. (2001) ‘Making connections: the relevance of the social model of disability for people with learning difficulties’, *British journal of learning disabilities*, 29(2), pp. 45–50. doi:10.1046/j.1468-3156.2001.00084.x.

Charlton, J.I. (1998) *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley, CA: University of California Press.

Cheshire, L., Easthope, H. and ten Have, C. (2021) ‘Unneighbourliness and the Unmaking of Home’, *Housing, theory, and society*, 38(2), pp. 133–151. doi: 10.1080/14036096.2019.1705384.

Clandinin, D.J. (2006) ‘Narrative Inquiry: A Methodology for Studying Lived Experience’, *Research studies in music education*, 27(1), pp. 44–54. doi:10.1177/1321103X060270010301.

Coccia, E. (2024) *Philosophy of the home : domestic space and happiness.* London: Penguin Books.

Connolly, M., Kiraly M., McCrae L. and Mitchell G. (2017) ‘A Kinship Care Practice Framework: Using a Life Course Approach’, *The British journal of social work*, 47(1), pp. 87–105. doi: 10.1093/bjsw/bcw041.

Connor, D. J. (2006) ‘Michael's Story: "I get into so much trouble just by walking": Narrative Knowing and Life at the Intersections of Learning Disability, Race, and Class’, *Equity & excellence in education*, 39(2), pp. 154–165. doi: 10.1080/10665680500533942.

Connors, C. and Stalker, K. (2007) ‘Children's experiences of disability: pointers to a social model of childhood disability’, *Disability & society*, 22(1), pp. 19–33. doi:10.1080/09687590601056162.

Cosenza, J. (2010) 'SLOW: Crip theory, dyslexia and the borderlands of disability and ablebodiedness', *Liminalities: A Journal of Performance Studies*, 6(2), pp. 1-10.

Conway, S. and Meyer, D. (2008) ‘Developing support for siblings of young people with disabilities’, *Support for learning*, 23(3), pp. 113–117. doi:10.1111/j.1467-9604.2008.00381.x.

Crow, L. (1992) ‘Renewing the Social Model of Disability’, *Coalition*, July, pp. 5–9.

Cumberbatch, G. and Negrine, R. (2022). *Images of disability on television.* Routledge: London.

Cumella, S. and Lyons, M. (2018) ‘Shared-life communities for people with a learning disability: A review of the evidence’, *British journal of learning disabilities*, 46(3), pp. 163–171. doi: 10.1111/bld.12224.

D’Angelo, J. D. and Moreno, M. A. (2019) ‘Not at the dinner table - take it to your room: adolescent reports of parental screen time rules’, *Communication research reports*, 36(5), pp. 426–436. doi: 10.1080/08824096.2019.1683528.

Davies, H. (2015a) *Understanding children's personal lives and relationships*. Houndmills, Basingstoke, Hampshire; New York, NY: Palgrave Macmillan.

Davies, K. (2015b) ‘Siblings, Stories and the Self: The Sociological Significance of Young People's Sibling Relationships’, *Sociology* (Oxford), 49(4), pp. 679–695. doi:10.1177/0038038514551091.

Davies, K. (2019) ‘‘Sticky’ proximities: Sibling relationships and education’, *The Sociological review* (Keele), 67(1), pp. 210–225. doi:10.1177/0038026118784832.

Davies, K. (2023) *Siblings and sociology*. Manchester: Manchester University Press.

Davis, L. J. (1995) *Enforcing normalcy : disability, deafness, and the body*. London ; New York: Verso.

Davis, L. J. (2008). *Obsession: A history*. Chicago, IL: University of Chicago Press.

de Villiers, C., Muhammad Bilal Farooq and Molinari, M. (2022) ‘Qualitative research interviews using online video technology – challenges and opportunities’, *Meditari Accountancy Research*, 30(6), pp. 1764–1782. doi: 10.1108/MEDAR-03-2021-1252.

Dean, J., Furness, P., Verrier, D., Lennon, H., Bennett, C. and Spencer, S. (2018) 'Desert island data: an investigation into researcher positionality', *Qualitative Research*, 18(3), pp. 273-289.

Deleuze G. and Guattari, F. (1987) *A Thousand Plateaus*, London: Continuum.

Delgado, R. (1984) ‘The Imperial Scholar: Reflections on a Review of Civil Rights Literature’, *University of Pennsylvania law review*, 132(3), pp. 561–578. doi: 10.2307/3311882.

Dellve, L., Cernerud, L. and Hallberg, L. R. M. (2000) ‘Harmonizing dilemmas - Siblings of children with DAMP and Asperger syndrome's experiences of coping with their life situations’, *Scandinavian journal of caring sciences*, 14(3), pp. 172–178. doi: 10.1080/028393100750018797.

Dermott, E. and Seymour, J. (2011), ‘Developing ‘Displaying Families’: A Possibility for the Future of the Sociology of Personal Life’, in Dermott, E. and Seymour, J. (eds) *Displaying* *families [electronic resource] : a new concept for the sociology of family life*. Basingstoke: Palgrave Macmillan. pp. 3-18.

DeVault, M. L. (1991) *Feeding the family : the social organization of caring as gendered work*. Chicago: University of Chicago Press.

Dewsbury, G., Clarke, K., Randall, D., Rouncefield, M. and Sommerville, I. (2004) 'The anti-social model of disability', *Disability & society*, 19(2), pp. 145-158.

Dingman, H.F. (1968) ‘A plea for social research in mental retardation’, *American journal of mental deficiency*, 73(1), pp.1-4.

Docherty, D., Hughes, R., Phillips, P., Corbett, D., Regan, B., Barber, A., Adams, M., Boxall. K., Kaplan, I. and Izzidien, S. (2010) ‘This is What We Think’, in Davis, L. J., ed., *The Disability Studies Reader*, London: Routledge: pp. 432-40.

Dorsman, N. I., Waninge, A., van der Schans, C. P., Luijkx, J. and Van der Putten, A. A. J. (2023) ‘The roles of adult siblings of individuals with a profound intellectual disability’, *Journal of applied research in intellectual disabilities*, 36(6), pp. 1308–1318. doi: 10.1111/jar.13149.

Douglas, M. (1991) *The idea of a home – a kind of space*. Social Research 58. pp. 287–307.

Dunn, J. (1984). *Sisters and Brothers*. Fontana: London.

Dunn, J. and Kendrick, C. (1982) *Siblings : love, envy & understanding*. London: Grant McIntyre.

Dyck, I., Kontos, P., Angus, J., and McKeever, P. (2005) ‘The home as a site for long-term care: Meanings and management of bodies and spaces’, *Health & Place.* 11(2), pp. 173–185.

Dyregrov, K. (2004). Bereaved parents' experience of research participation. *Social Science and Medicine*, 58. pp. 391-400.

Dyson, L. L. (2003) ‘Children with Learning Disabilities Within the Family Context: A Comparison with Siblings in Global Self-Concept, Academic Self-Perception, and Social Competence’, *Learning disabilities research and practice*, 18(1), pp. 1–9. doi: 10.1111/1540-5826.00053.

Easthope, H. (2004) ‘A place called home’, *Housing, theory, and society*, 21(3), pp. 128–138. doi: 10.1080/14036090410021360.

Edery, C. and Harvey, C. (2025) ‘Narratives of siblinghood: exploring perspectives of adult siblings of autistic individuals’, *Disability & society*, pp. 1–27. doi: 10.1080/09687599.2025.2455091.

Edwards, C. and Loughnane, C. (2024) '"Plenty of Disabled People Care": Revealing Reciprocity and Interdependence in Disabled People's Everyday Caregiving Practices', *Scandinavian journal of disability research : SJDR*, 26(1), pp. 588–600. doi: 10.16993/sjdr.1182.

Edwards, R., Hadfield, L., Lucey, H. and Mauthner, M. (2006) *Sibling identity and relationships : sisters and brothers*. Abingdon ; New York: Routledge.

Edwards, R., Mauthner, M. and Hadfield, L. (2005) 'Children's sibling relationships and gendered practices: talk, activity and dealing with change', *Gender and education*, 17(5), pp. 499–513. doi:10.1080/09540250500192678.

Eisenhauer, J. (2007) 'Just Looking and Staring Back: Challenging Ableism through Disability Performance Art', *Studies in art education*, 49(1), pp. 7–22. Available at: https://doi.org/10.1080/00393541.2007.11518721.

Elias, N. (1994), *The Civilizing Process*, Oxford: Blackwell Publishing.

Emerson, E., Hatton, C., Baines, S. and Robertson, J. (2016) 'The physical health of British adults with intellectual disability: Cross sectional study', *International journal for equity in health*, 15(1), pp. 11–11. doi: 10.1186/s12939-016-0296-x.

Erevelles, N. (2011) *Disability and difference in global contexts : enabling a transformative body politic*. (1st ed). New York: Palgrave Macmillan.

Everts, E. (2003) 'Identifying a particular family humor style: A sociolinguistic discourse analysis', *Humor* (Berlin, Germany), 16(4), pp. 369–412. doi:10.1515/humr.2003.021.

Feely, M. (2016) 'Sexual surveillance and control in a community-based intellectual disability service', *Sexualities*, 19(5–6), pp. 725–750. doi: 10.1177/1363460715620575.

Fiadotava, A. (2021) '"If we don't quarrel, we joke": Emic perspectives on Belarusian families' humorous folklore', *Humor* (Berlin, Germany), 34(1), pp. 1–20. doi:10.1515/humor-2019-0052.

Fiese, B. H. and Marjinsky, K. A. T. (1999) 'Dinnertime Stories: Connecting Family Practices with Relationship Beliefs and Child Adjustment', *Monographs of the Society for Research in Child Development*, 64(2), pp. 52–68. doi: 10.1111/1540-5834.00019.

Finch, J. (2007) 'Displaying Families', *Sociology (Oxford)*, 41(1), pp. 65–81. doi: 10.1177/0038038507072284.

Finch, J. and Mason, J. (1993) *Negotiating family responsibilities*. London: Routledge.

Fine, M. (1992). *Disruptive voices: The possibilities of feminist research*. Ann Arbor: University of Michigan.

Fisher, P. and Goodley, D. (2007) ‘The linear medical model of disability: mothers of disabled babies resist with counter-narratives’, *Sociology of health & illness*, 29(1), pp. 66–81. doi: 10.1111/j.1467-9566.2007.00518.x.

Fives, A, Kennan D, Canavan J and Brady B. (2019) ‘Why we still need the term ‘Young Carer’’, *Critical social work*, 14(1). doi: 10.22329/csw.v14i1.5872.

Fletcher, J., Mailick, M., Song, J. and Wolfe, B. (2013) ‘A Sibling Death in the Family: Common and Consequential’, *Demography*, 50(3), pp. 803–826. doi: 10.1007/s13524-012-0162-4.

Fox, S. A. and Giles, H. (1996) ‘Interability Communication: Evaluating Patronizing Encounters’, *Journal of language and social psychology*, 15(3), pp. 265–290. doi: 10.1177/0261927X960153004.

Frances, J. (2014) ‘Damaged or unusual bodies: Staring, or seeing and feeling’, *Body, movement and dance in psychotherapy*, 9(4), pp. 198–210. doi: 10.1080/17432979.2014.931887.

Frank, A. W. (2010) *Letting stories breathe : a socio-narratology*. Chicago, Ill.: University of Chicago Press.

Frank, A.W. (2013) *The wounded storyteller: body, illness, and ethics*. Second edition. Chicago: The University of Chicago Press.

Frehse, F. (2021) ‘Time and The production of space in sociology’, *Sociologia & Antropologia*, 11(2), pp. 389–414. doi: 10.1590/2238-38752021v1122.

Gabb, J. (2011) ‘Troubling displays: The Affect of Gender, Sexuality and Class’ in Dermott, E. and Seymour, J. (eds) *Displaying families [electronic resource] : a new concept for the sociology of family life*. Basingstoke: Palgrave Macmillan. pp 38-58.

Gabriel, N. (2021) ‘Beyond “developmentalism”: A relational and embodied approach to young children’s development’, *Children & society*, 35(1), pp. 48–61. doi: 10.1111/chso.12381.

Gani, J. K. and Khan, R. M. (2024) ‘Positionality Statements as a Function of Coloniality: Interrogating Reflexive Methodologies’, *International studies quarterly*, 68(2). doi: 10.1093/isq/sqae038.

Garland-Thomson, R. (1997) *Extraordinary bodies : figuring physical disability in American culture and literature*. New York: Columbia University Press.

Garland-Thomson, R. (2002) ‘Integrating Disability, Transforming Feminist Theory’, *Feminist formations*, 14(3), pp. 1–32.

Garland-Thomson, R. (2005a) ‘Feminist Disability Studies’, *Signs: Journal of Women in Culture and Society*, 30(2), pp. 1557–1587. doi: 10.1086/423352.

Garland-Thomson, R. (2005b) ‘Staring at the Other’, *Disability studies quarterly*, 25(4). doi: 10.18061/dsq.v25i4.610.

Garland-Thomson, R. (2007) ‘Shape Structures Story: Fresh and Feisty Stories about Disability’, *Narrative* (Columbus, Ohio), 15(1), pp. 113–123. doi: 10.1353/nar.2007.0005.

Garland-Thomson, R. (2011) ‘Misfits: A Feminist Materialist Disability Concept’, *Hypatia*, 26(3), pp. 591–609. doi: 10.1111/j.1527-2001.2011.01206.x.

Gass, K., Jenkins, J. and Dunn, J. (2007) ‘Are sibling relationships protective? A longitudinal study’, *Journal of child psychology and psychiatry*, 48(2), pp. 167–175. doi:10.1111/j.1469-7610.2006.01699.x.

Gates, B. and Mafuba, K. (2016). ‘Use of the Term" Learning Disabilities" in the United Kingdom: Issues for International Researchers and Practitioners’. *Learning Disabilities-A Contemporary Journal*, 14(1).

Gee, J. P. (2005) *An introduction to discourse analysis : theory and method* (2nd ed), New York, N.Y. ; Abingdon: Routledge.

Gelles R. (1997). *Intimate Violence in Families*. Sage: London.

Gelles, R. J. and Cornell, C. P. (1990) *Intimate violence in families* (2nd ed), Newbury Park (Calif.) ; London: Sage Publications.

Ghisleni, M. (2017) ‘The sociology of everyday life: A research program on contemporary sociality’, *Social Science Information*, 56(4), pp. 526–543. doi:10.1177/0539018417734975.

Gibbons, H.M. and Gibbons, C.M. (2016) ‘Siblings with disabilities: a duoethnography on the intersections between a sibling relationship and disability’, *Disability & Society*, 31(6), pp. 820–837. doi:10.1080/09687599.2016.1203291.

Gieryn, T. F. (2000) ‘A Space for Place in Sociology’, *Annual review of sociology*, 26(1), pp. 463–496. doi: 10.1146/annurev.soc.26.1.463.

Gillies V. and Lucey H. (2006) ‘“It's a connection you can't get away from”: Brothers, Sisters and Social Capital’, *Journal of Youth Studies*, Vol. 9, No. 4, p. 479–493.

Gillis, J. (1996) ‘Making Time for Family: the Invention of Family Time(S) and the Reinvention of Family History’, *Journal of family history*, 21(1), pp. 4–Y 21. doi: 10.1177/036319909602100102.

Gilligan, M., Stocker, C. M. and Jewsbury Conger, K. (2020) 'Sibling relationships in adulthood: Research findings and new frontiers', *Journal of Family Theory & Review*, 12(3), pp. 305-320.

Gioia, D. A., Corley, K. G. and Hamilton, A. L. (2013) ‘Seeking Qualitative Rigor in Inductive Research: Notes on the Gioia Methodology’, *Organizational research methods*, 16(1), pp. 15–31. doi: 10.1177/1094428112452151.

Goffman, E. (1969) *The presentation of self in everyday life*. London: Allen Lane.

Goffman, E. (1990) *Stigma : notes on the management of spoiled identity*. Harmondsworth: Penguin.

Goodfellow J. and Laverty, J. (2003) ‘Grandparents Supporting Working Families’, *Family Matters*, (66), pp. 14–19.

Goodey, C. F. (2016) *Learning disability and inclusion phobia : past, present, future*. London, [England] ; New York, New York: Routledge.

Goodley, D. (2001) ‘'Learning Difficulties', the Social Model of Disability and Impairment: Challenging epistemologies’, *Disability & society,* 16(2), pp. 207–231. doi: 10.1080/09687590120035816.

Goodley, D. (2013) ‘Dis/entangling critical disability studies’, *Disability & society*, 28(5), pp. 631–644. doi:10.1080/09687599.2012.717884.

Goodley, D. (2014) *Dis/ability studies : theorising disablism and ableism*. Abingdon, Oxon ; New York, New York: Routledge.

Goodley, D. (2017) *Disability studies : an interdisciplinary introduction*. Second edition. London: SAGE.

Goodley, D. (2021) *Disability and other human questions*. Bingley, England: Emerald Publishing Limited.

Goodley, D. (2023) ‘Being human as praxis: for people with learning disabilities’, *Subjectivity*, 30(2), pp. 167–184. doi: 10.1057/s41286-023-00159-6.

Goodley, D. and Lawthom, R. (2019) ‘Critical disability studies, Brexit and Trump: a time of neoliberal-ableism’, *Rethinking history*, 23(2), pp. 233–251. doi: 10.1080/13642529.2019.1607476.

Goodley, D. and Rapley, M. (2002) 'Changing the subject: postmodernity and people with ‘learning difficulties’', in Corker, M. and Shakespeare, T. (eds.) *Disability/postmodernity: Embodying disability theory*. London: Continuum, pp. 127-142.

Goodley, D. and Runswick-Cole, K. (2012) ‘Reading Rosie: The postmodern disabled child’, *Educational and Child Psychology*, 29(2), 53-66.

Goodley, D. and Tregaskis, C. (2006) ‘Storying Disability and Impairment: Retrospective Accounts of Disabled Family Life’, *Qualitative health research*, 16(5), pp. 630–646. doi: 10.1177/1049732305285840.

Goodley, D., Lawthom, R., Liddiard, K. and Rinswick-Cole, K. (2017) 'Critical disability studies', in Gough, B. (ed.) *The Palgrave handbook of critical social psychology*. London: Palgrave Macmillan, pp. 491-505.

Goodley, D., Lawthom, R., Liddiard , K., and Runswick-Cole, K. (2019) ‘Provocations for Critical Disability Studies’, *Disability & Society*, 34(6), pp. 972–997. doi: 10.1080/09687599.2019.1566889.

Gozu, H. and Newman, J. (2020) ‘Parental Differential Treatment of Siblings and Fairness Perception: Moderating Role of Personality’, *Journal of child and family studies*, 29(11), pp. 3129–3141. doi: 10.1007/s10826-020-01811-4.

Green, C. and Vandall-Walker, V. (2017) ‘So you think you’ve designed an effective recruitment protocol?’, *Nurse Researcher*, 24(4), pp. 32-34, doi: 10.7748/nr.2017.e1502.

Green, S., Kearbey, J., Wolgemuth, J., Agosto, V., Romano, J., Riley, M. and Frier, A. (2015) ‘Past, present, and future of assessment in schools: A thematic narrative analysis’, *Qualitative report*, 20(7). doi:10.46743/2160-3715/2015.2229.

Grue, J. (2016) ‘The problem with inspiration porn: a tentative definition and a provisional critique’, *Disability & society*, 31(6), pp. 838–849. doi: 10.1080/09687599.2016.1205473.

Grue, J. (2021). *I Live a Life Like Yours*. Pushkin Press.

Guillemin, M. and Gillam, L. (2004) ‘Ethics, Reflexivity, and “Ethically Important Moments” in Research’, *Qualitative inquiry*, 10(2), pp. 261–280. Available at: https://doi.org/10.1177/1077800403262360.

Gulløv, E., Palludan, C. and Winther, I. W. (2015) ‘Engaging siblingships’, *Childhood* (Copenhagen, Denmark), 22(4), pp. 506–519. doi: 10.1177/0907568214555147.

Hall, E. (2010) ‘Spaces of social inclusion and belonging for people with intellectual disabilities’, *Journal of intellectual disability research*, 54(s1), pp. 48–57. doi: 10.1111/j.1365-2788.2009.01237.x.

Hanvey, I., Malovic, A. and Ntontis, E. (2022) ‘Glass children: The lived experiences of siblings of people with a disability or chronic illness’, *Journal of community & applied social psychology*, 32(5), pp. 936–948. doi: 10.1002/casp.2602.

Harter, L.M., Scott, J. A., Novak, D. R., Leeman, M. and Morris, J. F. (2006) ‘Freedom Through Flight: Performing a Counter-Narrative of Disability’, *Journal of Applied Communication Research*, 34(1), pp. 3–29. doi:10.1080/00909880500420192.

Harwood, D. (2010) ‘The Phenomenon of Sibling Teasing: Three Mothers' Perceptions of Their Children's Teasing Behaviours’, *Journal of research in childhood education*, 24(4), pp. 366–385. doi:10.1080/02568543.2010.510080.

Harris, J, (2025), ‘Labour’s historic attack on disabled people is already wrecking lives. Just ask Kevin’, *The Guardian* [online], 30th March, Available from: https://www.theguardian.com/commentisfree/2025/mar/30/labour-attack-disabled-people-benefits-cuts [Accessed: 04/04/2025]

Hasler, F. (1993) ‘Developments in the disabled people’s movement’ in J.Swain, French, S., Barnes, C. and Thomas, C. (Eds.), *Disabling barriers, enabling environments*. London: Sage

Hayden, N. K. and Hastings, R. P. (2022) ‘Chapter 1. Family theories and siblings of people with intellectual and developmental disabilities’, *International Review of Research in Developmental Disabilities*. 63, 1-49. https://doi.org/10.1016/bs.irrdd.2022.09.001

Heath, S. (2018) ‘Siblings, fairness and parental support for housing in the UK’, *Housing studies,* 33(2), pp. 284–298. doi:10.1080/02673037.2017.1291914.

Heath, S., Fuller, A. and Johnston, B. (2010) ‘Young people, social capital and network-based educational decision-making’, *British journal of sociology of education*, 31(4), pp. 395–411. doi:10.1080/01425692.2010.484918.

Hedin L, Höjer I and Brunnberg E. (2012) ‘Jokes and routines make everyday life a good life – on ‘doing family’ for young people in foster care in Sweden’, *European Journal of Social Work*, 15(5): 613–628.

Heller, T. and Arnold, C. K. (2010) ‘Siblings of Adults With Developmental Disabilities: Psychosocial Outcomes, Relationships, and Future Planning’, *Journal of policy and practice in intellectual disabilities*, 7(1), pp. 16–25. doi: 10.1111/j.1741-1130.2010.00243.x.

Helmer, K. (2016) ‘Reading queer counter-narratives in the high-school literature classroom: possibilities and challenges’, *Discourse* (Abingdon, England), 37(6), pp. 902–916. doi: 10.1080/01596306.2015.1120943.

Hemmings, C. (2005) ‘Telling feminist stories’, *Feminist theory*, 6(2), pp. 115–139. doi: 10.1177/1464700105053690.

Hennink, M. and Kaiser, B.N. (2022) ‘Sample sizes for saturation in qualitative research: A systematic review of empirical tests’, *Social science & medicine* (1982), 292, pp. 114523–114523. doi:10.1016/j.socscimed.2021.114523.

Henry, G. T. (2009) ‘Practical sampling’, in Bickman, L. and Rog, D.J. (eds.) (2009) *The SAGE handbook of applied social research methods* 2nd ed. Los Angeles ; London: SAGE. pp. 77-105.

Highmore, B. (2010) *Ordinary lives : studies in the everyday*. New York: Routledge.

Hoffman, L. (1993) *Exchanging voices : a collaborative approach to family therapy*. London: Karnac Books.

Holland, J. (2008) ‘Young people and Social Capital: What can it do for us?’, Families and Social Capital Research Group Working Paper No. 24 London South Bank University. Available from: https://www.lsbu.ac.uk/__data/assets/pdf_file/0005/9437/young-people-social-capital-families-research-working-paper.pdf [Accessed 22/06/22]

hooks, b, (1994) *Teaching to transgress : education as the practice of freedom*. New York, New York ; Oxfordshire, England: Routledge.

Hourigan, S., Fanagan, S., Kell, C. (2017), HRB Statistics series 37 Annual report of the national intellectual disability database committee 2017 Main Findings.

Hughes, B., Goodley, D. and Davis, L. (2012) ‘Conclusion’. In: Goodley, D., Hughes, B. and Davis, L. (eds.), *Disability and social theory.* Basingstoke: Palgrave Macmillan. pp. 308-317.

Hwang, S. K. and Charnley, H. (2010) ‘Honourable Sacrifice: A Visual Ethnography of the Family Lives of Korean Children with Autistic Siblings’, *Children & society*, 24(6), pp. 437–448. doi: 10.1111/j.1099-0860.2009.00228.x.

Imrie, R. (2004) ‘Disability, embodiment and the meaning of the home’, *Housing studies*, 19(5), pp. 745–763. doi: 10.1080/0267303042000249189.

Jacobs, P. and MacMahon, K. (2017) ‘“It’s different, but it’s the same”: perspectives of young adults with siblings with intellectual disabilities in residential care’, *British journal of learning disabilities*, 45(1), pp. 12–20. doi: 10.1111/bld.12169.

Jacobsen, S. E. (2023) ‘Social class, disability, and institutional interactions: the case of families with disabled children in the welfare state’, *Disability & society*, ahead-of-print(ahead-of-print), pp. 1–21. doi: 10.1080/09687599.2023.2230349.

James, A. and Prout, A. (1990) *Constructing and reconstructing childhood*, London: Falmer Press.

Jarrett, S. (2020) *Those they called idiots : the idea of the disabled mind from 1700 to the present day*. London, England: Reaktion Books.

Jayanetti, C. (2025), ‘MPs to vote on disability benefit cuts without knowing ‘full impact’’, *The Guardian* [online], 30th March, Available from: https://www.theguardian.com/world/2025/mar/30/mps-to-vote-on-disability-benefit-cuts-without-knowing-full-impact [Accessed: 04/04/2025]

Jenkins, R. (2004) *Social identity*. 2nd ed. London: Routledge.

Jones, C. (2019) ‘That time I punched a boy in the forehead: sibling stories ahead of research’, *Disability & society*, 34(4), pp. 657–662. Available at: https://doi.org/10.1080/09687599.2019.1567012.

Jones, C. and Hackett, S. (2011) ‘The role of "family practices" and "displays of family" in the creation of adoptive kinship’, *The British Journal of Social Work*, 41(1), pp. 40–56. doi:10.1093/bjsw/bcq017.

Kafai, S. (2021). *Crip kinship: The disability justice and art activism of Sins Invalid*. Arsenal Pulp Press.

Kafer, A. (2013) *Feminist, queer, crip*. Bloomington, Indiana: Indiana University Press.

Kafer, A. (2017). ‘Health rebels: A crip manifesto for social justice [Keynote]’, Shepard Symposium on Social Justice, Laramie, WY.

Kafer, A. (2021) ‘After crip, crip afters’, *The South Atlantic quarterly*, 120(2), pp. 415–434. doi: 10.1215/00382876-8916158.

Kalekin-Fishman, D. (2013) ‘Sociology of everyday life’, *Current sociology*, 61(5–6), pp. 714–732. doi:10.1177/0011392113482112.

Kalekin-Fishman, D. (2016), ‘The quest for lived truths: modifying methodologies’, in Goodson, T., Antikainen, A., Sikes, P., and Andrews, M. (eds.), *The Routledge International Handbook on Narrative and Life History*, Abingdon, Oxon ; New York, NY: Routledge. pp. 144-156.

Kelada, L., Wakefield C. E,, Drew D, Ooi C. Y., Palmer E. E., Bye A., De Marchi, S., Jaffe, A. and Kennedy, S. (2022) ‘Siblings of young people with chronic illness: Caring responsibilities and psychosocial functioning’, *Journal of child health care*, 26(4), pp. 581–596. doi: 10.1177/13674935211033466.

Keltner, D., Young, R. C., Heerey, E. A., Oemig, C. and Monarch, N. D. (1998) ‘Teasing in Hierarchical and Intimate Relations’, *Journal of personality and social psychology*, 75(5), pp. 1231–1247. doi:10.1037/0022-3514.75.5.1231.

Kenway, E. (2023). *Who Cares: The Hidden Crisis of Caregiving, and how We Solve it*. Seal Press.

Kenyon, E., Beail, N. and Jackson, T. (2014) ‘Learning disability: experience of diagnosis’, *British journal of learning disabilities*, 42(4), pp. 257–263. doi: 10.1111/bld.12054.

Kettrey, H. H. and Emery, B. C. (2006) ‘The discourse of sibling violence’, *Journal of family violence*, 21(6), pp. 407–416. doi: 10.1007/s10896-006-9036-0.

Khalifeh, H., Howard LM, Osborn D, Moran P and Johnson S. (2013) ‘Violence against People with Disability in England and Wales: Findings from a National Cross-Sectional Survey’, *PloS one*, 8(2), pp. e55952–e55952. doi: 10.1371/journal.pone.0055952.

Kiselica, M.S. and Morrill-Richards, M. (2007) ‘Sibling Maltreatment: The Forgotten Abuse’, *Journal of counseling and development*, 85(2), pp. 148–160. doi:10.1002/j.1556-6678.2007.tb00457.x.

Kittay, E. F. (1999), *Love’s labour: Essays on women, equality and dependency*. New York, NY: Routledge.

Kittay, E. F. (2001) ‘When Caring Is Just and Justice Is Caring: Justice and Mental Retardation’, *Public culture*, 13(3), pp. 557–580. doi: 10.1215/08992363-13-3-557.

Kittay, E. F. (2006) ‘Thoughts on the Desire for Normality’ in Parens, E. (eds.) *Surgically shaping children : technology, ethics, and the pursuit of normality* (1st ed), Baltimore, Md: Johns Hopkins University Press. Pp. 90-110.

Kittay, E. F. (2009) ‘The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield’, *Metaphilosophy*, 40(3–4), pp. 606–627. doi: 10.1111/j.1467-9973.2009.01600.x.

Kittay, E. F. (2020) ‘We Have Seen the Mutants—and They Are Us: Gifts and Burdens of a Genetic Diagnosis’, *The Hastings Center report*, 50(1), pp. S44–S53. doi: 10.1002/hast.1155.

Kleinsasser, A. M. (2000) ‘Researchers, Reflexivity, and Good Data: Writing to Unlearn’, *Theory into practice*, 39(3), pp. 155–162. doi: 10.1207/s15430421tip3903_6.

Klinge, D., Carlson, S. and Kahle, L. (2020) 'Countering the master-narrative of “good parenting”?: Non-academic parents’ stories about choosing a secondary school for their child', in Lueg, K. and Lundholt, M.W. (eds.) *Routledge Handbook of Counter-Narratives*. Abingdon: Taylor & Francis, pp. 225-237.

Knox, M. and Bigby, C. (2007) ‘Moving towards Midlife Care as Negotiated Family Business: Accounts of people with intellectual disabilities and their families "Just getting along with their lives together"’, *International journal of disability, development, and education*, 54(3), pp. 287–304. doi: 10.1080/10349120701488749.

Kolar, K., Ahmad, F., Chan, L. and Erickson, P. G. (2015) ‘Timeline Mapping in Qualitative Interviews: A Study of Resilience with Marginalized Groups’, *International journal of* *qualitative methods*, 14(3), pp. 13–32. Available at: https://doi.org/10.1177/160940691501400302.

Koslowski, A.S. (2009). ‘Grandparents and the Care of Their Grandchildren’ in: Kneale, D., Coast, E. and Stillwell, J. (eds.) *Fertility, Living Arrangements, Care and Mobility. Understanding Population Trends and Processes*, vol 1. Springer, Dordrecht. 171-190. https://doi.org/10.1007/978-1-4020-9682-2_9

Kovshoff, H., Cebula, K., Tsai, H.-W. J., and Hastings, R. P. (2017) ‘Siblings of children with autism: The SiblingsEmbedded Systems Framework’, *Current Developmental Disorders Reports*, 4(2), 37–45. https://doi.org/10.1007/s40474-017-0110-5

Kramer, J., Hall, A. and Heller, T. (2013) ‘Reciprocity and Social Capital in Sibling Relationships of People With Disabilities’, *Intellectual and developmental disabilities*, 51(6), pp. 482–495. doi:10.1352/1934-9556-51.6.482.

Ktenidis, A. (2022) ‘En/counters with disablist school violence: experiences of young people with dwarfism in the United Kingdom’, *British journal of sociology of education*, 43(8), pp. 1196–1215. doi: 10.1080/01425692.2022.2122940.

Ktenidis, A. (2024) ‘Ethical Complexities of Having Difficult Research Conversations: A Reflective Account And A Cautionary Tale On Speaking For ‘Others’’, in Fleming, K. and Demissie, F. (eds.), *Nurturing ‘difficult conversations’ in education : empowerment, agency and social justice in the UK*. London: Bloomsbury Academic. pp. 203-223.

Kuhn, A. (2002) *Family secrets : acts of memory and imagination*. New ed. London: Verso.

Kuipers, G. (2009) ‘Humor styles and symbolic boundaries’ *Journal of Literary Theory*, 3(2), pp. 219–239.

Kuo, Y. (2014) ‘Brothers’ Experiences Caring for a Sibling With Down Syndrome’, *Qualitative health research*, 24(8), pp. 1102–1113. doi: 10.1177/1049732314543110.

Labov, W., & Waletzky, J. (1997) ‘Narrative analysis: Oral versions of personal experience’, *Journal of Narrative & Life History*, 7(1-4), 3–38. https://doi.org/10.1075/jnlh.7.02nar

Lampert, M.D. and Ervin-Tripp, S.M. (2006) ‘Risky laughter: Teasing and self-directed joking among male and female friends’, *Journal of pragmatics*, 38(1), pp. 51–72. doi:10.1016/j.pragma.2005.06.004.

Landon, O., Ganong, L. and Sanner, C. (2022) ‘“Stop going in my room”: A grounded theory study of conflict among stepsiblings’, *Family relations*, 71(1), pp. 256–278. doi: 10.1111/fare.12595.

Landsman, G. (2003) ‘Emplotting children's lives: developmental delay vs. disability’, *Social science & medicine* (1982), 56(9), pp. 1947–1960. doi: 10.1016/S0277-9536(02)00215-0.

Landsman, G. H. (2009), *Reconstructing disability and motherhood in the age of perfect babies*. New York: Routledge.

Lardieri, L.A., Blacher, J. and Swanson, H.L. (2000) ‘Sibling Relationships and Parent Stress in Families of Children with and without Learning Disabilities’, *Learning disability quarterly*, 23(2), pp. 105–116. doi:10.2307/1511140.

Law, J. (2004) *After method : mess in social science research*. London: Routledge.

Leane, M. (2019) ‘Siblings caring for siblings with Intellectual Disabilities: Naming and negotiating emotional tensions’, *Social science & medicine* (1982), 230, pp. 264–270. doi: 10.1016/j.socscimed.2019.04.022.

Leane, M. (2024) ‘Sibling carers of adults with intellectual disabilities in Ireland report high levels of health but feel overwhelmed by care responsibilities’, *Evidence-based nursing*, 27(1), pp. 35–35. doi: 10.1136/ebnurs-2023-103789.

Leaning, B. and Adderley, H. (2016) ‘From long-stay hospitals to community care: reconstructing the narratives of people with learning disabilities’, *British journal of learning disabilities*, 44(2), pp. 167–171. doi: 10.1111/bld.12139.

Lee, M. and Gardner, J. E. (2010) ‘Grandparents’ Involvement and Support in Families with Children with Disabilities’, *Educational gerontology*, 36(6), pp. 467–499. doi: 10.1080/03601270903212419.

Lee, C.E., Hagiwara, M., Burke, M. M. and Arnold, C. K. (2024) ‘Family Support and Disability Policies: Perspectives of Siblings of People With Intellectual and Developmental Disabilities’, *Journal of disability policy studies*. Available at: https://doi.org/10.1177/10442073241289088.

Lefley, H. P. (1997) ‘Synthesizing the Family Caregiving Studies: Implications for Service Planning, Social Policy, and Further Research’, *Family relations*, 46(4), pp. 443–450. doi: 10.2307/585104.

Lester, J.N. and Nusbaum, E.A. (2018) ‘“Reclaiming” Disability in Critical Qualitative Research: Introduction to the Special Issue’, *Qualitative inquiry*, 24(1), pp. 3–7. doi:10.1177/1077800417727761.

Leung, P. P. Y. (2010) ‘Autobiographical Timeline: A Narrative and Life Story Approach in Understanding Meaning-Making in Cancer Patients’, *Illness, crisis, and loss*, 18(2), pp. 111–127. doi: 10.2190/IL.18.2.c.

Levante, A., Martis, C., Del Prete, C. M., Martino, P., Primiceri, P. and Lecciso, F. (2025) ‘Siblings of Persons with Disabilities: A Systematic Integrative Review of the Empirical

Literature’, *Clinical child and family psychology review*, 28(1). Available at: https://doi.org/10.1007/s10567-024-00502-6.

Levy, S. and Young, H. (2020) ‘Arts, disability and crip theory: Temporal re-imagining in social care for people with profound and multiple learning disabilities’, *Scandinavian journal of disability research : SJDR*, 22(1), pp. 68–79. doi: 10.16993/sjdr.620.

Liddiard, K. (2018) *The intimate lives of disabled people*. New York, New York ; London, [England]: Routledge.

Lieblich, A., Tuval-Mashiach, R. and Zilber, T. B. (1998) *Narrative research: reading, analysis and interpretation*. Thousand Oaks, Calif. ; London: SAGE.

Lincoln, S. (2015) ‘‘My Bedroom is me’: Young people, private space, consumption and the family home’, in Casey, E. and Taylor, Y. (eds.) *Intimacies, critical consumption and diverse economies.* Houndmills, Basingstoke Hampshire ; New York, NY: Palgrave Macmillan. pp. 87-107.

Lockwood, R.L., Kitzmann, K.M. and Cohen, R. (2001) ‘The impact of sibling warmth and conflict on children's social competence with peers’, *Child Study Journal*, 31(1), pp.47-47.

Löfgren-Mårtenson, L. (2013) ‘“Hip to be Crip?” About Crip Theory, Sexuality and People with Intellectual Disabilities’, *Sexuality and disability*, 31(4), pp. 413–424. doi: 10.1007/s11195-013-9287-7.

Lowe, J., and DeVerteuil, G. (2022) ‘The role of the ‘ambiguous home’ in service users’ management of their mental health’, *Social & Cultural Geography*, 23(3), 443–459. https://doi.org/10.1080/14649365.2020.1744706

Lueg, K., Bager, A. S. and Lundholt, M. W. (2020) 'Introduction: What counter-narratives are: Dimensions and levels of a theory of middle range', in Lueg, K. and Lundholt, M.W. (eds.) *Routledge handbook of counter-narratives.* Abingdon: Taylor & Francis, pp. 1-14.

Lundeby, H. and T⊘ssebro, J. (2008) ‘Exploring the Experiences of “Not Being Listened To” from the Perspective of Parents with Disabled Children’, *Scandinavian journal of disability research : SJDR*, 10(4), pp. 258–274. doi: 10.1080/15017410802469700.

Lyons, V. and Fitzgerald, M. (2004) ‘Humor in autism and Asperger syndrome’, *Journal of autism and developmental disorders*, 34(5), pp. 521–531. doi: 10.1007/s10803-004-2547-8.

Mallett, R. and Runswick-Cole, K. (2014) *Approaching disability : critical issues and perspectives*. Oxfordshire, England ; New York: Routledge.

Mallett, R. and Runswick-Cole, (2016) ‘The ‘urge to know’ normal: theorising how impairment labels function’ in Mallett, R., Ogden, C. A. and Slater, J. (eds.) *Theorising normalcy and the* *mundane : precarious positions* (1st ed), Chester, [England]: University of Chester Press. pp. 95-119.

Mallett, S. (2004) ‘Understanding home: a critical review of the literature’, *The Sociological review* (Keele), 52(1), pp. 62–89. doi: 10.1111/j.1467-954X.2004.00442.x.

Malli, M. A., Sams, L., Forrester-Jones, R., Murphy, G., and Henwood, M. (2018) ‘Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature’, *Disability & society*, 33(9), pp. 1412–1435. doi: 10.1080/09687599.2018.1497950.

Mann, B. W. (2019) ‘Autism Narratives in Media Coverage of the MMR Vaccine-Autism Controversy under a Crip Futurism Framework’, *Health communication*, 34(9), pp. 984–990. doi: 10.1080/10410236.2018.1449071.

Mannay, D. (2010) ‘Making the familiar strange: can visual research methods render the familiar setting more perceptible?’, *Qualitative research: QR*, 10(1), pp. 91–111. doi:10.1177/1468794109348684.

Marks, D. (1999) 'Dimensions of oppression: Theorising the embodied subject', *Disability & Society*, 14(5), pp. 611-626.

Marx, K. (1933) *Critique of the Gotha Programme*. London: M. Lawrence.

Mason, J. (2004) ‘Personal narratives, relational selves: residential histories in the living and telling’, *The Sociological review* (Keele), 52(2), pp. 162–179. doi: 10.1111/j.1467-954X.2004.00463.x

Mason, J. (2018) *Affinities : potent connections in personal life*. Cambridge: Polity Press.

Mason, J. and Davies, K. (2009) ‘Coming to our senses? A critical approach to sensory methodology’, *Qualitative research : QR*, 9(5), pp. 587–603. doi: 10.1177/1468794109343628.

Mason, J. and Muir, S. (2013) ‘Conjuring up traditions: atmospheres, eras and family Christmases’, *The Sociological review* (Keele), 61(3), pp. 607–629. doi: 10.1111/j.1467-954X.2012.02138.x.

Mason, J. and Tipper, B. (2008) ‘Being Related’, *Childhood* (Copenhagen, Denmark), 15(4), pp. 441–460. doi:10.1177/0907568208097201.

Massey, D. B. (1994) *Space, place, and gender* (1st ed), Minneapolis: University of Minnesota Press.

Matthews, M. (2019) ‘Why Sheldon Cooper can’t be Black: The visual rhetoric of autism and ethnicity’, *Journal of Literary & Cultural Disability Studies*, 13(1), pp.57-74.

Mauldin, L. and Saxena, M. (2018) ‘Mutual Exchange: Caregiving and Life Enhancement in Siblings of Individuals With Developmental Disabilities’, *Journal of family issues*, 39(8), pp. 2232–2264. doi: 10.1177/0192513X17746452.

Mauthner, M. (2005) ‘Distant Lives, Still Voices: Sistering in Family Sociology’, *Sociology* (Oxford), 39(4), pp. 623–642. doi: 10.1177/0038038505056022.

Mauthner, N. S. and Doucet, A. (2003) ‘Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis’, *Sociology (Oxford)*, 37(3), pp. 413–431. doi: 10.1177/00380385030373002.

Mawyer R. (2007), ‘The postmodern turn in disability studies’, *Atenea*, 25(1), 61–75.

May, V. (2019) ‘Personal Life Across the Lifecourse’ in May, V. and Nordqvist, P. (eds.) (2019) *The Sociology of Personal Life* (2nd ed), Basingstoke: Palgrave, pp 87-100.

McIntosh, I. and Punch, S. (2009) ‘‘Barter', `Deals', `Bribes' and `Threats'', *Childhood* (Copenhagen, Denmark), 16(1), pp. 49–65. doi:10.1177/0907568208101690.

McLaughlin, J. and Coleman-Fountain, E. (2019) ‘Visual methods and voice in disabled childhoods research: troubling narrative authenticity’, *Qualitative research : QR*, 19(4), pp. 363–381. doi: 10.1177/1468794118760705.

McNamee, S. (1998), ‘The Home: Youth, Gender and Video Games: Power and Control in the Home’, in Skelton, T. and Valentine, G. (eds.) *Cool Places: Geographies of Youth Cultures*, (London: Routledge),pp. 195–206.

McNamee, S. (1999) ‘‘I Won’t Let Her in My Room’: Sibling Strategies of Power and Resistance around Computer and Video Games’, In Seymour, J. and Bagguley, P. (eds.) *Relating intimacies : power and resistance. Basingstoke: Macmillan.* pp. 246-260.

McRuer, R. (2006) *Crip theory [electronic resource] : cultural signs of queerness and disability*. New York: New York University Press.

McRuer, R. and Wilkerson, A. (2003) ‘Desiring disability: Queer theory meets disability studies - Introduction’, *GLQ*, 9(1-2), pp. 1–23. doi: 10.1215/10642684-9-1-2-1.

Mears, A. (2013) ‘Ethnography as Precarious Work: First-Person Ethnography’, *Sociological quarterly*, 54(1), pp. 20–34.

Medved, M.I. and Brockmeier, J. (2008) ‘Continuity Amid Chaos: Neurotrauma, Loss of Memory, and Sense of Self’, *Qualitative health research*, 18(4), pp. 469–479. doi:10.1177/1049732308315731.

Meltzer, A. (2017) ''I couldn't just entirely be her sister': the relational and social policy implications of care between young adult siblings with and without disabilities', *Journal of youth studies*, 20(8), pp. 1013–1027. doi:10.1080/13676261.2017.1287889.

Meltzer, A. (2018) 'Embodying and enacting disability as siblings: experiencing disability in relationships between young adult siblings with and without disabilities', *Disability & society*, 33(8), pp. 1212–1233. doi:10.1080/09687599.2018.1481016.

Meltzer, A. and Kramer, J. (2016) 'Siblinghood through disability studies perspectives: diversifying discourse and knowledge about siblings with and without disabilities', *Disability & society*, 31(1), pp. 17–32. doi:10.1080/09687599.2015.1127212.

Meyers, A. (2017) 'Lifting the veil: The lived experience of sibling abuse', *Qualitative social work : QSW : research and practice*, 16(3), pp. 333–350. doi: 10.1177/1473325015612143.

Michalko, R. (2002) *The Difference That Disability Makes*. Philadelphia, Pa: Project MUSE.

Mikulak, M., Ryan, S., Bebbington, P., Bennett, S., Carter, J., Davidson, L., Liddell, K., Angeli, V., Albury, C. (2022) ''Ethno…graphy?!? I can't even say it": Co‐designing training for ethnographic research for people with learning disabilities and carers', *British journal of learning disabilities*, 50(1), pp. 52–60. doi:10.1111/bld.12424.

Mills, C. W. (1999) *The sociological imagination*. New York: OUP USA.

Mohamed, K. (2024) 'Debilitating Research: Scholarship of the Obvious and Epistemic Trauma', *African studies* (Johannesburg), pp. 1–18. doi: 10.1080/00020184.2024.2431801.

Mohanty, C. T. (1989) 'On Race and Voice: Challenges for Liberal Education in the 1990s', *Cultural critique*, (14), pp. 179–208. doi: 10.2307/1354297.

Moran‐Morbey, E., Blackwell, C., Ryan, T., Hayden N. K. (2024) '"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', *Journal of community & applied social psychology*, 34(6), doi: 10.1002/casp.70015.

Morgan, D. H. J. (1996) *Family connections : an introduction to family studies*. Cambridge, UK : Cambridge, MA: Polity Press ; Blackwell Publishers.

Morgan, D. H. J, (1999), 'Risk and family practices: accounting for change and fluidity in family life', in Silva, E.B. and Smart, C. (eds.), *the new family?,* London: SAGE. pp. 13-30.

Morgan, D. H. J. (2011) *Rethinking family practices*. Basingstoke: Palgrave Macmillan.

Morreall, J. (2009), *Comic relief : a comprehensive philosophy of humor* (1st ed), Malden, MA: Wiley-Blackwell.

Morris, J. (1993) *Independent lives? : community care and disabled people*. Basingstoke: Macmillan Press.

Morrow, V. (2008) ‘Responsible Children and Children's Responsibilities? Sibling Caretaking and Babysitting by School-age in Children’, in Bridgeman, J., Keating, H.M. and Lind, C. (eds.), *Responsibility, law and the family.* Aldershot: Ashgate.

Moss, M. S. and Moss, S. Z. (2012) ‘Multiple social contexts in qualitative bereavement research’, *Journal of aging studies*, 26(4), pp. 459–466. doi: 10.1016/j.jaging.2012.06.005.

Moyson, T. and Roeyers, H. (2012) ‘'The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of life of siblings of children with intellectual disability: the siblings' perspectives’, *Journal of intellectual disability research*, 56(1), pp. 87–101. doi:10.1111/j.1365-2788.2011.01393.x.

Müller, M., and Frandsen, S. (2021) ‘Counter-narratives as analytical strategies: Methodological implications’ in Lueg, K. and Lundholt, M. W. (eds.) *Routledge handbook of counter-narratives*. London: Routledge. pp. 110-121.

Naudé, L., Nel, L. and de Beer, A. (2024) ‘Towards interdependence: reciprocal relationships between students living with disability and their significant others’, *Disability & society*, 39(2), pp. 319–339. doi: 10.1080/09687599.2022.2071224.

Neal, S. and Murji, K. (2015) ‘Sociologies of Everyday Life: Editors’ Introduction to the Special Issue’, *Sociology* (Oxford), 49(5), pp. 811–819. doi:10.1177/0038038515602160.

Nelson, H. L. (1995) ‘Resistance and Insubordination’, *Hypatia*, 10(2), pp. 23–40. doi: 10.1111/j.1527-2001.1995.tb01367.x.

Nelson, H. L. (2001) *Damaged identities, narrative repair*. Ithaca: Cornell University Press.

Niedbalski, J. (2024) ‘Role Dynamics as Evinced by Typically Developing Siblings in the Lives of Brothers or Sisters with Profound Intellectual and Multiple Disabilities: A Qualitative Study’, *The Family journal* (Alexandria, Va.). doi: 10.1177/10664807241256131.

Nishida, A. (2016) ‘Understanding political development through an intersectionality framework: Life stories of disability activists’, *Disability studies quarterly*, 36(2). Available at: https://doi.org/10.18061/dsq.v36i2.4449.

Nguyen, L, Jack, S. M., Davies, H., Bellefeuille, S., Arafeh, D., Di Rezze, B., Ketelaar, M. and Gorter, J. W.. (2024) ‘Being a sibling of a youth with a neurodisability: A qualitative study about the roles and responsibilities during the transition to adulthood’, *Child : care, health & development*, 50(2), pp. e13241–e13241. doi: 10.1111/cch.13241.

O’Brien, C. and Charura, D. (2024) ‘Object elicitation: A compassionate and culturally informed method for psychotherapy research’, *Counselling and psychotherapy research*, 24(1), pp. 39–50. doi: 10.1002/capr.12703.

O’Brien, J. (1994) ‘Down stairs that are never your own: Supporting people with developmental disabilities in their own homes’, *Mental Retardation*, 32, pp. 1-6.

Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan

Oliver, M. (2004) 'The social model in action: If I had a hammer', in Barnes, C. and Mercer, G. (eds.) *Implementing the social model of disability: Theory and research*. Leeds: The Disability Press, pp. 18-31.

Oliver, M. (2013) ‘The social model of disability: thirty years on’, *Disability & society*, 28(7), pp. 1024–1026. doi: 10.1080/09687599.2013.818773.

Oliver, M. and Barnes, C. (2012) *The new politics of disablement*. New York: Palgrave Macmillan.

Opperman, S. and Alant, E. (2003) ‘The coping responses of the adolescent siblings of children with severe disabilities’, *Disability and rehabilitation*, 25(9), pp. 441–454. doi: 10.1080/0963828031000069735.

Otter, B. (2024) ‘Joy Beyond the Gender Binary: Experiences, Constructions, and Barriers of Joy in Nonbinary Lives’, *Sociological quarterly*. doi: 10.1080/00380253.2024.2392527.

Owens, J. (2015) ‘Exploring the critiques of the social model of disability: the transformative possibility of Arendt’s notion of power’, *Sociology of health & illness*, 37(3), pp. 385–403. doi: 10.1111/1467-9566.12199.

Paechter, C. (1996) ‘Power, Knowledge and the Confessional in Qualitative Research’, *Discourse* (Abingdon, England), 17(1), pp. 75–84. doi:10.1080/0159630960170106.

Paine, A.L., Howe, N., Karajian, G., Hay, D.F. and DeHart, G. (2019). ‘‘H, I, J, K, L, M, N, O, PEE! Get it? Pee!’: Siblings’ shared humour in childhood’, *British journal of developmental psychology*, 37(3), pp. 336–353. doi: 10.1111/bjdp.12277.

Palinkas, L.A., Horwitz S. M., Green, C. A., Wisdom, J. P., Duan, N., and Hoagwood, K.. (2013) ‘Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research’, *Administration and policy in mental health and mental health services researc*h, 42(5), pp. 533–544. doi:10.1007/s10488-013-0528-y.

Palludan, C. and Winther, I. W. (2017) ‘‘Having my own room would be really cool’: Children’s rooms as the social and material organizing of siblings’, *Journal of material culture*, 22(1), pp. 34–50. doi: 10.1177/1359183516662675.

Pankhurst, M., Mehta K, Matwiejczyk L, Moores CJ, Prichard I, Mortimer S. and Lucinda, B. (2019) ‘Treats are a tool of the trade: an exploration of food treats among grandparents who provide informal childcare’, *Public health nutrition*, 22(14), pp. 2643–2652. doi: 10.1017/S1368980019000685.

Parekh, G. (2024) *Ableism in education : rethinking school practices and policies*. New York: Routledge.

Pavlopoulou, G. and Dimitriou, D. (2019) ‘‘I don't live with autism; I live with my sister’. Sisters’ accounts on growing up with their preverbal autistic siblings’, *Research in developmental disabilities*, 88, pp. 1–15. doi:10.1016/j.ridd.2019.01.013.

Pavlopoulou, G, Burns, C., Cleghorn, R., Skyria, T. and Avnon, J (2022) ‘“I often have to explain to school staff what she needs”. School experiences of non-autistic siblings growing up with an autistic brother or sister’, *Research in developmental disabilities*, 129, pp. 104323–104323. doi: 10.1016/j.ridd.2022.104323.

Pell, B., Williams, D., Phillips, R., Sanders, J., Edwards, A., Choy, E., and Grant, A. (2020) ‘Using Visual Timelines in Telephone Interviews: Reflections and Lessons Learned From the Star Family Study’, *International journal of qualitative methods*, 19, pp. 1609406920913675–1609406920913675. doi: 10.1177/1609406920913675.

Petalas, M.A., Hasting, R. P., Nash, S., Dowey, A. and Reilly, D. (2009) ‘"I Like That He Always Shows Who He Is": The perceptions and experiences of siblings with a brother with autism spectrum disorder’, *International journal of disability, development, and education*, 56(4), pp. 381–399. doi:10.1080/10349120903306715.

Peterson, T. L., Scott, C. B., Ombayo, B., Davis, T. and Sullivan, D. (2019) ‘Biggest concerns of school personnel about students raised by grandparents’, *Children and youth services review*, 102, pp. 201–209. doi: 10.1016/j.childyouth.2019.05.004.

Pillow, W. (2003) ‘Confession, catharsis, or cure? Rethinking the uses of reflexivity as methodological power in qualitative research’, *International Journal of Qualitative Studies in Education*, 16(2), pp. 175–96

Pink, S. (2012), *Situating Everyday Life*, London: SAGE.

Polkinghorne, D. E. (2007) ‘Validity Issues in Narrative Research’, *Qualitative inquiry*, 13(4), pp. 471–486. doi: 10.1177/1077800406297670.

Powell, B. and Steelman, L. C. (1990) ‘Beyond Sibship Size: Sibling Density, Sex Composition, and Educational Outcomes’, *Social forces*, 69(1), pp. 181–206. doi: 10.1093/sf/69.1.181.

Punch, S. (2005) ‘The Generationing of Power: A Comparison of Child-Parent and Sibling Relations in Scotland’, *Sociological Studies of Children and Youth*. Vol 10. Emerald Group Publishing Limited, pp. 169–188. doi:10.1016/S1537-4661(04)10009-3.

Punch, S. (2008) ‘'You can do Nasty Things to your Brothers and Sisters without a Reason': Siblings' Backstage Behaviour’, *Children & society*, 22(5), pp. 333–344. doi:10.1111/j.1099-0860.2007.00119.x

Rapp, R. (1999) ‘Foreword’, In L. Layne (Ed.), *Transformative motherhood: on giving and getting in a consumer culture* (pp.xi-xix). New York University Press.

Rapp, R. and Ginsburg, F. (2001) ‘Enabling Disability: Rewriting Kinship, Reimagining Citizenship’, *Public culture*, 13(3), pp. 533–556. Available at: https://doi.org/10.1215/08992363-13-3-533.

Rapp, R. and Ginsburg, F. (2011) ‘Reverberations: Disability and the New Kinship Imaginary’, *Anthropological quarterly*, 84(2), pp. 379–410. doi: 10.1353/anq.2011.0030.

Ray, C.D., Scharp, K. M., Parker, E. and Donohoe, D. E. (2025) ‘Withholding Social Support Because Those in Need Do Not Deserve It: A Thematic Narrative Analysis’, *Communication research*, 52(3), pp. 316–345. doi:10.1177/00936502221146629.

Read, T. and Wuest, J. (2007) ‘Daughters Caring for Dying Parents: A Process of Relinquishing’, *Qualitative health research*, 17(7), pp. 932–944. doi: 10.1177/1049732307306123.

Reid, D.K., Stoughton, E.H. and Smith, R.M. (2006) ‘The Humorous Construction of Disability: 'Stand-Up' Comedians in the United States’, *Disability & society*, 21(6), pp. 629–643. doi:10.1080/09687590600918354.

Richardson, S.L.L. and Jordan, L.S. (2017) ‘Qualitative inquiry of sibling relationships: reinforcement of disability devaluation through the exclusion of voices’, *Disability & society*, 32(10), pp. 1534–1554. doi:10.1080/09687599.2017.1351330.

Richardson, S. L. L. and Stoneman, Z. (2019) ‘It takes a sister: sisterhood and Black womanhood in families of people with intellectual and developmental disabilities’, *Disability & society*, 34(4), pp. 607–628. doi: 10.1080/09687599.2018.1555451.

Rieger, A. and McGrail, J. P. (2013) ‘Coping Humor and Family Functioning in Parents of Children With Disabilities’, *Rehabilitation psychology*, 58(1), pp. 89–97. doi: 10.1037/a0031556.

Riessman, C. K. (1993) *Narrative analysis*. Newbury Park, Calif. ; London: Sage Publications.

Riessman, C. K. (2008) *Narrative methods for the human sciences*. Los Angeles: Sage Publications.

Rittenour, C. E., Myers, S. A. and Brann, M. (2007) 'Commitment and emotional closeness in the sibling relationship', *Southern Communication Journal*, 72(2), pp. 169-183.

Roaldsen, B.L., Sørlie, T. and Lorem, G.F. (2015) 'Cancer survivors' experiences of humour while navigating through challenging landscapes - a socio-narrative approach', *Scandinavian Journal of Caring Sciences*, 29(4), pp. 724–733. Doi: 10.1111/scs.12203.

Roberts, S. (2014) '"Out" in the field. Reflecting on the dilemmas of insider status on data collection and conducting interviews with gay men', *Equality, Diversity and Inclusion*, 33(5), pp. 451–461. doi: 10.1108/EDI-07-2013-0056.

Robinson, S., Weiss JA, Lunsky Y and Ouellette-Kuntz H. (2016) 'Informal Support and Burden among Parents of Adults with Intellectual and/or Developmental Disabilities', *Journal of applied research in intellectual disabilities*, 29(4), pp. 356–365. doi: 10.1111/jar.12184.

Robinson, V. (2015) 'Reconceptualising the Mundane and the Extraordinary: A Lens through Which to Explore Transformation within Women's Everyday Footwear Practices', *Sociology* (Oxford), 49(5), pp. 903–918. doi:10.1177/0038038515591942.

Rodríguez-Dorans, E. (2022). *Narrative portraits in qualitative research*. London: Routledge.

Rodríguez-Dorans, E. and Jacobs, P. (2020) 'Making narrative portraits: a methodological approach to analysing qualitative data', *International journal of social research methodology*, 23(6), pp. 611–623. doi: 10.1080/13645579.2020.1719609.

Ronksley-Pavia, M. and Pendergast, D. (2020) 'Countering the paradox of twice exceptional students: Counter-narratives of parenting children with both high ability and disability', in Lueg, K. and Lundholt, M.W. (eds.) *Routledge Handbook of Counter-Narratives*, Abingdon: Taylor & Francis, pp. 238-254.

Rosenthal, G. (2007) Biographical research. In: Seale, C., Gobo, G., Gubrium, J. F. and Silverman, D. (eds.) *Qualitative Research Practice*. London: SAGE.

Rowsell, J. (2025) 'Affecting photos: Photographs as shared, affective ethnographic spaces', *Qualitative research : QR*, 25(1), pp. 207–226. doi: 10.1177/14687941241246173.

Runswick-Cole, K and Goodley, D, (2023), 'Seeking Sunflowers: The biopolitics of autism at the airport' in Milton, D. and Ryan, S. (eds.), *The Routledge international handbook of critical autism studies*. London: Routledge. pp. 218-225.

Runswick-Cole, K. and Ryan, S. (2019) 'Liminal still? Unmothering disabled children', *Disability & society*, 34(7-8), pp. 1125–1139. doi: 10.1080/09687599.2019.1602509.

Runswick-Cole, K., Ellwood, A, Fox, K. and Ryan, S. (2022), ‘Scholar Activism- Mothering, Disability and Academic Activism’ in Kagan, C. (ed.) The Routledge international handbook of community psychology: facing global crises with hope. London: Routledge. Pp. 307-324.

Runswick-Cole, K., Lawthom, R. and Goodley, D. (2016) ‘The trouble with 'hard working families’’, *Community, work & family*, 19(2), pp. 257–260. doi:10.1080/13668803.2016.1134153.

Runswick-Cole, K., Smith, M., Ryan, S. and Douglas, P. (2024) ‘Dis/Entangling Disability, Mental Health, and the Cultural Politics of Care’, *Scandinavian journal of disability research : SJDR,* 26(1), pp. 28-28–43. doi: 10.16993/sjdr.1101.

Ryan, F. (2020) *Crippled : austerity and the demonization of disabled people*. Second edition. London: Verso.

Ryan, S. (2010) ‘‘Meltdowns’, surveillance and managing emotions; going out with children with autism’, *Health & place*, 16(5), pp. 868–875. doi: 10.1016/j.healthplace.2010.04.012.

Ryan, S. and Runswick-Cole, K. (2008) ‘Repositioning mothers: mothers, disabled children and disability studies’, *Disability & society*, 23(3), pp. 199–210. doi:10.1080/09687590801953937.

Ryan, S. and Runswick-Cole, K. (2009) ‘From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum’, J*ournal of applied research in intellectual disabilities*., 22(1), pp. 43–53. doi:10.1111/j.1468-3148.2008.00438.x.

Sandahl, C. (2003) ‘Queering the Crip or Cripping the Queer?’, *GLQ*, 9(1-2), pp. 25–56. doi: 10.1215/10642684-9-1-2-25.

Sanders R. (2004). *Sibling Relationships: Theory and Issues for Practice*. Palgrave: Basingstoke.

Santinele Martino, A., Perrotta, A. and McGillion, B. J. (2024) ‘Who can you trust these days?: Dealing with imposter participants during online recruitment and data collection’, *Qualitative research : QR*. doi: 10.1177/14687941231224591.

Sauer, J.S. and Lalvani, P. (2017) ‘From Advocacy to Activism: Families, Communities, and Collective Change’, *Journal of policy and practice in intellectual disabilities*, 14(1), pp. 51–58. doi:10.1111/jppi.12219.

Scavarda, A. (2023) ‘Disability by association for siblings of adolescents and adults with cognitive disabilities’, *Disability & Society*, doi: 10.1080/09687599.2023.2215393.

Schmid, S. J. (2024) ‘The Ableist stare: an interdisciplinary, narrative-driven exploration of staring at disabled bodies’, *Medical humanities*, doi: 10.1136/medhum-2023-012636.

Scott, S. K, Lavan, N., Chen, S., and McGettigan, C. (2014) ‘The social life of laughter’, *Trends in cognitive sciences*, 18(12), pp. 618–620. doi: 10.1016/j.tics.2014.09.002.

Scuro, J. (2018) *Addressing ableism : philosophical questions via disability studies*. Lanham, Maryland: Lexington Books.

Seymour, J. and Walsh, J. (2013) ‘Displaying Families, Migrant Families and Community Connectedness: The Application of an Emerging Concept in Family Life’, *Journal of comparative family studies*, 44(6), pp. 689–698. doi: 10.3138/jcfs.44.6.689.

Shakespeare, T. (1999) ‘Joking a Part’, *Body & society*, 5(4), pp. 47–52. doi: 10.1177/1357034X99005004004.

Shakespeare, T. (2013) *Disability rights and wrongs revisited*. Second edition. London: Routledge.

Shenoy, S., Howells, R., Dunn, A. and Boateng, T. (2025) ‘Am I my Brother’s Keeper? Interviews with Individuals who have Siblings with Disabilities’, *Research in Social Sciences*, 8(3), pp.51-61.

Sheridan, J., Chamberlain, K. and Dupuis, A. (2011) ‘Timelining: visualizing experience’, *Qualitative research : QR*, 11(5), pp. 552–569. doi: 10.1177/1468794111413235.

Sherman, A., Lansford, J. and Volling, B. (2006) ‘Sibling relationships and best friendships in young adulthood: Warmth, conflict, and well-being’, *Personal relationships*, 13(2), pp. 151–165. doi:10.1111/j.1475-6811.2006.00110.x.

Sherry, M. (2004) ‘Overlaps and contradictions between queer theory and disability studies’, *Disability & society*, 19(7), pp. 769–783. doi: 10.1080/0968759042000284231.

Shildrick, M. (2012) ‘Critical disability studies: rethinking the conventions for the age of postmodernity’ in Watson, N. and Vehmas, S. (eds.) *Routledge handbook of disability studies: Routledge*, pp. 30-42.

Shrodes, A. (2023) ‘"The word 'getting over' is really weird": Storying disability in desired futures’, *Curriculum inquiry*, pp. 1–20. doi: 10.1080/03626784.2023.2206932.

Shuster, S. M. and Westbrook, L. (2022) ‘Reducing the Joy Deficit in Sociology: A Study of Transgender Joy’, *Social Problems* (Berkeley, Calif.). doi: 10.1093/socpro/spac034.

Sibs, (2025), *Frequently asked questions (FAQs)*, Available at: https://www.sibs.org.uk/support-for-adult-siblings/find-help [Accessed 15/09/25].

Siklos, S. and Kerns, K. A. (2006) ‘Assessing need for social support in parents of children with autism and Down syndrome’, *Journal of autism and developmental disorders*, 36(7), pp. 921–933. doi: 10.1007/s10803-006-0129-7.

Silva, E.B. and Smart, C. (1999) *The new family?* [electronic resource]. London: SAGE.

Slater, J, (2016) ‘The (Normal) Non-Normativity of Youth’ in Mallett, R., Ogden, C. A. and Slater, J. (eds.) *Theorising normalcy and the mundane : precarious positions* (1st ed), Chester, [England]: University of Chester Press. pp. 14-44.

Sleeter, C. (2010) ‘Why Is There Learning Disabilities? A Critical Analysis of the Birth of the Field in Its Social Context’, *Disability studies quarterly*, 30(2). doi: 10.18061/dsq.v30i2.1261.

Smart, C. (2007) *Personal life: new directions in sociological thinking*. Cambridge: Polity Press.

Smart, C. and Neale, B. (1999) *Family fragments?*, Cambridge: Polity Press.

Smedema, S. M., Ebener, D. and Grist-Gordon, V. (2012) ‘The impact of humorous media on attitudes toward persons with disabilities’, *Disability and rehabilitation*, 34(17), pp. 1431–1437. doi: 10.3109/09638288.2011.645109.

Smith, B. (2017). ‘Narrative analysis in sport and exercise: How can it be done?’. In Smith, B. and Sparkes, A.C. (eds.) *Routledge handbook of qualitative research in sport and exercise.* London, [England] ; Routledge. pp. 282-295.

Smith, B. and Sparkes, A.C. (2008) ‘Narrative and its potential contribution to disability studies’, *Disability & society*, 23(1), pp. 17–28. doi:10.1080/09687590701725542.

Smyth, C., Blaxland, M. and Cass, B. (2011) ‘'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers’, *Journal of youth studies*, 14(2), pp. 145–160. doi: 10.1080/13676261.2010.506524.

Smyth, J. and McInerney, P. (2013) ‘Whose side are you on? Advocacy ethnography: some methodological aspects of narrative portraits of disadvantaged young people, in socially critical research’, *International journal of qualitative studies in education*, 26(1), pp. 1–20. doi: 10.1080/09518398.2011.604649.

Snipstad, Ø. I. M. (2022) ‘Concerns regarding the use of the vulnerability concept in research on people with intellectual disability’, *British journal of learning disabilities*, 50(1), pp. 107–114. doi: 10.1111/bld.12366.

Solórzano, D.G. and Yosso, T.J. (2002) ‘Critical Race Methodology: Counter-Storytelling as an Analytical Framework for Education Research’, *Qualitative inquiry*, 8(1), pp. 23–44. doi:10.1177/107780040200800103.

Spagnuolo, N., Boulanger, J. and Ries, H. (2025), ‘Sibling Relationships and Developmental Disability Services: From Coerced Care to Entitlement’, *Disability Studies Quarterly*, Vol. 44 No. 2, doi: 10.18061/dsq.v44i2

Sparkes, A. C. and Smith, B. (2011) ‘Inhabiting different bodies over time: narrative and pedagogical challenges’, *Sport, education and society*, 16(3), pp. 357–370. doi: 10.1080/13573322.2011.565967.

Spence, D. P. (1982) *Narrative truth and historical truth : meaning and interpretation in psychoanalysis*, New York ; London: Norton.

Stainton, T. and Besser, H. (1998) ‘The positive impact of children with an intellectual disability on the family’, *Journal of Intellectual and Developmental Disability*, 23(1), pp. 57–70. doi:10.1080/13668259800033581.

Stalker, K. (2012) 'Theorising the position of people with learning difficulties within disability studies: Progress and pitfalls', in Watson, N. and Vehmas, S. (eds.) *Routledge handbook of disability studies: Routledge*, pp. 122-135.

Stalkers, K. and Connors, C, (2010), ‘Children with learning disabilities talking about their everyday lives’, in Grant, G. (ed), *Learning disability : a life cycle approach* (2nd ed). Maidenhead: McGraw-Hill/Open University Press.

Stehlik, D. (2017) ‘Rurality, disability and place identity’. In Soldatic, K., and Johnson, K. (eds.), *Disability and rurality: Identity, gender and belonging* (pp. 69–81). Routledge. https://doi.org/10.4324/9781315577340-6

Stone, E. and Priestley, M. (1996) ‘Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers’, *The British journal of sociology*, 47(4), pp. 699–716. doi:10.2307/591081.

Stoneman Z. (2005) ‘Siblings of children with disabilities: research themes’. *Mental Retardation*. 43(5):339-50. doi: 10.1352/0047-6765.

Sunderland, N., Catalano, T. and Kendall, E. (2009) ‘Missing discourses: concepts of joy and happiness in disability’, *Disability & society*, 24(6), pp. 703–714. doi: 10.1080/09687590903160175.

Taylor, S. (1996), ‘Disability Studies and Mental Retardation’, *Disability Studies Quarterly*, 16(3), pp. 4-13.

Taylor, J. L. and Shivers, C. M. (2011) ‘Predictors of helping profession choice and volunteerism among siblings of adults with mild intellectual deficits’, *American journal on intellectual and developmental disabilities*, 116(4), pp. 263–277. doi: 10.1352/1944-7558-116.3.263.

Thavakugathasalingam, M. and Schwind, J. K. (2022) ‘Experience of childhood cancer: A narrative inquiry’, *Journal for specialists in pediatric nursing*, 27(2), p. e12367–n/a. doi: 10.1111/jspn.12367.

Thomas, C. (1999). *Female forms: Experiencing and understanding disability.* Buckingham: Open University Press.

Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology*. London: Springer.

Thomas, G. M. (2021) ‘Dis-mantling stigma: Parenting disabled children in an age of ‘neoliberal-ableism’’, *The Sociological review* (Keele), 69(2), pp. 451–467. doi: 10.1177/0038026120963481.

Thomas, G. M. (2024) ‘We Wouldn’t Change Him for the World, but We’d Change the World for Him: Parents, Disability, and the Cultivation of a Positive Imaginary’, *Current anthropology*, 65(S26), pp. S32–S54. doi: 10.1086/732175.

Thomas, G. M. and Sakellariou, D. (2018) ‘Introduction: Disability, normalcy, and the everyday’, In Thomas, G. M. and Sakellariou, D. (eds.), *Disability, normalcy, and the everyday* (pp. 3–16). Routledge.

Thomas, P. (2011) ‘'Mate crime': ridicule, hostility and targeted attacks against disabled people’, *Disability & society*, 26(1), pp. 107–111. doi: 10.1080/09687599.2011.532590.

Thompson, S. (2022) ‘“Not your ‘poor dear’”: Practices and politics of care in women’s non-profit housing in Vancouver, Canada’, *Gender, place and culture : a journal of feminist geography*, 29(8), pp. 1121–1140. doi: 10.1080/0966369X.2021.1937063.

Tozer, R. and Atkin, K. (2015) ‘'Recognized, Valued and Supported'? The Experiences of Adult Siblings of People with Autism Plus Learning Disability’, *Journal of applied research in intellectual disabilities*, 28(4), pp. 341–351. doi:10.1111/jar.12145.

Tozer, R., Atkin, K. and Wenham, A. (2013) ‘Continuity, commitment and context: adult siblings of people with autism plus learning disability’, *Health & social care in the community*, 21(5), pp. 480–488. doi: 10.1111/hsc.12034.

Travers, H.E., Carlton, M.E. and Carter, E.W. (2020) ‘Social Connections Among Siblings With and Without Intellectual Disability or Autism’, *Intellectual and developmental disabilities*, 58(1), pp. 19–33. Available at: https://doi.org/10.1352/1934-9556-58.1.19.

Truesdale, M., Taggart, L., Ryan, A. and McConkey, R. (2021) ‘Experiences of Reciprocal Caring Among Adults With an Intellectual Disability Caring for an Older Family Member’, *Journal of policy and practice in intellectual disabilities*, 18(3), pp. 240–248. doi:10.1111/jppi.12380.

Tyler, I. (2020) *Stigma / the machinery of inequality*. London: Zed Books.

UPIAS. (1976) *Fundamental Principles of Disability*. London: Union of the Physically Impaired Against Segregation.

Vaccaro, A. (2010) ‘Toward Inclusivity in Family Narratives: Counter-Stories from Queer Multi-Parent Families’, *Journal of GLBT family studies*, 6(4), pp. 425–446. doi: 10.1080/1550428X.2010.511086.

Valentine, G. and Hughes, K. (2012) ‘Shared space, distant lives? Understanding family and intimacy at home through the lens of internet gambling’, *Transactions - Institute of British Geographers* (1965), 37(2), pp. 242–255. doi: 10.1111/j.1475-5661.2011.00469.x.

Van Volkom, M., Machiz, C. and Reich, A.E. (2011) ‘Sibling relationships in the college years: Do gender, birth order, and age spacing matter?’, *North American Journal of Psychology*, 13(1).

Vanhoutteghem, I., Van Hove, G., D'haene, G. and Soyez, V. (2014) ‘'I never thought I would have to do this': narrative study with siblings-in-law who live together with a family member with a disability’, *British journal of learning disabilities*, 42(4), pp. 315–322. doi:10.1111/bld.12077.

Vehmas, S. and Mietola, R. (2021) *Narrowed lives : meaning, moral value, and profound intellectual disability*. Stockholm, Sweden: Stockholm University Press.

Vehmas, S. and Watson, N. (2016) ‘Exploring normativity in disability studies’, *Disability & society*, 31(1), pp. 1–16. doi: 10.1080/09687599.2015.1120657.

Walker, T., Mitchell, P. and Dlouhy, S. (2020) ‘Cultivating Passion through Collaborative Art: A Dialogic Exploration of Disability, Storytelling, and Social Change’, *Health communication*, 35(7), pp. 917–920. doi:10.1080/10410236.2019.1596868.

Walkerdine, V. (1993) ‘Beyond Developmentalism?’, *Theory & psychology*, 3(4), pp. 451–469. doi: 10.1177/0959354393034004.

Walmsley, J. (1997), 'Including people with learning difficulties: Theory and practice’, In Barton, L. and Oliver, M., (eds) *Disability studies: Past, Present and Future*. Leeds: The Disability Press: pp. 45-61.

Walmsley, J. (2001) ‘Normalisation, Emancipatory Research and Inclusive Research in Learning Disability’, *Disability & society*, 16(2), pp. 187–205. doi: 10.1080/09687590120035807.

Walsh, J., McNamee, S. and Seymour, J. (2020) ‘Family display, family type, or community? Limitations in the application of a concept’, *Families, relationships and societies*, 9(3), pp. 345–360. doi: 10.1332/204674319X15647592551202.

Walton, G. (2011) ‘Spinning our wheels: reconceptualizing bullying beyond behaviour-focused approaches’, *Discourse* (Abingdon, England), 32(1), pp. 131–144. doi: 10.1080/01596306.2011.537079.

Wanzer, M., Booth-Butterfield, M. and Booth-Butterfield, S. (2005) ‘“If We Didn’t Use Humor, We’d Cry”: Humorous Coping Communication in Health Care Settings’, *Journal of health communication*, 10(2), pp. 105–125. doi: 10.1080/10810730590915092.

Ward, N. (2011) ‘Care Ethics and Carers with Learning Disabilities: A Challenge to Dependence and Paternalism’, *Ethics and social welfare,* 5(2), pp. 168–180. doi: 10.1080/17496535.2011.571066.

Ward, N. (2015) ‘Thirteen: Reciprocity and mutuality: people with learning disabilities as carers’, In Barnes, M., Brannelly, T., Ward, L. and Ward, N., *Ethics of Care*, Bristol, UK: Policy Press.

Wasilewski, M. B., Stinson, J. N., Webster, F., and Cameron, J. I. (2019) ‘Using Twitter to recruit participants for health research: An example from a caregiving study’, *Health informatics journal*, 25(4), pp. 1485–1497. doi: 10.1177/1460458218775158.

Webber, R. (2023) ‘Experiences of ‘sensory space-time compression’ in migrant homemaking’, *Social & Cultural Geography*. https://doi.org/10.1080/14649365.2023.2183246.

Webster, M. (2018) ‘Siblings' caring roles in families with a child with epilepsy’, *Sociology of health & illness*, 40(1), pp. 204–217. doi:10.1111/1467-9566.12627.

Wells, K. (2011) *Narrative inquiry*. New York: Oxford University Press.

Wendell, S. (1989) ‘Toward a Feminist Theory of Disability’, *Hypatia*, 4(2), pp. 104–124. doi: 10.1111/j.1527-2001.1989.tb00576.x.

Wendell, S. (1996) *The rejected body : feminist philosophical reflections on disability*. New York: London : Routledge.

Widmer, E. D., Castrėn, A., Jallinoja, R., and Ketokivi, K. (2008) ‘Introduction’, In Widmer, E. D. and Jallinoja, R. (eds.) *Beyond the Nuclear Family: Families in a Configurational Perspective*. Bern: Peter Lang. pp. 1-11.

Wikle, J. S., Jensen, A. C. and Hoagland, A. M. (2018) ‘Adolescent caretaking of younger siblings’, *Social science research*, 71, pp. 72–84. doi: 10.1016/j.ssresearch.2017.12.007.

Winther, IW. (2009) ‘Homing oneself: Home as a practice’, in: Penner, B. and Pavlovits, D. (eds.) *Haecceity Papers*, 4(2). Sydney: Sydney University Press.

Winther, W. I. , Palludan, C. , Gulløv, E. , and Middelboe Rehder, M. (2015), *Sibling: Practical and Sensitive Relations*, Copenhagen: Egmont Fonden, Aarhus University Press.

Whalen, J.M., Doyle, A. and Pexman, P.M. (2020) ‘Sarcasm between siblings: Children's use of relationship information in processing ironic remarks’, *Journal of pragmatics*, 156, pp. 149–159. doi:10.1016/j.pragma.2019.05.005.

Wolff, B., Glasson, E.J. and Pestell, C.F. (2024) ‘“Broken fragments or a breathtaking mosaic”: A mixed methods study of self‐reported attributes and aspirations of siblings of individuals with and without neurodevelopmental conditions’, *Journal of research on adolescence*, 34(3), pp. 1005–1017. Available at: https://doi.org/10.1111/jora.12981.

Woods, R. (2023), ‘Rational (Pathological) Demand Avoidance: As a mental disorder and an evolving social construct’, in Milton, D. and Ryan, S. (eds.), *The Routledge international handbook of critical autism studies*. London: Routledge. pp. 56-75.

Yates, S., Dyson, S. and Hiles, D. (2008) ‘Beyond normalization and impairment: theorizing subjectivity in learning difficulties - theory and practice’, *Disability & society*, 23(3), pp. 247–258. doi: 10.1080/09687590801954018.

Appendices

Appendix 1. Recruitment Poster

Call for PhD research participants!

I'm looking for people aged 18-32 who have a sibling with learning disabilities to take part in my PhD research. The project is exploring the stories siblings share with the aim of generating data that disrupts the ways in which learning disability and siblinghood are commonly understood.

Your participation would be in the form of an interview where you can tell your story about growing up with your sibling. I ask that you bring along a timeline and photos to discuss. Participants can choose if they want their photos or timeline to be included in the final submission.

If this is something you are interested in, or you would like to hear more about please contact me on email: tjryan1@sheffield.ac.uk or send a message through X (Twitter).

I am a PhD researcher at the University of Sheffield based in the School of Education with both family experience of learning disability and work experience.

University of Sheffield

Appendix 2. Participant Information

Pseudonym	Age	Gender	Ethnicity	Pen Portrait
Zara	23	Female	White British	Zara is training to be a therapist. Zara grew up in the south of England with 3 siblings and her parents. Zara is the youngest, with a brother, Jake, and two sisters, Jenny and Mia. Jenny has learning disabilities and uses a wheelchair. They grew up in a middle-class family in the south of England.
Hannah	27	Female	White British	Hannah is an occupational therapist. Hannah is the middle child of 3, her older sister Anna has learning disabilities and uses a wheelchair. She has a younger brother called Harvey. They grew up in a middle-class family in the midlands.

Emily	26	Female	White British	Emily is a PhD student. She is the oldest of 3, her middle sibling Claire has learning disabilities and she also has a younger brother, Adam. They grew up in a middle-class family in a northern town in the UK.
Ellie	30	Female	White British	Ellie is an academic. She is the youngest of 4, with 3 older brothers, James, Erik and Harry. Harry has learning disabilities. They grew up in a middle-class family in the south of England.
Oscar	22	Male	White British	Oscar is a graduate who is living at home taking a year off after university. He is the oldest of 4 with two brothers, Liam and Owen, and a sister, Jane. Oscar’s brother Owen had learning disabilities, he passed away in 2021. They grew up in a middle-class family in the south of England.
Eva	22	Female	White British	Eva is a master’s student currently studying in Amsterdam. She is the oldest of 4 with 3 younger brothers, Tim, David and George. Tim has learning disabilities. They grew up in a middle-class family in the south of England.
Martha	24	Female	White British	Martha is a social worker who works with young people. She has two older siblings, John and Guy. Guy has learning disabilities. They grew up in a middle-class family in the south of England.
Zack	28	Male	White British	Zack is a teacher based in China, he grew up in a middle-class family in a northern city with an older brother and a younger sister, Josh and Beth. Beth has learning disabilities.
Alex	22	Male	White British	Alex recently graduated from university and is currently looking for jobs. Alex has an older sister called Lola. He grew up in a middle-class family in the midlands.

Susan	19	Female	White British	Susan is a foundation year student studying Law at university. She is the youngest of 3, with an older brother, Peter, and older sister, Gemma. Peter has learning disabilities. They grew up in the south of England.
Dina	22	Female	White European	Dina is a geography student currently studying abroad. She is the middle child, with an older sister, Tyler, and a younger brother, Samuel. Tyler has learning disabilities. They grew up in the south of England.
Kerry	19	Female	White British	Kerry is doing an apprenticeship in engineering. She is the oldest of two, with a younger brother, Jack. Kerry was diagnosed with autism and ADHD when she was 16. They grew up in the south of England.
Scott	32	Male	White British	Scott works in the public sector. He has an older brother, Dean. They grew up in the south east of England.
Faye	29	Female	Mixed white and black Caribbean	Faye is a PhD student. She grew up in a working-class household in the south of England with her mum and two older brothers, Luke and Sami. Luke has learning disabilities. She also has half siblings that were born after she left home.

Appendix 3. Information Sheet

Participant information sheet

1. Research project title

Disability, sibling relationships and everyday life: exploring mundane realities as counter-stories

2. Invitation

You are invited to participate in a research study which looks at the childhood experiences of siblings of people with learning disabilities. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask me if you would like more information or if there is anything that you do not understand. I would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

3. What is the project's purpose?

The project aims to explore sibling experiences of learning disability during their childhoods. Whilst this is a topic that has been researched previously, the approach taken has often been one that contributes to more 'deficit' understandings of learning disability, which presents family experiences of learning disability in a negative light. The research aims to seek counter-stories which provide a more comprehensive insight into people's experiences of having a sibling with learning disabilities. This will be done using narrative interviews alongside the creative methods of photo elicitation and timeline mapping.

4. Why have I been chosen?

I'm looking for adult participants who have siblings with learning disabilities and feel comfortable discussing their childhoods in interviews.

5. Do I have to take part?

Participation is voluntary and you are free to withdraw at any time without explanation and without incurring a disadvantage.

6. What will happen to me if I take part? What do I have to do?

Participants will be asked to attend an interview with the researcher that will be split into two parts. This can be online or in-person depending on discussions with the participants. The first part will be a biographical interview with participants asked to bring along a timeline of their childhood and some photos to discuss in the session. The second part will follow a more conventional interview structure with the researcher asking the participant questions about their childhood, and asking them to elaborate on topics mentioned in the first half. The interview sessions should not last more than two hours, with participants free to take breaks when they feel like it. Participants can book a follow up interview, or go longer than the allotted time if they wish.

TOPIC GUIDES

The second part of the interview will include questions, whilst these will change depending on what is discussed in the biographical section these examples provide some insight into the sorts of questions that may be asked:

- Tell me about your sibling?
- What did you do for fun growing up?
- Did you spend a lot of time with your siblings growing up? If so, what did you do?
- What was dinner time like at your house?
- How did you spend your free time growing up? (weekends, after school)
- What were your school holidays like? How did you pass the time?

Alongside questions like this, the researcher will make notes during the first part of the interview to then ask questions which elaborate on topics raised.

7. What are the possible disadvantages and risks of taking part?

Participating in the research is not anticipated to cause you any disadvantage or discomfort. No potential physical or psychological harm or distress is expected. This said, the nature of the topic of the research could see it being a distressing interview in some parts. It is important to reiterate:

- Participants can withdraw from the process at any time without reason
- Participants do not have to answer every question in the interview

- Participants have the right to stop the interview at any point without reason

8. What are the possible benefits of taking part?

Though taking part in the study will likely not benefit you directly, the project provides the opportunity to tell your story and contribute to affirmative research into disability and siblinghood.

9. Will my taking part in this project be kept confidential? Will I remain anonymous?

All the information collected about you during the course of the research will be kept strictly confidential. You will not be identified or identifiable in any of the material associated with this project. Data will be anonymised, and any data collected about you in an interview will be stored in a form protected by passwords, or in a locked space. The interview data as a whole, once anonymised, will only be accessible by the researcher and their supervisors. Any references to your interview in the thesis, or subsequent papers will be anonymised also.

10. What is the legal basis for processing my personal data?

According to data protection legislation, it is required that you are informed that the legal basis being applied to process your personal data is that ‘processing is necessary for the performance of a task carried out in the public interest’ (Article 6(1)(e)). Further information can be found in the University’s Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

The Data Controller for this study is the University of Sheffield, meaning that this University is responsible for looking after your information and using it properly.

11. What will happen to the results/findings of the research project?

Results of the research will be given in the form of a thesis discussing the findings and the appendix including the interview transcripts and optionally the timelines and photos. You will not be identified in the research; your name will be changed and any identifiable answers (for example places) will be changed. There is potential that the data (anonymised) is used in publications after the thesis has been submitted.

Future research: The Economic and Social Research Council (ESRC), funds this research project. All ESRC-funded research must make all data generated by the project available via the UK Data Service. This means that the data collected can be made available to other researchers that find the data collected to be useful in answering future research questions. Your explicit consent will be required for your data to be shared in this way and if you agree, we will ensure that the data collected about you is untraceable back to you before allowing others to use it. If you have any questions about this, don't hesitate to ask.

12. What happens if the research project stops earlier than expected?

Although unlikely, if for any reason the research project stops earlier than expected, you will be offered a full and clear explanation as to why.

13. What if something goes wrong?

If something goes wrong or you would like to raise an issue or concern, the first point of contact would be Tom Ryan the researcher on the project. Tom's contact details can be found at the end of the document in the case that you would prefer to raise the concern not to Tom, the supervisor Professor Dan Goodley or the department safeguarding lead Professor Rebecca Lawthom can be contacted here:

Professor Dan Goodley (Supervisor)
Professor of Disability Studies and Education
The School of Education, The Wave, 2 Whitham Rd, Sheffield S10 2AH,
Email: d.goodley@sheffield.ac.uk

Professor Rebecca Lawthom
Head of School
The School of Education, The Wave, 2 Whitham Rd, Sheffield S10 2AH,
Tel: +44 (0) 114 222 8172
Email: r.lawthom@sheffield.ac.uk

If your complaint relates to how your personal data has been handled, information about how to raise a complaint can be found in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

14. Who has ethically reviewed the project?

This project has been ethically reviewed by the School of Education Ethics Committee at the University of Sheffield.

15. Contact for further information

Tom Ryan
PhD student
School of Education, The Wave, 2 Whitham Rd, Sheffield S10 2AH
Email: tjryan1@sheffield.ac.uk

16. Who is funding the research?

The research is funded by the ESRC, The Economic and Social Science Research Council.

Appendix 4. Consent Form

Consent form: Disability, sibling relationships and everyday life: exploring mundane realities as counter-stories

Please tick the appropriate boxes	**Yes**	**No**
Taking Part in the Project		
I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.		
I agree to take part in the project. I understand that taking part in the project will include participating in an interview that is being recorded (audio and video).		
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.		
I understand that by choosing to participate as a volunteer in this research, this does not create a legally binding agreement nor is it intended to create an employment relationship with the University of Sheffield.		
How my information will be stored		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.		
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.		
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.		
I agree to my anonymised timeline being used in the research, and future publications, reports, web pages and other research outputs.		

I agree to the photos I provided in being used in the research submission.		
I give permission for my interview transcript to be deposited in the UK Data Service and ORDA so it can be used for future research and learning.		

Please sign below

Name of participant [printed] Signature Date

Name of Researcher [printed] Signature Date

Appendix 6. Examples of Narrative Notes

Ellie

Ellie's interview was interesting as she made reference to her position in relation to her brother as time went on, moving from annoying younger sister who he could make fun of, to cool sister who volunteered at the charity he attended and could help him when needed. This also led to some interesting reflections regarding care as Ellie was told by her mum that she could take over her brother's care when they got older, something Ellie noted as she has two other older brothers who didn't get this conversation. Ellie reflected on the potential gendered nature of this, but also acknowledged that she is the only one without kids which may have been a factor. The role of care was very interesting in this narrative though, returning throughout in how Ellie and her brother interacted, with Ellie feeling protective of her older brother at different points. Alongside these reflections, the other main takeaway was the way that the fun of being a sibling was captured in this narrative, with Ellie reflecting on things like Christmas and family get togethers and the excitement of these, using the term atmosphere to try to capture the feeling of closeness she feels to her siblings and wider family.

Emily

Emily's narrative featured key themes/ codes of family support networks and humour. Regarding the former, Emily's family had a strong group of family friends who all had children who would all hang out. This led to Emily noting that even before any of her siblings were born she never felt like an only child. Alongside this, Emily noted the role her grandparents played in her upbringing and mentioned some particularly good teachers and a charity they used to holiday with. All of these were threaded throughout her narrative creating a real sense of the potential of good support. Alongside this, Emily herself was very humorous both in her delivery and in the stories she told, noting how her family were all quite like this and how they use humour a lot in their interactions with each other. Disability is addressed in the narrative, again I think there is something in how siblings tend to embody human praxis through the prioritising of human stories. Even when disability is provided as context, it remains as just that in most cases.

Oscar

Oscar’s interview was slightly different as his sibling has passed away, whilst I didn’t want to say no to the interview, I was conscious of questions asked and took particular care to just allow him the time to speak about what he wanted. The interview focused mainly on navigating disability, with Oscar’s timeline being almost framed through the support and medication his sibling was receiving at different times. This led to interesting reflections around disability throughout the narrative, with Oscar’s love for his sibling still coming through but also more of a frank recognition of how difficult his brother’s epilepsy could be. Alongside this were reflections around lack of support, or fighting for support that tied into the ‘outside the family’ code, with Oscar’s mum having to fight for his brother's support throughout his life. There were also some really nice reflections on good support, or family friends and things in which Oscar makes clear how he understands inclusion.

Dina

Dina’s narrative centred a lot around care and sharing space, with some really interesting reflections around siblinghood. Dina is the middle child, with her older sister having learning disabilities. She felt as though a lot of the care role fell on her, not because her parents expected it but more so as her younger brother would never think to step up. This came up throughout the narrative, with Dina frustrated about her brother’s lack of help. The reflections around sharing space centred mostly around Dina’s sister’s lifestyle infringing on Dina’s use of their home. For example her sister didn’t like the noises the Nintendo Wii made and so her parents made them move it out of the living room. Dina also noted how she used to really want an older sister that was at her school and could offer advice about things, this changed as she got older but was a theme she returned to throughout the interview.