Parent Carer Agency: *Exploring the Lived Experience of Advocating for a Disabled Child While Engaging with Professionals and Institutions*

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ABSTRACT

Previous research has shown that parent carers, despite their vital role in securing their children's rights and wellbeing, often encounter systemic barriers that undermine their agency and advocacy. This study addresses the gap in understanding parent carer agency by exploring the impacts of care provision, examining barriers to seeking help, and identifying factors that could improve the advocacy experience. It employs an innovative approach by combining interpretative phenomenological analysis (IPA) with visual elicitation and a social justice lens to explore the lived experience of a parent carer advocating for a disabled child. The findings reveal that parent carer agency is a complex phenomenon, deeply rooted in the interconnected relationship between parent and child and intensified by disability. Four main themes emerged, each centred around this relationship: the specialness of the bond between a parent carer and child; the advocacy journey as a battle for voice and knowing; the particular importance of justice as recognition and rebalancing; and how time affects agency and recovery. The essence of parent carer agency is thus defined by the complex interplay of fragility and strength within this unique relationship. Enhancing parent carer agency is therefore important for dismantling systemic barriers to advocacy and ensuring the wellbeing of both the parent carer and their child. Supporting parent carers means listening to their stories and letting their lived experience and knowledge guide professional and institutional engagement. The study's insights offer valuable contributions to pave the way for further research aimed at shaping policy and encouraging more reflexive and sensitive approaches to working with parent carers. Recommendations include mandatory lived experience training for professionals throughout the UK and the prioritisation of collaboration between universities, policymakers, and practitioners to promote anti-oppressive practices. These measures can help build a more empathetic system that genuinely supports parent carers in effectively advocating for their children, improves their advocacy experience, and recognises the importance of parent carer agency in advocacy partnerships.

ACRONYMS AND ABBREVIATIONS

ADASS	Association of Directors of Adult Social Services
ALN	Additional Learning Needs
ASN	Additional Special Needs
BASW	British Association of Social Workers
BSA	British Sociological Association
EbE	Expert by Experience
EHC	Education, Health and Care plan
EHCP	Education, Health and Care Plan
GET	Group Experiential Theme
ICO	Information Commissioner’s Office
IPA	Interpretative Phenomenological Analysis
LA	Local Authority
NHS	National Health Service
ONS	Office for National Statistics
PET	Personal Experiential Theme
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
UWTSD	University of Wales Trinity Saint David
VET	Visual Elicitation Technique

1. INTRODUCTION

This study explores the lived experience of agency for a parent carer advocating for a disabled child while engaging with professionals and institutions. Prompted by the researcher's own lived experience as a parent carer, the study employs interpretative phenomenological analysis (IPA), chosen for its focus on meaning-making and lived experience (Smith, Flowers & Larkin, 2009, pp. 1–2; 2022, pp. 26–27). This approach is complemented by the innovative use of visual elicitation techniques (VETs), including a child's artwork and a toy, to deepen understanding. By incorporating a social justice lens, the research highlights how structural aspects influence agency, demonstrating its relevance for research, policy, and practice. The aim (see Appendix 2, p. 1) is to generate insights that empower parent carers to strengthen their agency and support professionals in adopting reflexive and anti-oppressive practices (Dalrymple & Burke, 2006) within a social justice framework. The hope is to move beyond the often negative advocacy experiences of many parent carers, offering solutions that recognise lived experience as a valuable source of knowledge for practitioners working with parent carer advocacy.

The paradoxical issue at the heart of parent carers' experiences is that they are simultaneously central to their child's welfare yet marginalised by external support systems (Lam & Kwong, 2014). Caring for a disabled child is a complex and challenging experience, requiring parents to negotiate myriad systems and interactions with professionals and institutions across social care, health, and education sectors (Disabled Children's Partnership, 2022). Research has demonstrated that parent carers fulfil multiple roles, including advocating for their children, and a significant part of this unpaid advocacy involves voicing concerns about their children's care (Wright &

Taylor, 2014, p. 591). The ambiguous position of parent carers as advocates – on the periphery of the decision-making process, despite being key providers of the children's needs (Johnson, 2023d, p. 3; Page *et al.*, 2020, pp. 1144–1154) – creates a social context that promotes stress for the parent. Additional systemic, personal, cultural, and economic barriers to parent carer advocacy exacerbate tensions, impacting parental health (O'Dwyer *et al.*, 2024, pp. 1–2; Walmsley *et al.*, 2017, p. 1366). Therefore, as discussed in the literature review (Chapter 2), parent carers' complex roles and duties are a source of, and subject to, internal and external conflicts that can erode parental agency and advocacy.

The Need to Explore Parent Carer Agency

As noted previously, there is a clear need to explore parent carer agency in advocacy relationships, especially as inadequate support can hinder their ability to effectively advocate for their children (Rossetti *et al.*, 2021, p. 438). While parental support is vital for a child's psycho-emotional wellbeing, research on disabled children remains limited with an academic focus (Dyches *et al.*, 2012, pp. 2213–2215; Kagan, 1999, p. 164). In the broader social context of an increasing prevalence of disability among children in the UK and around the world (Kirk-Wade, Stiebahl & Wong, 2024, pp. 5, 8; Olusanya *et al.*, 2022, pp. 1–2), there is a pressing need for more research on the lived experience of parent carer agency in the parent-to-professional advocacy relationship. This study uses IPA, an approach that foregrounds lived experience, to provide valuable insights into the body of previous work in this area, with a social justice perspective to illuminate the structural inequalities that impede parent carer agency.

Although the importance of the parental role is known, parent carers continue to experience systemic barriers that prevent their voices from being heard. Addressing this issue, Boughey and McSherry (2019, pp. 23–28) emphasise the need for policymakers to acknowledge the perspectives of parent carers. However, a subsequent critical report by Clements and Aiello (2021, pp. 6–7) raises concerns about the continuing inequitable treatment of one of the UK's most disadvantaged groups by social care practitioners. Despite the exposure of 'institutionalised parent carer blame' (BBC, 2021; Clements & Aiello, 2021, p. 2) – a form of discrimination not explicitly protected under the UK's primary disability legislation, the *Equality Act 2010* – the requisite changes in professional practice have yet to take place. Indeed, discriminatory practices persist in all primary services, as confirmed by a recent report by the Association of Directors of Adult Social Services (ADASS, 2024).

While policymakers appear to be increasingly aware of the issues that parent carers experience, this has not translated into increased financial support (Lefton & Fleming, 2024; The Scottish Government, 2022; Williams, K., 2024). Even though parent carers face significant costs in raising their children, the government-funded Carer's Allowance is 'the lowest benefit of its kind' (Carers UK, 2025; Department for Work and Pensions, 2012), failing to reflect how much society gains from the care services that they provide (Carers Week, 2019). Parent carers, therefore, face various barriers that hinder their ability to advocate for their children, with this limited support weakening their capacity to act. The findings of these authors underscore the tangible reality of the reduced agency experienced by this marginalised group of health and social care users. These various role-related challenges and responsibilities are discussed – along with parent carers' lived experience of agency, voice, and choice –

in the literature review. The following section introduces the approach chosen to explore a parent carer's lived experience of agency.

Understanding Parent Carer Agency: Study Aim and Objectives

The study's aim of understanding the lived experience of parent carer agency within the advocacy relationship has directed each phase of the research design (Ridley, 2012, p. 106), from identifying the research gap in the literature review to the choice of IPA. For clarity, the study's objectives, which support and align with the aim, are reiterated below (see Appendix 2, pp. 1–2) and are to:

- Understand the impacts on a parent carer of providing primary care for their disabled child.
- Examine the barriers that a parent carer faces when seeking help for or raising concerns about their child's care.
- Identify factors that would improve a parent carer's experience when advocating for their child's care.
- Gain insights from in-depth, rich single-participant data gathered for the doctoral dissertation.
- Harness insights into a parent carer's lived experience of agency to inform policy and professional practice.

Exploring the impacts of caring and the barriers to effective advocacy – as part of the dual role of parent carers – is expected to reveal the factors that enhance the experiences of parent carers. Knowledge of these factors could then lead to meaningful changes in professional practice. Although the original proposal addressed parent carers broadly (see Appendix 2, p. 1), this study focuses on rich, single-participant data to provide in-depth insights that meet these objectives, all of which are designed to answer the unifying central research question: *What is the lived experience of agency for a parent carer advocating for a disabled child while engaging with professionals and institutions?*

This introduction has laid the foundation for exploring a parent carer's lived experience of agency while advocating for a disabled child. Chapter 2 reviews the existing literature, highlighting the tensions and contradictions in parent carers' advocacy role when seeking support for their child while facing systemic barriers. Chapter 3 outlines the methodological approach, explaining how IPA – when combined with additional theory – provides a flexible and nuanced means of capturing individual experiences and broader social factors. The findings and analysis in Chapter 4 draw on IPA's rich data, complemented by a social justice perspective, to reveal the personal and structural dimensions of parent carer agency. Finally, Chapter 5 brings together these insights to provide theoretical and practical recommendations and suggest directions for future research.

2. LITERATURE REVIEW

2.1. Introduction

This literature review critically evaluates the body of research on parent carer experiences in advocacy contexts. By doing so, this chapter identifies potential gaps in the literature on parent carer agency and helps fulfil the study's aim of understanding the lived experience of a parent carer of a disabled child while engaging with professionals and their respective institutions. The critical synthesis of current and past literature should reveal the complexities of parent carer agency, providing a substantive rationale for the research question and design as outlined in the proposal (see Appendix 2). The complexity of definitions is discussed in section 2.2, with an additional glossary (see Appendix 11) that contextualises parent carer agency in current research terms. The foundational theory of parent carers' lived experience, based on IPA's philosophical phenomenological origins, as detailed by Smith, Flowers and Larkin (2009, pp. 11–39; 2022, pp. 7–33), is discussed in detail in the methodology review (Chapter 3). The choice of IPA as an approach aligns with the empirical findings discussed in the present chapter (Chapter 2). As will be shown, the need for critical reflection on parent carers' lived experience is particularly pertinent considering the uneven landscape of research for this group.

An overview of the current literature reveals significant gaps in understanding parent carers' lived experience of agency. While there has been a substantial amount of global research on parent carers, the focus has primarily been on the mental and emotional impacts of care, with parents occupying a peripheral position relative to their children (Cameron, 2014, pp. 21–23; Scherer, Verhey & Kuper, 2019; Tebar-Yébana *et al.*, 2024). This marginalisation is compounded by incomplete demographic data, as shown by the ONS (2023) census disability figures for England and Wales, which reveal a statistical blind spot regarding the precise number of parent carers. The modest number of advocacy studies has tended to focus on mothers, overlooking fathers and minority groups (Choe *et al.*, 2023; Ryan & Runswick-Cole, 2008; Todd & Jones, 2003). Here, agency and powerlessness are underlying rather than overt themes, yet they play a vital part in parent carers' experiences of autonomy and choice when negotiating with professionals (Johnson, 2023d, p. 7; Todd & Higgins, 1998, p. 227). More research is therefore needed to fill this research gap, which becomes increasingly evident when examining the methodological approaches used in previous studies.

Current methodological approaches for parent carers have both strengths and limitations, leaving a research gap around questions concerning this group's lived experience of agency. For instance, Clements and Aiello (2021) conducted a mixed-methods study, employing both quantitative and qualitative data, that exemplifies this broader yet less in-depth approach to exploring parent carers' lives (Creswell & Creswell, 2023, pp. 250–254). While this research design can help identify patterns and the scale of an issue – and indeed, Clements' (2024) study on parent carer blame served as a touchstone for this research – it cannot enable the in-depth analysis of IPA found in studies such as the Hunt and Smith (2004) nuanced study of carers of stroke survivors. Therefore, this literature review addresses both epistemological and methodological shortcomings by critically examining parent carers' experiences, particularly focusing on experiences of agency, voice, and choice in professional and institutional interactions. To fully address these gaps and ensure comprehensive coverage of all stages of the research, the following section describes how the review was conducted, including the search strategy, inclusion criteria, and analytical approach used to identify the research gap that informed the original research question.

Literature Review Methodology

The literature review employed a systematic and comprehensive methodology to identify the research gap and justify IPA as a suitable approach for the investigation. The first research strategy began with keyword searches of multiple academic databases, including the university library; Google Scholar; the BSA (2025), to which the researcher belongs; and ResearchGate (2025). A Boolean operator search (Ryan, 2022) followed to further refine and pinpoint the research gap and the research question. The funnelling technique (Ridley, 2012, p. 102) was used to identify broader issues, such as parent carer health impacts related to the care role, which were then narrowed down to the advocacy role and its significance. In addition to searches of peer-reviewed journals, analogue research-note techniques were used (see Appendix 3), guided by the proposals of Ridley (2012) and Hart (2018). Ridley (2012, pp. 27–29) provides guidance on the importance of including the historical and contemporary context of research, and this was incorporated into the current literature review, taking a long-term perspective on the issues faced by this group. The following section, on disability definitions and legislation, clarifies parent carers' position in this social, legal, and research landscape.

2.2. Disability: Definitions and Legislation

The complexity of legal definitions and changing sociological concepts adds to the social care minefield that parent carers must traverse. Key concepts in this study of agency, voice, and lived experience are subject to ongoing academic debate and discussion (see Appendix 11). Additionally, the language used to describe disabilities continues to evolve. This study uses identity-first language, rather than person-first language as originally proposed (see Appendix 2), to reflect the empowering social model of disability, the research aims, and the researcher's view that disability is a social construct (Oliver, 2013). While the social model may represent a forward step in understanding disability, parent carers still occupy a precarious position. Such precariousness is exemplified in current UK legislation, which protects children's rights but leaves parents in a marginal position (*Children Act 1989*; *Children and Families Act 2014*; *Social Services and Well-being [Wales] Act 2014).* While parent carers are responsible for care, as stated in section 97(2) of the *Children and Families Act 2014a*, they do not have protected status under section 4 of the *Equality Act 2010a*. This legislative gap can significantly impact their agency and advocacy efforts when navigating systems as experts by experience (EbE). A glossary of terms (see Appendix 11) at the end of the study provides an easily accessible list of contextual definitions used throughout this study. These definitions further elucidate the position of parent carers in the social and research landscape, as well as the researcher's positionality as a parent carer, which is an integral aspect of IPA.

2.3. Parent Carer of a Disabled Child: Challenges and Responsibilities

Historical Relationship Between Parent Carers and Professionals

Historically, the relationship between parent carers and social, educational, and healthcare professionals has been complicated. In a national survey by the University of York (Beresford, B., 1995, pp. 2–5), only 50% of parent carers reported having had positive experiences with professionals, a figure showing no improvement since the 1970s. This report suggested that these negative interactions were likely due to the dualistic care system, which is grounded in the medical model of disability. Here, professionals, not parents, are the experts who provide essential services and control access to them. This power dynamic can force a parent to reduce or leave employment to care for their child. This in turn can contribute to widespread poverty, as evidenced by a follow-up study by Sloper and Beresford (2006), which found that over half of UK families with a disabled family member were living in poverty. These persistent difficulties testify to the failings of the medical model's expert-centred approach, encouraging a growing recognition that professionals must work in partnership with parents and families to provide support for both the parent and the child (Chambers & Chambers, 2015). The tensions embedded in the parent–professional relationship become especially clear when considering the competing models of disability that parent carers must work within as they care for their children and seek support.

The Medical and Social Models of Disability

The historical dominance of the medical model of disability has led to tensions between parents and professionals. It has contributed to a divide between how disability is discussed and treated: while professionals increasingly adopt language from the social model of disability, their actions often remain entrenched in harmful medical model perspectives (Zaks, 2024, p. 3233). As Lalvani and Polvere (2013) have argued, the medical model views disabled children as a burden to parents, neglecting the broader sociocultural factors shaping society's understanding of disability and reducing the complexity of lived experience to a medical diagnosis. Although the medical field appears to have shifted towards the social model, which sees disability as created by societal barriers and attitudes (Oliver, 2009, pp. 15–18; Sense, 2021), discriminatory practices by social care professionals persist (Clements, 2023). This contradiction between theoretical attitudes and practices is evident in advocacy interactions with parent carers, especially mothers, who embrace a social model of disability when advocating for their children's rights (Ryan & Runswick-Cole, 2008, p. 50). Yet parents continue to face resistance from professionals familiar with more progressive models of disability, perhaps due in part to what Olkin (2022) calls a lack of consistent, measurable data from disabled people on the impacts of the different models. This *model dissonance*, evident in the persistent gap between professional rhetoric and action, creates additional challenges and responsibilities that impact parent carer advocacy and agency.

Interconnectivity of Challenges and Responsibilities

The challenges and responsibilities of being a parent carer are closely intertwined, making the role especially demanding. Increased care duties can lead to feelings of isolation and difficulties participating in social, civic, and employment activities (Carers Trust, 2022; Sellmaier, Stewart & Brennan, 2020). Financial strain from unemployment can add to the anxiety of caring for a disabled child. Such constant stress can impact parent carers' mental health, heightening the risk of anxiety and depression. The stress burden is further compounded by societal stigma. As Ryan and Runswick-Cole (2008, p. 47) observe, parents experience greater strain when witnessing their child being stigmatised. Similarly, Lipkin and Crepeau-Hobson (2022, p. 1546) discuss how ongoing advocacy to challenge harmful stereotypes increases parental stress.

Such stressors and challenges can, in turn, shape parent carers' responsibilities, particularly regarding the quality of care they can provide. Studies show that factors such as location, poverty, and levels of responsibility can create a cycle of declining parental health and inadequate care for a child (Geere *et al.*, 2012, p. 381; Raina *et al.,* 2004). When caring becomes overwhelming, parent carers may struggle to maintain healthy family relationships (Chambers & Chambers, 2015) and find it hard to advocate for their children's needs (Clements & Aiello, 2021). Taken together, these studies provide evidence of how the interconnectedness of challenges and responsibilities creates systemic and personal barriers for parent carers, limiting their advocacy efforts and their sense of agency. Recognising these links is therefore vital for supporting parent carers in their involuntary advocacy role, as discussed below.

Advocacy: An Unsought and Unprotected Role

Parent carer advocacy is often an unsought role, and the expectation to fulfil it can be burdensome (Rossetti *et al*., 2021, p. 451; Todd & Jones, 2003, pp. 230–239). Unlike independent advocacy (Bateman, 2000, p. 18; Johnson, 2023a, b, c), parent carer advocacy is typically informal and unpaid and requires parents to work with healthcare, social services, and schools. UK law gives parent carers limited protection from discrimination (Working Families, 2025). While disabled parent carers are protected under sections 4 and 13 of the *Equality Act 2010a, c,* non-disabled parent carers are only protected *by association* with their disabled child (The Ministry of Justice, 2012). Advocacy support, which helps counter discriminatory practices towards marginalised groups, varies widely across the UK (Mercer & Petty, 2023, p. 26). Statutory advocacy (The Advocacy People, 2024) exists for disabled adult carers who experience substantial difficulty in making decisions, and non-statutory advocacy may be available through charitable organisations (VoiceAbility, 2025). However, eligibility rules for independent advocacy are strict, as per section 67 of the *Care Act 2014b*.

These legal complexities reveal an unfair system that may make it more difficult for parent carers to access support. Furthermore, inequalities are found not only between different groups but also between countries – for instance, Wales and England have different legal frameworks. In Wales, carers have the same rights as those they care for, under sections 19 and 24 of the *Social Services and Well-being [Wales] Act 2014b, c*. As Clements (2018, pp. 32–33) notes, sections 181–183 of the same Act (*Social Services and Well-being [Wales] Act 2014d, e, f*) diverge from English rules by offering a right to statutory advocacy, although this provision has not yet been fully implemented. Nevertheless, Welsh social care policy emphasises 'voice, wellbeing, and co-production' (Social Care Wales 2014, pp. 1–2, 13) as its key principles. This suggests a more inclusive approach to supporting parent carers than in England and may empower parent carers in their advocacy roles. However, as discussed next, the impacts of advocacy can be mixed.

Impact of Advocacy on Parent Carers

Parent carer advocacy, while potentially empowering, can have both positive and negative effects on parental wellbeing. Studies show that parents, particularly mothers, adopt varied advocacy roles – from educating professionals to driving social change through activism (Carers First, 2024; Eley & John, 2023, p. 2; Ryan & Runswick-Cole, 2008, pp. 43–50). Wang *et al.* (2004, pp. 148–149) argue that parent carer advocacy has a dual effect, fostering resilience while also generating stress. Parents must learn coping strategies and expand their peer-advocacy support while also engaging in a struggle for services in a confrontational relationship with professionals. However, these findings contrast with those of other studies (Rios, Aleman-Tovar & Burke, 2021; Scherer, Verhey & Kuper, 2019) that suggest parental advocacy is primarily stressful and adversely impacts health. Despite these challenges, authors agree that parent carers' firsthand experiential knowledge can make a valuable contribution to professional partnerships. These studies demonstrate a complex interplay between advocacy, resilience, and agency, in which positive experiences of advocacy can empower parent carers to tackle future challenges. However, as noted earlier, there is a need for recognition of the potential for advocacy-related stress amongst parent carers, as discussed next.

Parent Carer Advocacy as a Site of Conflict and Resolution

Parent carer advocacy can be a site of conflict or resolution for parents and professionals, who are both working towards ensuring that the rights and needs of a disabled child are met. Various motivations can shape individual views on what is best for a child. While Ryan and Runswick-Cole (2008, p. 48) and Wright and Taylor (2014, p. 592) observe that parents' and families' primary aims are to secure their children's needs, the routes to achieving these aims can be challenging. Parent carers can face barriers to advocacy, including cultural and linguistic obstacles, systemic bias, and intersectional identities (Choe *et al.*, 2023, pp. 133–134), which may lead to misunderstandings and conflicts. Unequal power relations between parents and professionals, as noted by Todd and Higgins (1998, pp. 227–235) and Lipkin and Crepeau-Hobson (2022, p. 1550), are among the primary threats to parent carer advocacy and voice. Parental and family advocacy is particularly important for its protective role against institutional abuse, as demonstrated in cases such as Winterbourne and Whorton Hall (Department of Health, 2012; Murphy, 2020; Walmsley *et al.*, 2017, p. 1367). This research, therefore, emphasises the need to address the power dynamics between parents and professionals, strengthening parent carer agency to benefit parents and safeguard children’s rights, ensuring their needs are met within care systems and society.

2.4. Parent Carers’ Lived Experience of Agency, Voice, and Choice when Engaging with Professionals and Institutions

Agency and Advocacy: Voice and Choice

Like parent carer responsibilities and challenges, the concepts of agency, advocacy, and voice are deeply interconnected and form the basis of effective parental engagement with disability support systems. A sense of agency, expressed through parent carers’ exercise of voice and choice (see Appendix 11), can help to support them and their child’s needs (Coram, 2024; Mentally Healthy Schools, 2025). Understanding *how* these elements connect within parent carers’ lived experience of advocacy is essential to overcoming barriers to agency and creating successful partnerships with professionals. However, although the need for parent and professional collaboration is theoretically recognised, professionals often overlook parent carers’ experiences and expertise and, thereby, reduce their agency (Reeder & Morris, 2021, pp. 110–118; Walmsley *et al*., 2017, p. 1374).

Seen from both structural and personal perspectives, a failure to support the necessary elements of parent carer advocacy can significantly impact this group’s lived experience of advocating for services. For instance, when professionals enable parent carer agency by hearing and acting upon a parent carer’s voice, as in the case of ‘Renata’ in Tirraoro (2014), this leads to meaningful choices and improved outcomes for families. Conversely, undermining parent carer agency by professional bullying and silencing – as illustrated by the case of Renata caring for a child with complex needs

(Tirraoro, 2014) – profoundly impacts parental mental wellbeing and a child's development, as evidenced by Clements and Aiello (2021, p. 32). Recent research has underscored the importance of these interconnected elements, emphasising that voice in parent carer agency is as much about a parent carer being listened to as it is about them speaking out for their child (Clements, 2025; Shropshire Parent and Carer Council, 2025). These findings show that integrating agency, advocacy, voice, and choice can empower parent carers to advocate effectively – while the valued voice of lived experience, as discussed next, is also necessary.

The Voice of Lived Experience

The devaluation of parent carer expertise in education, healthcare, and social care creates a barrier to effective advocacy. This is evident in early intervention when parent carers become 'a voice for children' with SEND who need an EHCP for mainstream or special education (Department for Education, 2012; Guralnick, 2011; Schraml-Block & Ostrosky, 2021, p. 157). Parent carers, as EbEs (see Appendix 11), provide vital firsthand knowledge, especially in healthcare, which theory cannot replicate (Tirraoro, 2014). Institutions undermine this expertise by privileging formal qualifications over lived experience, creating a power imbalance within the 'exosystem' of parental ecological systems (Bronfenbrenner, 1979, p. 25; Guy-Evans, 2024; Todd & Higgins, 1998). When professional judgement overrides parental knowledge, it weakens parent carers' agency and their ability to advocate for their children. Addressing these systemic power imbalances by ensuring parent carers have a voice in their children's care and an understanding of relevant policy that can improve their lived experience is therefore integral to effective advocacy, as discussed in the next section.

The Importance of Lived Experience in Policy and Research

Lived experience has become increasingly valued in influencing policy and research. Researchers argue that incorporating firsthand perspectives creates more responsive and equitable policies (Beresford, P., 2013; McIntosh & Wright, 2018, p. 463). Similarly, Given (2008) notes that lived experience not only informs knowledge but also strengthens individual agency, which is important for parents negotiating complex systems. This study's specific focus on the lived experience of agency is especially relevant to parent carers of disabled children, whose experiences are often invisible within policy frameworks. By centring parent carers' voices – beginning with this single participant study – research can better illuminate how agency, knowledge, and power intersect within lived experience, especially as parent carers advocate for essential services for their child (Ryan & Runswick-Cole, 2008). The scarcity of in-depth research in this area influenced the choice of IPA for this study, an approach well-suited to generating rich data on the lived experience of the complex dynamics of parent carer agency. This research gap is compounded by the statistical invisibility of parent carers, a subject discussed in the next section.

Statistical Invisibility in Research and Policy

Despite growing recognition of the importance of understanding the lived experience of parent carers, this group remains statistically invisible in government records (ONS, 2023). Yet, the number of disabled children is rising across the UK. In England alone, over 1.6 million pupils have SEN, many of whom have disabilities (Department for Education, 2024). In Wales, a recent study revealed that nearly half of children have additional learning needs (ALN; Knight *et al.*, 2022). In Scotland, the number of children with additional special needs (ASN) has reached a record high, with a disproportionate number from low-income areas (Scottish Children's Services Coalition, 2025). Beyond children themselves, recent figures show there are a total of 5.8 million carers in the UK (Carers UK, 2023). However, the absence of disaggregated data specifically for parent carers highlights the need for further data collection to identify and address their distinct needs, enabling greater voice and choice in their children's care. Past and present governments have appeared to recognise the contribution of unpaid carers, with a recent announcement of £22.6 million pledged in technical-innovation support (Department of Health and Social Care, 2024; HM Government, 2008, p. 9). Nevertheless, without specific recognition and targeted support, families may be left struggling to cope (The Challenging Behaviour Foundation, 2022), and parent carers' inability to care for their children could present a broader social problem (Leon-Guerrero, 2019, p. 4). The persistent void of specific data on parent carers not only limits effective policy and practice (Behrend, 2023), but is also mirrored in the research gap, as discussed next.

A Gap in Research

During research for this dissertation, it has become apparent that the statistical oversight and lack of parent carer data are evident in both quantitative research and qualitative studies. Studies on the lived experiences of parent carers are considerably fewer than on parental advocacy, with most focusing solely on the caring aspect. For example, a recent phenomenological study by Cook, Tovin and Kenyon (2022, p. 1) examined the lived experience of caring for a child with cerebral palsy. Similarly, research exploring the lived experience of agency is limited, with the Bergström *et al.* (2014) study of stroke survivors being one of the few examples. Notably, no studies appear to have focused specifically on the agency of parent carers. Yet, the interrelated concepts of agency, voice, and choice are intrinsic to parent carer advocacy because they influence both a parent's sense of control and overall wellbeing. Although agency is a well-established sociological concept (see Appendix 11), it is often only referenced implicitly in studies of parent carers and typically framed within the parent-to-professional power dynamic (Clements, 2018; Szlamka *et al.,* 2022). The scarcity of qualitative research on the lived experience of parent carers, especially concerning agency in advocacy contexts, underlines the need for this study. To meet that need, IPA is used to best explore how parent carers experience their lack of agency within the parent–professional relationship. The enactment of agency within those authority-influenced relations will be discussed in Chapter 4 from a social justice perspective.

2.5. Conclusion

This chapter highlights significant changes in parent carer advocacy. Once seen as a barrier to children's agency (Walmsley *et al*., 2017, p. 1371), parent carer advocacy is now recognised as essential for the welfare of both the child and their family and has transformed systemic advocacy (Rossetti *et al*., 2021, p. 432; Wright & Taylor, 2014, p. 594). However, parent carers still face challenges when advocating with professionals. Their lack of agency is tied to their dual role, which involves meeting their children's needs while trying to maintain influence in decision-making. Despite being one of the most economically disadvantaged groups in the UK (Clements & Aiello, 2021), parent carers remain statistically invisible. Like their children, parent carers are part of a disability community described by Behrend (2023) as an 'invisible minority' that receives insufficient research attention or meaningful input in policy discussions.

The invisibility of parent carers is further complicated by the intricate connection between responsibilities, challenges, agency, voice, and choice in their lived experience. The study of lived experience offers significant insights for effective advocacy and collaborative practice involving parental carers and professionals (Bebbington, 2024). Therefore, this study aims to address this research gap using an IPA approach that concretises a parent carer's lived experience as an inescapable, socially shaping 'being-in-the-world' (Heidegger, 2010, pp. 52–62). The addition of a voice and choice empowerment-focused social justice lens for the IPA analysis is motivated by the researcher's lived experience and desire to rectify societal inequalities (Dorling, 2010; 2015). The next chapter demonstrates the suitability of IPA for exploring the lived experience of agency for a parent carer when advocating for their child.

3. METHODOLOGY REVIEW

3.1. Introduction

Using IPA and visual elicitation, this study aims to explore a parent carer's lived experience of agency when advocating for their disabled child while engaging with institutions and professionals (Pink, 2021; Smith, Flowers & Larkin, 2009; 2022). The research question and objectives were defined by identifying the problem of parent carers lacking agency in their advocacy role and the absence of research in this area, as highlighted in the literature review (Chapter 2). IPA is a qualitative research method best suited to understanding the lived experience of a phenomenon and is, therefore, ideal for the context of this study, as discussed in section 3.2. Section 3.3 justifies IPA by showing how it aligns with the researcher's interpretivist paradigmatic stance and lived experience, valuing firsthand knowledge from both the researcher and the participant. The methods used, including an in-person interview combined with visual elicitation, are discussed in section 3.4. The use of a research diary for reflexivity is explained in section 3.5. Additionally, the importance of ethical considerations is highlighted in sections 3.6 and 3.7, serving as indicators of trustworthiness and quality. The analysis of the data is detailed in section 3.8. The concluding section, 3.9, emphasises IPA's research alignment (Ridley, 2012, p. 106), explaining how each phase is designed to answer the research question.

3.2. Context of Study

The choice of IPA as an approach stems from the social-contextual difficulties encountered by parent carers as they navigate complex systems while advocating for their children's wellbeing and rights (Reeder & Morris, 2021). The suppression of parent carers' voice and choice, critically examined in the literature review, is most evident in the pervasive experiences of systemic blame directed at parent carers – a form of discrimination underscored by the work of Cerebra (2024) and Clements (2024). While parliament has acknowledged the urgent need to address this systemic discrimination (Clements & Aiello, 2021, p. 2), an NHS England-commissioned report (ADASS, 2024) highlights ongoing communication hurdles between parent carers and health and social care professionals. These contextual factors underscore the need for a flexible IPA approach to articulate the complex and nuanced nature of a parent carer's interactions with professionals and institutions, while simultaneously amplifying the parent's voice, allowing for choice in the co-productive design, and fostering effective communication within the research framework.

The macro-level view of parent carer challenges and their impacts is also manifest at the micro-level. Research discussed in the literature review has shown that advocacy can be both positive and negative, with Wang *et al.* (2004, p. 152) calling parental advocacy 'a two-edged sword' that can both strengthen and weaken coping skills. Similarly, Wright and Taylor (2014, p. 594) note the adversarial aspect as a potential stressor, while the fear of blame, as highlighted by Clements and Aiello (2021), can reduce the capacity for effective advocacy. Rossetti *et al.* (2021, pp. 438–439) observe that advocacy as an obligation can disadvantage some parents, and this becomes overwhelming when advocacy turns into a battlefield. These findings underscore the need to understand the nuanced agential aspects of a parent carer's lived experience of advocacy within the parent–professional relationship.

3.3. Justification for Methodology

IPA was selected as the methodology because it aligned with the researcher's interpretivist-constructivist 'worldview', a term coined by Guba and Lincoln (1994, p. 107) to describe the ontological, epistemological, and axiological researcher beliefs that form a research paradigm. An interpretivist paradigm acknowledges that multiple realities exist and are shaped by individual experiences. This worldview positions reality as subjective and co-constructed, reflecting the researcher's ontological outlook. Epistemologically, IPA views knowledge as emerging through the interpretation of lived experience, with a constructivist element in the co-production of meaning by the researcher and the participant. Axiologically, this stance recognises that research is never value-free. The researcher approaches the process with integrity and compassion, valuing the knowledge participants bring through their lived experience.

The aforementioned philosophical worldview not only shaped the study's methodology but also connects with the researcher's position as both an academic and a parent carer, as stated in the research diary (see Appendix 4). The impetus for this study, to explore the lives of other parent carers and close the research gap on agency, arose directly from this dual perspective. Lived experience is not only foundational to parent carer advocacy (Bebbington, 2024), but when recognised as a valuable form of insight, it can increase understanding of agency within the advocacy relationship. As noted in section 2.4 of the literature review, a lack of agency is a barrier to effective advocacy, which is further complicated by the parent carer role. Therefore, to understand the complexity of this experience, IPA, with its core concept of the 'double hermeneutic' (Smith & Nizza, 2022, p. 8), can be extended to include the 'intersubjectivity' (Beyer, 2022; Husserl, 1982, p. 30; Smith, Flowers & Larkin, 2009, pp. 35–36, 80; 2022, p. 29) within the parent and child relationship. By exploring the lived experience of parent carer agency using IPA with an additional social justice lens, this study enables a deeper understanding of how advocacy is experienced in real life, thus helping to identify factors that can improve it, in line with the study's objectives. The philosophical foundation of IPA and its influence on the research design are further discussed in the next section.

IPA's Philosophical Context

As previously stated, IPA is situated within an interpretivist research framework with constructivist elements, which focus on subjective human experiences, meaning-making, and social phenomena (Lincoln, Lynham & Guba, 2024, p. 81). Grounded in phenomenological, hermeneutical, and idiographic principles, IPA examines the detailed meaning-making of lived experience (Pietkiewicz & Smith, 2014, pp. 361–363; Smith & Nizza, 2022, pp. 6–10). In stark contrast to other perspectives, such as the structural Marxism of Althusser (2006; Johnson, 2024), which views individual choices as constrained by socioeconomic factors, phenomenology recognises a parent carer's ability to choose within their context, extending beyond mere freedom (Coole, 2005). This distinction highlights that parent carers can actively interpret their experiences rather than merely react to structural constraints.

In IPA, therefore, both the researcher *and* participant are empowered, active agents that contribute to knowledge co-production (Flick, 2023, p. 29; Smith, Flowers & Larkin, 2022, pp. 119–120). The co-production of knowledge embeds the notion of praxis (Freire, 2017, p. 52) in the research design, as reflected upon in the research diary in section 3.5. IPA more effectively exemplifies and promotes collaborative and anti-oppressive practice (Dalrymple & Burke, 2006) than extensive, quantitative, and positivist-focused research. The systemic structure and agency aspects of a parent carer's lived experience are accommodated by the addition of a social justice lens, a diverse area (Capeheart & Milovanovic, 2007, p. 1) that works well with IPA while allowing for emergent themes. Thus, the philosophical basis of IPA, with its reflexive and flexible approach addressing agency and structure within parent carers' lived experience, guided the choice of design and methods, discussed below.

Parent Carer Research Methods

The studies outlined in the literature review, including the mixed-methods report by Clements and Aiello (2021, pp. 23–24) and the systematic review by ADASS (2024), reflect common themes on the experiences of parent carers. These studies employ medium-to-large-scale research designs and may use either qualitative or quantitative methods. 'Mixed-methods' research (Creswell & Creswell, 2023, pp. 18; 231) integrates both types of data and can assess the scale and complexity of a social issue. Quantitative research frequently combines numerical data with statistical analysis to measure objective truths (Newby, 2014, pp. 47–48). Systematic reviews, for example, use quantitative methods and are considered reliable by researchers, providing, as Peričić and Tanveer (2019) and Ridley (2012, pp. 188–190) concur, a helpful overview of the topic that can identify gaps in understanding and inform policy. Similarly, a meta-analysis (Ridley, 2012, pp. 102–194) can be valuable for synthesising multiple studies as part of a systematic review, but these types of large-scale studies require a significant input of resources beyond the scope of this study.

Although quantitative and qualitative research have their place, they serve different purposes. Quantitative research tends to focus on numerical data and statistical analysis, while qualitative studies, such as IPA, generate rich descriptions and individual experiences. Mixed-methods research attempts to bridge these two approaches. However, as Teddlie and Tashakkori (2011, p. 295) point out, researchers must be competent in both methodologies to apply this type of design effectively. Therefore, a single-participant pilot IPA study was chosen, allowing for both practical and theoretical considerations while laying the groundwork for a broader analysis. Although Newby (2014, p. 56) notes the limitations of a single case study for transferability, setting clear boundaries in purpose and scope at the proposal stage (see Appendix 2) helped to address these concerns. As IPA authors Smith and Nizza (2022, p. 15) argue, this approach, even with a single case, can still provide valuable and in-depth insights into the chosen subject matter. These points qualify the use of IPA for this study. The next section will explore its strengths and limitations in more detail.

Strengths and Limitations of IPA

IPA enables a concrete exploration of agency as a lived experience for parent carers. While phenomenology emphasises the value of lived experience, its meaning and suitability for research have been questioned by some critics. For example, Paley (2017, p. 121) has challenged IPA founders Smith, Flowers and Larkin (2009; 2022) for claiming that the approach can derive meaning from text without *a priori* knowledge or theoretical preconceptions. As Finlay (2009, p. 13) argues, all researchers bring some subjectivity into their studies. However, this subjectivity can be constructively applied, particularly through the interpretative role of the researcher in IPA. Husserl (1982, p. 10; 2023, p. 63) proposes the concepts of 'bracketing' and 'epoché', which can help the researcher to suspend their own preconceptions (Moran & Cohen, 2012, p. 52), without denying their existence. Nevertheless, the critique shared by Paley (2017) provides a helpful benchmark for assessing trustworthiness, and his work has influenced the design of this study, as discussed in the next section.

Several approaches were considered for this study, including narrative analysis, which offers potential for understanding life experiences, and thematic analysis, which, like IPA, identifies patterns and records themes in participants' responses (Newby, 2014, p. 484). Various methods under the heading of IPA were also examined, as IPA can be part of mixed-methods research. However, the scope of this pilot study (In, 2017) meant that IPA would be the most appropriate approach, focused on the particular and the whole, with the experiential themes forming the basis for 'cross-case analysis' (Smith, Flowers & Larkin, 2022, pp. 76, 100–104) for the doctoral dissertation. While the method of Van Manen (2014; 2016) can seem vague (Paley, 2017, p. 66; Peoples, 2021, pp. 118–119), his use of metaphor is valuable in sense-making for this study, as demonstrated in the data-analysis section (3.8). Although IPA's specificity and subjectivity may limit the generalisability of the research findings to other contexts or populations (Flick, 2023, p. 548), its main strength lies in what Peoples (2021, p. 117) terms its 'hybridity', making it uniquely suited to uncovering the sense-making processes of parent carer agency in everyday lived experience.

3.4. Interviewing/IPA

Methodological, ethical, and practical concerns informed the interview, which was supplemented by visual elicitation. The choice of location was informed by the ethical guidance of Clark *et al.* (2021, p. 117) on minimising harm to both the participant and researcher. Hence, both parties agreed on the interview venue – a civic building meeting room – as a safe and convenient space (see Appendices 1, p. 16; 2, p. 11). Reflecting the co-productive principles of this research (Smith, Flowers & Larkin, 2022, p. 130), the participant chose her pseudonym ('Charlotte'), and she is referred to in this way in the results and discussion (Chapter 4). She was given an informed consent and right of withdrawal form and the interview guide (see Appendices 5 and 6) beforehand, as recommended by Clark *et al.* (2021, p. 428) for semi-structured interviews and novice IPA researchers. A semi-structured interview lasting 2–3 hours (Smith, Flowers & Larkin, 2009, pp. 56–78; 2022, pp. 53–73) was the primary data method. The interview questions were open and progressed from general to specific, as recommended by Smith, Flowers and Larkin (2009, pp. 79–107; 2022, pp. 75–108). However, in line with the Paley (2017, p. 128) critique of IPA interviews, the questions were kept clear and specific to avoid causing the participant anxiety.

To supplement the interview, a fresh adaptation of the 'photo-elicitation' method proposed by Collier (1957; Pink, 2021, p. 109) was used as a visual elicitation technique (VET), inspired by the researcher's background in art as an expression of human experience. The participant was asked to bring their child's artwork to the interview, thereby extending the 'double hermeneutic' (Smith, Flowers & Larkin, 2022, p. 29) of sense-making between researcher and participant to also include the parent-child relationship. The researcher interpreted the participant's experiences through the world shared with their child, expressed through the creative medium of art. In an exercise of parental agency, the participant also brought their child's soft toy, which yielded richer insights than would have been gained through an interview alone. Although Pink (2021, p. 110) has raised concerns that the use of the word 'elicitation' is not in the spirit of co-production, the participant was given the option to change it, but declined, thus affirming her agency. These combined data-collection methods formed part of the interview and were guided by the study's aim to uncover rich details of a parent carer's lived experience when advocating for their child.

3.5. Research Diary

A research diary is an essential component of IPA analysis (Smith, Flowers & Larkin, 2009, p. 57; 2022, p. 54), serving both methodological and practical purposes. This aligns with the researcher's interpretivist view, exemplified by Lincoln, Lynham and Guba (2011, p. 103), of researchers co-constructing knowledge through their lived experience. It also facilitates IPA's 'double hermeneutic' (Smith, Flowers & Larkin, 2009, pp. 35–36; 2022, p. 29), a central component of this approach's interpretive process, which occurs between the researcher and participant during interpretation – with the researcher focusing on the participant, who concentrates on making sense of their own experience. The researcher maintained a diary of thoughts and feelings that contributed to the analysis and results. However, care was taken not to focus overly on the self to the detriment of the participant's voice, as per the guidance from Gubrium (2025) on the pitfalls of diary-keeping. Instead, the diary was used for 'enhancing ethical and methodological rigour' (Smith, 1999, p. 359) through reflexivity and transparency, while uncovering facets of lived experience.

The research diary also added practical research insights. These included notes from the member check (see Appendix 4), particularly the participant's feedback about needing more breaks during the interview, which will be incorporated into the doctoral study design. This approach therefore may not only enhance the wellbeing of both participants and researchers but also yield richer data through stronger rapport. The research diary thus formed a useful practical and theoretical tool, its reflexive nature assisting ethical considerations, as discussed next.

3.6. Ethics

The study adhered to strict ethical guidelines throughout, guided by the ethical policies of the university (University of Wales Trinity Saint David, 2022) and the BSA (2025), of which the researcher is a member. Ethical approval (see Appendix 1) was granted before data collection commenced, as described in section 3.4. Informed consent (Kumar, 2014, p. 285; Smith, Flowers & Larkin, 2009, pp. 53–54; 2022, pp. 48–50) was obtained from the participant before the interview began, and the study's purpose, risks, and benefits were explained, as well as their right to withdraw from the study (see Appendix 5). The methods employed, such as keeping a research diary, promoted reflection and care. The researcher recognises the responsibility that feminist authors Kitzinger and Wilkinson (1996, pp. 1–32) refer to as 'representing the other'.

Maintaining participant confidentiality was therefore an ethical priority throughout the research process. Responsible information handling was ensured, with an emphasis on secure data handling and data anonymisation, including the removal of locations and third-party identification (Clark *et al.*, 2021, p. 124). The participant understood how their data would be used and stored, in accordance with Chapter 29 of the Act (*Data Protection Act 2018*) and ICO (2022) guidelines. As mentioned in section 3.4, 'Charlotte' is a pseudonym used to protect the participant's identity. After the analysis was completed, work samples were sent to the supervisor for comments as a 'mini audit' (Smith, Flowers & Larkin, 2022, p. 153). IPA's qualitative and co-productive design is exemplified in the sampling technique detailed below.

Sampling, Ethics, and Academic Rigour

Sampling is essential to academic design and rigour (Omona, 2013), forming a bridge between ethics and trustworthiness, and it differs in quantitative and qualitative research. This study used non-probability purposive sampling (Creswell & Creswell, 2023, p. 198), reflecting the research aims and approach. Although the initial proposal (see Appendix 2) suggested multiple participants, the pilot study uses a single participant in line with its pilot nature and IPA's idiographic focus. Accordingly, a parent carer of a disabled child who regularly engages with professionals and institutions as part of their role, was identified through a local charity, the West Sussex Parent Carer Forum (WSPCF, 2024). The ethical considerations of the sampling technique were addressed in the proposal form and further elaborated upon in the ethics form (see Appendices 1 and 2). The primary ethical principle of avoiding harm informed this study (Smith, Flowers and Larkin, 2022, pp. 47–50), including consideration of both personal and systemic risks to the university's reputation (see Appendix 1, p. 12). Ethics are integral to trustworthiness, a relationship implicitly reflected in the next section's focus on integrity and rigour.

3.7. Trustworthiness

Trustworthiness in research pertains to the integrity and quality of the design, its process, and its findings. As an overall criterion, trust reflects how credible, reliable, and transparent the research methods are, as well as how the issue of bias has been addressed, depending on the research framework (Flick, 2023, p. 497). In quantitative research, trustworthiness is directly derived from validity, which involves the accurate measurement and reporting of findings. In contrast, reliability pertains to the consistency and repeatability of the study, ensuring that similar results are obtained under the same conditions (Flick, 2023, p. 552). Qualitative research authors (Denzin & Lincoln, 2000, p. 22; Lincoln & Guba, 1985, p. 43; Lincoln, Lynham & Guba, 2011, p. 108) have long suggested that ‘credibility, transferability, dependability, and confirmability’ should be employed as quality indicators of trustworthiness within an interpretivist paradigm. The appropriate criteria for trustworthiness are contingent upon the research paradigm and study objectives (Newby, 2014, p. 96; Pietkiewicz & Smith, 2014). Consequently, for an IPA study of lived experience, qualitative criteria were used as indicators of quality. To demonstrate the trustworthiness of this study, the similarities between qualitative and quantitative criteria are compared below.

Credibility, which in qualitative research is similar to internal validity in quantitative research (Flick, 2023, p. 546), asks whether the findings accurately represent the participants’ experiences. In this study, credibility was achieved through multiple data-point-triangulation techniques of visual elicitation (described in section 3.4), co-participatory member checking of the results with the participant, supervisory checks in place of ‘peer debriefing’ (Delve & Limpaecher, 2023a; Smith, Flowers & Larkin, 2022, p. 153), and thick description in the data analysis (section 3.8). Transferability, like external validity, refers to the applicability of findings to other contexts and is achieved through detailed descriptions of how the research design addresses the research question.

Dependability, akin to quantitative reliability, was demonstrated by maintaining an audit trail with one-to-one university supervision (Flick, 2023, p. 552). Confirmability, which parallels quantitative objectivity, was addressed using a research diary (see Appendix 4), which helped to mitigate bias by facilitating documented reflexivity (Kumar, 2014, p. 287). Although a research diary does not constitute triangulation as visual elicitation does, it is essential for reflexivity (Delve & Limpaecher, 2023b; Nadin & Cassell, 2006; Smith, Flowers & Larkin, 2009, p. 57; 2022, p. 54). Thus, the researcher's lived experience positionality was articulated early in the research phase in the diary and proposal (see Appendices 2 and 4), thereby enhancing validity according to Creswell and Creswell (2023, pp. 213–214). While the terminology for trustworthiness differs between quantitative and qualitative research, the goal of integrity and rigour remains the same and informs every stage of a study, including data analysis, discussed next.

3.8. Thematic Analysis

There is no single right way to do IPA, but – as authors Smith, Flowers and Larkin (2009, pp. 57–9, 60, 181; 2022, p. 119) emphasise – it is an inductive rather than deductive process that should be 'iterative, idiographic, interpretative and in-depth'. It should also be noted that key IPA terms have changed (Smith, Flowers & Larkin, 2009; 2022, p. 76), and that the most recent terminology will be used in the results section of Chapter 4. Two copies of the verbatim audio transcription were printed (University Transcription Services, 2020) and anonymised, as per sections 3.6 and 3.7, to ensure that the qualitative findings were ethical and trustworthy. Although the recording was not hand-transcribed, familiarity with the data was gained through repeated listening to the interview and by noting hesitations and non-verbal cues. Following a range of IPA guidance, colour-coded, exploratory first-impression notes – categorised as 'descriptive, linguistic and conceptual' (Smith, Flowers & Larkin, 2009, p. 84; 2022, pp. 79–81; Wilde, 2021) – were made on the right side of the margins by the researcher before moving to the next stage.

During the next step of analysis, experiential statements with a deeper level of interpretation were noted in the left-hand margins (see Appendix 7). On the second copy of the transcript, the experiential statements were cut out, separated, and laid out to identify conceptual connections (Smith, Flowers & Larkin, 2022, pp. 88–93). Once the themes were clustered and analysed again, with the researcher repeatedly listening to the audio throughout this process, PETS were placed on a table (see Appendix 8). Data analysis of the interview text was strengthened by triangulation using the VETs of the participant's child's artwork and soft toy (see Appendix 9; Clark *et al.*, 2021, p. 364; Delve & Limpaecher, 2023a; Pink, 2021). Simple numeration (see Appendix 10; Databasic.io, 2025), noting the frequency of words that the participant attached significance to in the interview, was added to the table's final column (see Appendix 8). To enhance the quality of analysis, extracts of the anonymised data were sent to the study supervisor, as recommended by Smith, Flowers and Larkin (2022, p. 75) for an audit. This ensured that each of the analysis steps was clearly documented for transparency and trustworthiness.

Following the previously described quality-assurance measures, the researcher adopted a reflexive stance towards the study. This reflexivity was achieved by 'bracketing' assumptions, as advised by Smith, Flowers and Larkin (2009, p. 99) and Van Manen (2014, p. 27; 2016, p. 175). In practice, this approach involved writing down thoughts and feelings about the analysis and findings in a research diary, some extracts of which were shared with the supervisor (see Appendix 4). The write-up of the findings in the results and discussion (Chapter 4) follows the guidelines set by Smith, Flowers and Larkin (2022, pp. 109–118), while also seeking to advance this approach through the innovative application of the VETs. According to Smith, Flowers and Larkin (2009, p. 196; 2022, pp. 140–141), IPA's flexibility enables it to effectively incorporate additional perspectives. Therefore, a social justice perspective was applied to the data in the discussion (section 4.8) to better achieve the study's aim of a broader understanding of a parent carer's lived experience of agency.

3.9. Conclusion

This chapter detailed and analysed the IPA approach combined with visual elicitation to explore the lived experience of a parent carer advocating for their child while engaging with professionals and institutions. The research aims and questions were reiterated in the introduction (section 3.1). Section 3.2 then discussed the study context, emphasising the importance of a parent carer's multidimensional role for their children and the problem of their lacking agency. A literature methodology was included in this section to demonstrate how the issue was identified. The choice of a qualitative, subjective, and nuanced agentic approach, as outlined in IPA, was justified in section 3.3. (Larkin, Watts & Clifton, 2006). IPA's strengths and limitations were analysed, and the criticisms set forth by Paley (2017) were acknowledged and incorporated to ensure transparency and rigour. The integration of VETs (see Appendix 11) into the IPA framework, as discussed in section 3.4, provided a richer understanding of the lived experience under study. Furthermore, as will be seen in the following section, the participant's introduction of an unsolicited object yielded a more nuanced and meaningful response.

The use of a research diary enhanced reflexivity and addressed possible bias, as discussed in section 3.5. Similarly, the ethical considerations discussed in section 3.6, concerned the importance of informed consent and data management and ensured the integrity of the research. Trustworthiness, as emphasised in section 3.7, is vital for academic integrity and, with well-considered and transparent research practices, qualitative research can be just as rigorous as quantitative research. The significance of integrous practices embedded in the research design was discussed in the data analysis section 3.8, particularly concerning member checking post-interview and a supervisory audit. The member check was necessary for maintaining the co-production of knowledge and ensuring the participant's wellbeing. Finally, section 3.8 described the process of IPA data analysis and the identification of emerging themes (Smith, Flowers & Larkin, 2009, p. 99; 2022, p. 116). The following chapter uses IPA to analyse the data and apply an appropriate social justice lens to the results, thereby deepening understanding of the lived experience of parent carer agency when advocating for a disabled child. This critical perspective helps this study reach its goal of changing policy and improving professional practice.

4. RESULTS AND DISCUSSION

4.1. Introduction

Following the data analysis process set out in the previous chapter, this chapter presents the results. A profile of the participant is outlined in section 4.2, giving context to the analysis. From sections 4.3 to 4.6, the findings of the IPA are organised into four main personal experiential themes (PETS), with additional subthemes. The present tense is used here to convey immediacy and the ongoing relevance of the participant's words, following IPA conventions (Smith, Flowers & Larkin, 2022, pp. 109–118), while the past tense describes specific actions or moments in the interview. This approach strikes a balance between analytical interpretation and narrative context. An IPA summary is completed for each PET and included in section 4.6. This chapter uses phenomenology to explore the participant's lived experience and promotes a social justice perspective by integrating multiple viewpoints for nuanced insights. The essence of the results is illustrated in a visual representation of the participant's lived experience in the concluding section 4.7. Because this is a single-case study, it does not include group experiential themes (GETs). Nonetheless, the case remains valuable both independently and for subsequent research (Smith, Flowers & Larkin, 2022, pp. 25–26, 99).

4.2. Profile of Participant

Charlotte is a parent carer of a physically impaired child with a condition defined as a disability under section 6 of the Act (*Equality Act 2010b)*. The child is under seven years old and has an EHCP in place. Charlotte is married, and her partner lives with her. They have other children living at home, including non-disabled children.

4.3. Personal Experiential Theme 1

THE SPECIALNESS OF THE BOND BETWEEN A PARENT CARER AND CHILD

a. Parent carer and child's interconnectedness

The bond between parent carer and child – and the specialness and strength of this bond – are clear in Charlotte's descriptions. The interconnectedness – that is, the mutual shaping of their experience – is articulated in several ways. First, this is demonstrated through the VET method of using Charlotte's child's artwork (see Appendix 9) to uncover meaning. Charlotte said that the 'Family of Pixies' in her child's paintings represented their family and seemed pleased that the researcher picked up on it:

> *The drawings show me when she's upset, the drawings and the paintings that she does are a reflection of how she's feeling on that day… Sometimes we talk about certain different topics… Then I'll pick up on that with the colours that she uses. If they're bright colours, that means she's happy. If it's dull or dark colours, that indicates she's sad. Or she will draw emoji faces with teardrops or sad faces* (p. 2, lines 18–25).

As part of VETs, Charlotte also brought in her child's unicorn toy, which she held and stroked throughout the interview as if it were her child, saying, '*But the teddy bear, it represents comfort… when I touch it… I think of her*' (p. 64, lines 1829–1830). The toy has become a shared world of safety to Charlotte, a '*high-level safe space, but within a teddy bear, if that makes sense*' (p. 64, lines 1839–1840). Charlotte closely identifies with her child's world and her suffering and uses metaphor to try to understand her own childlike need to escape her everyday world.

The specialness of the relationship between a parent carer and their child is expressed in the interconnectedness of their relationship, as highlighted by Charlotte's allegorical descriptions of a nightmarish world that she and her child entered through 'the door' of disability and advocacy. In this new and unfamiliar world, Charlotte feels her child's pain in the hospital and uses the idiomatic phrase for suffocation to describe it: '*I could see my child cry… it's like taking a fish out of water… it's going to gasp for air*' (p. 7, lines 155–157). Charlotte and her child's emotions become one in their shared powerlessness, as shown in her admission that '*I do feel helpless at times, powerless… like I'm not in control… of my child's wellbeing*' (p. 16, lines 417–419).

Throughout the interview journey, aided by the VET items, Charlotte reflects on her position of shared agony as a parent carer in relation to her child. She does this using metaphor to make sense of what she and her child have experienced. Her lived experience of parenting as a dualistic role, providing care and advocacy, is characterised by her need to escape the emotional and psychological pain of dealing with professionals. She also feels a need for control over her everyday life, heightened by the vulnerability of having a disabled child.

b. Parent carer and child's experiences: Us against the world

Charlotte views the interconnected challenges facing her and her child as leading to a nightmare world, which she describes as being led '*through a dark passage and you want someone to hold your hand and take you through, you're scared*' (p. 35, lines 994–996). Charlotte's childlike vulnerability contrasts with her view of herself as an adult parent and heroic protector in the nightmare, which she sees as specific to her role and gender: '*To protect… like a mother would… protect her child, from these monsters*'

(p. 19, lines 520–521). However, Charlotte's view of professionals varies at times, with one professional described in reverential terms when Charlotte said the family '*were blessed with her*' (p. 34, line 948). Nevertheless, Charlotte's overriding perception of institutions and professionals when advocating is that they are a single threatening entity, as shown by her explanation of their behaviour: '*They did all that because they had the backing of another professional body*' (p. 14, lines 381–382).

c. Self is part of the whole: Mutual dependency

Charlotte's enmeshed identity with her child amplifies her need to protect her child from external and hostile forces by becoming her child's comfort blanket: '*When I wrap my arms around... I know I can protect her. I keep her safe*' (p. 40, lines 1147–1148). The weight of this parental responsibility is shown in Charlotte's repeated use of the word 'toll', as in, '*It took a toll on my own marriage. It took a toll on the rest of the kids*' (p. 37, lines 1052–1053). Charlotte's sense of herself is intertwined with that of her children and her efforts to protect them. She repeatedly uses the word 'fear' while holding the unicorn toy and says, '*It's that fear, the fear of... losing your kids, losing yourself even, in this process*' (p. 13, lines 329–330). Charlotte's fearful language thus reveals how her encounter with professional views of disability through her bond with her child poses an existential threat to her sense of self.

IPA Summary:

For Charlotte, the close bond between parent and child (Popov & Ilesanmi, 2015) defines their relationship. Husserl's (1982, p. 30; 2001, p. 107; Smith, 2024) concepts of 'intentionality' – the idea that consciousness is always about something – and 'intersubjectivity' or shared meaning-making are reflected in Charlotte's interpretation of her child's artwork: bright yellow symbolises happiness, while dark blue represents sadness (see Appendix 9). Charlotte's parenting journey soon becomes a nightmare, leaving her feeling lost in the woods. Sharing her child's perspective, she uses universally understood fairytale symbolism, in the way described by Tatar (2015, pp. 5–7), to make sense of emotional conflict. From the Merleau-Pontian (1962, p. 213) perspective, Charlotte feels her child's pain as her own, and her child perceives the family's pain, with both being 'fishes out of water' in this unfamiliar world. To Charlotte, the toy represents her child and their shared magical world of escape. Her repeated phrase 'bodies/professional body' (see Appendix 8, cell 10G) implies a broader personification of the institution, contrasting with its depersonalised professional members, whom Charlotte perceives as either monsters or angels in her and her child's shared lifeworld.

4.4. Personal Experiential Theme 2

THE ADVOCACY JOURNEY: BATTLING FOR VOICE AND KNOWING

a. Advocacy as a battle: For voice, knowing and self

Charlotte views her parent carer advocacy as transforming from a nightmarish journey through a forest into a battlefield. For her, the advocacy battle is '*scarring… because it's so vivid, it's like you've been raped… it's that severe*' (p. 63, lines 1795–1796). Charlotte's sense of her and her family being attacked by professionals is shown in this simile of violation and in her repeated use of the word 'horrific' when referring to her experiences (see Appendix 8, cell 16G). Charlotte feels compelled to be the voice of her child, who '*doesn't have a voice*' (p. 8, line 197). However, fear of blame is always present when using her voice to raise concerns, with Charlotte insisting that '*speaking up… causes problems as well. They [professionals] do not like awkward parents*' (p.

15, lines 395–396). Charlotte's fear of professionals is heightened by a greater fear that society will see her as a bad parent for speaking out. This fear is expressed in words: '*It's how society looks at you*' (p. 63, line 1804). Closely linked to voice as an experience of being heard is 'knowing' as knowledge and understanding, with Charlotte's view that '*Professionals don't listen because they think they know more*' (p. 6, lines 141–142). Charlotte mimics the knowing professional voice as an assertion of power at times: '*They said, "We know better, because we are the professionals"*' (p. 6, lines 141–142). She challenges this 'knowledge to power' by asserting her EbE parent carer status: '*I may not have the qualifications, but I do know my child*' (p. 6, lines 145–146).

b. Advocacy, knowledge and empowerment

Charlotte experiences advocacy not only as a battlefield but also as a series of necessary, though often painful, phases of becoming knowledgeable and gaining power. She describes her feeling of being '*disempowered*' (p. 41, lines 1169–1170) when at the hospital with her child as a necessary part of the advocacy journey's '*phases… this is why it's called lived experience*' (p. 41, lines 1172–1174). The word 'knowing' is mentioned frequently throughout the interview (see Appendix 10), and it is used in terms of enabling both voice, as discussed in the previous section, and self-growth through the acquisition of knowledge. Charlotte recognises the value of exchanging knowledge with other parent carers to learn and grow, as shown when she says: '*I learned most of my stuff through the other people, really, through their lived experiences*' (p. 51, lines 1467–1468).

c. Advocacy as a transformative journey

Charlotte perceives herself as changing in a way that mirrors the phases of human development (McMahon, 2016), beginning as a newborn baby, exemplified in her admission: '*And it's like coming out in the world*' (p. 6, line 130). This sense of innocent wonderment is compounded by the way she refers to her development as an advocate, saying, '*I was very naïve to all of this*' (p. 44, line 1247). Charlotte extends the newborn baby simile to incorporate that of a toddler when she says, '*And you know the first time the training wheels come off [when] you're on your bike*' (p. 6, lines 130–131). Charlotte's awareness of gaining advocacy knowledge brings about a sense of resilience, shown by her affirmation that '*Going forth… it's made me a stronger person*' (p. 59, line 1677). Moreover, Charlotte is aware that her advocacy journey has transformed her and her family's sense of self from ordinary to extraordinary: at the start, she says, they '*didn't know anything… like a regular Joe Bloggs*' (p. 50, lines 1436–1438). This awakening of knowledge and self-awareness brings a personal cost, leaving Charlotte feeling disillusioned with the professionals and institutions that she once thought of as '*superheroes*' (p. 50, line 441), of whom she long had '*high hopes*' (p. 4, lines 58–59; p. 10, line 246). Charlotte's bittersweet comment, '*We are all human*' (p. 54, lines 1558–1559), reflects her sadness and her deeper understanding of the humanness of those, at times, 'monstrous' individuals who act as barriers to advocacy.

<u>IPA Summary:</u>

Charlotte makes sense of advocacy as a battle and a journey in which she is the wounded warrior with invisible scars who must win the fight to protect her child's person and rights. She perceives advocacy as necessary to shield her family from emotional harm but also to enable her child to have the voice which has been denied, as shown in the black, open, silent mouths of the 'Family of Pixies' (see Appendix 9). Charlotte's advocacy and life journey are closely entwined with her personal growth and understanding of lived experience. Seen from the perspective of Van Manen (2014, p. 213), Charlotte's reflexive narration of her lived experience highlights a transformation of self through reflective engagement with professionals. A contrasting Heideggerian (2010, p. 42) view of personal growth as authenticity or '*eigentlichkeit*' is also relevant here, with Charlotte overcoming doubt to become her authentic self.

4.5. Personal Experiential Theme 3

PARTICULAR IMPORTANCE OF JUSTICE AS RECOGNITION AND REBALANCING

a. Justice lies in the balance of knowing and power

The theme of advocacy as transformation, developed in the previous section, is further explored through Charlotte's evolving self-perception. Here, in her advocacy role, she embodies justice, understood as fairness, voice, and recognition. The newly knowledgeable Charlotte can confidently state, '*I do a lot of research now… it's given me a good balance*' (p. 53, lines 1518–1519). When Charlotte speaks about these balancing effects of advocacy, her tone is calmer, and she observes that they enable her '*to see where that person's coming from*' (p. 53, line 1514) – again humanising professionals and moving away from the demon-angel binary comparisons in PET 1.

b. Justice as recognition: Destigmatises and restores value and voice

Charlotte expresses how advocacy – speaking out and being listened to – has boosted her self-esteem, making her '*more confident*' by amplifying her voice as she becomes '*more vocal*' (p. 52, line 1502). Recognition as a good parent is important to Charlotte, and she relays her pleasure at one professional calling her '*a very good mum'* who is doing '*a very good job*' (p. 44, line 1261). However, advocacy makes her feel even better about herself than being a good parent, and she describes herself as '*on top of the world*' (p. 58, line 1667) when her views are taken seriously by professionals. This feeling of being raised-up contrasts with Charlotte's view of her pre-advocacy self, when she felt she '*was absolutely nothing*' (p. 58, line 1668). Charlotte's advocacy, therefore, gives her the sense that her voice is valued and provides a feeling of personal justice through a restored and destigmatised self with a high-level position in the advocacy relationship with professionals.

c. Justice in empowering others to uncover what is hidden.

Charlotte feels satisfaction about uncovering injustices which the '*professionals have kept… hidden… from the parents*' (p. 59, 1684). From her perspective, justice lies in sharing knowledge because, as she explains, '*collectively, you know… you*'*ll also be heard a lot more*' (p. 57, lines 1646–1647). Personal justice can lead to group empowerment by revealing hidden sources of professional knowledge and the systems that enable them.

IPA Summary:

Justice, for Charlotte, restores the self, leaving her with a sense of being valued and whole, bringing balance and calm. Her perception of justice as encompassing physical, emotional, and psychological restoration aligns with the Merleau-Pontian (1962) notion of the lived body or mind–body unity, which unifies experience as aspects of being-in-the-world – that is, the situatedness of a person in their everyday context. Charlotte's personal renewal is reflected by her view of herself changing from nothing to something through advocacy. This transformation echoes Sartre's (2018) idea in *Being and*

Nothingness – of the need to confront and overcome the negated self so that the being becomes something and someone of value. In addition, Charlotte's emphasis on uncovering what is concealed corresponds with Heidegger's (2010, p. 33–34; Dahlstrom, 2013, pp. 10–11) notion of 'aletheia', or bringing the hidden into awareness, as a prerequisite for authenticity.

4.6. Personal Experiential Theme 4

HOW TIME AFFECTS AGENCY AND RECOVERY

a. Parent carer understands the rules of the game

Charlotte's advocacy experience increases her understanding of how professionals use language to undermine her status and knowledge. She expresses this by revealing her strategy for teaching herself to understand the professional '*dialects*' (p. 13, line 325) – the hidden code of professional language used with parents – and her confident assertion of her newfound understanding: '*How they used to use it [language] against me, now I've learned [to use] it against them*' (p. 52, lines 1488–1490). Understanding how professionals use language is part of knowing the rules of the game, which includes Charlotte adopting a positive persona in meetings, where she will '*always go in with a positive foot*' (p. 54, line 1565).

b. Experiences can affect a parent carer's wellbeing and ability to advocate

Charlotte perceives interactions with professionals as mainly negative. The effect of these encounters is reflected in her description of them as something that '*does haunt you*' (p. 40, line 1137), like a returning ghost that threatens her sense of wellbeing and her ability to care for herself and her child. Her feeling of '*trying to keep it together… and you're broken yourself*' (p. 40, line 1143) echoes in her interpretation of the Family of Pixies artwork (see Appendix 9). Charlotte sees the grey, ghost-like figures as a reflection of her child's unhappiness, with a subtle recognition of her own. The figures are interpreted by Charlotte as symbolising her child's unhappiness, which she closely identifies with. Conversely, positive experiences leave Charlotte feeling empowered: '*I've got more things… under control. I have more power over everything*' (p. 60, lines 1714–1715). Here, her empowered language, alongside the artwork, signifies a sense of agency – not only in her own life but also in the world she shares with her child.

c. Agency and recovery: The future is uncertain

Charlotte believes that institutions should change the way they treat families with disabled children but remains doubtful that they will. She says, '*That does need to change… but I don't really think that ever would*' (p. 12, lines 319–321). The closeness between Charlotte and her child, as highlighted in PET 1, means that her recovery is inextricably linked to her child's wellbeing. However, Charlotte does not place her hope in systems changing but instead in her faith in God and a better world. Despite her self-growth and greater sense of agency, uncertainty about the future for her and her child remains: '*I just hope to God that it does get better and… that I can actually help her to get over this*' (p. 66, lines 1891–1892). Charlotte's wish for change but fear of uncertainty is further elucidated by her treatment of the soft unicorn toy (see Appendix 9), which she was holding and stroking for comfort throughout the interview, identifying it as her child and their safe world.

IPA Summary:

For Charlotte, the passage of time leads to an existential doubt over her sense of stability connected to her role as a parent carer. While time brought systemic knowledge and, with it, confidence and resilience, Charlotte's fears remain embodied – in Merleau-Pontian (1962) terms – in the lived mind–body and disembodied in the haunting ghost of her fears from her initial darkening fairytale journey. Her sense of disorientation, like a child learning, echoes the Heidegger (2010, p. 133) notion of being thrown into the world unprepared in a situation not chosen, further demonstrated by her childlike need to retreat into the magical world of the toy unicorn (see Appendix 9).

Summary Overview of PETS and Phenomenological Perspectives

The table below relates each of the PETs to the relevant phenomenological theories that underpin IPA, providing clarity and theoretical context to the results.

Table: Summary of PETS and Phenomenological Concepts Relating to the Participant's Lived Experience of Agency

Personal Experiential Themes (PET)	Charlotte's lived experience sense-making	Concepts related to themes	Phenomenologists
1. THE SPECIALNESS OF THE BOND BETWEEN A PARENT CARER AND CHILD	Parent and Child	Lifeworld	Husserl
	Shared pain	Intersubjectivity/ Embodiment	Husserl Merleau-Ponty
	Nightmare fairytale	Metaphor	Van Manen
	Unpreparedness	Thrown/Thrownness	Heidegger
2. THE ADVOCACY JOURNEY: BATTLING FOR VOICE AND KNOWING	Advocacy as a journey/battle	Metaphor	Van Manen
	Wounded warrior self	Embodiment	Merleau-Ponty
	Self-discovery in voice	Authentic self	Heidegger
3. PARTICULAR IMPORTANCE OF JUSTICE AS RECOGNITION AND REBALANCING	Justice in:		
	Recognition/ rebalancing self	Authentic self	Heidegger
	Restored self as healing	Embodiment	Merleau-Ponty
	Uncovering what is hidden	Uncovering/ Discovery	Heidegger
4. HOW TIME AFFECTS AGENCY AND RECOVERY	Embodied perceptions/ disembodied fears	Embodiment	Merleau-Ponty
	Agency fluctuates with experiences over time	Time	Heidegger

Source: Author's own

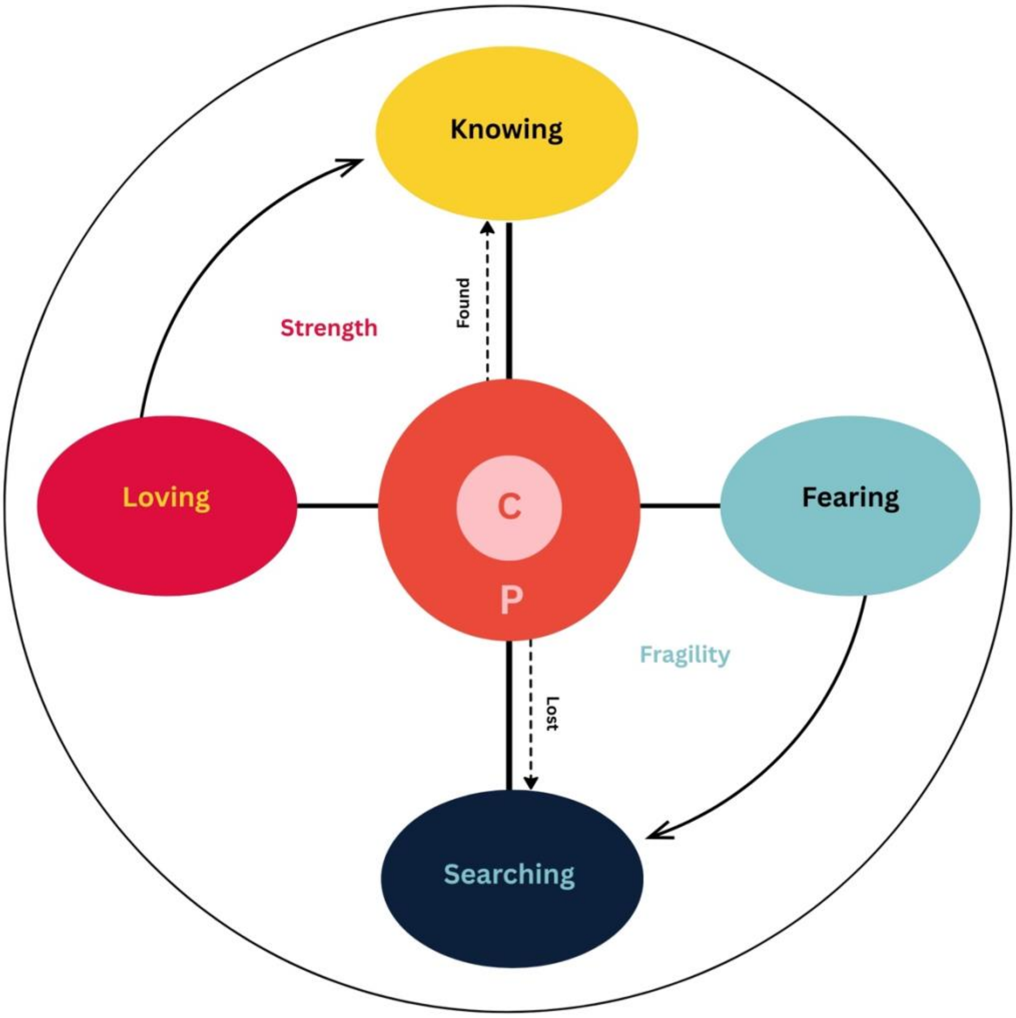
The contextual table shows how Charlotte’s journey as a parent carer has unfolded through shifting experiences that reveal her agency as both her capacity for intentional action and her vulnerability, with these tensions often putting her wellbeing at risk. Applying IPA’s phenomenological framework, the table shows how her sense of agency develops over time. At the beginning, her everyday ‘lifeworld’ (see Appendix 11) is sharply altered by her experience of disability through her disabled child. As Charlotte’s advocacy journey progresses, she enters what Van Manen (2016, p. 39) might interpret as a metaphorical nightmare, with dark fairytale landscapes morphing into a battlefield. Frequent interactions with professionals empower Charlotte with a sense of agency. While her search for justice leads to a restored authentic self, this is continually at risk of being undermined by feelings of powerlessness and situations beyond her control.

Applying IPA’s hermeneutic circle (Smith, Flowers & Larkin, 2022, pp. 22–23) – the interpretative process of understanding each part of the narrative in relation to the whole – to the thematic elements of Charlotte’s story clarifies how the final theme, Charlotte’s uncertainty and vulnerability as a parent carer, connects with the first theme of the bond with her child. Tracing the movement from the last point (PET 4) back to the first (PET 1), the analysis shows that Charlotte’s uncertain agency is rooted in her early negative experiences as a parent carer. This circular process underlines how Charlotte’s fluctuating sense of agency is continually shaped by her interconnected relationship with her child and the challenges she faces. This unpredictable dynamic makes it difficult for her to feel secure in her role, responsibilities, and sense of agency, which are at the core of the parent–child bond.

4.7. Conclusion

The essence of Charlotte’s lived experience of agency is depicted in Figure 1 (overleaf). This model is inspired by the Cook, Tovin and Kenyon (2022, p. 5) visualisation of caring for a child with cerebral palsy, as well as a discussion with the study supervisor. It illustrates Charlotte’s experience as an active, dynamic process by using the continuous verbs ‘loving, knowing, fearing’ and ‘searching’. Her experience encompasses not only mental and physical components but also Husserlian (2023, p. 21) ‘spatio-temporal’ and directional elements operating in a dualistic dialectic. Forward movement signifies positive progress, while backward movement indicates a negative shift, linked to Charlotte’s fears of being lost and her desire to find herself through a sense of personal justice. The model colours reflect Charlotte’s perception of the symbolism in her child’s artwork (see Appendix 9 and PET 1) and the researcher’s interpretation of its meaning. Charlotte’s lived experience is shown to be a search for agency through her advocacy journey and an existential longing for safety and justice in a world she has created with her child. This imagined realm of safety and restorative justice exists beyond the present and is symbolised by the unicorn toy, highlighting systemic inequalities to be explored next through the social justice lens.

Figure 1. Model of a Parent Carer’s Lived Experience of Agency: Charlotte



Key

●	Inner World
P	Parent Carer
C	Child
●	Elements of Agency
—	Connection
------->	Direction
╭	Orientation
○	Outer World

Source: Original model, this study.

4.8. DISCUSSION: SOCIAL JUSTICE PERSPECTIVE

These IPA findings reveal the interplay between agency, power, and lived experience within parent carer advocacy. As stated in the introduction (Chapter 1), a social justice lens (see Appendix 11) was applied to the IPA to illuminate the structural elements of parent carer agency. Far from being superficially overlaid, this lens is woven throughout the analysis of the PETs, grounding insights equally in the data and the researcher's interpretation. Four themes around agency and advocacy are discussed below.

Agency as Action and Influence: Loving and Fearing

'*It's our high-level safe space, but within a teddy bear…*' (p. 64, lines 1839–1840).

The loving and fearing facets of Charlotte's lived experience of agency shape her actions and influence within advocacy partnerships. Bergström *et al.* (2014, p. 43) define agency as 'an element of choice, the power to act, and an ability to influence the outcomes of one's actions', and this resonates with Charlotte's desire for control over the world she creates with her child. In this world, the relationship between Charlotte and her child is a sanctuary, symbolised by the unicorn toy (see Appendix 9), which shields them from institutional influences. Husserl's (1973, p. 166; Serban, 2024, p. 169) emphasis on the interconnected specialness of the parent–child relationship with its 'instinctual care' (*triebhafte Fürsorge*) is reflected throughout Charlotte's story and explains how this bond strengthens her capacity to advocate while also creating vulnerability. This presents a more nuanced view of agency than is found in the literature, showing that the deep bond between parent carer and child can both empower the parent and expose them to the external demands of institutional coercion and manipulation.

Charlotte's lived experience therefore operates in a micro world of responsibility and a macro world of institutional authority, creating a two-fold fear: the anxiety of protecting her child and that of what Sennett (1993) would call a historical, human-based fear of professional authority. Drawing on Dahl (1957) and Weber (2019), this dual fear is shaped by complex relational and socially constructed power dynamics. This confirms the research findings in the literature review (Rossetti *et al.*, 2021; Todd & Higgins, 1998), showing that professionals can dismiss or override the agentic voice of parent carers, leaving them feeling powerless. These situational experiences of reduced agency underscore the need for professionals to respect a parent carer's voice as part of anti-oppressive practice.

Advocacy as Voice and Choice: Searching and Knowing

'*She doesn*'*t have a voice*' (p. 8, line 197).

Charlotte's experience of voice and choice has been defined by uncertainty since the start of her advocacy journey. As Clear (1999) suggests, advocacy is a vital way for parent carers to demonstrate agency. Exercising voice and choice involves articulating needs and making decisions – skills central to both agency and advocacy. This allows a parent carer to articulate the needs and rights of their child, as well as their own. For Charlotte, advocating means being her child's voice and forging a path through uncharted territory. She describes her advocacy role as both mentally and physically demanding. Her focus on her child's wellbeing at the expense of her own is a pattern commonly observed among parent carers in the existing literature (Ryan & Runswick-Cole, 2008; Walmsley *et al.,* 2017; Wright & Taylor, 2014). Yet throughout her journey, Charlotte's uncertainty is shaping her entire lived experience.

Charlotte's uncertainty of agency is exacerbated by what Lam and Kwong (2014, p. 183) refer to as an 'empowerment paradox', in which professionals aim to empower parents while retaining their own power. This creates tension between professional expertise and parental knowledge, undermining the potential for true partnership and agency. Todd and Higgins (1998, p. 235) note that power is not held by one side but emerges through these situational moments of tension. For Charlotte, her repeated insistence on 'knowing' as a way of both understanding and being heard suggests a fear of how easily her voice can be minimised. In Charlotte's lifeworld, advocacy is not a straightforward act of agency but an uncertain search for voice and choice, complicated by the need to play multiple roles. The structural barriers of stigma and silencing further complicate this destabilising experience.

Barriers to Empowerment and Agency: Stigma and Silencing

'*It*'*s how society looks at you*' (p. 63, line 1804).

Charlotte's advocacy experience as a parent carer seeking support shows how negative judgements by professionals can influence interactions and self-perception. This is confirmed by the literature review, which reveals that parents face stigma and blame when accessing public-sector services, which harms their wellbeing (Broady, Stoyles & Morse, 2015; Clements, 2023). Using Goffman's (1986) concept of stigma and particularly the idea of 'spoiled identities', Charlotte's descriptions of scarring demonstrate the damage caused by being unfairly labelled and feeling devalued. However, although these experiences were harmful, Charlotte developed resilience through her lived experience, presenting her best self in meetings. Seen from the apt dramaturgical perspective of Goffman (1961, p. 31), this can be viewed as 'forced deference' – a survival strategy for coping with and subtly resisting stigma.

Goffman's (1961) idea of institutions as isolating and controlling are evident in Charlotte's story. Furthermore, her experience reveals that an institution's power extends beyond its four walls. Indeed, as has been discussed, the complex role of parent carers can lead to a loss of self, as seen in Charlotte's advocacy experience and her search for identity and fairness. When Charlotte steps into the 'superhero/good parent' persona in meetings, institutions shape her behaviour and self-perception in ways that she is unconscious of. Hominh (2022) refers to the changes resulting from these subtle systemic limitations as 'unfreedom', and this intersects with and affects the phenomenological everydayness of Charlotte's world. More subtle than the Althusser (2006) puppet individual, Charlotte's 'superhero' role may internalise a Marxist 'false consciousness' (Engels, 1893, para. 4). Consequently, her display of strength may conceal systemic oppression, turning agency into compliance. This performance alienates her from her authentic self, as revealed in her fears of losing her children, who are part of her. An examination of the stigma and silence surrounding Charlotte's superhero role reveals that empowerment, agency, and survival are intricately intertwined with negotiation and resistance.

Agency and Advocacy: Resistance and Resilience

'*It made me feel like… I was on top of the world*' (p. 58, line 1667).

Charlotte's advocacy journey shows how resistance and resilience are built through social practices. Barnes (2000) makes the argument that social relationships shape agency, and this is reflected in how Charlotte's increased understanding and widening circle of connections empower her to resist stigma and adapt strategies to overcome systemic barriers to helping her child. Growing more confident in her advocacy role, Charlotte finds that her sense of her capacity to change herself and her world grows, leaving her feeling on top of the world. Charlotte's resilience and sense of self-worth are strengthened through knowledge exchange within the parent carer community. In turn, an accumulation of experience enables Charlotte to find her voice, allowing her to challenge power imbalances and support others. This echoes the call from Reeder and Morris (2021, p. 120) for professionals to acknowledge differences in power and the value of parent carers as experts and co-partners in their child's care. Charlotte's experiences demonstrate that the qualities of agency and resilience are not static traits but can be developed through social practice.

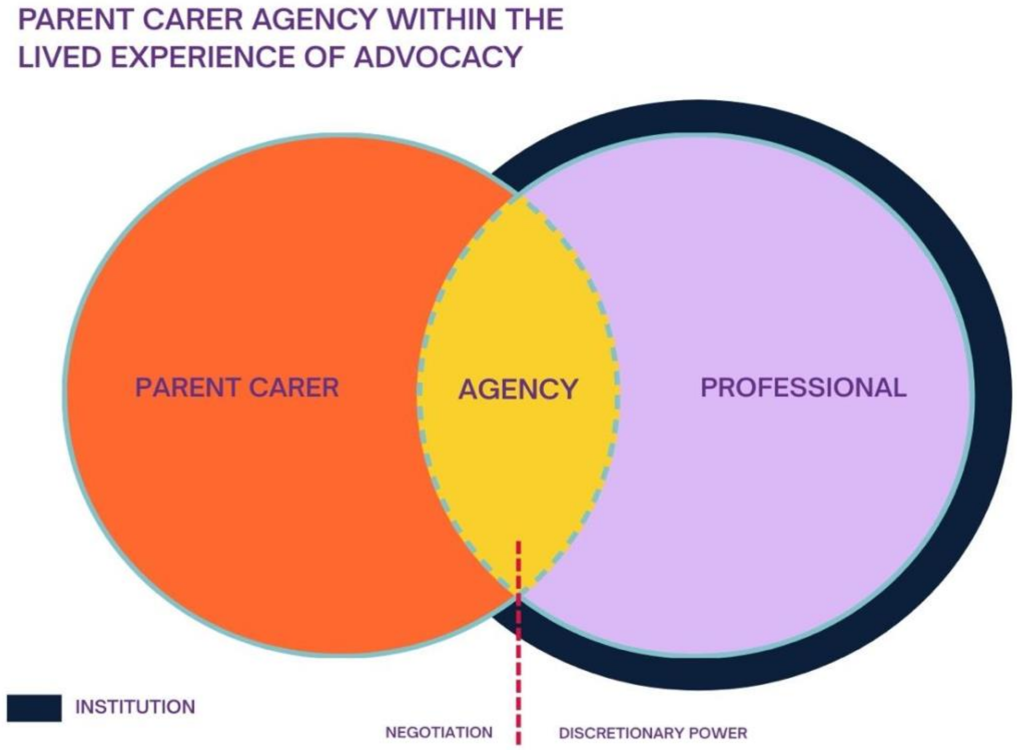
Charlotte's shift from self-advocacy to helping others shows how revealing power differences can enable collective action. This confirms the findings of research showing that advocacy influences agency (Carers First, 2024; Eley & John, 2023; Ryan & Runswick-Cole, 2008, pp. 43–50). This synthesis offers insights into the structure-agency relationship of parent carers, who build agency through networks and knowledge sharing. While institutions can be limiting, they can also create spaces for strategic agency, as shown in Charlotte's changing views of professionals – from seeing them as 'institutional monsters' to recognising their humanness. However, Charlotte's experiences reveal a complex perspective on agency that challenges the literature's binary view of power and its assumptions about resilience as a positive outcome in a parent carer's advocacy journey. The agency-structure dialectic is far more complex – as these theories demonstrate – when viewed from the individual perspective of a parent carer.

Agency and Structure: The Individual and the Institution

'*Monsters I call them, because… in reality, that's what they are*' (p. 19, lines 521–522).

The complex interplay between agency and structure is conveyed through Charlotte's interactions with institutions. Her story offers a dialectical understanding that transcends simple binary distinctions. Weber's (2019) theory of bureaucratic rationalism helps to explain how formal hierarchies can depersonalise interactions, which is shown in how Charlotte perceives professionals as part of institutions. In contrast to Weber (2019), Lipsky (1980), with his ground-level view, explains how these professionals are also shaped by institutional power, wielding discretionary authority that can diminish empathy. Charlotte's views of professionals as monsters and humans reveal an internal ambiguity and tension as these individuals become frightening embodiments of the institutions. Phenomenological theory further illuminates the complexity of institutional humanity. Heidegger's (2010) concept of being shaped by time is reflected in Charlotte's perception that professionals inhabit a different temporal realm, separated by bureaucracy. Her experience of the realities of bureaucracy and everyday policy as enforced decisions often leaves her feeling marginalised and complicates her role as a parent carer in these institutional systems. This interplay undermines parent carer agency, leaving Charlotte occupying an uncertain space between empathy and systemic authority, as illustrated in Figure 2 (overleaf).

Figure 2. Parent Carer Agency Within the Lived Experience of Advocacy: Charlotte



Source: Original model, this study.

Summary Overview

These findings emphasise the complexity of parent carer agency, which is shaped by unequal power dynamics and can be both fragile and strong. Such power disparities may affect whether a parent carer's voice is heard, the choices they can make for their child, and the impact on their self-esteem. These results, supported by the VETs and the social justice perspective, show that Charlotte's agency is a strategic and precarious space and experience. This suggests that understanding agency in the advocacy context requires both a particular view of individual experiences and a broader focus on systems and how parent carers can effectively navigate them. The study's innovative approach, therefore, enables a nuanced account of power, advocacy, and agency, which, through praxis (see Appendix 11), can have significant implications for research, policy, and professional practice.

5. CONCLUSION AND RECOMMENDATIONS

The purpose of this study was to explore a parent carer's lived experience of agency when advocating for their disabled child while engaging with professionals and institutions. The literature review highlighted numerous challenges faced by parent carers and identified a gap in the research on their experiences of diminished agency. This study adopted an innovative approach by combining an in-depth IPA interview with participant-led VETs. This method integrates IPA's strengths while recognising its limitations. Incorporating a critical perspective provided further insights into the power dynamics between parent carers and institutions. The findings contribute to the literature by shedding light on the challenges and opportunities related to parent carer agency. Guided by the central research question – *What is the lived experience of agency for a parent carer advocating for a disabled child while engaging with professionals and institutions?* – this concluding chapter revisits the study's aim and context and presents its recommendations accordingly.

Methodological Innovations and Co-productive Insights

An innovative multi-method approach provided a deeper understanding of how parent carers experience agency in advocacy and how this impacts their voice, choices, and lived experience, as well as their responsibilities and challenges. A significant participant-led methodological insight arose from the collaborative nature of the research. Just before the interview, Charlotte unexpectedly introduced her child's rainbow-coloured unicorn toy as a VET alongside the artwork. This object became more than a source of comfort: it came to symbolise her journey as a parent carer and her lifeworld shared with her child.

Through alignment between each phase of the research, the study successfully met its core objectives to:

- Understand the impacts on a parent carer of providing primary care, revealed through a rich narrative account of the physical and emotional toll of caring (Cook, Tovin & Kenyon, 2022).
- Examine the barriers to parent carer advocacy, illustrated through detailed descriptions of bureaucratic obstacles and professional resistance (Jones, 2024).
- Identify factors that would improve a parent carer's advocacy experiences (Walmsley *et al.,* 2017; Wright & Taylor, 2014), achieved through careful analysis of both challenging and successful advocacy moments.
- Gain rich single-participant data for doctoral research development, achieved by completing the IPA study (see Appendix 2).
- Harness insights to inform policy and professional practice, as per the study's recommendations.

Parent Carer Agency: A Complex Interplay of Fragility and Strength

This study offers a nuanced response to prior research on parent carer agency and advocacy, emphasising the intricate power dynamics between parent carers and professionals. Charlotte, like other parent carers, experiences diminished agency and voice, often feeling unheard when seeking support for her disabled child. This manifests as parent carer blame, exclusion, and silencing (Clements & Aiello, 2021; Lipkin & Crepeau-Hobson, 2022). However, the study also revealed a complexity to the issue of agency that went beyond the initial finding of a parent carer's lack of power and capacity to influence decisions. Charlotte, for instance, poignantly reflects on her advocacy journey and status, analogising her journey to that of a newborn, which she describes as '*coming out in[to] the world*' (p. 6, line 130). She compares her progress to that of a toddler learning to ride, tentative at first, then suddenly '*the training wheels… come off*' (p. 6, lines 130–131). Despite moments of confidence, Charlotte's lived experience of agency has been and remains uncertain. This uncertainty relates to her growing understanding, developed through lived experience, of the advocacy and agency needed to tackle the inequality between herself and the professionals. These recommendations, therefore, acknowledge the inherent power difference between parent carers and professionals and institutions. They advance a hearts-and-minds perspective to drive holistic, systemic change, as outlined in the third and final recommendation.

Recommendation 1: Mandatory training programmes for professionals

Being a parent carer is not recognised as a protected characteristic under the UK's primary anti-discrimination legislation, the *Equality Act 2010*. Professional training on anti-oppressive practice incorporating praxis (see Appendix 11) should therefore address the unique challenges parent carers face due to their multifaceted role. However, an overreliance on formal training risks overlooking the complexity of a parent carer's lived experience, so future training must be informed by in-depth research. Professional bodies like BASW (2024) must prioritise and support this training so that parent carers receive the help they need to care for their children.

Recommendation 2: Rebalancing power in advocacy services

Reform of current advocacy services is necessary to address the ways in which parent carers are disadvantaged by a relative lack of power, compared to professionals. Professionals benefit from institutional support, policies, and resources, whereas parent carers often navigate complex systems on their own. These unequal power relations hinder parent carers from influencing decisions about their child's care. Their lack of agency and the stress of caring, in turn, weaken their ability to advocate effectively. Greater access to advocacy services can help redress this power imbalance, ensuring that parent carers have the support they need to articulate their child's needs and protect their interests.

Recommendation 3: A coalition of theory, policy and practice

Progress for parent carers depends on overcoming systemic barriers to agency and advocacy. These challenges persist not merely due to lack of empathy or awareness, but because institutions often resist change (Hubbart, 2023). Therefore, to realise the social policy revolution predicted by McIntosh and Wright (2018), a coalition that unites theory, policy, and practice is essential. By aligning academic research, policy, development, and grassroots-level advocacy, such a coalition can dismantle entrenched power structures and build public support. Partnerships between universities, local organisations, and policymakers should work together to amplify the voices of parent carers. The lived experience and knowledge of parent carers must be central to this process to bring about change.

Final Thoughts: Looking Towards the Future

This study suggests that parent carer agency may be more complex than previously thought, warranting further research. The IPA revealed that Charlotte's lived experience is a delicate balance between loving and fearing and searching and knowing. The unicorn toy she introduced became emblematic of the intertwined lives of a parent carer and child. Its inclusion in the research was an important act of co-production and agency, deepening the study's insights. Thus, while Charlotte feels brave and empowered, the paradoxical tension that comes from the specialness of the relationship with her child creates uncertainty and a sense of powerlessness in the face of institutional resistance (Lam & Kwong, 2014). Charlotte's story captures this duality and goes beyond it, expressing the fluid and dialectical essence of each element of her lived experience. This insight informs analysis of wider dynamics.

Critical analysis of the data uncovered how interpersonal, systemic and temporal dynamics affect parent carer agency. Therefore, interventions should not just build advocacy skills but address the causes of powerlessness and find ways to value a parent carer's lived experience. Enhancing agency as a complex *lived experience* requires equal, empathic partnerships between parent carers and professionals. Both parties must acknowledge their shared goal: namely, the care of the child. In doing so, they recognise their common humanity, which helps resist institutional dehumanisation. While this study's limited scope means further exploration of practical and theoretical aspects is needed to improve parent carers' experiences, these will be addressed in the doctoral dissertation. For now, in a study rooted in agency and co-production, the final words belong to Charlotte, who reminds us, '*We are all human at the end of the day.*'

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SECTION B: Approval for Research Activity

1	Has the research activity received approval in principle? (please check the Guidance Notes as to the appropriate approval process for different levels of research by different categories of individual)	**YES**	☐	**NO**	☒
				Date	
2	If Yes, please indicate source of approval (and date where known): ***Approval in principle must be obtained from the relevant source prior to seeking ethical approval***	Research Degrees Committee	☐		
		Institute Research Committee	☐		
		Other (write in)	☐		

SECTION C: Internal and External Ethical Guidance Materials

	Please list the core ethical guidance documents that have been referred to during the completion of this form (including any discipline-specific codes of research ethics, location-specific codes of research ethics, and also any specific ethical guidance relating to the proposed methodology). Please tick to confirm that your research proposal adheres to these codes and guidelines. You may add rows to this table if needed.	
1	**UWTSD Research Ethics & Integrity Code of Practice**	☒
2	**UWTSD Research Data Management Policy**	☐
3	*[List any other relevant documents here]*	☐

SECTION D: External Collaborative Research Activity
If there are external collaborators then you should gain consent from the contact persons to share their personal data with the university. If there are no external collaborators then leave this section blank and continue to section E.

1	Institution					
2	Contact person name					
3	Contact person e-mail address					
4	Is your research externally funded?		**YES**	☐	**NO**	☐
5	Are you in receipt of a KESS scholarship?		**YES**	☐	**NO**	☐
6	Are you specifically employed to undertake this research in either a paid or voluntary capacity?	Voluntary	**YES**	☐	**NO**	☐
7		Employed	**YES**	☐	**NO**	☐
8	Is the research being undertaken within an existing UWTSD Athrofa Professional Learning Partnership (APLP)?	If YES then the permission question below does not need to be answered.	**YES**	☐	**NO**	☐
9	Has permission to undertake the research has been provided by the partner organisation?	(If YES attach copy) If NO the application cannot continue	**YES**	☐	**NO**	☐

Where research activity is carried out in collaboration with an external organisation

10	Does this organisation have its own ethics approval system?	**YES**	☐	**NO**	☐
	If Yes, please attach a copy of any final approval (or interim approval) from the organisation (this may be a copy of an email if appropriate).				

SECTION E: Details of Research Activity

1	Indicative title:	Parent Carer Agency: Exploring the Lived Experience of Advocating for a Disabled Child *[Child with a Disability] While Engaging with Professionals and Institutions		
2	Proposed start date:	01/10/24	Proposed end date:	30/09/24

Introduction to the Research (maximum 300 words per section)

Ensure that you write for a <u>Non-Specialist Audience</u> when outlining your response to the points below:

Purpose of Research Activity
Proposed Research Question
Aims of Research Activity
Objectives of Research Activity

Demonstrate, briefly, how **<u>Existing Research</u>** has informed the proposed activity and explain

What the research activity will add to the body of knowledge
How it addresses an area of importance.

3

Purpose of Research Activity

As stated in the research proposal (Johnson, 2023; 2024) the purpose of this study is to:

- Understand the lived experiences of parents who provide primary care for a disabled child * [child with disability] with a specific focus on the lived experience of agency or parent carers advocating for their child while engaging with professionals and institutions. (Johnson, 2023, pp. 2–3).

Parent carers play a vital role in the wellbeing of their children, yet research on the lives of unpaid parent carers has been sporadic despite an increasing number of children who are disabled are increasing in the UK and world-wide (Kirk-Wade, Stiebahl & Wong, 2024, pp. 5, 8; Olusanya *et al.,* pp. 1–2, 2022). A key recent report (Clements & Aiello, 2021) has highlighted problems parents experience when advocating for their children with a disability. Past and recent research (Johnson, 2023b, p. 2; Lipkin & Crepeau-Hobson, 2022, p. 1546; Todd & Higgins, 1998, pp. 227–236) confirms Clement and Aiello's (2021) study findings.

This research is, therefore, designed to uncover deeper insights into those lived experiences of parent carer agency in the parent to professional relationship. The chosen IPA approach (Smith, Flowers & Larkin, 2009; 2022) best uncovers a person's lived experience and shapes methodology and subsequent methods chose of a single participant pilot case study from which in-depth insights can be used to shape a doctoral study. This also suits the dissertation's limited size and scope by focusing on one important aspect of the lived experience of a parent carer, which is their lived experience of agency – defined in this context as the capability to make decisions and the power to influence outcomes, when advocating for services and support from professionals and the institutions and organisations they belong to across health, education and social care.

References

Clements, L. & Aiello, A.L. (2021) *Institutionalising parent carer blame.* Cerebra, University of Leeds. Available at: https://cerebra.org.uk/wp-content/uploads/2021/07/Final-Parent-Blame-Report-20-July-21-03.pdf (Accessed: 25 October 2024).

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Kirk-Wade, E., Stiebahl, S. & Wong, H. (2024) *UK disability statistics: prevalence and life experiences*. House of Commons Library, pp.1–44. Available at: https://researchbriefings.files.parliament.uk/documents/CBP-9602/CBP-9602.pdf (Accessed: 27 October 2024).

Lipkin, M. & Crepeau-Hobson, F. (2022) 'The impact of the COVID-19 school closures on families with children with disabilities: a qualitative analysis', *Psychology in the Schools*, 60(5). Available at: https://doi.org/10.1002/pits.22706

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Todd, E.S. & Higgins, S. (1998) 'Powerlessness in professional and parent partnerships', *British Journal of Sociology of Education*, 19(2), pp. 227–236. Available at: https://doi.org/10.1080/0142569980190205

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*** NB: In the final dissertation, the researcher changed the disability language from person-first to identity-first to align with the social model of disability (see Appendix 11).**

4

Research Question

RQ) What is the lived experience of agency for parent carers advocating for a disabled child *[child with a disability] while engaging with professionals and institutions?

5

Aims of Research Activity

- Understand the lived experiences of parents who provide primary care for their disabled child *[child with a disability – with a specific focus on parental agency when parent carers advocate for their child while engaging with professionals and institutions.

6

Objectives of Research Activity

- Understand the impacts parent carers experience when providing primary care for their child
- Understand the barriers that parent carers face when seeking help for or raising concerns about their child's care's care.
- Understand how experiences shape a parent carer's sense of autonomy and empowerment when advocating for their child.
- Identify factors that would improve the parent carer's experience when advocating for their child.
- Gain insights from an in-depth, rich single participant data for my doctoral dissertation.
- Harness the study's insights to inform professional practice.

(this box should expand as you type)

Proposed methods (maximum 600 words)

Provide a brief summary of all the methods that **may** be used in the research activity, making it clear what specific techniques may be used. If methods other than those listed in this section are deemed appropriate later, additional ethical approval for those methods will be needed. You do not need to justify the methods here but should instead describe how you intend to collect the data necessary for you to complete your project.

7

There will be a main semi structured interview of 2–3 hours including the use of visual media (Pink, 2007). The researcher will also keep a diary for reflexivity as per Smith, Flowers & Larkin's (2009; 2022) recommendations. Reflexivity is helpful in qualitative research such as this to address the question of researcher bias (Johnson, 2023, p, 13; Kumar, 2014, p. 287).

The entire research process including the conduct the researcher will be conducted according to the university's code of practice (University of Wales Trinity Saint David (UWTSD), 2022). Added to this, as a British Sociological Association (2017, p. 57) member, there are helpful guidelines for researchers in sociology, and notably, within them, the participant's wellbeing is paramount. In addition, being a qualified Independent Advocate for vulnerable adults and children has helped as preparation for research with some of the key principles of advocacy (The Advocacy Project, 2014) including equality of status and integrity, which is also emphasised by the university (University of Wales Trinity Saint David (UWTSD), 2022, p. 4). In terms of rigour in using the correct methods and ethical practice in the application of those methods in IPA Analysis, this will be carried out with strict adherence to the guidelines provided by Smith, Flowers and Larkin (2009, pp. 53–54; 2022, pp. 47–50) whose overarching principle is that a researcher must be to do now harm. Such practices include obtaining informed consent from the participant, making sure they have the right to withdraw at any time, carrying out research in sensitive manner and making sure that the participant has avenues of support during and after the time of data collection when the interview takes place. Smith, Flowers and Larkin (2009, p. 53; 2022, p. 48) have noted that

	whilst a researcher can offer anonymity, complete confidentiality can be misleading because the data may be seen by the supervisor for instance. However, the participant's identity may not be known by the supervisor in this type of approach which is based on the essence of the lived experiences of a parent carer, and not focussed on who they are according to name. In IPA studies, sometimes the first name is used or a pseudonym. **References** British Sociological Association (2017) *Statement of ethical practice*. Available at: https://www.britsoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf (Accessed: 9 November 2024). Johnson, E.-L. (2023) 'ECED7005Q: Assignment 1: Through a lens, brightly: exploring the lived experience of parents who are the primary carers for their disabled child.' Assignment for *ECED7005Q, MA. Equity and Diversity in Society.* UWTSD. Unpublished. Kumar, R. (2014) *Research methodology: a step-by-step guide for beginners*. 4th edn. Los Angeles, CA: Sage. Pink, S. (2013) *Doing visual ethnography*. Los Angeles: Sage. Smith, J.A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: theory, method and research*. London: SAGE. Smith, J.A., Flowers, P. & Larkin, M. (2022) *Interpretative Phenomenological Analysis: theory, method and research*. 2nd edn. Los Angeles: SAGE. The Advocacy Project. (2014) *Principles of advocacy*. Available at: https://www.advocacyproject.org.uk/home/advocacy/how-we-work/principles-of-advocacy/ (Accessed: 25 November 2024). University of Wales Trinity Saint David (UWTSD) (2022) *Research ethics and integrity code of practice*. Available at: https://www.uwtsd.ac.uk/media/uwtsd-website/content-assets/documents/research/REICoP-July-2022.pdf. (Accessed: 22 October 2024). (this box should expand as you type)
	Location of research activity Identify all locations where research activity will take place.
8	The main interview will be held in a private meeting room in Roffey Millenium Hall, Horsham, West Sussex, RH12 4DT (2022). To ensure the research process was co-participatory, the participant was asked where they were most comfortable taking part beforehand and this was their chosen setting. **Reference** North Horsham Parish Council (2022) *Roffey Millennium Hall*. Available at: https://northhorsham-pc.gov.uk/halls-for-hire/roffey-millennium-hall/ (Accessed: 24 November 2024). (this box should expand as you type)
	Research activity outside of the UK If research activity will take place overseas, you are responsible for ensuring that local ethical considerations are complied with and that the relevant permissions are sought. Specify any local guidelines (e.g. from local professional associations/learned societies/universities) that exist and whether these involve any ethical stipulations beyond those usual in the UK (provide details of any licenses or permissions required). Also specify whether there are any specific ethical issues raised by the local context in which the research activity is taking place, for example, particular cultural and/or legal sensitivities or vulnerabilities of participants. If you live in the country where you will do the research then please state this.
9	N/A *(this box should expand as you type)*

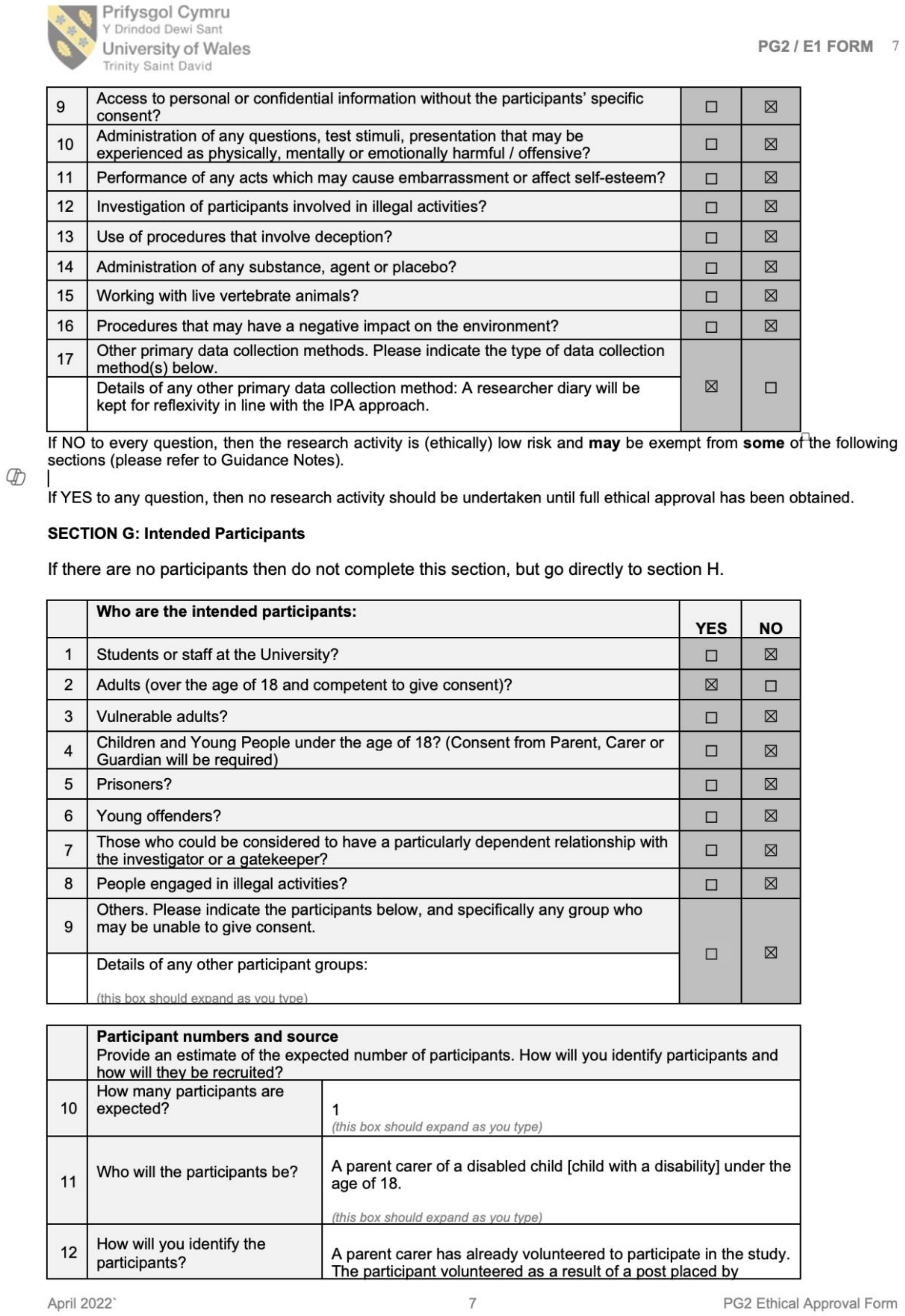
10	Use of documentation not in the public domain: Are any documents **NOT** publicly available?	**NO**	☒
		YES	☐

11	If Yes, please provide details here of how you will gain access to specific documentation that is not in the public domain and that this is in accordance with the current data protection law of the country in question and that of England and Wales. *(this box should expand as you type)*

	Does your research relate to one or more of the seven aims of the Well-being of Future Generations (Wales) Act 2015?	**YES**	**NO**
12	A prosperous Wales	☐	☒
13	A resilient Wales	☒	☐
14	A healthier Wales	☐	☒
15	A more equal Wales	☒	☐
16	A Wales of cohesive communities	☐	☒
17	A Wales of vibrant culture and thriving Welsh language	☐	☒
18	A globally responsible Wales	☐	☒
19	If YES to any of the above, please give details:		
	(14) This research will focus on parent carers' wellbeing. By identifying factors that would help their experience of advocating with professionals, the research can be used to shape programmes and policies put in place by institutions and organisations for their employees. (15) Parent carers are one of the most deprived groups in the UK (Clements & Aiello, 2021) Research that aids understanding of the be barriers they face can be used to bring about change, with greater equity and equality for this neglected section of society. This pilot study will be the foundation for a wider doctoral study in Wales and its findings can help parent carers across the UK, empowering them through greater understanding of their experiences when seeking services or help from professionals and organisations. **References** Clements, L. & Aiello, A.L. (2021) *Institutionalising parent carer blame*. *Cerebra*, University of Leeds, pp.1–53. Available at: https://cerebra.org.uk/wp-content/uploads/2021/07/Final-Parent-Blame-Report-20-July-21-03.pdf (Accessed: 14 November 2024). (this box should expand as you type)		

SECTION F: Scope of Research Activity

	Will the research activity include:	**YES**	**NO**
1	Use of a questionnaire or similar research instrument?	☐	☒
2	Use of interviews?	☒	☐
3	Use of focus groups?	☐	☒
4	Use of participant diaries?	☐	☒
5	Use of video or audio recording?	☒	☐
6	Use of computer-generated log files?	☐	☒
7	Participant observation with their knowledge?	☒	☐
8	Participant observation without their knowledge?	☐	☒



9	Access to personal or confidential information without the participants' specific consent?	☐	☒
10	Administration of any questions, test stimuli, presentation that may be experienced as physically, mentally or emotionally harmful / offensive?	☐	☒
11	Performance of any acts which may cause embarrassment or affect self-esteem?	☐	☒
12	Investigation of participants involved in illegal activities?	☐	☒
13	Use of procedures that involve deception?	☐	☒
14	Administration of any substance, agent or placebo?	☐	☒
15	Working with live vertebrate animals?	☐	☒
16	Procedures that may have a negative impact on the environment?	☐	☒
17	Other primary data collection methods. Please indicate the type of data collection method(s) below.	☒	☐
	Details of any other primary data collection method: A researcher diary will be kept for reflexivity in line with the IPA approach.		

If NO to every question, then the research activity is (ethically) low risk and **may** be exempt from **some** of the following sections (please refer to Guidance Notes).

If YES to any question, then no research activity should be undertaken until full ethical approval has been obtained.

SECTION G: Intended Participants

If there are no participants then do not complete this section, but go directly to section H.

	Who are the intended participants:	**YES**	**NO**
1	Students or staff at the University?	☐	☒
2	Adults (over the age of 18 and competent to give consent)?	☒	☐
3	Vulnerable adults?	☐	☒
4	Children and Young People under the age of 18? (Consent from Parent, Carer or Guardian will be required)	☐	☒
5	Prisoners?	☐	☒
6	Young offenders?	☐	☒
7	Those who could be considered to have a particularly dependent relationship with the investigator or a gatekeeper?	☐	☒
8	People engaged in illegal activities?	☐	☒
9	Others. Please indicate the participants below, and specifically any group who may be unable to give consent.	☐	☒
	Details of any other participant groups: (this box should expand as you type)		

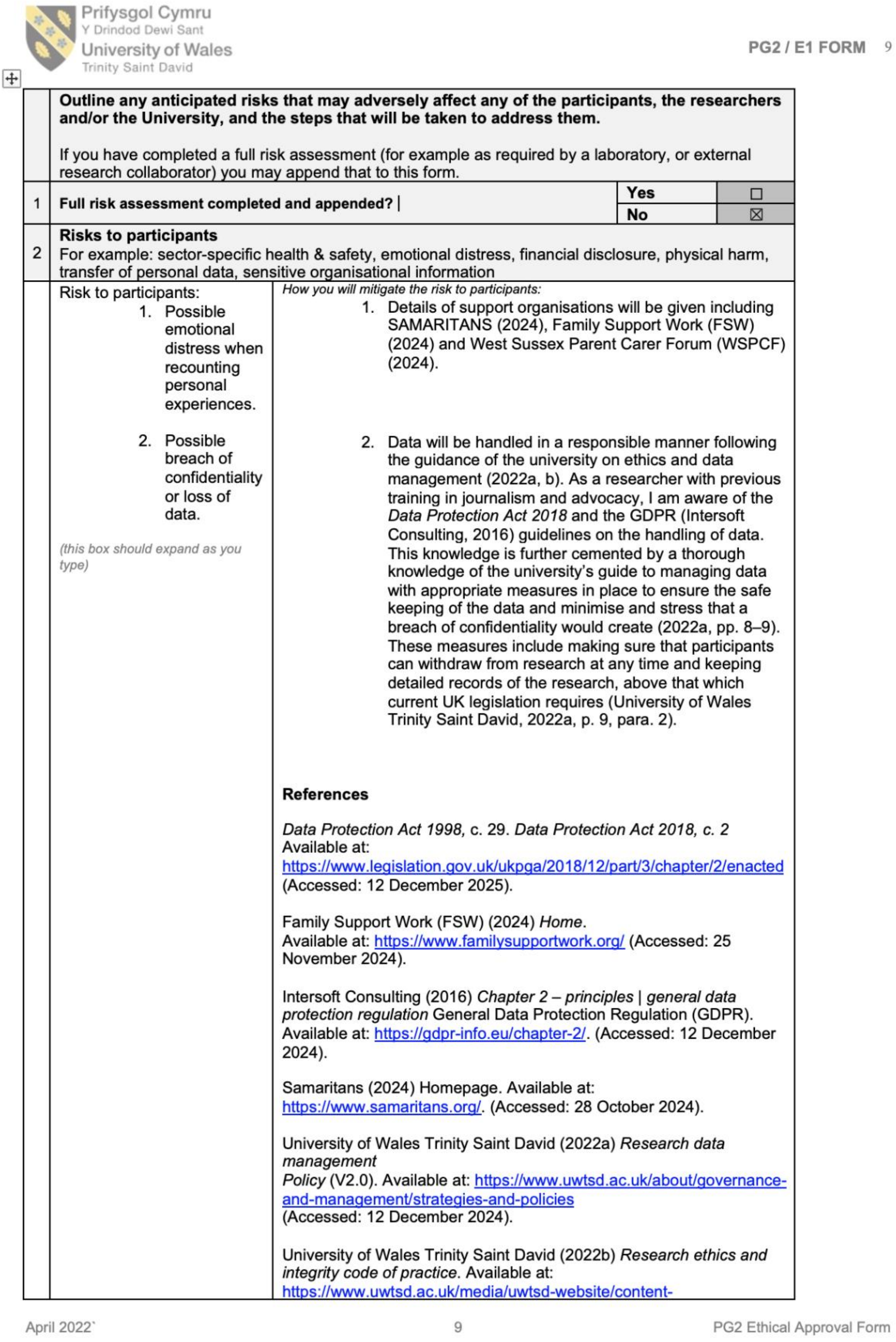
	Participant numbers and source Provide an estimate of the expected number of participants. How will you identify participants and how will they be recruited?	
10	How many participants are expected?	1 *(this box should expand as you type)*
11	Who will the participants be?	A parent carer of a disabled child [child with a disability] under the age of 18. *(this box should expand as you type)*
12	How will you identify the participants?	A parent carer has already volunteered to participate in the study. The participant volunteered as a result of a post placed by

		established local charity, West Sussex Parent Carer Forum (2024). **Reference** West Sussex Parent Carer Forum (2024) *West Sussex Parent Carer Forum* (WSPCF). Available at: https://www.wspcf.org.uk/ (Accessed: 28 October 2024). *(this box should expand as you type)*

	Information for participants:	**YES**	**NO**	**N/A**
13	Will you describe the main research procedures to participants in advance, so that they are informed about what to expect?	☒	☐	☐
14	Will you tell participants that their participation is voluntary?	☒	☐	☐
15	Will you obtain written consent for participation?	☒	☐	☐
16	Will you explain to participants that refusal to participate in the research will not affect their treatment or education (if relevant)?	☒	☐	☐
17	If the research is observational, will you ask participants for their consent to being observed?	☒	☐	☐
18	Will you tell participants that they may withdraw from the research at any time and for any reason?	☒	☐	☐
19	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	☐	☐	☒
20	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	☒	☐	☐
21	Will you debrief participants at the end of their participation, in a way appropriate to the type of research undertaken?	☒	☐	☐
22	If NO to any of above questions, please give an explanation			
	A single participant parent carer has volunteered to take part in the research. They volunteered from West Sussex Parent Carer Forum (WSPCF) (2024) a local charity who I contacted to ask about potential research participants for my study. **Reference** West Sussex Parent Carer Forum (2024) *West Sussex Parent Carer Forum (WSPCF)*. Available at: https://www.wspcf.org.uk/ (Accessed: 28 October 2024). *(this box should expand as you type)*			

	Information for participants:	**YES**	**NO**	**N/A**
24	Will participants be paid?	☐	☒	☐
25	Is specialist electrical or other equipment to be used with participants?	☐	☒	☐
26	Are there any financial or other interests to the investigator or University arising from this study?	☐	☒	☐
27	Will the research activity involve deliberately misleading participants in any way, or the partial or full concealment of the specific study aims?	☐	☒	☐
28	If YES to any question, please provide full details			
	(this box should expand as you type)			

SECTION H: Anticipated Risks



	Outline any anticipated risks that may adversely affect any of the participants, the researchers and/or the University, and the steps that will be taken to address them. If you have completed a full risk assessment (for example as required by a laboratory, or external research collaborator) you may append that to this form.		
1	**Full risk assessment completed and appended?**	**Yes** **No**	☐ ☒
2	**Risks to participants** For example: sector-specific health & safety, emotional distress, financial disclosure, physical harm, transfer of personal data, sensitive organisational information		
	Risk to participants: 1. Possible emotional distress when recounting personal experiences. 2. Possible breach of confidentiality or loss of data. *(this box should expand as you type)*	*How you will mitigate the risk to participants:* 1. Details of support organisations will be given including SAMARITANS (2024), Family Support Work (FSW) (2024) and West Sussex Parent Carer Forum (WSPCF) (2024). 2. Data will be handled in a responsible manner following the guidance of the university on ethics and data management (2022a, b). As a researcher with previous training in journalism and advocacy, I am aware of the *Data Protection Act 2018* and the GDPR (Intersoft Consulting, 2016) guidelines on the handling of data. This knowledge is further cemented by a thorough knowledge of the university's guide to managing data with appropriate measures in place to ensure the safe keeping of the data and minimise and stress that a breach of confidentiality would create (2022a, pp. 8–9). These measures include making sure that participants can withdraw from research at any time and keeping detailed records of the research, above that which current UK legislation requires (University of Wales Trinity Saint David, 2022a, p. 9, para. 2). **References** *Data Protection Act 1998,* c. 29. *Data Protection Act 2018, c. 2* Available at: https://www.legislation.gov.uk/ukpga/2018/12/part/3/chapter/2/enacted (Accessed: 12 December 2025). Family Support Work (FSW) (2024) *Home*. Available at: https://www.familysupportwork.org/ (Accessed: 25 November 2024). Intersoft Consulting (2016) *Chapter 2 – principles | general data protection regulation* General Data Protection Regulation (GDPR). Available at: https://gdpr-info.eu/chapter-2/. (Accessed: 12 December 2024). Samaritans (2024) Homepage. Available at: https://www.samaritans.org/. (Accessed: 28 October 2024). University of Wales Trinity Saint David (2022a) *Research data management Policy* (V2.0). Available at: https://www.uwtsd.ac.uk/about/governance-and-management/strategies-and-policies (Accessed: 12 December 2024). University of Wales Trinity Saint David (2022b) *Research ethics and integrity code of practice*. Available at: https://www.uwtsd.ac.uk/media/uwtsd-website/content-	

		assets/documents/research/REICoP-July-2022.pdf (Accessed: 25 November 2024). West Sussex Parent Carer Forum (WSPCF) (2024). *Homepage*. Available at: https://www.wspcf.org.uk/ (Accessed: 12 December 2024). *(this box should expand as you type)*
3	If research activity may include sensitive, embarrassing or upsetting topics (e.g. sexual activity, drug use) or issues likely to disclose information requiring further action (e.g. criminal activity), give details of the procedures to deal with these issues, including any support/advice (e.g. helpline numbers) to be offered to participants. Note that where applicable, consent procedures should make it clear that if something potentially or actually illegal is discovered in the course of a project, it may need to be disclosed to the proper authorities	
	As an Independent Advocate for vulnerable adults and children, I am trained in safeguarding procedures. As such, I am aware that there are exemptions to confidentiality for the participant which include safeguarding risks. The participant will be fully informed of these exemptions to confidentiality before beginning research. If the participant discloses any criminal or safeguarding activity the plan of action will depend on whether this risk is to the adult participant or to their child, a minor, or both. If the risk is to the adult participant only, then the local Sussex Police (2024) will be contacted. If the risk involves the child who is a minor, then the local and social services hub (Integrated Front Door (IDF), 2024; Sussex Police, 2024) will be contacted. If the research took place in Wales, then then the same procedure would take place, but as well as the university's safeguarding officer would also be alerted. **References** Sussex Police (2024) *Report a crime*. Available at: https://www.sussex.police.uk/ro/report/ocr/af/how-to-report-a-crime/ (Accessed: 12 December 2024). West Sussex SCP (2024) *Making a referral – the West Sussex Integrated Front Door (IFD) portal*. Available at: https://www.westsussexscp.org.uk/professionals/working-together/making-a-referral (Accessed: 12 December 2024). *(this box should expand as you type)*	
4	**Risks to the investigator** For example: personal health & safety, physical harm, emotional distress, risk of accusation of harm/impropriety, conflict of interest	
	Risk to the investigator: Possible emotional stress at hearing the participant's experiences. *(this box should expand as you type)*	*How you will mitigate the risk to the investigator:* Student support services can be contacted if needed. However, I have supportive partner who is my main source of help. *(this box should expand as you type)*
5	**University/institutional risks** For example: adverse publicity, financial loss, data protection	
	Risk to the University: 1. Possible complaint by the research participant regarding emotional or psychological harm. 2. Data Breach resulting in legal proceedings under the Data Protection Act 2018 and the researcher being reported to the Information Commissioner's Office (ICO) (2023)	*How you will mitigate the risk to the University:* 1. The research will be carried out to high ethical standards as stated in the university guidelines (University of Wales Trinity Saint David, 2022b). This will include informing participants of their rights to withdraw from the research at any time as well as maintaining transparency throughout the research process. A comprehensive record will be kept of the methods used with ethical conduct at the heart of the study as recommended by Smith, Flowers and Larkin (2009, pp. 53–54; 2022, p. 47–50). 2. Research will be carried out scrupulously with data collected and stored securely. Notably, the university guidelines on the management of data (University of Wales Trinity Saint David 2022a, p. 19). state a difference in consent needed to take part in research but not for processing data. However, it should be noted that the participant can still withdraw at any time.

	which could issue a fine to the university. 3. Negative publicity resulting from points 1 and 2. *(this box should expand as you type)*	3. Negative publicity is mitigated, similarly to the above, by carrying out the research in an ethical and timely manner, keeping the participant informed, being transparent in practice and aware of not only the university guidelines, but UK law (*Data Protection Act 2018*) and how it protects an individual's data. **References** *Data Protection Act 1998,* c. 29. Available at: https://www.legislation.gov.uk/ukpga/1998/29/schedule/1/enacted (Accessed: 12 December 2024). Information Commissioner's Office (ICO) (2023) *Personal data breaches: a guide*. Available at: https://ico.org.uk/for-organisations/report-a-breach/personal-data-breach/personal-data-breaches-a-guide/ (Accessed: 12 December 2024). Smith, J.A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: theory, method and research*. London: SAGE. Smith, J.A., Flowers, P. & Larkin, M. (2022) *Interpretative Phenomenological Analysis: theory, method and research*. 2nd edn. Los Angeles: SAGE. University of Wales Trinity Saint David (2022a) *Research data management Policy* (V2.0). Available at: https://www.uwtsd.ac.uk/about/governance-and-management/strategies-and-policies (Accessed: 12 December 2024). University of Wales Trinity Saint David (2022b) *Research ethics and integrity code of practice*. Available at: https://www.uwtsd.ac.uk/media/uwtsd-website/content-assets/documents/research/REICoP-July-2022.pdf. (Accessed: 22 October 2024). *(this box should expand as you type)*
6	**Environmental risks** For example: accidental spillage of pollutants, damage to local ecosystems	
	Risk to the environment: N/A *(this box should expand as you type)*	*How you will mitigate the risk to environment:* *(this box should expand as you type)*

	Disclosure and Barring Service			
	If the research activity involves children or vulnerable adults, a Disclosure and Barring Service (DBS) certificate must be obtained before any contact with such participants.	**YES**	**NO**	**N/A**
7	Does your research require you to hold a current DBS Certificate?	☐	☒	☐
8	If YES, please give the certificate number. If the certificate number is not available, please write "Pending"; in this case any ethical approval will be subject to providing the appropriate certificate number.			

SECTION I: Feedback, Consent and Confidentiality

1	**Feedback** What de-briefing and feedback will be provided to participants, how will this be done and when?

	Following the interview, the participant will receive a telephone debriefing. Any questions they may have will be addressed, and they will have opportunity to discuss how they felt the interview went. The participant will be reminded of their rights during the study, including their right to withdraw from taking part at any time during the research process.
2	**Informed consent** Describe the arrangements to inform potential participants, before providing consent, of what is involved in participating. Describe the arrangements for participants to provide full consent before data collection begins. If gaining consent in this way is inappropriate, explain how consent will be obtained and recorded in accordance with prevailing data protection legislation.
	Every attempt will be taken to guarantee that the participant entered the study voluntarily and freely and gave their prior consent after being fully informed. Before the interview begins, the participant will get a letter of explanation of what informed consent (Smith, Flowers & Larkin, 2022, p. 48) is, which they must sign before any interview or data collection may begin. **Reference** Smith, J.A., Flowers, P. & Larkin, M. (2022) *Interpretative Phenomenological Analysis: theory, method and research*. 2nd edn. Los Angeles: SAGE.
3	**Confidentiality / Anonymity** Set out how anonymity of participants and confidentiality will be ensured in any outputs. If anonymity is not being offered, explain why this is the case.
	Participants will be informed that all research will be confidential and that the data that is collected will be anonymised which means they will be given a different and agreed pseudonym to protect both the identity and that of their family. Smith, Flowers and Larkin (2022, p. 48) emphasise that whilst anonymity should be offered to participants, confidentiality can be more complex if other members of an immediate research team see the data. However, in this single participant study, unless my supervisor requests otherwise, I intend to be the only person to see the raw data. The analysed data will be masked in the results table so that both the participant, their child and family cannot be identified by any readers of the study (Uwe, 2023, p. 130). **References** Smith, J.A., Flowers, P. & Larkin, M. (2022) *Interpretative Phenomenological Analysis: theory, method and research*. 2nd edn. Los Angeles: SAGE. Flick, U. (2023) *Introduction to qualitative research.* 7th edn. London: Sage Publications. *(this box should expand as you type)*

SECTION J: Data Protection and Storage

	Does the research activity involve personal data (as defined by the General Data Protection Regulation 2016 “GDPR” and the Data Protection Act 2018 “DPA”)?	**YES**	**NO**
1	***“Personal data”*** *means any information relating to an identified or identifiable natural person (‘data subject’). An identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person. Any video or audio recordings of participants is considered to be personal data.*	☒	☐
	If YES, provide a description of the data and explain why this data needs to be collected:		
2	Interpretative Phenomenological Analysis often involves in person interviews which are recorded by audio and transcribed so that they can be coded by the researcher from which meaningful deep insights can be gained. This type of data collection is recommended by IPA research experts, Smith, Flowers and Larkin (2009, pp. 64–66; 2022, pp. 54–56) who are the current experts on this type of research approach and methods.		

	References: Smith, J.A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: theory, method and research*. London: SAGE. Smith, J.A., Flowers, P. & Larkin, M. (2022) *Interpretative Phenomenological Analysis: theory, method and research*. 2nd edn. Los Angeles: SAGE. *(this box should expand as you type)*		
	Does it involve special category data (as defined by the GDPR)?	**YES**	**NO**
3	***"Special category data"*** *means sensitive personal data consisting of information as to the data subjects' –* *(a) racial or ethnic origin,* *(b) political opinions,* *(c) religious beliefs or other beliefs of a similar nature,* *(d) membership of a trade union (within the meaning of the Trade Union and Labour Relations (Consolidation) Act 1992),* *(e) physical or mental health or condition,* *(f) sexual life,* *(g) genetics,* *(h) biometric data (as used for ID purposes),*	☐	☒
	If YES, provide a description of the special category data and explain why this data needs to be collected:		
4	*(this box should expand as you type)*		

	Will data from the research activity (collected data, drafts of the thesis, or materials for publication) be stored in any of the following ways?	**YES**	**NO**
5	Manual files (i.e. in paper form)?	☒	☐
6	University computers?	☐	☒
7	Private company computers?	☐	☒
8	Home or other personal computers?	☒	☐
9	Laptop computers/ CDs/ Portable disk-drives/ memory sticks?	☐	☒
10	"Cloud" storage or websites?	☐	☒
11	Other – specify:	☐	☒
12	For all stored data, explain the measures in place to ensure the security of the data collected, data confidentiality, including details of backup procedures, password protection, encryption, anonymisation and pseudonymisation:		
	I have a secure and separate study room where my computer is stored, on which all research data will be held until such time it is not needed in accordance with the *Data Protection Act 2018*. This room is always locked when not being used. My computer is also password protected (encrypted) and only I know the password. **Reference** *Data Protection Act 1998*, c. 29. Available at: https://www.legislation.gov.uk/ukpga/1998/29/schedule/1/enacted (Accessed: 12 December 2024). *(this box should expand as you type)*		

	Data Protection		
	Will the research activity involve any of the following activities:	**YES**	**NO**
13	Electronic transfer of data in any form?	☒	☐
14	Sharing of data with others at the University outside of the immediate research team?	☐	☒

15	Sharing of data with other organisations?	☒	☐
16	Export of data outside the UK or importing of data from outside the UK?	☐	☒
17	Use of personal addresses, postcodes, faxes, emails or telephone numbers?	☒	☐
18	Publication of data that might allow identification of individuals?	☐	☒
19	Use of data management system?	☐	☒
20	Data archiving?	☒	☐

21 If YES to any question, please provide full details, explaining how this will be conducted in accordance with the GDPR and Data Protection Act (2018) (and any international equivalents, where appropriate):

The audio transcription file will be sent from my computer which is password protected to a trustworthy audio transcriber (University Transcription Services, 2022) who will then return it to me for analysis. Data analysis involves coding by hand on paper (Smith, Flowers & Larkin, 2009, pp. 183–184; 2022, pp. 153–154) and the results will be recorded in table for my dissertation. A well-documented audit trail of all research work undertaken will be kept throughout which I can show my supervisor on request if necessary.

To ensure that data is protected and secure and that participants cannot be identified, I will use a university authorised encrypted audio recording device and transcription service on advice from the university's IT Department.

When the dissertation is complete and accepted by the supervisor, it will be securely uploaded and stored on the university's repository.

The audio recording will take place at a private meeting room in a safe and secure civic building (North Horsham Parish Council, 2022). I have a separate researcher's mobile telephone number to contact the participant to arrange the interview. The participant has provided a mobile phone number for me to contact them on. This information will only be kept for a as long as is necessary according to chapter 29 of the Act (*Data Protection 2018*) and GDPR principles (Intersoft Consulting, 2016). I can provide the participant with data they request by calling them and arranging to meet at the interview venue. Therefore, no personal addresses or e-mails are needed for this research to take place.

References

Data Protection Act 1998, c. 29. Available at: https://www.legislation.gov.uk/ukpga/1998/29/schedule/1/enacted (Accessed: 12 December 2024).

Intersoft Consulting (2016) *Chapter 2 – principles | general data protection regulation* General Data Protection Regulation (GDPR). Available at: https://gdpr-info.eu/chapter-2/. (Accessed 12 December 2024).

North Horsham Parish Council (2022) *Roffey Millennium Hall*. Available at: https://northhorsham-pc.gov.uk/halls-for-hire/roffey-millennium-hall/ (Accessed: 24 November 2024).

Smith, J.A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: theory, method and research*. London: SAGE.

Smith, J.A., Flowers, P. & Larkin, M. (2022) *Interpretative Phenomenological Analysis: theory, method and research*. 2nd edn. Los Angeles: SAGE.

University Transcription Services. (2020) *University of Wales Trinity Saint David – University Transcription Services*. Available at: https://universitytranscriptions.co.uk/university-of-wales-trinity-saint-david-2/ (Accessed: 12 October 2024).

(this box should expand as you type)

22 List all who will have access to the data generated by the research activity:

- Emma-Louise Johnson – Researcher/student
- Darrel Williams – Supervisor

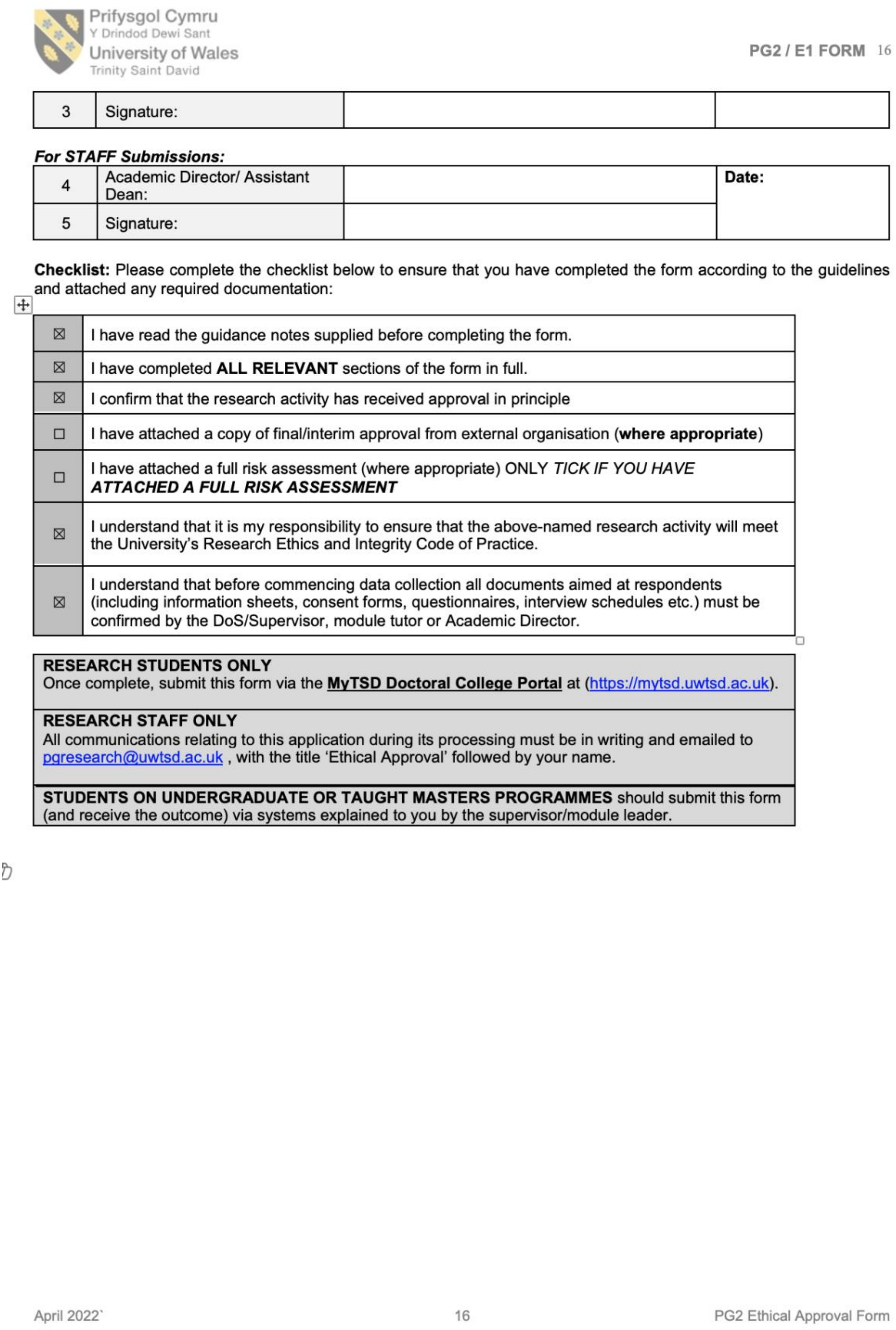
	(this box should expand as you type)		
23	List who will have control of, and act as custodian(s) for, data generated by the research activity:		
	Emma-Louise Johnson *(this box should expand as you type)*		
24	Give details of data storage arrangements, including security measures in place to protect the data, where data will be stored, how long for, and in what form. Will data be archived – if so how and if not why not.		
	Data will be stored on my password encrypted secure personal computer and kept for as long as is necessary according to Chapter 29, Part 1 of the *Data Protection Act 1998.* Guidelines on the use of data will also be followed according to ICO (2022) General Data Protection Regulation (GDPR) (Intersoft Consulting, 2016) principles. This study is a pilot for my doctoral dissertation and may therefore be kept for up to six years after it has been collected. It can also be stored on the university's One Drive as per my supervisor's instructions. The participant will be informed beforehand of how their data is being kept and for how long a period before beginning the research. I am trained in the handling of data as a qualified Independent Advocate as part of my training with Black Belt Advocacy (2024) by Kate Mercer. **References** *Data Protection Act 2018,* c. 29. Available at: https://www.legislation.gov.uk/ukpga/1998/29/schedule/1/enacted(Accessed: 28 November 2024). ICO (2022) *General data protection regulation (GDPR).* Available at: https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/principles/ (Accessed: 28 October 2024). Intersoft Consulting (2016) *Chapter 2 – principles | general data protection regulation* General Data Protection Regulation (GDPR). Available at: https://gdpr-info.eu/chapter-2/. (Accessed: 12 December 2024). Kate Mercer Training (2024) *Advocacy Courses Qualifications | United Kingdom | Black belt advocacy*. Available at: https://www.blackbeltadvocacy.com/ (Accessed: 25 November 2024). *(this box should expand as you type)*		
25	Please indicate if your data will be stored in the UWTSD Research Data Repository (see https://researchdata.uwtsd.ac.uk/). If so please explain. (*Most relevant to academic staff)*		
	The results of the data will be stored in the UWTSD Research Data Repository and my MA dissertation submitted to the repository on successful completion. *(this box should expand as you type)*		
26	Confirm that you have read the UWTSD guidance on data management (see https://www.uwtsd.ac.uk/library/research-data-management/)	**YES**	☒
27	Confirm that you are aware that you need to keep all data until after your research has completed or the end of your funding	**YES**	☒

SECTION K: Declaration

	The information which I have provided is correct and complete to the best of my knowledge. I have attempted to identify any risks and issues related to the research activity and acknowledge my obligations and the rights of the participants. In submitting this application I hereby confirm that I undertake to ensure that the above named research activity will meet the University's Research Ethics and Integrity Code of Practice which is published on the website: https://www.uwtsd.ac.uk/research/research-ethics/		
1	**Signature of applicant:**	Emma-Louise Johnson	**Date: 12/12/24**

For STUDENT Submissions:

2	Director of Studies/Supervisor:	Darrel Williams	**Date:**



Prifysgol Cymru
Y Drindod Dewi Sant
University of Wales
Trinity Saint David

PG2 / E1 FORM 16

3	Signature:		

For STAFF Submissions:

4	Academic Director/ Assistant Dean:		**Date:**
5	Signature:		

Checklist: Please complete the checklist below to ensure that you have completed the form according to the guidelines and attached any required documentation:

☒	I have read the guidance notes supplied before completing the form.
☒	I have completed **ALL RELEVANT** sections of the form in full.
☒	I confirm that the research activity has received approval in principle
☐	I have attached a copy of final/interim approval from external organisation (**where appropriate**)
☐	I have attached a full risk assessment (where appropriate) ONLY *TICK IF YOU HAVE* ***ATTACHED A FULL RISK ASSESSMENT***
☒	I understand that it is my responsibility to ensure that the above-named research activity will meet the University's Research Ethics and Integrity Code of Practice.
☒	I understand that before commencing data collection all documents aimed at respondents (including information sheets, consent forms, questionnaires, interview schedules etc.) must be confirmed by the DoS/Supervisor, module tutor or Academic Director.

RESEARCH STUDENTS ONLY
Once complete, submit this form via the **MyTSD Doctoral College Portal** at (https://mytsd.uwtsd.ac.uk).

RESEARCH STAFF ONLY
All communications relating to this application during its processing must be in writing and emailed to pgresearch@uwtsd.ac.uk , with the title 'Ethical Approval' followed by your name.

STUDENTS ON UNDERGRADUATE OR TAUGHT MASTERS PROGRAMMES should submit this form (and receive the outcome) via systems explained to you by the supervisor/module leader.

April 2022` 16 PG2 Ethical Approval Form

(Johnson, 2025a)

7.2. Appendix 2 Proposal Form

Institute of Education and Humanities/
Yr Athrofa Addysg a'r Dyniaethau

MA Dissertation Approval Form/
Ffurflen Gymeradwyo Traethawd Hir MA
ECGE7002Q/ECED7010

Student Name/ *Enw Myfyriwr*	Emma-Louise Johnson		
Degree Scheme/ *Cynllun Gradd*	MA – Equity and Diversity in Society		
Start date/ *Dyddiad cychwyn*	01/10/24	End Date / Dyddiad TBC	30/09/25

Title of Dissertation/*Teitl eich Traethawd Hir*
Parent Carer Agency: Exploring the Lived Experience of Advocating for a Disabled Child *[Child with a Disability] While Engaging with Professionals and Institutions
Research Question/Cwestiwn Ymchwil
• RQ) What is the lived experience of agency for parent carers advocating for a disabled child *[a child with a disability'] while engaging with professionals and institutions?
Aims and Objectives/*Nodau ac Amcanion*
Aim: Understand the lived experiences of parent carers who provide primary care for their child – with a specific focus on the experience of agency for parent carers advocating for their child with a disability while engaging with professionals and institutions. Objectives: • Understand the impacts parent carers experience when providing primary care for their child. • Understand the barriers that parent carers face when seeking help for or raising concerns about their child's care. • Identifying factors that would improve the parent carer's experience when advocating for their child's care. • Gain insights from an in-depth, rich single participant data for my doctoral dissertation.

- Harness insights into a parent carer’s lived experience of agency to inform policy and professional practice.

*** NB: In the final dissertation, the researcher changed the disability language from person-first to identity-first to align with the social model of disability (see Appendix 11).**

Outline of your Dissertation/ Amlinelliad o'ch Traethawd Hir

Introduction

Caring for a disabled child can be a complex and challenging experience, requiring parents to navigate a myriad of systems and interactions with various professionals and institutions across various sectors of social care, health and education. Existing research has shown that parent carers fulfil multiple roles, including advocating for their child, and that part of this informal advocacy role includes giving voice to concerns about their child’s care (Wright & Taylor, 2014, p. 591). As informal advocates tasked with securing their children’s care, parent carers experience additional systemic and personal barriers to the reduced power dynamic when requesting help. Such obstacles include UK neoliberal policies and austerity measures, which Walmsley *et al.* (2017, p. 1366) have noted add to the necessity of understanding the lived experience of carers, which can aid ‘family-centred care’. Given the increasing prevalence of children identified with disabilities in the UK and throughout the world (Kirk-Wade, Stiebahl & Wong, 2024, pp. 5, 8; Olusanya *et al.,* pp. 1–2, 2022) and the recognised significance of parental support for their child’s psycho-emotional wellbeing and outcomes—albeit with limited research on children with disabilities (Kagan, 1999, p. 164; Dyches *et al.,* 2012, pp. 2213–2215)—it is vital that more research is conducted on the lives of parent carers as well as their children and that it relates to this issue of lack of parental agency in the advocacy relationship as it is directly experienced. This research can thereby contribute to the broader topic of parent carers’ lived experiences (Johnson, 2023d).

Whilst the UK Government and government bodies like the NHS have recognised the importance of parent carers’ voice as participation on policy making and their socio-economic contribution of care, as noted in a report by Boughey & McSherry (2019, pp. 23–28). A subsequent key report by Clement and Aeillo (2021, p. 6–7; Johnson, 2023a, p.6; 2023b, p. 1; 2023c, pp, 3,7; 2023d, p. 4; 2024a, p. 8) questioned the effectiveness of professionals and government run organisations to engage fairly and effectively with one of the most deprived groups in the country. Despite the urgency of the issue of parent carer blame its related negation of parent carer agency and voice (Clements & Aiello, 2021, p. 2), a more recent report by the Association of Directors of Adult Social Services ((ADASS), 2024) has found discriminatory practices continue from professionals to parents across all the main services. Past and recent research (Lipkin & Crepeau-Hobson, 2022, p. 1546; Todd & Higgins, 1998, pp. 227–236) confirms Clement and Aiello’s (2021) research findings that parent carers feel powerless, lacking agency and voice when seeking help and support for their children. These studies highlight the *tangible* nature of lived experience of marginalised groups of health and service care users, and which is increasingly recognised by policy makers (The Scottish Government, 2022; Lefton & Fleming, 2024; Williams, 2024). The need for theoretical research to bring about actual change provides the impetus, rationale, and choice of interpretive Phenomenological Analysis (IPA) design combined with post data collection interpretation through a social justice lens.

Rooted in phenomenological philosophy and research, lived experience is therefore well suited to this type of study. Although it has various meanings, lived experience can be described as a first-hand experience of any experience (Chandlar & Munday, p. 270). Similarly, the term agency like its relation 'power', is as Gidden and Sutton have stated (2021, p. 95), a central debated issue in sociology and the structure-agency debate. The nuances of these terms as concepts will be explored later in the paper, however an indicative definition of agency can be given according to Payne (2021, pp. 13–14) as the power and capacity to influence decisions on behalf of their children. Parent carers' lack of agency, therefore, is reflected in their beliefs that they are not viewed as capable in their decision-making, and they are both unseen and unheard by professionals and their respective institutions (Johnson, 2023d, p. 7). Agency will be examined as a convergence of influence and power within the parent-professional relationship, intersecting with the associated ideas of voice and choice. These concepts will be enlivened by application to a parent carer's lived experiences in a normal, everyday taken-for-granted situation, which phenomenology is good at showing (Smith, Flowers & Larkin, 2022, p. 8). Agency will be examined as a convergence of influence and power within the parent-professional relationship, intersecting with the associated ideas of voice and choice. These concepts will be enlivened by application to a parent carer's lived experiences in a normal, everyday taken-for-granted situation, which phenomenology is good at showing (Smith, Flowers & Larkin, 2022, p. 8). The use of a diary also aids reflexivity and is recommended by Smith, Flowers and Larkin (2009, p. 57; 2022, p. 54; Johnson, 2023d, p. 13).

After data collection, insights and emergent themes will be further analysed, from which insights can be drawn and used in a larger study for the doctoral dissertation. As the work of Smith, Flowers and Larkin (2009; 2022) showcases and Delve and Limpaecher (2023) concur, IPA has an inherent flexibility compared to other forms of research methods that it can be combined with a variety fields and perspectives. For this study, the IPA approach will be combined with a social justice perspective, to analyse a parent carer's experience of when advocating for services and support for their child. Possible emerging themes will be related to the dissertation aims and objectives and as a pilot for a wider study. Emergent themes may be the implications for individual agency, autonomy, and voice in the context of parents being required to engage with professionals and institutions with varying levels of power when seeking services on behalf of their children.

The initial motivation behind this study is the lived experience of the researcher. Each stage of the research design and its interpretivist-constructivist framework or paradigm, as originally defined by Guba and Lincoln (1994, p. 7; Johnson, 2023d, p. 14) as based on the researcher's 'worldview', will align with the overall aim to understand the lives parents who provide primary care for a disabled child or child/children with a disability, with a focus on the lived experience of agency and its lack thereof. To achieve this aim, the study seeks to fulfil each objective of understanding the impacts (Moody, 2022) in a qualitative sense of parent carers experience when providing primary care for their child, the barriers that parent carers face when seeking help for or raising concerns about their child's care which should allow the identification of factors that would improve the parent carer's experience when advocating for their child's care. This study aims not only to benefit parent carers, but the rich, in-depth data can help inform professional practice, creating what this author has termed an 'empathetic bridge' (Johnson, 2023d, p. 14) between parents and professionals. From a social justice vantage, research that empowers a disadvantaged group with a known low socioeconomic status (Wyjadlowska *et al.,* 2024, p. 3) can also help on a macro level. Authors Picket and Wilkinson (2015) and Dorling (2010; 2015) are vocal in noting the impact of inequality on health and well-being, regardless of a person's geographical location and social status. This study will support the view that there is a need for further, in-depth research into the lives of parents caring for a disabled child.

The following literature review illustrates how the lived experience of parent carers has received little and sporadic attention in research despite the growing awareness of policymakers mentioned earlier in this section. The barriers and challenges of parenting a child with a disability will be discussed and analysed, as will the daily issues this marginalised and disadvantaged group faces due to their demanding role. The connections between agency and voice and choice will be explored in the context of a parent carer's lived experience and posited as the reason for the choice of IPA which, as Smith, Flowers and Larkin (2009, pp. 1–2; 2022, pp. 1–3) relate, can uncover how an individuals can make sense of their lived experience. The following review of the current deficit of in-depth data on the experiences of parent carers will support the view that further research is needed to fulfil the study's aims and objectives.

Literature Review

- Introduction

As has been previously stated, the complexity and importance of parent carers' role in ensuring their children's wellbeing is known. A central aspect of the parent carer's function is advocating for their children to secure services from professionals and their respective organisations or institutions. Yet recent and past literature on the lives of parent carers is less than that of disability studies generally (Johnson, 2023, p. 3; Cameron, 2014). A search of literature revealed there are a small number of studies of lived experience for parent carers focussing mainly on the caring element, for instance in a study carried out a study by Cook, Tovin and Kenyan (2022, p.1). There is a reasonable though limited amount of research on the advocacy role of parent carers (Johnson, 2023b) and also studies of the disempowerment of parents. This powerlessness was highlighted in Clement and Aeillo's (2021) landmark study which suggested a lack of agency of parent carers when engaging with professionals. However, there are very few studies such as that by Bergström *et al.,* (2014), which have studied the lived experience of agency. Research has not yet fully explored this phenomena of parent carers experiencing and attempting to make sense of their need for and lack of agency when they adopt the advocacy role. This gap in research is the impetus for this study powerlessness of parent carers with the importance of lived experience in research and social policy which has been raised by the following authors.

Lived experience in policy and research
In both theory and methodology, Mcintosh and Wright (2018, p. 463; Johnson, 2023d, p. 2) stress the importance of understanding lived experience for social policy. Similarly, Given (2008) emphasizes the role of lived experience in shaping knowledge. Lived experience intersects therefore with a framework that considers the axes of agency, knowledge, power and research in a way that is fruitful for understanding parent carer's experiences. The broader aim of this research is, therefore, to explore the experience of a parent as primary care giver of a child with disability, focusing on the lack of agency

with professionals and institutions, in their role of informal advocate for their children when securing services. The scarcity of research in this area, has influenced the choice of IPA as a research approach. IPA's idiographic nature is well suited to rich data lived experience studies (Smith, Flowers & Larkin, 2009; p. 29; 2022, p. 3).

Advocacy by parent carers
Research shows both positive and negative impact of parents advocating for their children which is part of the parent carer role. Authors like Wang *et al*. (2004, p. 114) have stated parent carer advocacy has a dual effect of creating resilience as well as stress. Their findings contrast other studies such as Rios, Aleman-Tovar and Burke (2021) whose studies have emphasised the stressfulness of parent carer's unsought advocacy role. Nevertheless, these researchers agree that parent carers' first-hand knowledge can make a valuable contribution in partnership with professionals.

For the purposes of this study, the following definitions will be used in accordance with UK law.

- **Disability: Definitions and Legislation**

    - Advocacy is defined according to Payne (2021, p. 6) as 'speaking on behalf of or in the interests of a person or group of people'. Parent carers informally advocate for their children in contrast to legal or formal advocacy that currently exists in the UK (Johnson, 2023b, c).

    - Agency is a widely debated term in sociology but is defined according to Payne (2021, pp. 13–14) as parent carers' power and capacity to influence decisions on behalf of their children.

    - Child is defined according to UK law as section 105 and 3 of the Acts (*Children Act 1989; Social Services and Well-being (Wales) Act 2014a*), as being anyone under the age of 18. This is also in Article 1 of the Convention on the Rights of the Child (1989) which the UK has ratified.

    - Disability is defined in section 6 of the *Equality Act 2010* as a person with a physical or mental impairment who has 'as a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.'

    - Experts by experience (Ebe) is defined as people with lived experience of an area of knowledge (Davies, 2024, para. 1) . Parent carers have lived experience of advocating for their child or children in cross sector services in health, education and social care.

    - Institution has multiple meanings that have changed throughout history according to Scott (2008, pp. x, 8–9). In the context of parent carers as seeking services for their children, it is defined according to Rojas (2013, para. 1) as a 'formal social structure that governs a field of action'. This definition combines the contrasting definitions of Riojas (2013) who defines institutions as the same with that of Giddens and Sutton (2021, pp. 91–94) who view them as separate. This allows for the difference of Government with governmental departments and organisations such as the Department for Health and Social Care and the NHS. It also allows for what Scott (2008, p. 50) calls the regulatory and cultural components of institutions that emphasises the ‘total’ nature of institutions as emphasised by Goffman (1961, p.11; Johnson, 2024a, p. 2) in his work, *Asylums*.

  - Lived experience refers to a person’s direct engagement with their environment and the knowledge and understanding they get from it. Chandler and Munday’s (2011, p. 270) first definition notably relates to subsequent phenomenological notion of lived experience, which pertains to the significance of the quotidian, often overlooked, aspects of an individual's life.

  - Parent carer is defined in section 97 of the *Children and Families Act 2014* as ‘a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility’. In section 97 of the Act (*Children and Families Act 2014*) and section 24 of Welsh legislation (*Social Services and Well-being (Wales) Act 2014b*) local authorities have a duty to assess parent carers’ needs for support if it is needed.

- **Parent Carer of a Child with a Disability: Challenges and Responsibilities**

  - Parenting a child with a disability involves challenges and responsibilities that are beyond that of usual parenting with parent carers having to fulfil multiple roles. Parent carers can face systemic and personal barriers to securing care for their child. One of the central responsibilities of parent carers requires them to take on the systemic role of informal advocates for their children, and this is an informal type of advocacy which differs to legal and professional advocacy (Bateman, 2000, p. 18; Johnson, 2023a, p. 7; Johnson, 2023c, pp. 2, 6, 8, 21). However, one of the main barriers to effective advocacy, which has been mentioned, includes parents lack of agency with them feeling powerless when seeking help and support for their children with disabilities (Lipkin & Crepeau-Hobson, 2022, p. 1546; Todd & Higgins, 1998, pp. 227–236).

  - Whilst being a parent carer can have both positive and negative on caregiver’s health according to Phillips *et al*. (2022, p.1), whose scoping review was carried out to address the gap in literature that compared both sides of the care experience, recent research shows overall that parent carers experience significant stress levels that negatively affect their wellbeing (Cheng & Lai, 2023, pp. 1–2; Scheibner *et al*., 2024, pp. 1–2). These challenges include the impact on their health and social well-being because of the demanding nature of care.

  - Although the necessity for effective collaboration between parents and professionals is known (Reeder & Morris, 2020, pp. 110–112), it has so far been hindered by professionals' inability to recognise the value of parent carers' knowledge gained from their multifaceted status as advocates of their children, the barriers parent carers face when securing care for a child with a disability and the personal impact of these processes on health and wellbeing. The professional and institutional undervaluing of lived experience as knowledge ironically contributes to the lack of agency within the parent to professional relationship. The consequent powerlessness of parent carers in their capacity as decision makers for their children is discussed in relation to agency, voice and choice in the next section.

- **Parent carers' Lived Experience of Agency, Voice and Choice in Engaging with Professionals and Institutions**

  - Agency, voice and choice are closely connected as concepts and in lived experience of an individual. These will be explored as they relate to parent carers when advocating for their children covering the sub components of each.

  - Having analysed and clarified the connections between agency, voice and choice through the available literature and within the context of a parent carer advocating for their child and the necessary engagement with professionals and their institutions that entails, this section will emphasise the suitability of IPA analysis of exploring the lived experience of a parent carers of agency as autonomy and control.

- **Conclusion**

  - Lived experience is becoming increasingly important in social policy and phenomenological research (Johnson, 2023d, p 14; McIntosh & Wright, 2018). Although phenomenology may have its detractors (Paley, 2016), more recent forms of analysis, such as interpretive phenomenological analysis (IPA), provide an innovative means of highlighting the perspectives of marginalised and under-represented groups, like parents of children with disabilities, giving them a voice and allowing for an in-depth expression of their experiences. When outcomes are further analysed and interpreted from a social justice perspective which recognises as Dorling's (2010; 2015; Johnson, 2024b, pp. 2, 6, 9, 10) works have argued that inequality harms the whole of society this strategy gains even greater traction and has the potential to influence societal change.

Methodology and Methods

- **Introduction**

  - The choice of IPA Analysis approach with the concomitant methods aligns with the purpose of this study which is to explore the lived experiences of agency of a parent carer when advocating for their child with a disability while engaging with professionals and institutions. The approach also aligns with the researcher's interpretivist ontological stance which views the world as fluid and dynamic nature of the world and mean-making within that world and the epistemological view that knowledge is not objective as positivists believe but constructed. As such, lived experience can be equal to that of theoretical knowledge. Thus, this researcher's views and lived experience shaped the choice of a phenomenological approach which in its combination of theory and research recognises the value of first-hand knowledge as agreed on by Smith, Flowers and Larkin (2009: 2022) and Van Manen (2014; 2016). This experience of agency and the lack thereof when parent carers engage with professionals and institutions forms a significant part of the overall aim of understanding the lived experience of this group. The literature review has shown that lived experience of parent carer agency has received little attention and that research gap is the rationale for this study and the paradigmatic choices that have been made from the original research question through to the choice of the IPA approach otherwise known as the methodology.

- **Context of Study**

  - This study takes place in the context of ongoing issues identified in research of the parent carer agency when advocating for services and for the entitlements of those services through engagement with professionals and institutions. The denial of voice agency and choice previously discussed is encapsulated in parent carer blame, a type of discrimination highlighted by the ongoing work of Cerebra (2024) Professor of Law, Luke Clements (2024). Despite an MP of the government at that time stressing the urgency of a response (Clements & Aiello, 2021, p. 2) these issues remain unresolved with Clements (2023) highlighting a more recent NHS England commissioned report by the Association of Directors of Adult Social Services (ADASS), 2024) which shows that parent carers are still being treated unfairly across health and social care sectors.

  - Although these reports show that current literature exists on parent carers as informal advocates for their children, there is yet the research to uncover the deeper meanings and insights into the essence of this experience and the lack of agency that ensures from this form of engagement. This paucity of in-depth research on the lived experience of parent carers of agency within advocacy element of their role has shaped the choice of IPA as an approach and the methods used within it, the justification of which will be discussed in the next section.

The research design is therefore chosen to align with the study's aims which is to understand the lived experiences of parent carers who provide primary care for their child – with a specific focus on the experience of agency for parent carers advocating for their child while engaging with professionals and institutions. The objectives to achieve this aim are reiterated as follows and they are to:

- Understand the impacts parent carers experience when providing primary care for their child.
- Understand the barriers that parent carers face when seeking help for or raising concerns about their child's care.
- Identifying factors that would improve the parent carer's experience when advocating for their child's care.
- Gain insights from an in-depth, rich single participant data for my doctoral dissertation.
- Harness insights into a parent carers' lived experience of agency to inform professional practice.

- **Justification for Methodology**

  - As the previous section notes, there is some recent literature that highlights the issues of parent carer agency and its urgency to be addressed in social policy. Clements and Aiello's (2021, pp. 23–24) mixed methods report and ADASS's systemic review credible according to research standards providing as Peričić and Tanveer (2019, para. 9) have stated, a useful topic overview and gaps in understanding. These gaps have provided an impetus for this research and can supplement it, but they do not give an in-depth analysis on the experience of agency as power imbalance within the advocacy relationship between parent carers and professionals is scarce. IPA's main concern in theory, method and practice is as Smith, Flowers and Larkin (2022) maintain throughout their work, the examination of human lived experience.
  - Although the value of lived experience and, its meaning and suitability for research has been questioned by critics such as Paley (2017) exploring first-hand experience, concretises the exploration of agency and problematic power relations between a marginalised and more powerful group in the parent-professional relationship and in doing so, agency as concept becomes agency as experience. Paley's (2017) criticisms nevertheless provide a benchmark by which to measure the trustworthiness of this approach and in meeting his questions at last part of the way, the criteria for what is trustworthy in qualitative research can be

met. To reiterate once more, the justification for IPA Analysis is to uncover rich in-depth data on parent carer lives.

  - In order to recover this rich data, an interpretivist-constructivist – An Interpretivist research philosophy is adopted as per Lincoln, Lynham and Guba's (2024, p. 81) well known and useful paradigmatic categories, focussing on the interpretation and understanding of the behaviour of human beings and social phenomena whilst recognising the importance of experiences. However, IPA also recognises that knowledge is constructed between the researcher and the participant (Flick, 2023, p. 29; Smith, Flowers & Larkin, 2022, pp. 119–120) with the latter co-producers in the research process.

- IPA Analysis

  - IPA analysis according to Smith, Flowers and Larkin (2022, p. 75) is about process and principle with flexibility and a researcher commitment to the participant necessary. The authors have provided an up-to-date guide on how to carry out the analysis in Chapter 5 of their most recent guide (Smith, Flowers & Larkin, 2022, pp. 75–108) which updates their first book, *Interpretative Phenomenological Analysis* (2009, pp. 79–107) describing how to carry this type of research.

- Sampling

  - Purposive sampling (Creswell & Creswell, 2023, p. 198) was used in this study and this was based on the research aims, and approach. The rationale for the sampling is that a small purposive sample better aligns with understanding meanings in qualitative research IPA approach. A single participant parent carer of a child with disability who regularly engages with professionals and institutions as part of their role was therefore sought through a local charity, West Sussex (West Sussex Parent Carer Forum (WSPCF), 2024. The participant contacted me by e-mail shortly afterwards, followed by a telephone conversation in which I made sure that the participant understood what the research involved. Before agreeing to take part in the study, the participant was verbally reassured about the ethical considerations including anonymity, informed consent and confidentiality in the handling of data.

- **Interviewing/IPA**

  - Initial informal short interview.

  - Main semi-structured interview 2–3 hours including the use of visual media (Smith, Flowers & Larkin, 2009, pp. 57–78; Pink, 2013). To take place in an agreed area which is safe for both the participant and the interviewer.

  - Smith, Flowers and Larkin (2009, pp. 56–78; 2022, 2022, pp. 53–73) recommend the semi-structured interview as a way of collecting rich detail and accounts of personal experiences best relayed in the first rather than the third person.

- **Research Diary**
    - Reflexivity – A research diary is part of IPA Analysis (Smith, Flowers & Larkin, 2009, p. 57; 2022, p. 54). IPA recognises that meaning is co-constructed and that a 'double hermeneutic' (Smith, Flowers & Larkin, 2009, pp. 35–36, 80; 2022, p. 29) takes place between the researcher and participant in the interpretative process in which the researcher focusses on the participant who is then focussed on their own experience.
- **Ethics**
    - The study will follow university guidelines on ethical practices (University of Wales Trinity Saint David, 2022).
    - The methods used like the research diary encourage reflection and the research is aware of the responsibility of what feminist authors Kitzinger and Wilkinson (1996, pp. 1–32) have called 'representing the other'.
    - Informed consent (Johnson, 2023a, p. 9; Kumar, 2014, p, 285; Smith, Flowers and Larkin, 2009, pp. 53–54; 2022, pp. 48–50) will be sought from the participant before research begins and they will understand they have the right to withdrawal from the research at any time.
    - The guiding principle of ethical practice which is part of Smith, Flowers and Larkins (2022, pp. 47–50) remit is to avoid harm and take care in the handling of data so that participants can not only opt out of the research at data collection point but also at the point of sharing their data.
    - Data will be handled responsibly, according to the principles in chapter 29 of the Act (*Data Protection Act 2018)* and ICO (2022) guidelines which explain how personal data should be managed in accordance with this legislation.
- Trustworthiness etc
    - This is a pilot study (In, 2017) to identify what was previously called 'emergent themes' and is now known as 'experiential statements' for doctoral dissertation with the aim of identifying themes for 'cross-case analysis' (Smith, Flowers & Larkin, 2022, pp. 76, 100–104). This will allow for the researcher to hone skills in the pilot stage that can be used in the larger study.
    - IPA analysis values the position of the researcher and incorporates it into the methodological approach. It is a key element of reflexivity that ensures trustworthiness from the criteria of qualitative rather than quantitative

research. As Creswell and Creswell (2023, pp. 213–214) posit, validity is an asset of qualitative research and the clarification of position which could be interpreted as potential bias is strategically necessary at the proposal stage.

  - The reflexivity of the researcher mitigates the question of bias (Johnson, 2023d, p, 13; Kumar, 2014, p. 287). Smith, Flowers and Larkin (2009; p. 35; 2022, p. 54) recommend using a diary for the researcher to reflect on their position which for this study is one of being a parent carer with lived experience of the study group. They also advise the use of 'bracketing' of the researcher's position as part of this reflective process similar to that of hermeneutic phenomenologist, Van Manen (2014, p. 27; 2016, p. 175; Smith, Flowers & Larkin, 2009, p. 35; 2020, p. 29).

- **Data Analysis**

  IPA Analysis is iterative, idiographic, interpretative and in-depth according to Smith, Flowers & Larkin (2009, pp. 57–9, 60, 181; 2022, p. 119).

  - Researcher's diary will be kept throughout the study. Diary keeping assists reflexivity (Nadine & Cassell, 2006; Smith, Flowers & Larkin, 2009; 2022) and mitigates the question of bias.

  - It should be noted as per Smith, Flowers and Larkin (2022, p. 76) that key terms in IPA have now changed and these will be explained further as part of the analysis. A table of the key term changes will be provided in an appendix at the end of the study.

  - IPA's flexibility as an approach means, according to Smith, Flowers and Larkin (2009, p. 196; 2022, pp. 1410–141) it can be fruitfully combined with a social justice lens including critical theory and Foucauldian power analyses as chosen by the researcher according to what themes emerge. Since power is integral to agency, and to social justice theories, a critical lens can be applied to this experience of agency as a composite of power and autonomy in the experience of being denied or having a voice and choice within the advocacy relationship of parents and professionals.

Conclusion

The conclusion of the data analysis will allow for emergent themes with possible convergence and divergence as to the issue of parent carer agency.
The insights gained from a single case pilot study (In, 2017) will be discussed to inform the doctoral dissertation. The positive and negative aspects of using IPA analysis will be evaluated regarding how they fulfilled the study aims.

Conclusion and Recommendations

- Overview of your Dissertation.

- Then link your Research Question to your discussion.

- Then make Recommendation(s) Further research required. Reiterate this was a single case pilot study (Heale & Twycross, 2018, p. 7; In, 2017, p. 601) in which insights and themes can be further examined in a larger study for the doctoral dissertation (Smith, Flowers & Larkin, 2022, pp. 105–106).

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* Note in the final dissertation the researcher changed the disability language from first-person to identity first. See appendix 10.

Appendices

- **Appendix 1: Proposal Form**
- **Appendix 2: Ethics Form**
- **Appendix 3: TBC**

- ***‘**Impacts’ used in a qualitative sense of how the participant psycho- emotional experience of a phenomena. This will be qualified with reference to previous studies (Moody, 2022).

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Proposed Supervisor/*Goruchwyliwr awgrymedig*

Darrel Williams

Please indicate whether ethical approval for project is needed – YES/NO
Nodwch a oes angen cymeradwyaeth foesegol ar gyfer y prosiect - OES / NAC OES

Please indicate whether sufficient resources are available for the project – YES/NO
Nodwch a oes digon o adnoddau ar gael ar gyfer y prosiect - OES / NAC OES

The above topic, proposal, and supervisor have been agreed:
Cytunwyd ar y pwnc, y cynnig a'r goruchwyliwr uchod:

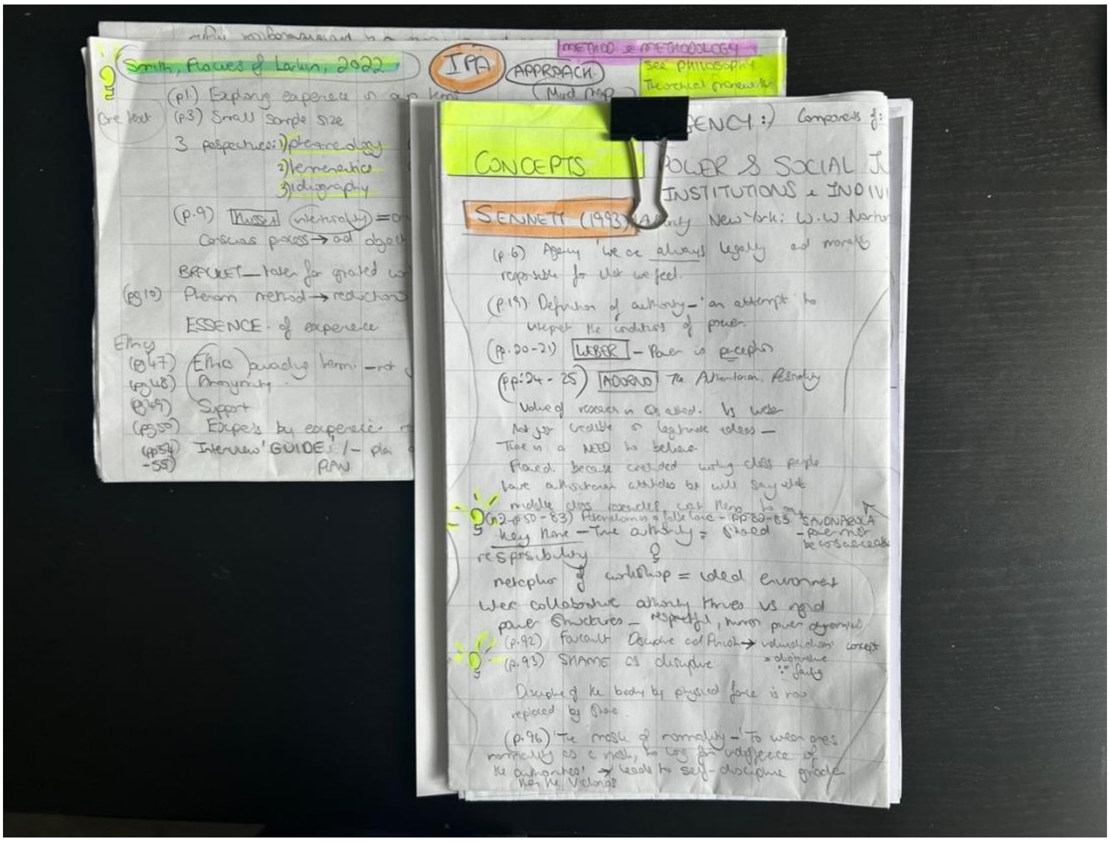
Signed : …………………………………………………..Programme Director/
Llofnod Cyfarwyddwr y rhaglen

Date:…………………………………………………
Dyddiad

Please return this form to your Programme Director.
Dychwelwch y ffurflen hon at eich Cyfarwyddwr Rhaglen.

(Johnson, 2025b)

7.3. Appendix 3 Researcher Note System



METHOD & METHODOLOGY

Smith, Flowers & Larkin, 2022

IPA

APPROACH

(Mind Map)

See PHILOSOPHY
Theoretical framework

Core text

(p.1) Exploring experience in

(p.3) Small sample size

3 perspectives: 1) phenomenology
2) hermeneutics
3) idiography

(p.9) Husserl (intentionality) =

Conscious process → and object

BRACKET — taken for granted

(pg 10) Phenom method → reductions

ESSENCE of experience

Ethics
(pg 47) Ethics avoiding harm — not
(pg 48) Anonymity
(pg 49) Support
(pg 50) Experts by experience
(pp 54-55) Interview 'GUIDE' / - pla
RAW

CONCEPTS

ENCY :) Components of:
POWER & SOCIAL J
INSTITUTIONS & INDIVI

SENNETT (1993) Authority New York: W.W Norton

(p.6) Agency 'We are always legally and morally responsible for what we feel.

(p.19) Definition of authority - 'an attempt to interpret the conditions of power.

(pp. 20-21) WEBER - Power is perception

(pp. 24-25) ADORNO The Authoritarian Personality

Value of research in [illegible] asked. Vs Weber
Not just credible or legitimate ideas —
There is a NEED to believe.
Flawed. because concluded working class people have authoritarian attitudes but will say what middle class researchers want them to say.

([illegible] - pp 50 - 83) Paternalism a false love - pp 82-83 SAVONAROLA - power must be [illegible]

key theme — True authority = shared responsibility

metaphor of workshop = ideal environment where collaborative authority thrives vs rigid power structures — respectful, human power dynamics

(p.92) Foucault Discipline and Punish → 'individualisation' concept = distinctive ∵ faulty

(p.93) SHAME as discipline

Discipline of the body by physical force is now replaced by Shame.

(p.96) 'The mask of normality - 'To wear one's normality as a mask, to long for indifference of the authorities' → leads to self-discipline [illegible] then the Victorians?

Source: Author's own

The image above shows sample pages from the researcher's analogue note system. This system was used to categorise themes, concepts, authors and theories in IPA and power and institutional theory. This separation of the strands of the research question helped to clarify the connections between the key study concepts of agency, advocacy, and lived experience within the context of a parent carer engaging with professionals and institutions when seeking help for their child. The lightbulb symbol highlights a key idea or concept for the researcher to remember.

7.4. Appendix 4 Research Diary Extracts

Extract 1. Being a Parent Carer Researcher: Positionality. 12 December 2025

I think it's good to reflect early on about my position as a lived experience researcher. As a parent carer, I have experienced discrimination and blame, and this led me to research the subject further. It's important to me that my study's participant is represented accurately and fairly and that this study is focused on them, whilst acknowledging that the resulting meaning is co-created. I am prepared and open to the results giving fresh insights on the live experience of a parent carer – adopting a phenomenological mindset!

Extract 2. Member Check, 11 April 2025

I met up with the participant, 'Charlotte' [the pseudonym she chose after the interview] today for the member check meet-up, and we went through the research findings so far to make sure that I am on the right track.

I was glad to hear that she felt I was 'spot on' with my analysis. She seemed pleased and surprised I had picked up on as much as I did. I can move on soon to the next stage of writing up the findings.

On a practical front, I asked if more breaks should have been offered as part of the meeting, and Charlotte replied that was a good idea. Talking about past upsetting events can be tiring. Doing a pilot before a broader study has been helpful on several levels, such as learning the research techniques and how best to carry them out in practice.

Extract 3. Thematic Table Finished, 18 April 2025

I finished the tale of themes today. When I printed it off, it didn't look a lot, but it was a huge amount of work. I now have a better understanding of how in-depth this type of analysis is and how much work each case study will involve for my doctorate.

Having carried out this type of analysis, I can confidently say that themes do 'emerge' from the data as part of the iteration. This contradicts Paley's (2017) view that researchers' preconceptions taint the interpretation phase with bias. IPA incorporates the researcher's views as a strength and not a weakness. Reflexivity and member checking help strengthen academic rigour and validity.

IPA's philosophical underpinnings provide a kind of theoretical transparency in that they acknowledge people, including researchers, cannot escape their own subjectivity.

Source: Author's own

7.5. Appendix 5 Informed Consent and Right of Withdrawal Form

Participant Consent and Right of Withdrawal Form (copy)

Principal Researcher: Emma-Louise Johnson
Place of Study: University of Wales Trinity Saint David (UWTSD)
Course: MA Equity and Diversity in Society
Department: Humanities
Contact Telephone Number:

Before research begins, the participant is advised of the following information, rights and safeguards for collecting and storing their personal data.

- Voluntary Participation by Consent – Participating in this study is voluntary and the following information will ensure that you understand your rights before the interview takes place.

- Right of Withdrawal – As a participant in this study, you have the right to withdraw your consent at any stage during the research without prejudice.

- Confidentiality – All the information provided will not be accessed by anyone other than myself, the sole researcher, unless you consent to me doing so.

- Data Security – All data will be stored securely in the researcher's home in line with the principles of the *Data Protection Act 2018* and the GDPR (Intersoft Consulting, 2016), which are adhered to by the university as noted in their policies (University of Wales Trinity Saint David, 2022a, b). A guide explaining the data protection principles can be found on the ICO (2023) website, listed in the references section at the bottom of this form.

- Data Processing – The university can process the participant's data under certain circumstances. It should be noted that withdrawing from research when data analysis has begun can make data removal more difficult, but reasonable efforts will be made to withdraw data and remove any identifying information. Further information can be found in the UWTSD Research Data Management Policy (2022a), and a printed copy can be provided upon request.

- Research Aim(s) and objectives – Understanding, who, how and why it is conducted in this format.

  This information will be in a verbal introduction before the interview takes place and is summarised in below:

  I, Emma-Louise Johnson, am the sole researcher of this study for my Masters dissertation. I am also a parent carer with lived experience of caring for disabled children.

This study aims to understand a parent carer's lived experiences when advocating for their child's rights and needs. Advocacy here is a term used to mean the informal rather than professional type of seeking help from someone (Bateman, 2000, pp. 16–18). The study objectives (Johnson, 2025a, pp. 1–2) include understanding the barriers parents face when seeking help for their child or raising concerns about them and identifying ways that might improve the parent carer's experience when doing this. It is hoped that this research can thereby improve professional practice.

- How the research will be used – This research is for an MA dissertation and is required to achieve the MA qualification. The completed study will be uploaded to the university's repository. As a pilot study, insights from the analysed data may be used in a further doctoral study.

- Member Check (Peoples, 2021, p. 70) – After the interview has been transcribed, I, the researcher, will contact you, the participant, to arrange a suitable date to meet up and discuss the findings. You will be able to give your views on what was said and make any contributions or amendments about meaning or intended meaning. This reflects the interpretative and reflective nature of IPA analysis, and the study aims to help parent carers be empowered through co-participation in the design of the study.

- If there is any part of this form you do not understand, you can ask either before the interview begins or at any point afterwards; you can contact me directly at the researcher's contact number in the box at the top of this page.

Informed and Voluntary Consent

Please can you confirm that you understand you are taking part in this study voluntarily and of your own consent, having been provided with all the necessary information.

Right of Withdrawal

Please confirm that you understand that you have the right to withdrawal at any time during the research, having been provided with all the necessary information.

Signatures Required:

Participant:

I confirm that I have read the above information and that I give my informed and consent to take part voluntarily in this study. I understand that I can withdraw from the research at any time, and I do not have to give a reason why I have done so.

Printed name: …………………………

Signed: …………………………

Researcher:

I confirm that I am the researcher of this study, and I have ensured the participant understands all of the above information and that my research complies with the Data *Protection Act 2018* and the university Guidelines (University of Wales Trinity Saint David, 2022a, b).

Printed name: Emma-Louise Johnson

Signed: …………………………

NB: The researcher and the participant should each have a copy of this form, which has been compiled using university and phenomenology research guidelines and policies with ethical approval given for this research (Jefferies, 2021; Johnson, 2025b; Peoples, 2021, pp. 152–157; Smith, Flowers & Larkin, 2009; 2022).

References:

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(Accessed: 08 January 2025).

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Source: Author's own

7.6. Appendix 6 Interview Guide

IPA Interview Guide

Title: Parent Carer Agency: Exploring the Lived Experience of Advocating for a Disabled Child While Engaging with Professionals and Institutions

Research Question: What is the lived experience of agency for a parent carer advocating for their disabled child while engaging with professionals and institutions?

Interview by: Emma-Louise Johnson
MA Equity and Diversity of Society
University of Wales Trinity Saint David

The Aim of the Interview Guide (for my supervisor and me)

This IPA interview guide is used to help conduct in-depth research to understand the lived experience of a parent carer when advocating for a disabled child while engaging with professionals and their respective institutions. As part of that, particular attention was paid to the following key areas:

- Design: This interview has been designed using a semi-structured interview to help collect detailed, rich data for analysis.

- Development: As part of its design and development, these questions have been revised several times to ensure they align with the aims and objectives of this study. Adopting a rigorous process should ensure meaningful data is captured.

- Ethical considerations were made in the interview design and development regarding the rights and well-being of the participant. The first consideration is to prevent harm to the participant with the appropriate safeguards in place.

- Analysis: The data collected from the interview will focus on understanding the participant's lived experience. Meaning making will come from the individual account of that experience and the broader context for which the IPA approach allows with the application of a social justice lens.

- Assessment of the data will also involve looking at the criteria of reliability, validity, and generalisability of results within the confines of qualitative research, specifically IPA.

- Further Uses of Data: This is a pilot study and having assessed the validity and reliability, the insights gained will be used in a broader study with a larger number of participants for my doctorate.

Introduction:

Before the interview (to the participant):

- Thank the participant for agreeing to be part of the research, reinforcing my appreciation for discussing important personal topics as part of the study.
- Introduce myself by name.
- State the purpose of this study: To understand the lived experience of a parent carer when they are advocating for a disabled child while engaging with professionals and institutions.
- Outline three main ethical concerns and ensure these will be met:
    - Confidentiality – I am the sole researcher of this study. The participant's information will be anonymised so that others cannot identify her and her family.
    - Voluntary participation and right of withdrawal at any time during the study.
    - Data protection – All data collected will be stored safely and securely and only for as long as is necessary according to UK law.

- Repeat the sensitive nature of some questions and that verbal consent will be sought again before asking those questions.

- Ask the participant if they have any questions before the interview begins.

- Depending on the situation, I will be mindful of the participant's reactions throughout the interview and monitor their body language and non-verbal cues to see if they become distressed. However, it is Ok for emotions to be expressed so it is balance in reading the situation before deciding on a break so do not be too quick to turn off the recording. If the participant says they would like a break turn of the audio device and calmly say to the participant: ‘We are pausing the interview at [insert time].’ When the participant is ready, the recording should restart as I say, ‘We are resuming the interview at [insert time].’

- Let the participant know I will use time markers to help convey timeframes during analysis. An explanation will make this less interrogative and formal.

- A member check will take place after the interview at an appropriate time agreed upon with the participant. This informal meeting will be arranged at which I will give the participant a summary of my findings with reflective notes so that they are involved in the research as a co-participant and co-producer of meaning. This will also allow the participant to reflect on the findings and add or amend any information, thus feeling empowered in the relationship and research process. A human rights approach to research will be taken throughout the study.

Interview Questions:

The interview recording will start at [insert time].

- Mention to the participant their child’s photo or artwork they have been asked to bring in. Say something like, ‘I see you brought a picture by your child. Can you tell me something about it?’ This visual elicitation technique can open the door to the first question and *build rapport.*

1. Can you tell me what your experience has been as a parent carer?

Prompts: a) Can you please tell me more about that? b) What did you do in response to that? c) Can you tell me about the emotions you have experienced as a result of these experiences?

2. Tell me about the most memorable example of advocating for your child?

Prompts: a) Can you tell me more about what made this particularly memorable? b) Was it the quality of the interaction/the timing of it/the outcome, or something else? c) What else does advocating for your child involve? d) What barriers did you experience in that situation?

3. Tell me about your interactions with professionals when advocating for your child?

Prompts: a) Do you want to tell me more about that? b) (If the participant only touches on one or two areas) What other types of impacts have you experienced?

4. What were your experiences like of interacting with professionals? Tell me about any that particularly stand out as memorable?

Prompt: a) Can you tell me more about that feeling? b) Can you tell me what it was like to be judged by professionals that way c) How did you respond?

5. How did these interactions with professionals affect you emotionally?

Prompts: a) How were you affected physically and/or psychologically? b) Can you tell me more about that?

6. Tell me about those different experiences (this may refer back to answers given in questions 3 and 4) when advocating for your child?

Prompts: a) Can you give me a positive example of this? b) Can you give me a negative example? c) What did you experience when feeling valued and/or devalued? d) What was your feeling at that moment of having a very different perspective of your child/the situation from that of the professional? e) What did it feel like when you were empowered/disempowered when advocating for your child?

7. Tell me about the experience you have had to prepare for advocacy?

Prompts: a) How did that work for you? b) What will you do the next time you have to advocate?

8. How has this experience of advocating for your child changed you as a parent, person and citizen? Can you give me one or two examples?

Prompts: a) Can you tell me more about that? b) How did that factor into the shaping of your life?

The interview is now over. Recording has stopped at [insert time].

Conclusion:

Post interview (to the participant)

- Thank the participant for their time and express my appreciation for her willingness to discuss sensitive personal topics.

- Reiterate how the information given will be kept private and confidential and emphasise the right to withdraw at any time.

- Give the participant a list of organisations where assistance is available (as stated in the university's Ethics Approval Form).

- End the interview with a hopeful message about how the study will help shed light on the parent carer experience to reinforce the importance of her contribution.

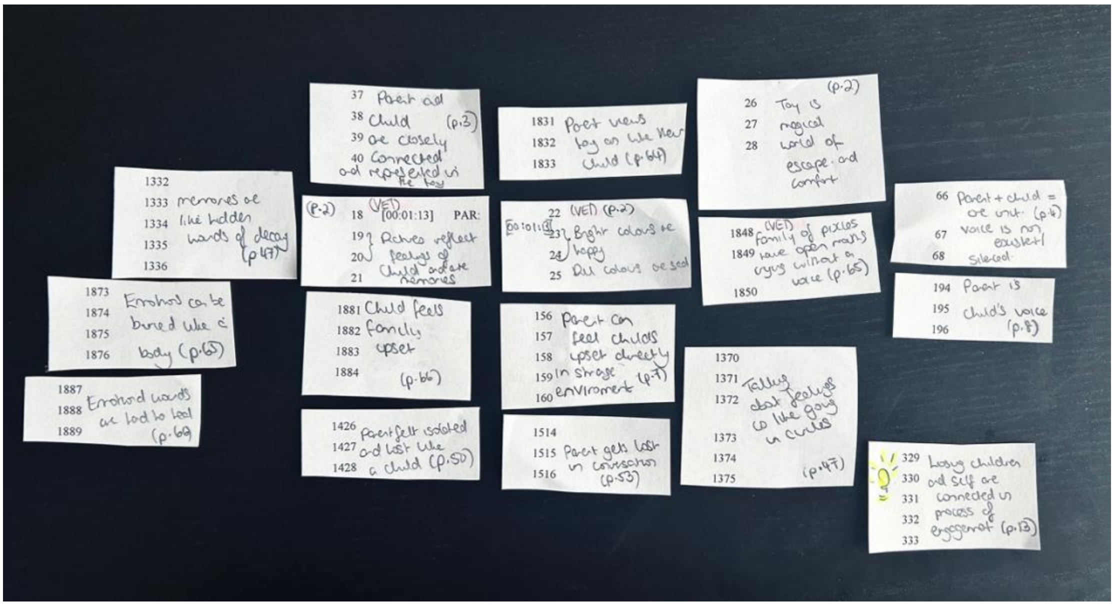
- A member check will take place after the interview at an appropriate time agreed with the participant. An informal meeting will be arranged at which I will give the participant a summary of my findings. This exchange ensures trustworthiness and transparency in the research process. It will also allow the participant to reflect on the findings and add or amend any information, thus feeling empowered as co-participants and co-producers of research. Aligning with a social justice viewpoint, a human rights approach will be taken throughout the study.

NB: (to self)

Write some reflective notes about the interview experience in the research diary after the interview, including how well the interview went, if there were any surprises in the participant's responses, and what was learnt from the interview experience as a researcher and a parent carer.

Source: Author's own

7.7. Appendix 7 Transcript Analysis Notes Example



1332
1333 memories are
1334 like hidden
1335 wounds of decay
1336 (p.47)

1873 Emotions can be
1874 buried like a
1875 body (p.65)
1876

1887 Emotional words
1888 are hard to feel
1889 (p.69)

37 Parent and
38 Child (p.3)
39 are closely
40 Connected
and represented in
the toy

(p.2) 18 (VET) [00:01:13] PAR:
19 Pictures reflect
20 feelings of
21 Child and are
memories

1881 Child feels
1882 family
1883 upset
1884 (p.66)

1426 parent felt isolated
1427 and lost like
1428 a child (p.50)

1831 Parent views
1832 toy as like their
1833 child (p.64)

22 (VET) (p.2)
[00:01:13] 23 Bright colours are
24 happy
25 Dull colours are sad

156 Parent can
157 feel childs
158 upset directly
159 in strange
160 enviroment (p.7)

1514
1515 Parent gets lost
1516 in conversation
(p.53)

26 Toy is (p.2)
27 magical
28 world of
escape and
comfort

1848 (VET) family of pixies
1849 have open mouths
crying without a
voice (p.65)
1850

1370
1371 Talking
1372 about feelings
is like going
1373 in circles
1374
1375 (p.47)

66 Parent + child =
one unit (p.4)
67 voice is non
existent
68 silenced

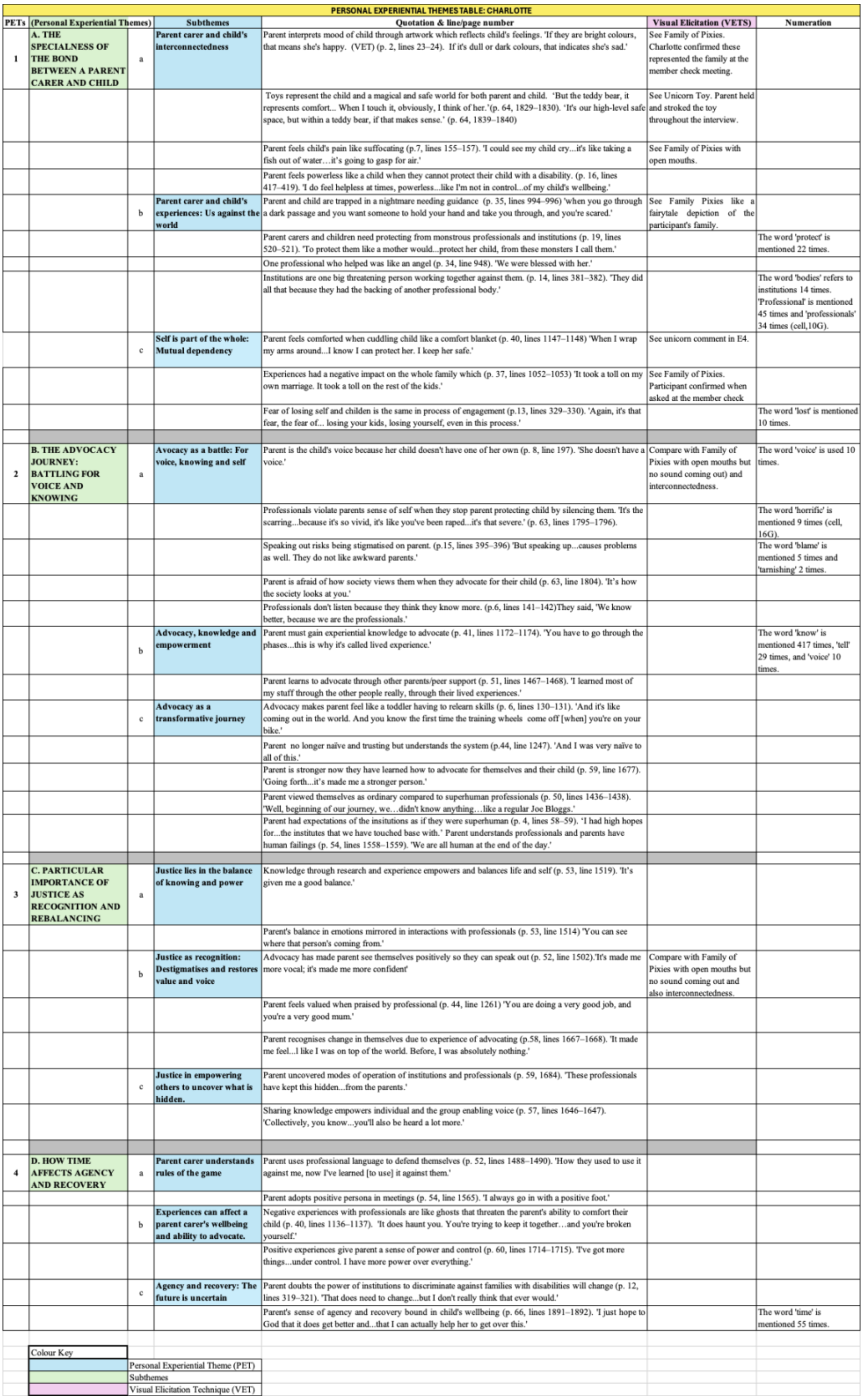
194 Parent is
195 child's voice
196 (p.8)

329 Losing children
330 and self are
331 connected in
332 process of
333 engagement (p.13)

Source: Author's own

The image above shows a theme as it emerged from close analysis of the data. The researcher followed the guidance of Smith, Flowers and Larkin (2009, pp. 79–107; 2022, pp. 75–108) but also made full use of IPA's flexibility by adapting it to the study design, its aims and the researcher's skills. After completing a line-by-line analysis, each of the themes were gathered into larger themes that formed cloud-like PETs. These PETs were then organised into a table (see Appendix 8), which helped to clarify how the themes and subthemes fitted together. The shape of the PETs, exemplified above, reflects the nonlinear, creative thought processes of the researcher, which, on reflection, appear to be well suited to IPA.

7.8. Appendix 8 Personal Experiential Themes (PETs) Table



PERSONAL EXPERIENTIAL THEMES TABLE: CHARLOTTE

PETs	(Personal Experiential Themes)		Subthemes	Quotation & line/page number	Visual Elicitation (VETS)	Numeration
1	**A. THE SPECIALNESS OF THE BOND BETWEEN A PARENT CARER AND CHILD**	a	**Parent carer and child's interconnectedness**	Parent interprets mood of child through artwork which reflects child's feelings. 'If they are bright colours, that means she's happy. (VET) (p. 2, lines 23–24). If it's dull or dark colours, that indicates she's sad.'	See Family of Pixies. Charlotte confirmed these represented the family at the member check meeting.	
				Toys represent the child and a magical and safe world for both parent and child. 'But the teddy bear, it represents comfort... When I touch it, obviously, I think of her.'(p. 64, 1829–1830). 'It's our high-level safe space, but within a teddy bear, if that makes sense.' (p. 64, 1839–1840)	See Unicorn Toy. Parent held and stroked the toy throughout the interview.	
				Parent feels child's pain like suffocating (p.7, lines 155–157). 'I could see my child cry...it's like taking a fish out of water…it's going to gasp for air.'	See Family of Pixies with open mouths.	
				Parent feels powerless like a child when they cannot protect their child with a disability. (p. 16, lines 417–419). 'I do feel helpless at times, powerless...like I'm not in control...of my child's wellbeing.'		
		b	**Parent carer and child's experiences: Us against the world**	Parent and child are trapped in a nightmare needing guidance (p. 35, lines 994–996) 'when you go through a dark passage and you want someone to hold your hand and take you through, and you're scared.'	See Family Pixies like a fairytale depiction of the participant's family.	
				Parent carers and children need protecting from monstrous professionals and institutions (p. 19, lines 520–521). 'To protect them like a mother would...protect her child, from these monsters I call them.'		The word 'protect' is mentioned 22 times.
				One professional who helped was like an angel (p. 34, line 948). 'We were blessed with her.'		
				Institutions are one big threatening person working together against them. (p. 14, lines 381–382). 'They did all that because they had the backing of another professional body.'		The word 'bodies' refers to institutions 14 times. 'Professional' is mentioned 45 times and 'professionals' 34 times (cell,10G).
		c	**Self is part of the whole: Mutual dependency**	Parent feels comforted when cuddling child like a comfort blanket (p. 40, lines 1147–1148) 'When I wrap my arms around...I know I can protect her. I keep her safe.'	See unicorn comment in E4.	
				Experiences had a negative impact on the whole family which (p. 37, lines 1052–1053) 'It took a toll on my own marriage. It took a toll on the rest of the kids.'	See Family of Pixies. Participant confirmed when asked at the member check	
				Fear of losing self and childen is the same in process of engagement (p.13, lines 329–330). 'Again, it's that fear, the fear of... losing your kids, losing yourself, even in this process.'		The word 'lost' is mentioned 10 times.
2	**B. THE ADVOCACY JOURNEY: BATTLING FOR VOICE AND KNOWING**	a	**Avocacy as a battle: For voice, knowing and self**	Parent is the child's voice because her child doesn't have one of her own (p. 8, line 197). 'She doesn't have a voice.'	Compare with Family of Pixies with open mouths but no sound coming out) and interconnectedness.	The word 'voice' is used 10 times.
				Professionals violate parents sense of self when they stop parent protecting child by silencing them. 'It's the scarring...because it's so vivid, it's like you've been raped...it's that severe.' (p. 63, lines 1795–1796).		The word 'horrific' is mentioned 9 times (cell, 16G).
				Speaking out risks being stigmatised on parent. (p.15, lines 395–396) 'But speaking up...causes problems as well. They do not like awkward parents.'		The word 'blame' is mentioned 5 times and 'tarnishing' 2 times.
				Parent is afraid of how society views them when they advocate for their child (p. 63, line 1804). 'It's how the society looks at you.'		
				Professionals don't listen because they think they know more. (p.6, lines 141–142)They said, 'We know better, because we are the professionals.'		
		b	**Advocacy, knowledge and empowerment**	Parent must gain experiential knowledge to advocate (p. 41, lines 1172–1174). 'You have to go through the phases...this is why it's called lived experience.'		The word 'know' is mentioned 417 times, 'tell' 29 times, and 'voice' 10 times.
				Parent learns to advocate through other parents/peer support (p. 51, lines 1467–1468). 'I learned most of my stuff through the other people really, through their lived experiences.'		
		c	**Advocacy as a transformative journey**	Advocacy makes parent feel like a toddler having to relearn skills (p. 6, lines 130–131). 'And it's like coming out in the world. And you know the first time the training wheels come off [when] you're on your bike.'		
				Parent no longer naïve and trusting but understands the system (p.44, line 1247). 'And I was very naïve to all of this.'		
				Parent is stronger now they have learned how to advocate for themselves and their child (p. 59, line 1677). 'Going forth...it's made me a stronger person.'		
				Parent viewed themselves as ordinary compared to superhuman professionals (p. 50, lines 1436–1438). 'Well, beginning of our journey, we…didn't know anything…like a regular Joe Bloggs.'		
				Parent had expectations of the insitutions as if they were superhuman (p. 4, lines 58–59). 'I had high hopes for...the institutes that we have touched base with.' Parent understands professionals and parents have human failings (p. 54, lines 1558–1559). 'We are all human at the end of the day.'		
3	**C. PARTICULAR IMPORTANCE OF JUSTICE AS RECOGNITION AND REBALANCING**	a	**Justice lies in the balance of knowing and power**	Knowledge through research and experience empowers and balances life and self (p. 53, line 1519). 'It's given me a good balance.'		
				Parent's balance in emotions mirrored in interactions with professionals (p. 53, line 1514) 'You can see where that person's coming from.'		
		b	**Justice as recognition: Destigmatises and restores value and voice**	Advocacy has made parent see themselves positively so they can speak out (p. 52, line 1502).'It's made me more vocal; it's made me more confident'	Compare with Family of Pixies with open mouths but no sound coming out and also interconnectedness.	
				Parent feels valued when praised by professional (p. 44, line 1261) 'You are doing a very good job, and you're a very good mum.'		
				Parent recognises change in themselves due to experience of advocating (p.58, lines 1667–1668). 'It made me feel...I like I was on top of the world. Before, I was absolutely nothing.'		
		c	**Justice in empowering others to uncover what is hidden.**	Parent uncovered modes of operation of institutions and professionals (p. 59, 1684). 'These professionals have kept this hidden...from the parents.'		
				Sharing knowledge empowers individual and the group enabling voice (p. 57, lines 1646–1647). 'Collectively, you know...you'll also be heard a lot more.'		
4	**D. HOW TIME AFFECTS AGENCY AND RECOVERY**	a	**Parent carer understands rules of the game**	Parent uses professional language to defend themselves (p. 52, lines 1488–1490). 'How they used to use it against me, now I've learned [to use] it against them.'		
				Parent adopts positive persona in meetings (p. 54, line 1565). 'I always go in with a positive foot.'		
		b	**Experiences can affect a parent carer's wellbeing and ability to advocate.**	Negative experiences with professionals are like ghosts that threaten the parent's ability to comfort their child (p. 40, lines 1136–1137). 'It does haunt you. You're trying to keep it together…and you're broken yourself.'		
				Positive experiences give parent a sense of power and control (p. 60, lines 1714–1715). 'I've got more things...under control. I have more power over everything.'		
		c	**Agency and recovery: The future is uncertain**	Parent doubts the power of institutions to discriminate against families with disabilities will change (p. 12, lines 319–321). 'That does need to change...but I don't really think that ever would.'		
				Parent's sense of agency and recovery bound in child's wellbeing (p. 66, lines 1891–1892). 'I just hope to God that it does get better and...that I can actually help her to get over this.'		The word 'time' is mentioned 55 times.

Colour Key	
🟦	Personal Experiential Theme (PET)
🟩	Subthemes
🟪	Visual Elicitation Technique (VET)

Source: Author's own (Zoom in to view)

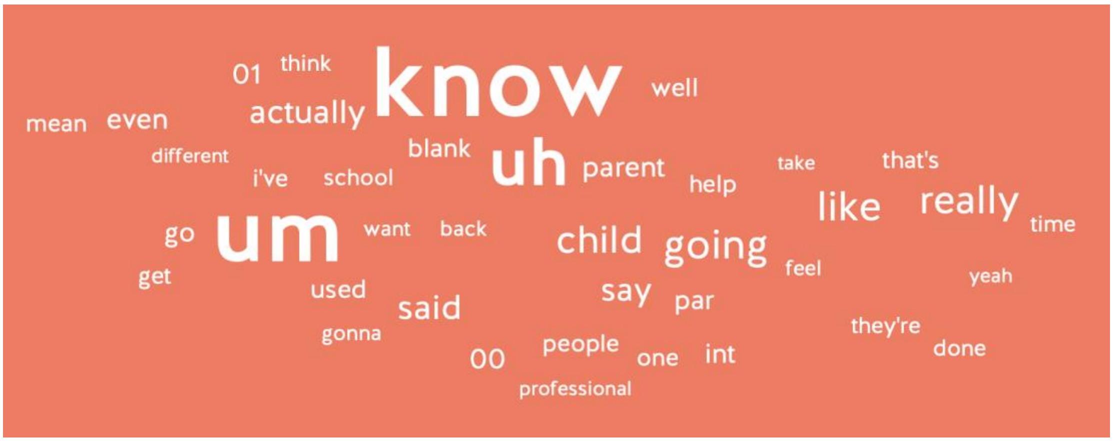
7.9. Appendix 9 Visual Elicitation: Artwork and Toy

Image 1. Artwork by Charlotte’s child (2025a)

Image 2. Artwork by Charlotte’s child (2025b)

Image 3. Photograph by Charlotte (2025) of her child’s toy unicorn

7.10. Appendix 10 Word Counter Data Cloud



(Source: Author's own data, with the image created using Databasic.io, 2025)

The data cloud generated from Charlotte's transcript offers some interesting – though limited – insights for the study. It introduces a small quantitative aspect to an otherwise qualitative framework and signposts certain features of a parent carer's lived experience of agency. For example, the word 'know' appeared most often, indicating both understanding and knowledge – a nuance that can only be revealed through careful reading of the transcript. This emphasis on 'knowing' is important to Charlotte and is reflected in the lived experience model in section 4.7.

It is worth noting that 'verbal filler' words (Seals & Coppock, 2022), such as 'um', appear often but do not carry any specific meaning for the analysis. Conversely, some powerful words – such as 'monsters', which Charlotte used to describe certain professionals – are missing from the data cloud, even though the oppressive behaviour of professionals and institutions is a significant theme discussed in the results and discussion (Chapter 4). Overall, while this exercise was helpful and may be included in the doctoral thesis, it highlights the limitations of quantitative methods for capturing individual experiences.

7.11. Appendix 11 Glossary

This glossary offers definitions of the key terms used in this pilot study. It reflects the study's size and scope and is not meant to be exhaustive. As a contextual glossary of theoretical, legal, and conceptual terms, it is designed to support section 2.2. Alongside standard definitions, some entries feature brief reflections, commentary, or explanations of how specific terms are understood and applied within the scope of this research. Where relevant, the glossary mentions the researcher's positionality as a parent carer with lived experience and acknowledges the evolving nature of language in this field.

○ Ableism/disablism: 'Ableism' is discrimination in favour of non-disabled people, while 'disablism' refers to discrimination or prejudice against disabled people (Scope, 2025).

○ Advocacy: Broadly means 'speaking on behalf of or in the interests of a person or group of people' (NHS, 2023; Payne, 2021, p. 6). There are many types of advocacy – paid or unpaid, professional or informal (Bateman, 2000, pp. 18–35). Parent carers typically act as unpaid, informal advocates for their children, seeking services and protecting their rights.

○ Agency: A widely debated concept in sociology, defined as 'people's capacity to control or influence their activities' (Payne, 2021, pp. 13–14). See also: autonomy, voice (and choice).

○ Anti-oppressive practice (AOP): A theory and approach to social work that often includes praxis (Freire, 2017, p. 52; Freire Institute, 2022). AOP promotes social justice by recognising and dismantling systemic barriers that keep people in disadvantaged positions (Dalrymple & Burke, 2006). Parent carers, who along with their children, are among the most disadvantaged groups in the UK (Clements & Aiello, 2021, p. 4), can benefit from AOP by professionals because, as Dalrymple and Burke (2006, p. 48) emphasise, it acknowledges and values an oppressed group's experiences and perspectives. As a result, AOP may improve parent carer advocacy efforts. See also: praxis.

○ Autonomy: The concept that people can – and have a right to – make their own choices and act independently, without being influenced or controlled by others (Payne, 2021, p. 27). For parent carers, autonomy is closely linked to agency and advocacy, as parent carers need to make choices and have their voices heard when seeking services for their child. Supporting autonomy can empower parent carers to make effective choices. See also agency, voice (and choice).

○ *Care Act 2014:* An Act reforming care and support legislation and the law regarding carers. This legislation supports children in need as they transition to adult services and, under section 10 of the Act (*Care Act 2014a*), places a duty on the local authority to provide information and support to carers of adults over 18.

○ Child: Defined according to UK law in sections 105 and 3 of the Acts (*Children Act 1989a; Social Services and Well-being [Wales] Act 2014a)* as anyone under the age of 18 years. This is also in Article 1 of the *Convention on the Rights of the Child* (1989), which the UK has ratified.

○ *Children Act 1989*: The primary legislation governing children's welfare in England and Wales, emphasising the child's welfare as paramount.

○ *Children and Families Act 2014:* Legislation that places a duty on local authorities to identify all disabled children in their area whilst protecting vulnerable children at risk of harm. It also gives parent carers the right to have their own needs assessed under section 97(1) of the Act (*Children and Families Act 2014a).*

○ Co-production: A type of partnership where the researcher and participant work together to shape the research. It is a key element of IPA (UK Research and Innovation [UKRI], 2024; Smith, Flowers & Larkin, 2022, p. 120). As part of this, the participant selected her pseudonym, 'Charlotte', and introduced a significant innovative element to the VETs used by bringing her child's unicorn toy. The soft toy became a focal point for Charlotte the shared 'lifeworld' (Husserl, 1970, p. 127) of both her and her child. See also: lifeworld.

○ Disability: A term that covers a wide range of definitions. Here it is defined as per section 6(1) of the *Equality Act 2010b* as a person with 'a physical or mental impairment [which has] a substantial and long-term adverse effect on [their] ability to carry out normal day-to-day activities'. However, there are many ways to view and therefore define disability. While the legal definition is helpful for this small pilot study, the researcher also acknowledges that disability is not merely an impairment but is influenced by the barriers that society creates and which prevent individuals from fully participating in various areas of life. It should also be noted that disability is not the same as neurodiversity, which refers to variations of brain function (Williams, E., 2023). However, disability and neurodiversity can overlap, and this will be discussed where it is relevant in the doctoral thesis depending on the selection of participants. See also: social model.

○ *Disability Discrimination Act 1995:* Former UK legislation that protected individuals with disabilities from discrimination in various areas, including employment and education. It was replaced with the *Equality Act 2010*.

○ Education, Health, and Care Plan (EHCP): A legal document for children and young people aged up to 25 years, outlining and providing for additional support needs in education. Also referred to as an 'EHC plan' (Department for Education, 2012).

○ *Equality Act 2010:* The primary legislation in the UK that safeguards individuals against discrimination. It superseded the *Disability Discrimination Act 1995* and applies to England, Wales, and Scotland.

○ Expert by experience (EbE): Defined as an individual with firsthand experience in an area of knowledge (Davies, 2024). Parent carers have lived experience in advocating for their child or children across various sectors, including health, education, and social care services. See also: lived experience.

○ *Human Rights Act 1998*: A UK law that outlines the rights and freedoms to which everyone is entitled, as specified in the European Convention on Human Rights (ECHR; Council of Europe, 1950). See also: social justice.

○ Identity-first (and person-first) language: Identity-first language (e.g. 'disabled person') prioritises the disability as part of a person's identity and aligns with the social model of disability (Oliver, 2013). Person-first language (e.g. 'person with a disability') emphasises the individual over their disability (Best *et al.,* 2022, p. 127) and is more commonly used in the United States. This study uses identity-first language, reflecting UK perspectives and the empowering aims of the social model, while also recognising that language is evolving and both forms are used as appropriate (Adsett, 2025). For transparency, as stated in definitions section 2.2, the researcher has shifted from using person-first to identity-first language to align with the UK stance and the aims and objectives of this study. That said, the aim is to be sensitive to language preferences and to recognise that there are times – such as when referring to people with learning disabilities – when person-first language is more appropriate. See also: medical model and social model.

○ Institution: An evolving term (Scott, 2008, pp. x, 8–9) which can be defined as a 'formal social structure that governs a field of action' (Rojas, 2013, p.1). This definition reconciles Rojas' (2013) view of institutions as organisations with Giddens and Sutton's (2021, pp. 91–94) perspective of them as separate entities. This clarification distinguishes the government from its departments and organisations, such as the NHS. Institutions embody regulatory and cultural elements (Scott, 2008, p. 50), highlighting their potential 'total' nature (Goffman, 1961, p. 11). As discussed in the literature review, parent carers frequently interact with institutions by engaging with the professionals when seeking help for their children. See also: professional.

○ Lifeworld: Defined according to Husserl's (1970, p. 127) conception as the taken-for-granted 'pre-reflective' – that is, what is lived through before reflection takes place – domain of everyday experiences, perceptions, and interactions. The lifeworld forms the basis for thought and inquiry, providing meaning before theory or abstraction (Brooks, 2015; Moran & Cohen, 2012, p. 191). It is not only individual but also intersubjective, shaped through shared social practices and language, as illustrated in the participant Charlotte's interactions with professionals. For Husserl, all scientific and theoretical knowledge rests on this lived foundation.

○ Lived experience: Refers to a person's direct engagement with their environment and the knowledge and understanding they gain from this (Chandler & Munday, 2011, p. 270). This straightforward definition is linked to the more complex phenomenological notion of lived experience, highlighting the significance of an individual's everyday life in how they make sense of the world and the knowledge they acquire. Parent carers' lived experience of caring gives them an understanding of their child's needs that theory alone does not. See also: expert by experience (EbE).

○ Medical model: A theoretical perspective that emphasises disabled people as abnormal and biologically inferior to the able people (Payne, 2021, p. 70). See also: social model.

○ Parent carer: Defined under section 97(2) of the *Children and Families Act 2014a* as 'a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility'.

○ Praxis: A combination of theory and practice that is often used in social work. According to Freire (2017, p. 52), praxis is 'the action and reflection of men and women upon their world in order to transform it'. Its goal is to empower people and free them from oppressive social structures. Praxis is incorporated into this study's design, which is consistent with IPA's reflexivity (Smith, Flowers & Larkin, 2022, p. 77). It is also part of the recommendations for mandatory anti-oppressive practice training for professionals, where reflection on the barriers faced by parent carers when advocating for their child is key. See also: anti-oppressive practice (AOP).

○ Professional: The definition of a professional person continues to change but for the purpose of this study, can be defined as a member of a profession, which is characterised by specialist knowledge, training, expertise and autonomy (Hughes & Hughes, 2013; Sharma, 1997). Professionals may be employed by institutions, particularly those working in the government-owned not-for-profit public sector (University of York, 2023), which covers the areas of social care, health and education, with which parent carers must engage when seeking services for their child. Professionals' theoretical knowledge contrasts with that of parent carers, which derives from their lived experience of caring for a disabled child. See also: institution.

○ Protected characteristic: Refers to a personal quality that is protected from discrimination under section 4 of the *Equality Act 2010a*. This includes disabled people with physical or mental impairments. It does not include non-disabled parents or family carers. See also: *Equality Act 2010.*

○ Social justice: A broad and contested concept, according to Capeheart and Milovanovic (2007), which rests on the principle of fair and equal access to resources, opportunities, and rights, with a particular connection to human rights (Coburn & Gormally, 2015). A social justice lens was applied after the IPA to uncover insights into the structural barriers faced by the participant Charlotte as a parent carer. Capeheart and Milovanovic (2007, p. 2) insist that social justice should focus not only on the individual, and it is noteworthy that Charlotte's individual experience leads her to think about the collective experiences of parent carers and to take part in informal systemic advocacy through sharing information.

○ Social model: A theoretical framework that defines disability as socially constructed by social and economic barriers (Payne, 2021, p. 71). See also: medical model.

○ *Social Services and Well-being (Wales) Act 2014*: Welsh legislation that aims to improve the wellbeing of people needing care whilst recognising the importance of providing support for carers.

○ Stigma: 'A human characteristic that people see as a flaw' (Payne, 2021, p. 207), which may be visible or invisible to the viewer. Unlike stereotyping, which involves making generalisations about a whole group which can be positive or negative, stigma focuses on a specific characteristic of an individual (Chandler & Munday, 2011, p. 466).

○ Visual elicitation technique (VET): A type of research method, based on a technique developed by Collier (1957), which involves using photos to spark discussion during interviews (Pink, 2021, p. 109). In this study, the VETs included pieces of artwork and a soft unicorn toy (see Appendix 9), which enabled Charlotte to share more profound insights and memories through discussion of these meaningful items related to her child. This then strengthened the data from the main IPA interview. See also: co-production.

○ Voice (and choice): Voice is a debated concept that refers to an individual's ability to express and act upon their perspectives, needs, and wishes (Rocha Menocal & Sharma, 2008, p. 5). Choice refers to the opportunity to select options and make decisions (Markus & Schwartz, 2010), which parent carers often do for their child. Clements and Aiello's (2021) report shows that when professionals and institutions blame parents seeking help for the child, the resultant stigma can stop parent carers from asking for help. This silencing of voice takes away parent carers' capacity to participate in the decision-making process with professionals. The suppression of voice, and consequently, choice, can therefore diminish the agency of a parent carer, like Charlotte, and adversely affect advocacy efforts and outcomes. See also: stigma.