Personal assistance, disabled parents and their children: roles and relationships

PhD Thesis

Nicola Jones

University of East Anglia
School of Social Work
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Abstract

This thesis reports a qualitative study undertaken to explore how disabled parents and their children experience personal assistance and the impact this has on their lives and relationships. Previous research establishes the inherently complex nature of the employer/personal assistant (PA) relationship, yet few studies have considered the influence on family life, or the impact on children. This study offers unique insights into the realities of both parenting and growing up with PA support and adds to our knowledge and understanding of the needs of families and the individuals within them.

Data were generated from a total of 29 participants. Interviews with parents (11) and children (10) were conducted face-to-face using accessible materials to promote their engagement with the research process. PAs (8) were primarily interviewed by telephone. Participants' accounts provide a compelling and detailed picture of family life and show that PA support can alter both the quality and nature of the parent/child relationship.

Thematic analysis revealed that PA support can respond flexibly to individual needs, enabling disabled people to express their parenting choices and preventing children from becoming 'young carers'. However, the presence of PAs can also create tension, anxiety and even destabilise family life. All participant groups expressed a degree of ambivalence about their relationships and were conscious of being continually observed. Parents and children spoke about feeling negatively judged and sometimes undermined by PAs. Children expressed strong views about PA involvement in maintaining family rules and 'discipline', with teenagers especially finding personal assistance difficult to adjust to and accept. Data reveal that whether parental impairment is lifelong, or acquired at a later stage, can have a significant impact on parental views, expectations and experiences of using personal assistance.

Based on these findings, suggestions are made for improvements to policy and practice which will better prepare disabled parents, PAs and children for their encounters.

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Introduction

This thesis is concerned with the experiences of disabled parents and their children, and how their relationships are shaped and influenced by the presence within their lives of personal assistants (often referred to, as in this thesis, as ‘PAs’). As will be demonstrated, little is currently known within the academic literature about this topic, which is an important, and growing, phenomenon. This study addresses the research gap through empirical research with people who have direct experience of living with this type of support.

Rationale and impetus for this study

Disabled parents in the UK

Disabled parents are a heterogeneous group of people. Their number includes those with physical and/or sensory impairments; learning difficulties and/or disabilities; mental health needs; long-term medical conditions, and parents who identify as part of the Deaf community. Some disabled parents may have newly acquired impairments, others will have been disabled since birth. Since disability, and close proximity to disability, has been shown to have a negative impact upon life opportunities (Office for Disability Issues and Department for Work and Pensions, 2014), understanding the needs of disabled parents and their children, and responding to these effectively is of great importance.

It is now over twenty years since Michele Wates (1997), a key figure within and chronicler of the UK disabled parenting movement, noted an increase in the number and profile of disabled parents as a sub-section within the general parenting population. This was attributed to several factors, including developments in medical technology which meant that many people born with impairments were surviving childhood to reach child-bearing age, deinstitutionalisation and decreased segregation following the introduction of ‘community care’ under the NHS and Community Care Act 1990, changing attitudes towards sexuality and increased opportunities for independent living and community participation. However, despite the significant amount of research conducted into disability issues, the number of disabled parents in the UK is unknown, and statistics in this area are incomplete, sometimes confusing, and up to date figures are difficult to obtain (Booth and Booth, 1994; Preston, 2005; Morris and Wates, 2006). This is surprising, particularly given the level of political and economic interest in the escalating costs of the social care budget. Perhaps the widespread diversity of disabled parents has led to difficulties in quantifying their number; as a group they are invisible, ‘atomised’ and not always known to statutory services. Additionally, research evidence suggests that many disabled people do not relate to the label of ‘disability’ (Grewal *et al.*, 2002) and may more strongly identify themselves by reference to their relationships with family and friends than as individuals with impairments (Watson, 2002). Others may resist being categorised as disabled due to fears that this may lead to increased and unwanted professional involvement in their lives.

Whilst exact numbers are uncertain, using information extrapolated from various government-produced surveys and studies, it has been suggested that approximately 12 per cent (or 1.7 million) of Britain’s 14.1 million parents are disabled, and that 1.1 million households with dependent children have at least one disabled parent (Morris and Wates, 2006; Commission for Social Care Inspection, 2009). Data are not currently collected about how many of the estimated 630,000 adults receiving specialised mental health services are parents or carers, however, it has been suggested that 30% of adults with mental ill health have dependent children (Ofsted and The Care Quality Commission, 2013). The situation relating to parents with learning difficulties is similarly unclear, with estimates of their number varying greatly. A large-scale survey of people with learning difficulties in England conducted in 2003/4 found that, in a sample of almost 3,000 people, 7% had children (Emerson *et al.*, 2005). Given that there are an estimated 796,000 adults with learning disabilities in England (Emerson and Hatton, 2004), there are likely to be more than 53,000 parents with learning disabilities in England alone. It is unsurprising, therefore, that research shows the number of parents with learning disability on the caseloads of community teams has risen significantly (Elvish *et al.*, 2007).

Uptake of personal assistance

Personal assistance is a model of support whereby disabled people themselves take control of recruiting, training and managing those that support them. This differs from traditional care services which disabled activists have challenged as a form of oppression and an expression of prejudice (Morris, 1997). Personal assistance enables the disabled person to make key decisions about how, when, and by whom they are supported. This support mechanism has been identified as pivotal in enabling disabled people to overcome disabling barriers imposed by society (Mladenov, 2012), empowering individuals to make autonomous decisions and take risks in their lives in the way that non-disabled people expect without question (Marfisi, 2002).

The shift away from traditional services and towards individually tailored support began with the introduction of direct payments in the 1990s; since this time, personal assistance has emerged as a key model for delivering social care. With the development of personal health budgets, personal assistance is also becoming an important feature of health services, with the government setting the goal of 50,000 – 100,000 people accessing NHS funded personal health budgets by 2020 (Department of Health and Social Care, 2018).

As Porter *et al.* (2020) observe, a striking feature of personal assistance in the UK is the relatively limited amount of regulation which governs its organisation; having been assessed as eligible to receive local authority assistance, disabled people are free to employ staff and organise their support with very few restrictions. As a result, the relationships which form and develop in this way are conducted largely unseen and unsupported by professionals.

The gap in current knowledge

Very little is currently known about how the relationships between disabled parents and their children are affected by the presence of personal assistants who provide care to both parent and child. However, a body of research has developed which provides an insight into the employer/PA relationship. These studies highlight the complexity and fluidity of this still relatively new support arrangement and demonstrate that personal assistance can be a powerful means by which disabled people take control of their lives. Concerns, risks and challenges for both parties to this relationship also emerge. Whilst there is little within the research literature which looks at the specific experiences of disabled parents using PA support, and the benefits and challenges this may present to families, insights into the lives and experiences of disabled parents and their PAs may be found, suggesting that complex emotional entanglements can arise in this support arrangement (Porter *et al.,* 2020). Additionally, whilst the views of children who are identified as 'young carers' have a recognised place within the literature, children who have disabled parents, but do not consider themselves to be 'carers', are very seldom heard. Given the increase in numbers of disabled parents, and the rise in employment of personal assistants, it is important that these young people can contribute to our understanding of their lives and needs.

This combination of factors provides the backdrop to the current study and highlights its importance and timeliness. Gaining a deeper understanding of the significance, influence, meaning and consequences of employing a PA to support family life would be of great benefit to a range of stakeholders involved with providing services to disabled parents and their families, as well as to families themselves. This study furthers our current knowledge about this topic and provides valuable new insights from the perspectives of disabled parents, their children, and PAs.

Structure of this thesis

This thesis is set out in four parts: Part 1 provides a review of the existing literature and is comprised of two chapters; over a further two chapters, Part 2 outlines the methodological considerations that informed how the study was designed and conducted; Part 3 sets out the study's findings, arranged in three chapters; Part 4 discusses the contribution to knowledge made by the study's findings and the implications for policy and practice with disabled parents and their children.

Part 1: The Literature Review

This part of the thesis explores issues arising from the existing body of literature of relevance to this study's aims. It is arranged in two chapters, the first of which examines personal assistance and paid family 'help', where workplace and home are co-located. The second chapter explores issues relating to children who have disabled parents. These chapters raise questions about the experience and meaning of personal assistance in the lives of disabled parents and their children, which this study sought to highlight and address.

Part 2: Methodological issues and considerations

This part of the thesis sets out the study's methodology and the theoretical approaches adopted in the research design. It discusses how ethical issues were addressed and the challenges that arose during the research process. A description is provided of how participants' accounts were analysed.

Part 3: Findings

Participant interview data yielded rich, complex and sometimes contradictory accounts of their experiences of living with personal assistance. The first findings chapter provides an overview of how participants use personal assistance in their daily lives, enriching our understanding of family life with PA support. The second chapter explores in more depth the complex relationship dynamics which develop between parents, children and personal assistants, and how these are experienced by individuals. The third chapter presents participants' experiences of the varied ways in which they seek to influence, control or 'manage' the behaviour of others in the parent/PA/child relationship triad.

Part 4: Discussion and conclusions

This final part of this thesis provides a discussion of the study's findings and conclusions. It presents an overview of the key themes identified from participants' accounts, exploring different parental perspectives on impairment and identity, and setting out a PA continuum of involvement. Parent/child relationships are examined, and attention is drawn to the experiences of children who have disabled parents and do not consider themselves to be 'carers'. The wider implications for policy and practice are also discussed and suggestions made to improve support to disabled parents and their children who live with personal assistance.

Part One:

Review of the Literature

Approach to the Literature Review

Introduction

Family life in the UK is shaped by of a raft of social policy, with ‘troubling’ families and the risk which may be posed to children growing up within these, the focus of social work research, concern and intervention (McCarthy and Gillies, 2018). As Olsen and Clarke (2003) note in their UK study of parenting, disability and mental health, disabled parents are significant by their absence from the research on parenting – they are both invisible and excluded. Their analysis of the literature highlights that where disabled parents feature within parenting studies, disability is commonly framed as a ‘problem’, revealing an underlying assumption that disabled people are the natural recipients, not providers, of care (Olsen and Clarke, 2003). Disabled parents are present, particularly within the clinical and counselling literature (Segal and Simkins, 1996; Rolland, 1999); however these studies typically adopt a ‘medical’ model of disability, with strands of research focusing on impairment-specific issues, for example: parents with multiple sclerosis (Diareme *et al.*, 2006), or parents who have visual impairments (Conley-Jung and Olkin, 2001; Rosenblum, *et al.,* 2009). The preoccupation with and search for deficits in parenting abilities or in family functioning (Collis and Brant, 1981; Westgren and Levi, 1994) reinforces negative frames of thinking about disabled people and does little to further our understanding of the lives of disabled parents and their children.

Perhaps surprisingly, the disability studies literature has also been slow to recognise the importance to disabled people of parenting roles and responsibilities. Whilst disabled feminists, notably Morris (1989, 1991), Wates (1997; Wates and Jade, 1999) and Finger (1990) have made important contributions to the development of this literature, significant gaps remain, and parenting issues occupy a marginal place only in thinking and writing about disability. A search of the current literature using the terms ‘disabled’ and ‘parents’ confirms both the relative invisibility of disabled parents and their continued characterisation as problematic. This indicates both the difficulties of producing research which challenges more individualising/medicalising models in this area and reinforces the importance of studies which attempt to do so.

Despite the marginalisation of disabled parenting within the literature, scholarly interest has developed gradually over the past twenty-five years. Initially, the focus was upon issues of parenting capacity; later, the rights and needs of children who may become ‘young carers’ were emphasized, before attention turned to consider the role of social networks in the lives of people with disabilities, including how these networks affect families led by disabled parents (Drew, 2009). Despite increasing levels of academic attention, to date there have been very few studies specifically concerned with the experience of parenting/growing up with personal assistance. A small number of studies have examined disabled children and young people’s views on personal assistance, where they themselves are the recipients of paid support. Over a similar period, a significant amount of literature has developed on the topic of ‘young carers’, however the views and experiences of children who have disabled parents, but who do not identify as having a caring role, have been overlooked.

Due to the limitations of the existing literature on disabled parents discussed above, it was not considered helpful to provide an in-depth discussion within this thesis. The literature review therefore locates the subject of this dissertation within what is currently known about disabled parenting, personal assistance, ‘young carers’ issues and relevant related literature including other forms of paid family support located within the home environment.

Approach to the literature search

Due to the scarcity of specific research available on this topic, a narrative approach was taken to searching and reviewing the literature (Burke, 2011). Narrative reviews are common in the social sciences, offering a flexible approach which allows the inclusion of a breadth of topics and sources.

Narrative reviews can be criticised for lacking structure and clarity, however, they can be highly effective (Carey, 2013); their open approach enables creative leaps to be made to widely dispersed related literature which may help to shed light on the subject. For example, this review draws on literature relating to nannies, au pairs and other domestic workers, ‘the home’ and ‘young carers’. This style of inquiry contrasts with a systematic review which seeks to locate and critically appraise as much research literature as possible, adhering to strict protocols, methods and techniques (Carey, 2013). However, to ensure a focused and comprehensive approach was taken to the literature review, the stages set out by Arksey and O’Malley (2005) in their framework for conducting scoping studies informed the process as follows:

Stage 1: Identifying the research question

The choice of topics included in each chapter was driven by the study’s research aims and question. Accordingly:

Chapter one reviews existing research concerning disabled parents, personal assistance and paid family support within the home.

Chapter two examines what is known about children with disabled parents, providing an evaluation of ‘young carers’ issues and debates, and setting out the available literature on children’s own views.

Stage 2: Identifying relevant studies

Many studies relating to personal assistance were known to me from previous study, however the literature on disabled parents and children who have disabled parents was less familiar. The literature search therefore progressed from the ‘known’ to the ‘unknown’; adopting a more structured approach helped to identify relevant studies in these less well-known topic areas. Specific search terms relating to the research question were formulated to scope the relevant literature concerning that topic (Burke, 2011). The following search terms were used: disabled parent*, personal assist*, direct payments, young carer*.

It should be noted that within the body of existing literature, there is very little which directly relates to children who have disabled parents but do not consider themselves to be ‘young carers’. There is however a wealth of research on ‘young carers’ issues; a decision was taken to include this related literature on the basis that it may reveal themes and contain insights applicable to this study.

Journal articles were retrieved by entering key search terms, into Applied Social Sciences Index (ASSIA), PsycINFO and SCOPUS databases. Research reports, policy and practice documents were retrieved by entering search terms into Google Scholar and Social Care Online.

In addition to systematic searches of electronic databases, further studies were located through the bibliographies of papers identified in the original search. As recommended by Blaxter *et al.* (2001), hand searching was carried out in key journals including: The British Journal of Social Work, Disability and Society and Disability Studies Quarterly. Attendance at key conferences provided opportunities to establish contacts with other researchers in the field, stay abreast of relevant developments and to locate additional literature through new and existing professional networks.

Stage 3: Study selection

Since the development of two key research strands – personal assistance and young carers – emerged roughly simultaneously, the majority of literature sourced dates from the mid 1990s. However, due to the paucity of research available on parenting with personal assistance, a wider range of topics was also included. Findings were limited to articles, books, conference papers, or dissertations that were theoretical and/or empirical in nature, and personal narratives that were not attached to a research agenda were excluded. Due to the specific social and political context of this study, the literature selected primarily focuses on the UK. However, since ‘cash for care’ schemes and models of personal assistance are well-established in Nordic countries, Germany, Switzerland, Italy, Ireland, the USA and Japan, and the experience of disability and parenting is by no means UK-specific, international studies published in English are also included.

Stage 4: Charting the data

Information was recorded on the study population (for example: disabled parent, disabled person, PA, care professional, child, young carer), study design, methodology, key results. The vast majority of studies examined employ qualitative methods with findings based on interviews and focus groups using small samples of disabled people, PAs and children.

Stage 5: Collating, summarising and reporting the results

The studies reviewed revealed several consistent themes in relation to each topic. The findings discussed in the chapters that follow are arranged thematically and the implications for this study are discussed.

Chapter 1: Personal assistance, family, and the home as a workplace

Introduction

This chapter will present, synthesise and critique the literature on personal assistance and paid family ‘help’, where workplace and home are co-located. Despite the rapid expansion of personalisation in recent years and the associated increase in use of PA support as a means of providing individually-tailored support to disabled people, academic research has not yet fully explored the role of personal assistance in family life, nor examined its impact on relationships between disabled parents and their children.

In fact, only one small-scale Swedish study (Selandar, 2015) was identified which examines parenting with personal assistance. This was discovered through contacts made at an international conference; although findings have not been published in English, the author provided a translated summary of her final report. This doctoral study explored the daily lives of eight disabled parents with physical impairments who had children under the age of 18 and used paid assistance. Findings highlight the dilemmas faced by parents when striving to maintain power and control in their everyday life and indicate the significant role played by family members – including children – in making PA support work. The life course perspective taken by this study indicated differences in the experiences and perspectives of parents who were either disabled from birth or acquired an impairment in later life. This had an impact on how parents used PA support and the strategies developed for managing PA relationships with their children. The study concludes that parenting with PA support increases opportunities for disabled people to participate in active partnering and parenting, however this greater freedom and autonomy for parents is balanced against the family’s needs for privacy.

Despite the lack of research specifically on the study topic, a body of literature relating to disabled people and personal assistance more generally exists, which provides a useful insight into key themes of relevance to this research. The chapter sets the context for this study by presenting the findings from the literature review on the role of paid assistance in family life, and the home as a workplace. The discussion is structured around four key themes which emerge from the literature, namely: *working within and beyond boundaries*; *the home as a work place*; *relationship dynamics* and *working with emotions*. It begins by providing an overview of current data on the number of people employed as PAs and how PAs are recruited.

PA support and the changing context of social care

The success of direct payments was central to the emergence of a new ‘personalisation agenda’, as underlined by the publication of the government’s ‘Putting People First’ manifesto (H M Government, 2007) which proclaimed a ‘shared vision and commitment to the transformation of Adult Social Care’. This is now embodied in the Care Act 2014 which made it mandatory for local authorities to provide direct payments to individuals with identified eligible needs. The change in law and social policy had a dramatic effect on the numbers of people receiving direct payments, with an increase from 65,000 in 2008 to around 240,000 in 2017 (Skills for Care, 2019). In their most recent survey of individual employers and the personal assistant workforce, Skills for Care (2019) estimate that around 70,000 of those receiving direct payments employ their own staff, thereby creating around 140,000 PA jobs. With this support mechanism now firmly established, the shift towards becoming an individual employer is changing the nature of the social care workforce. Working for a direct payment user is now the second most common job role in the social care sector after ‘care worker’, albeit the current proportion of PA jobs is estimated at 9% of the workforce (Skills for Care, 2019). This same survey illustrates that overall, the adult social care sector increased by 22% between 2009 and 2018; although most of these new jobs are based in the independent sector, jobs working for direct payment recipients increased by around 39% (an increase of 40,000 new jobs) during this time.

There remains some uncertainty surrounding the exact number of direct payment recipients employing staff, since ‘self-funders’ do not appear in official statistics, nor do they take into account self-employed PAs. However, two studies into PA employment conducted via survey (Griffiths *et al.*, 2017; Skills for Care, 2019) provide more information about individual employers and their workers, highlighting some interesting facets of the PA role. For example, in comparison to other care worker roles, PA jobs are more likely to be part-time, attract a higher hourly rate, and are more secure, with zero hours contracts being much less common than in other parts of the social care sector (Griffiths *et al.*, 2017). Additionally, many PAs – around 56% – had an existing relationship with their employer before taking on their paid role (Skills for Care, 2019). This supports data from a previous study which found a similar proportion of ‘known’ to ‘unknown’ employees (Stainton and Boyce, 2004), with the implication that PA users value trust, familiarity and empathy in this support relationship, and seek to ameliorate the potential risk posed by employing ‘strangers’ through the recruitment process. It appears that there are some key differences between ‘known’ PAs and those with no pre-existing relationship, for example non-family/friend PAs on average had longer work experience within the adult social care sector, were more likely to hold social care qualifications and to have received care-related training, and were better paid (Griffiths *et al.*, 2017). Another variance is linked to gender: whilst in the wider adult social care workforce, around 84% of workers are female, family/friend PAs were more likely to be male (21%) compared to non-family/friend PAs (11%) (Skills for Care, 2019). Employing PAs from outside existing networks can decrease dependence upon family and avoids the legal and financial implications – as well as possible emotional complications – brought about by formalising a hitherto purely personal relationship. Nevertheless, recruiting from existing networks is the preference of many employers; this includes disabled parents who occasionally feature in research which demonstrates the significant impact finding the ‘right’ PA can have upon both individual well-being and wider family life (Stainton and Boyce, 2004).

Recruiting via informal methods such as ‘word of mouth’ can affect the nature of the ensuing relationship, meaning that the boundaries between employment and friendship become less defined and more porous. Leading from this, problems have been shown to arise with boundary maintenance, perceived transgressions and ending commodified relationships (Ungerson, 1999). Of particular interest to this study, small-scale doctoral research (Woodin, 2006) has shown that, mindful of negative perceptions of disability and parenting, disabled parents sometimes prefer to recruit trusted individuals from within their existing network of friends. This recruitment strategy may enable them to manage risk more effectively. Data from Woodin’s (2006) study suggest that disabled lone mothers with young children, who feel their position as a parent is somewhat ‘insecure’ or open to question, may adopt this approach to finding workers. However, the experience of employing family members or friends can be fraught with dilemmas, even creating in some circumstances a “double dependency” (Selandar, 2015, p. 163).

The underlying philosophy of Independent Living played a key role in the development of personal assistance in the UK (Glasby and Littlechild, 2009). This policy initiative conceives personal assistance as a straightforward, pragmatic arrangement between individuals, based upon a financial transaction: whilst a contractual, exchange relationship exists, emotions are not considered to play a significant factor. The developing literature, however has begun to describe in more depth the intricacies of lived experiences of PA users and personal assistants, demonstrating that this support arrangement creates a unique and complex ‘hybrid’ form of relationship between individuals (Ungerson, 1999; Christensen, 2012). Operating fluidly between and across areas of life more often considered distinct and unconnected, the role of the personal assistant involves a blending of social and professional roles which can lead to a ‘blurring of boundaries' (Guldvik *et al.*, 2014) between personal and professional relationships, and public and private domains.

Research has also focused on the separate but related area of waged domestic labour, exploring the role and meaning of nannies, au pairs and cleaners in family life (Cox and Narula, 2003; Cox, 2006; Macdonald, 2010). There is some 'crossover' between these roles, as PAs working for disabled parents are likely to become involved with tasks typically completed by these other workers. As with personal assistance, these other paid roles are characterised by complex social relations which are typically grounded in close friendship or "false kinship relations" (Gregson and Lowe, 1994, p. 183).

Whatever the status of PAs when first employed, given the intimate nature of care tasks often undertaken in this role, and the setting of PA work in the private and informal environment of the family home, the relationship between individuals inevitably develops over time. Certainly, research consistently shows that strong emotional attachments – and detachments – develop between employers and their personal assistants, making this a complex and dynamic relationship (Zarb and Nadash, 1994; Ungerson, 1999; Twigg, 2000; Stainton and Boyce, 2004; Christensen, 2012). The discussion will now turn to examine key themes emerging from the literature; firstly, a consideration of boundaries:

Personal assistance: working within and beyond boundaries

The PA role itself can be hard to define, since each job is as individual as the employer and their identified needs, and each employee will interpret and enact the role of PA in their own way. However, PA roles can include, but are not limited to:

> personal care (transfer, mobility, bathing and toileting); domestic help (cleaning, washing, ironing, gardening, cooking and food preparation); health care (including bowel and bladder management, footcare,

> physiotherapy, medication, dressings, personal care during hospital admission and help using nebulizers and oxygen at home); help with personal finance; help to participate in education and training courses; and looking after pets. (Glendinning *et al.*, 2000, p. 201)

Somewhat surprisingly, whilst this extensive definition lists a great many possible tasks, including care of pets, it makes no reference to care of children or activities which may include contact with other family members.

Since PA roles typically resemble and encompass a variety of other roles, this may involve or generate feelings and actions that cross usually accepted social roles or norms of behaviour. For example, in a typical day, a PA may provide intimate personal care to their employer, provide support to attend a medical appointment, accompany on a social engagement, help with shopping, and assist to prepare a meal. The interactions between employer and employee in these different settings and with these tasks are subject to a variety of different social rules and patterns of conduct. This multiple crossing and re-drawing of social roles can have an impact on how disabled employers and their PAs feel about themselves and each other, their level of interaction, and how they communicate together. This can be a positive experience, with research showing that personal assistants highly value the personal relationship they develop with their employer, and find this an immensely satisfying aspect of their role (Eustis and Fischer, 1991; Leece, 2006). Nevertheless, challenges exist, as Glendinning *et al*. (2000) report that both employers and PAs can struggle to balance the formal and informal elements of their relationship; for PAs, this situation can lead to confusion over their duties and their feelings towards their employer. A Swedish study, (Ahlström and Wadensten, 2010), found a similar dilemma for personal assistants in distinguishing between their working relationship and personal friendship with their employer.

That PA support relationships develop and evolve on many different levels is perhaps to be expected, since it is part of the human condition to understand one's own life in relation to others. Creating this web of interconnection provides rich experience, satisfaction and diversion as well as constantly shifting patterns of complexity which may in turn generate a full range of emotions. Yet despite our deep seated inclination to relate to others, according to Josselson (1996), the vocabulary available to describe any kind of interpersonal relationship is surprisingly limited. This can make it difficult to attach precise meaning to even outwardly straightforward relationships; for example, the term ‘friend’ is highly subjective and can encompass a broad spectrum of associations and emotional connections between individuals. Josselson (1996) argues that labelling relationships is essentially unhelpful and limiting, whereas a careful consideration of the dimensions of the relationship in question may promote a better understanding of it.

Adopting this approach, Romer and Walker (2013) employed a dimensional framework in their appreciative inquiry with 16 personal assistants in the US. They asked PAs to describe the aspects of their work that they felt were crucial in offering person-centred support, and through this process identified several relationship dimensions as being characteristic of the personal support relationship. These include: presence, authentic listening, negotiation, moving with people, trust, and respect. They suggest that respect is the ‘web’ which is built from and holds all the elements of the support relationship. Respect was something which participants to this study also spoke about as being essential, however what this means in practice can vary enormously, and increasing familiarity between individuals can change how respect is expressed and experienced. Romer and Walker (2013) suggest that respect is created by the PA being fully attentive to the person supported, enabling them to express their choices and preferences, helping them to make informed decisions without taking control, being authentically themselves and honest at all times. Clearly, the role of personal assistant is highly demanding and goes beyond simply performing given tasks. However, while the authors discuss the importance of these characteristics to support relationships, they acknowledge the reality that: “it is another thing all together when discussing how to recruit and develop personal assistants with these qualities” (Romer and Walker, 2013, p. 193). This indicates the difficulty for employers in finding suitable workers, a situation which is commonly reported in the literature on personal assistance (Podro, 2013; Graham, 2015; Porter and Shakespeare, 2019).

Shakespeare (2014) proposes that personal assistance by its very nature causes a relationship to develop between the disabled person and their PA(s), arguing that support and assistance relationships are inherently complex and always bring about relational dynamics beyond the delivery of identified care tasks. Since personal assistance involves a unique and dynamic blending of social and professional roles, fluid relational and procedural boundaries are inevitably created. This can present emotional and practical challenges for both employer and employee, as the purpose of boundaries is to provide a clear framework for processes and interactions, and to maintain the separateness of and between these. Schelly (2008) discusses this issue of blended roles in his reflexive ethnography of working as a PA for an individual with learning difficulties. Over time, his relationship with his employer developed to create what he experienced as a merging of lives and emotions, a situation which established a deep and powerful connection between the two:

> What began as a pragmatically motivated job was inevitably and unexpectedly replaced by the lifestyle accompanied with being a live-in personal assistant. Indeed, SW's life quickly merged with my own so that our emotions were often reflective; days when he was happy were mirrored by my happiness. (Schelly, 2008, p. 728)

Many disabled people express a preference for relaxed and friendly relationships with their PAs – this is something which both Williams *et al.,* (2009) conclude in their conversational analysis of 14 dyads of people with learning disabilities and their PAs, and Woodin (2006) describes in her small-scale qualitative study as 'paid friendships'. However, this informal atmosphere can make it difficult for both parties to differentiate between what is 'work' and what is not. This has also been shown to be the case for other domestic workers, where day-to-day social relations can cause notions of waged work and friendship to become fused. In this way, research suggests that the employment relationship can become permeated by flexible notions of 'helping out' and 'doing favours' (Gregson and Lowe, 1994).

The concept of 'family' can become similarly stretched, leading to the development of 'false kinship' relationships. As Cox and Narula (2003) point out, however, in their examination of au pair employing households, false kinship relationships are not necessarily constructed by both parties, nor are they equally beneficial to them. For example, false kin relations can encourage home care workers to become ‘over-involved’ in the lives of their employers, creating a situation where over-work is seen as part of their role as “fictive family member” (Stacey, 2005, p. 839). For other domestic workers, the rhetoric of the ‘family bond’ can serve to mask the inequality and exploitation of the employment arrangement (Hondagneu-Sotelo, 2007). These issues are closely connected to the dynamics of power in the employer-employee relationship, which will be discussed later in this chapter.

As the foregoing discussion has demonstrated, the existing literature clearly indicates that the relationships which develop between employer and PA typically cross social and individual boundaries. As a result, they are unique, complex, and can become emotionally intense. These relationships are primarily located and play out within the intimate setting of the family home, the influence of which will now be considered in more detail.

Personal assistance and place: the workplace as a home

Although outwardly a straightforward concept, the home is a complex cultural construct, the meaning of which has changed over time. The home is discussed here, as it is the physical location and base for relationships between personal assistants, their employers and their children. In this way, the home is the place where public and private spheres meet. The emergence of the home as a private space is often linked to the separation of home and work brought about by the process of industrialisation and urbanisation (Allan and Crow, 1989). Ideas about the home are varied, and meanings are often conflated with, or closely related to notions of house, family, haven, identity, gender and journeying (Mallett, 2004). The developing literature on this subject raises questions about whether ‘home’ is a place, a space, a feeling, and/or a state of being in the world.

‘Home’ is commonly understood as a private domain, a place distinct from the public or ‘outside’ world, representing a secure and safe space (Dovey, 1985), as well as a central reference point in our lives. At home, there are different expectations and rules of engagement: it is often conceived as an intimate space that provides the context for close, caring relationships, removed from public scrutiny and surveillance (Mallett, 2004). This notion of the home as a haven can be contested, however, since the ‘separate’ nature of the environment can provide the conditions which make the home a dangerous and uncertain place: for some, the home is an isolated place where exploitation is obscured, and violent relationships can exist unseen and unchallenged. This stark reality is evident in official figures, with the Office for National Statistics (2018) estimating that in the year ending March 2018, 2 million adults aged 16 to 59 years experienced domestic abuse.

Although there is limited research into the abuse of disabled people by personal assistance providers, this has been identified as an area of potentially significant concern and in need of further research. A qualitative study of 72 women with physical and cognitive disabilities who used PA support (Saxton *et al.*, 2001) examined their perceptions and experiences of abuse by formal and informal carers. This research used focus groups to explore the topic, and found that participants who had experienced physical, emotional and financial abuse were often unable to identify their experiences of abuse as such. The researchers suggest that the subtle nature of the abuse, together with their social isolation, had prevented them from recognising it; discussing the subject within the focus groups provided an opportunity for participants to comprehend and define their experiences. This study highlights that the unique and complex relationship between consumer and provider creates an environment in which social and personal boundaries typically associated with employment are altered, leading to issues of privacy, autonomy and power imbalance. Participants struggled to determine what action to take when negative relationships develop; among their concerns were difficulty in replacing the PA, fear that the next PA might be worse, the lack of interim back-up support, and the risk of losing custody of their children due to having no support (Saxton *et al.*, 2001). These issues were echoed by participants to this study.

Working within the home can also pose a risk: quantitative research with Canadian in-home workers which analysed data from 292 female health and care professionals including nurses, social workers and other ‘specialist’ workers demonstrated a significant relationship between sexual harassment and workplace violence (Barling *et al.*, 2001). A later mixed methods study in the US which examined experiences of violence against home-care workers found that of the 83 care-worker participants, 44% had experienced physical violence, 65% psychological abuse, 41% sexual harassment, and 14% sexual violence (Nakaishi *et al.*, 2013). This study identified that real and perceived barriers to reporting violence, tolerance of violence and limited training increased the risk of violence against workers in the home setting.

For disabled people, the home is additionally complex: it is the primary location for ‘professional’, legally-defined activities such as social work assessment, upon which basis statutory services are provided to them. It is also the setting within which those care and support services are delivered. These ‘public’ activities blur the distinctions between public and private domains, disrupting the relationship between the individual and the home, changing its meaning and experience, both for disabled people themselves, and close family members.

It seems likely that the home plays an important role in shaping personal assistance relationships. The home has been identified as a power base for disabled people, since it contains “both ideological and material resources that can underpin their independence and power of determination” (Twigg, 1999, p. 391). This can make it possible for individuals to resist the dominance of ‘professionals’ and to exert greater control in their lives – at the simplest, most direct level, workers can be refused entry, or told to leave the property. The power of the home also operates in more subtle ways; individuals entering the home acquire the status of ‘guest’ and must adjust their actions and manner accordingly. This is not entirely straightforward, however, since cultural norms regarding access to the home are often determined by the relationship of visitors to home occupants and their relative status (Allan and Crow, 1989). Research underlines the unique challenge working in the home can present to professionals, with an interesting strand of literature relating to nursing. For example, it has been suggested that nursing rooted in the patient's real-life home situation influences practice and provides at least parity of control within the nurse–patient relationship (Carr, 2001). Peter (2002) further explores the role of place in nursing, demonstrating its influence upon quality of care, relationships, and power, suggesting that the notion of the nurse as 'guest' within the home diminishes the authority and potential influence of the nurse.

Building upon this, other research has examined home-nursing and its influence on practice. For example, a small-scale Swedish study which explored the ways in which 10 nurses caring for patients at home construct their roles found that two opposing positions exist: 'guest' and 'professional'. It was impossible for participants to enact both roles at the same time, and they therefore had to make a choice whether to perform as a guest or to a professional norm (Öresland *et al.*, 2008). By contrast, another small-scale qualitative study which set out to explore the relationships between 16 community nurses and 13 older patients within the home found that clear-cut boundaries between personal and professional were almost impossible to achieve, with both patients and nurses describing their relationships in terms of kinship (McGarry, 2010). These conflicting findings highlight the challenges for paid 'professionals' in providing home-based support; for disabled employers and their PAs, who do not have access to the same level of training, support and supervision, it seems likely that negotiating boundaries may be even more difficult.

For PAs, their workplace is their employer's home – unlike in other care settings, the space does not 'belong' to them, and there may be areas of the home from which they are excluded. The home environment therefore offers the potential for the usual power dynamics of care to be disrupted and replaced. This can provide opportunities for empowerment, however alongside this possibility for positive change, there is a risk that the boundaries between 'work' and 'home' could become indistinct over time, and that 'house rules' may be practically and socially difficult to enforce. Individuals may find the dynamics which arise as a result of working in the home unsettling; certainly, research suggests that some PAs can feel like an 'outsider' in their employer's home, and feelings of being 'out of place' can make them uncomfortable (Ahlström and Wadensten, 2010). A lack of formal oversight in the quality of care provided could also give rise to inappropriate or dangerous situations, and lead to disabled people feeling unsafe, unhappy, trapped and isolated in their homes.

The close association between 'home' and notions of identity and self-expression can also influence the nature of caring relationships. For Milligan (2003), the home operates as an anchor – not just to a particular physical or geographical locality, but also to personal history and relationships, forming a powerful continuity of memory and identity. This manifestation of the individual through the home can serve to place a limit on the degree to which an individual can become depersonalised by the experience of receiving care; surrounded by one's possessions, it is more difficult to be denied one's history, identity, preferences and choices. However, whilst the home can reinforce the individual identity and thereby strengthen the position of a care recipient, this balance can be undermined by a 'dis-location' of the home, where:

> Domestic space begins to take on characteristics of non-place as it becomes a site of transience and movement—the home-space becomes a place of work as living rooms take on features of the hospital ward and health professionals and care-workers move in and out, governed by time constraints and a lack of shared identity (thus understanding) with the cared-for. (Milligan, 2003, p. 462)

Given the home's strong connections to ideas of "privacy, safety, comfort and control" (Dyck *et al.*, 2005, p. 174), it may seem the 'natural' place in which to provide care for disabled people. Certainly, with the shift in the scale of care from communal to individual spaces, the home has become an increasingly important location of long-term care and support services. However, the act of providing care within the home changes its nature, bringing with it associated people, equipment, techniques and financial arrangements which can recreate the home as a newly "'vulnerable space', weighted with complex and embodied familial relations and meanings" (Hall, 2011, p. 592). In this way, the home can become a new kind of institution – an ambiguous, paradoxical, 'inbetween' space, "simultaneously both and neither private, public, nor individual nor social" (Dyck *et al.*, 2005, p. 181). This space then, becomes the setting for complex and often challenging relationships between the individual, paid worker and family members or co-habitants (Hall, 2011).

The close association between 'home' and 'family' is well established (Allan and Crow, 1989), albeit the meaning and significance of these terms remain keenly contested (Milligan, 2003). Nevertheless, the home typically symbolises the birth family dwelling and the family relationships and life courses enacted in this space. The home, therefore, is the location where parenting and care of children takes place, and although these activities are primarily undertaken by mothers, fathers and other close family members, paid workers often enter the domestic sphere to provide child-care and/or parenting support.

The literature related to nannies and au pairs suggests that some parents perceive a 'spiritual/menial split' in their role (Macdonald, 1998); this enables mothers to separate the routine, domestic aspects of their role and delegate these to a paid worker, enabling them to spend 'quality time' with their children whilst retaining the primary parent status. In this way, Macdonald (1998) describes in her qualitative study which drew on data from 36 child-care providers and 22 mothers, workers become an extension or 'shadow' of the parent: someone to provide love and care for their child in their absence, who will conveniently disappear upon the 'real' parent's return. This requires the care giver to achieve a complex balance: they must display enough warmth and affection to make the child feel loved, and the parent satisfied with the quality of care being provided, whilst also avoiding showing too much love, which would risk the child becoming overly attached and make the parent feel usurped in their affections. Nannies in this study found it difficult to determine and maintain the balance between being 'attached enough' and 'too attached' and lacked motivation to distinguish between children who were 'theirs' and 'not theirs', albeit they were careful not to let their level of attachment show. For Macdonald (1998), a particular image of parenthood is 'manufactured' by the process which takes place between the parent and care giver; this defines the nanny as peripheral to the family; enhances the mother within the family; and monitors the division of parent-work. In this way, the 'shadow' work of nannies and au pairs involves simultaneously building and concealing affective ties to children and maintaining family functioning.

It is evident from the literature that receiving care and giving care within the intimate surroundings of the home environment can bring about a complex blurring of boundaries between individuals. This can lead to role confusion, misunderstandings and tension between employer and employee. The literature also demonstrates the challenges for paid workers in balancing their emotions when working closely with children in their homes (Macdonald, 1998, 2010), a situation which may equally apply to PAs employed by disabled parents.

The discussion will now continue with an examination of dynamic relationships and power – an underpinning principle and key driver behind the development of the personal assistance model (Morris, 1993; Oliver *et al.,* 2012).

Dynamic relationships

Personal assistance was identified by the disability movement as a 'basic need', central to achieving the goal of independent living – a concept which is also closely associated to themes of empowerment, choice and control (Morris, 2004). Power has been described as the ability to influence the behaviour of others (Dunbar and Burgoon, 2005); the dynamics of power therefore are central to understanding direct employment relationships. As Leece (2010) suggests, the power of employers over personal assistants can be expressed in several ways, including: the ability to choose workers and shape the relationship; the power to determine the boundaries of the relationship; the power to 'set the agenda' of the relationship; and the power to make their own interests take precedence. However, this is not necessarily straightforward, as Dunbar and Burgoon (2005) highlight, power is a complex and fluid phenomenon which is based not only in the relationship between individuals but also influenced by wider society and cultural norms.

Relationships between PAs and their employers appear to contain a combination of features that foster the development of bonds which extend well beyond conventional remit of employer-employee relationships, entailing a complex set of interconnections between autonomy and dependency (Morris, 1993). Early research into direct payments tended to focus on the experiences of disabled people (Morris, 1993; Lakey, 1994; Kestenbaum, 1996), with relatively few studies examining the relationship from the perspective of personal assistants. This led commentators to reflect that the role of the support worker was "a curiously under examined feature of the policy changes and debates" (Cameron and Moss, 2001, p. 6). More recently, however, research has begun to shed light upon the complex nature of relationships between disabled employers and their PAs, and to examine the meaning this holds for both parties (Christensen, 2009; Leece, 2010; Guldvik *et al.*, 2014; Shakespeare *et al.*, 2017).

Drawing upon findings from qualitative research which studied 'cash for care' schemes in five countries, Ungerson (2005) considers elements of care, work and feeling in the development of commodified relationships, and describes relationships existing on a continuum between 'hot' and 'cold'. 'Cold' relationships are basically short-term, where worker and employer do not share a history. At the other extreme, 'hot' relationships are "essentially long-term relations which have survived despite tension" (Ungerson, 2005, p. 200). 'Hot' relationships are unequal, more volatile, and difficult to exit; they may occur where there is an over-dependence between the PA and their employer, or where feelings such as guilt prevent a worker from seeking alternative employment. In this study, 'warm' relationships were favoured;

these were experienced as equable and equitable by both parties and were seen to arise out of care relationships that had continued over a long period. The warmth experienced in these relationships meant that they were stable, however the positive feelings PAs and employers had developed for each other appeared to be “a matter of serendipity” (Ungerson, 2005, p. 199). Ungerson indicates that the extremes of emotion described in her typology are more likely to arise in relationships where there is hierarchy, inequality and overdependency, and that these qualities are more likely to occur in situations which allow for, and encourage, “unprofessionalised care work” (Ungerson, 2005, p. 202). Whilst this may suggest that professionalised relationships provide the best outcomes for both parties, Ungerson goes on to note that where family carers are employed, these relationships also appear to be ‘warm’, suggesting that:

> a shared past biography and recruitment through affect can smooth the edges of a purely contractual relationship, while the contract and payment, can, in themselves, act as cohesive agents, allowing these relationships to develop into warm inter- dependency within loosened time constraints” (Ungerson, 2005, p. 202)

Based on the findings of a qualitative cross-national study in Norway and the United Kingdom involving 19 physically disabled people, 13 PAs and 2 informal carers, Christensen (2012) proposes that the model of personal assistance in the UK tends to foster one of two kinds of relationships: “a master–servant type of relationship or a strong solidarity/emotionally-based relationship” (Christensen, 2012, p. 399). Christensen explains that tensions are created within support relationships by the dimensions of power and emotionalism. The combination of a weak involvement in the relationship with a strong hierarchical type of relationship, can result in subordination of the care worker in the ‘master-servant’ relationship, but may also lead to subordination of the disabled person. ‘Solidarity-based’ relationships are often emotionally-based and can involve ‘companion’ roles for personal assistants, which may be in tension with their roles as employees. For Christensen (2012), companionship can quickly turn into unpaid work, whereby PAs seek to create an emotional feeling, described by

Marquis and Jackson (2000, p. 418) in their study of 50 service users with physical and cognitive disabilities, as “sharing the inner circle” of the disabled person’s life. Christensen (2012) notes that certain individuals – especially migrant workers, lacking educational and professional qualifications, local networks and language skills – may be at greatest risk of taking on a ‘servant’ role, and further observes that in everyday practice, relationships can be mixed types.

A Japanese study (Yamaki and Yamazaki, 2004) which involved 31 PA users with physical disabilities also revealed different dimensions to the personal assistant relationship, with participants variously describing workers as ‘instruments’, ‘employees’, ‘companions’ and ‘social assets’, suggesting both functional and social/emotional elements to the role. A further qualitative study of 32 PAs based in Sweden (Ahlström and Wadensten, 2010), suggests that the relationship between the personal assistant and the disabled person is characterised by “incomplete mutuality” (Ahlström and Wadensten, 2010, p. 185); here relationships are asymmetric, and situations arise where the assistant includes the disabled person in the relationship, but the disabled person does not include the assistant. This can lead to negative feelings and experiences for personal assistants, including feeling that they are merely a ‘tool’ for the disabled person, and in some cases also for the disabled person’s close family members. In a later study which interviewed 30 PAs working for disabled people living with neurological disease or injury, the same authors report that some PAs find their role isolating and stressful (Ahlström and Wadensten, 2012). Furthermore, where a close friendship develops with their employer, PAs can find it hard to keep to their contracted hours and ‘over work’ can lead to them being taken advantage of. The evidence here is contradictory however, since a previous US study using focus groups made up of 24 disabled people and 15 PAs, reported that PAs experience a greater sense of meaning and satisfaction in their work where a bond of friendship exists with their employer (Matsuda *et al.*, 2005). Findings from the current study suggest that where PAs experience relationships with parents and children which contain elements of mutual regard and respect, they feel valued and are likely to remain longer in their employment.

There are some similarities between the role of au pair and PA in that they are both paid workers within the home, charged with completing specific practical and care-giving tasks relating to managing children and the household. The au pair role in the UK has been explored by Cox and Narula (2003); through a survey of 144 au pairs and 70 in-depth discussions with au pairs, employers and agencies, they found that families sought to control their au pairs in sometimes subtle ways – strategies include being either deliberately 'friendly and open' or 'distant' in their manner. This appears similar to the ways in which disabled people manage their relationships with PAs, typified by the 'hot/cold' relationships identified by Ungerson (2005) or 'master-servant / solidarity' based relationships noted by Christensen (2012).

More recent qualitative research into personal assistance relationships (Shakespeare *et al.,* 2017) demonstrates the wide variety of ways in which disabled people approach the employment and management of their workers. This can reflect different factors such as individual personality characteristics, goals, background and ideological commitment to independent living. Interviewing 30 disabled employers and 28 PAs, Shakespeare *et al.* (2017) found that relationships were conceived in a variety of ways, including as an extension of self; staff; colleague; professional; paid friend; and family. In this study, disabled people stressed 'friendship' with their assistants, while PAs were more likely to talk about 'friendliness', indicating an asymmetry in the relationship and that workers preferred to retain boundaries to shield their own lives from interrogation. This asymmetry works contrary to that described earlier by (Ahlström and Wadensten, 2012), however findings support other research which concludes that disabled people tend to prefer informal relationships with PAs, referring to them as being 'like family' (Eustis and Fischer, 1991; Yamaki and Yamazaki, 2004; Leece and Peace, 2010). On balance, the evidence from research is contradictory – both employers and their PAs seem to want elements of both formality and friendship in their relationships. Tension may arise where disparity exists between the desires, expectations or needs of the individuals involved in these relationships.

Developing close, family-type bonds can entail risk for both parties, leading to the development of intense, emotionally-charged relationships, which may be unsustainable. In relation to other domestic employees, Anderson (2001) observes that telling workers they are considered to be ‘part of the family’ often serves to conceal the real power relationships at work, leading to confusion and exploitation which can be difficult to resist. Holding the balance of power, employers can switch between adopting a familial or contractual role, depending on what is most convenient for them. In this way:

> Becoming ‘part of the family’ is not only a means of maximising labour extracted from the worker. It is an attempt to manage contradictions. For the employer it helps manage the contradictions of intimacy and status that attach to the domestic worker, who is at once privy to many of the intimate details of family life, yet also their status giver, their myth maker. (Anderson, 2000, p. 124)

For Anderson, incorporating a domestic worker into the family circle therefore provides a unilateral benefit, felt by employers only, who are able to encroach on worker’s off-duty time, without extending the advantages associated with kinship to the employee. Of course, not all employers encourage these false kinship relationships, and not all employees accept them. For example, Hondagneu-Sotelo (2007) found in her qualitative study of 50 domestic workers and employees that some employers considered establishing and maintaining friendly relations with their employees to be an unwelcome and time-consuming inconvenience, while Bakan and Stasiulis (1997, p. 11) assert that “many household workers have firmly rejected the notion that they are part of their employer’s family on the grounds that such kinship-like idioms mask their actual subordinate status”.

In an article which explores structural risks to personal assistance from the employee’s perspective, Guldvik *et al.* (2014) highlight that existing models may be incompatible with the concept of co-determination. They promote the need for increased professionalisation of this work, in order to establish stable recruitment and retention of PAs; formal education for PAs, delivered in co-operation with disabled people and based upon the social model of disability may, they suggest, promote solidarity and form the basis for a more symmetrical relationship between parties. Participants from this study however provide a contrasting view; while disabled parents acknowledged the constantly shifting and asymmetrical relationship dynamic with PAs and spoke about their difficulties with PA recruitment and retention, none suggested or appeared to welcome increased professionalisation of the PA workforce as a solution. Some PAs also expressed apprehension about group education, training or support sessions for workers, articulating concerns about confidentiality and power. It remains unclear whether disabled people would welcome a more professionalised workforce, and how an increase in workers' status might influence the balance of power between employers and employees.

Moving on, this review will now turn to consider what the literature can tell us about another key theme of relevance to this study: personal assistance and working with emotions.

Working with emotions

As outlined above, PA support necessarily involves the crossing of social boundaries. Frequently, relationships between employer and worker resemble friendships or develop into quasi familial relationships; these may mature into genuine friendships between individuals. Additionally, family members or existing friends are sometimes employed as PAs. As such, these relationships generate and demand a greater level and intensity of feelings and emotions than other types of employment. Whilst research indicates that close personal assistance relationships can hold benefits for both parties (Leece, 2006), many PAs express some ambivalence about this aspect of their role. Certainly, the development of friendship can present risk, as Ungerson observes:

> Once feelings of affection arise, then the consequences of crossing boundaries can range from the minor pain of social embarrassment to the personal risk of a broken heart. (Ungerson, 1999, p. 597)

Friendship can be difficult to resist, however, since structural and contextual factors surrounding the PA relationship can push both parties in this direction. For example, employers may present their assistants as ‘friends’ in certain social situations, to avoid having to explain their presence or role. However, this can give rise to uncertainty, if either party to the relationship is unclear upon what basis it is operating. Working with friends may have benefits in terms of maintaining the privacy of the family home, however in Woodin’s (2006) study of 30 disabled people and 20 family members or friends, disabled parents reported that they can find it difficult to re-configure their relationships with paid friends, with some making compromises relating to the quantity or quality of support provided, since they are unwilling to risk losing personal friendships as a result of work-related concerns. For example, one disabled parent who employed a personal friend found it difficult to challenge this individual’s practice of serving food to her children in what she felt was a hasty and untidy manner; when she tackled this issue, she received a response which undermined her authority and shut down further discussion on the subject. In another situation, the parent described feelings of guilt about asking her PA to clean the floor when they had earlier complained of feeling tired; in this situation, the employer empathised with the PA’s feelings of fatigue and pain to such a degree that she ended up struggling to perform this task herself once the PA had left for the day.

For Ahlström and Wadensten (2010), PA relationships routinely involve emotional work; indeed, they suggest that the encounter between the disabled person and their personal assistant is based upon a true and meaningful ‘intersubjective meeting’ which is reliant upon the emotional and cognitive engagement of the worker. In this study, feelings such as fear and anger were problematic to workers, since they felt they were impermissible and as such, had to be repressed. PAs expressed strongly that the ‘personal chemistry’ between themselves and their employer should be good and were disheartened when they felt they were reduced to being simply a ‘tool’, to meet their employer’s needs.

If caring for adults involves emotional work, caring for children is even more likely to engage one's feelings. Whilst a range of emotions may be experienced, according to Page (2011), loving children in professional contexts is not often discussed; and yet it is a salient factor for parents when choosing childcare. Although some research has examined the relationships between parents, nannies and childminders, and the meaning employed mothers give to having others take care of their children whilst they are away at work, including Uttal's (1996) qualitative study with 31 mothers, there is relatively little research into paid parenting support within the home. One small-scale UK study exploring choice in pre-school childcare and education however highlights the significant impact class and gender plays in the choices parents make about childcare (Vincent and Ball, 2001), and underlines the effort that mothers put in to "crafting" warm interpersonal relationships with paid carers in an attempt to "blur and alter the pecuniary basis of the childcare arrangement and thus bring care and love to the forefront" (Vincent and Ball, 2001).

Since Arlie Hochschild (1983) emphasised the harm that can be caused to workers by being made to enact emotions they do not feel for the benefit of others, there has been academic interest in the intersection of paid work and care. Hochschild (1983), describes three different types of emotion work: cognitive, bodily and expressive. These involve the attempt to change elements of the environment and others' feelings through the intentional use of the self and emotions. In her later work, Hochschild (2012) charts the accelerated advance of commercialisation into almost every aspect of intimate family life, emphasising the depersonalisation of family relationships, revealing a world in which intuitive and emotional human acts are now aspects of work for hire, where 'having it all' does not mean 'doing it all' and domestic workers must draw on complex mixes of both work and family cultures.

Hochschild's work is part of, and inspired, a developing literature from the US exploring how families and their networks are changing to accommodate the demands of twenty-first century life. In her review of empirical and theoretical work on this subject, England (2005) discusses ‘love and money’, a theme which can also be found in literature relating to foster care, another distinctive caring relationship that crosses public and private domains and results in myriad complexities (Kirton, 2001). England explains the ‘love and money’ framework as one which questions the dominant view that “someone is always harmed when care is sold” (England, 2005, p. 396). This perspective argues against the oppositional dichotomy between the family and the market and calls for further empirical study to reveal the mechanisms which cause specific barriers to care, such as inadequate availability of care, work rules that prevent the expression of emotion, and low pay.

Hansen (2005) further suggests that there is a fundamental contradiction between the ideology of independence espoused by parents and their practice of developing interdependent networks of support to help care for their children. The concepts of dependency, self-reliance, independence and autonomy which Hansen explores in her work with families mirror key themes relating to disability (Morris, 1993; Hansen, 2005). A later US study into the phenomenon of ‘outsourcing’ aspects of parenthood (Epp and Velagaleti, 2014) examined the relationship between ‘the market’ and family life. 23 families participated in this research, which uncovered “complex care assemblages that are shaped by parenting discourses and tensions of control, intimacy, and substitutability” (Epp and Velagaleti, 2014, p. 911). In this study, parents experienced three central tensions in retaining their distinction or primacy as a parent when considering the use of paid care services, namely: control, intimacy, and substitutability. The authors describe how these tensions may be experienced using the example of planning a child’s birthday party. Here, parents may question whether it is their role as a parent to do this? (substitutability) What will happen if things aren’t done the way they want them to be done? (control) Shouldn’t they be the person who created the excitement and joy for their child? (intimacy). Findings from the current study suggest that disabled parents work effectively with their PAs to resolve practical issues of substitutability but can experience tension and frustration in relation to control and intimacy.

Unresolved issues in these areas can lead to feelings of guilt on the part of parents.

Whilst there is very limited research specifically about parenting with PA support, the issue of how parents balance competing relationships between nannies and their children has been explored in some depth, again in the US context (Macdonald, 1998, 2010). Findings from data collected in interviews with 30 mother-employers and 50 caregivers demonstrate that nannies are engaged with a great deal of 'boundary work', to help create and maintain a distinction for parents and children between 'mother' and 'not-mother' and home and work lives (Macdonald, 2010). As described earlier, maintaining and negotiating boundaries is a key feature of the PA relationship (Ungerson, 1999; Ahlström and Wadensten, 2010), and a shared feature of these 'care taking' roles. In other aspects, the task and function of nannies and PAs differ, as nannies are employed to provide care directly to the child, and are typically 'on duty' when parents are not available or physically present to care for their children, whereas the PA role tends to be performed primarily in the company of and under the direction of their employer. Part of the work of the nanny is to minimise the sense of loss which both parents and children may feel as a result of their presence in the family home – in this way, nannies inhabit a borderline role – they are both welcome and not-welcome. Employers of nannies often express some ambivalence about them, minimising or 'erasing' their presence in depictions of family life, whilst at the same time referring to them as 'one of the family'. Other mothers felt their primacy as parent was undermined by the nanny (Macdonald, 2010).

The literature shows that employer/ employee relationships are also typically complex: parents want nannies to provide love and care and have positive relationships with their children, but also to 'switch this off' when the parent returns home. A discussion of the challenges in limiting the emotional element of a relationship with a child may be found in relation to the experiences of home-based day-care child providers (Nelson, 1990). In this study, which drew upon data gathered from 225 completed questionnaires and 86 interviews with US day-care providers, many workers expressed the view that a family day-care provider should be ‘like a mother’ to the children in their care, providing them with a family-like, home-like environment. Becoming a substitute mother for children in this way brought about a merging of paid and unpaid roles and created a tension: carers had to accept limited responsibility and limited authority for the children, and they experienced emotional loss when the children were removed from their care. To manage this, workers developed a ‘detached attachment’ (Nelson, 1990, p. 598) to children, explaining this as a daily balance they had to strike between emotional closeness and distance in order to avoid the pain of over-involvement. This contrasts with findings from this study, where PAs seeking to create and maintain emotional distance from their employer’s children were in the minority.

Summary

This chapter has examined the developing role of the personal assistant, bringing together key strands from within the different areas of academic research to highlight issues of relevance to this study. Several key elements of the PA/employer dynamic were outlined, including the importance of boundaries, place, power and emotion in shaping paid support relationships. Whilst there is no literature to date which addresses the experience of personal assistance in the lives of disabled parents and their children, the existing literature demonstrates the complexity and diversity of PA relationships, and the potential for conflict which can result. This is supported by the literature on paid parenting support from nannies, childminders and au pairs. It is evident that the influence of close, ‘helping’ personal assistance relationships extends beyond the immediate sphere of those directly involved and has an impact on close family members. This raises unanswered questions which this study seeks to address about the experience and meaning of personal assistance in the lives of disabled parents and their children, including:

What specific tasks do personal assistants routinely carry out to support families led by disabled parents?

How do disabled parents define and manage the boundaries of relationships between themselves and their PAs, and their children and PAs?

What key factors shape the development of relationships between disabled parents, personal assistants and children?

How do disabled parents, children and PAs experience and manage emotion in their interactions?

With these questions in mind, the next chapter goes on to explore what the existing literature can tell us about the lives of children who have disabled parents.

Chapter 2: Children with Disabled Parents

Introduction

This chapter of the literature review examines what is known about ‘young carers’ and the current context relating to Disabled People and their families. Academic research which focusses upon the interpersonal relationships between disabled parents and their children is somewhat limited; this serves to reinforce the unique contribution the current study makes to the existing knowledge base. Children who have disabled parents are certainly present within the literature however; a search for studies with a focus on this group quickly reveals a strong interest in their needs and lives based upon their characterisation as ‘young carers’. A significant body of enquiry has developed around this influential strand within the literature over the past twenty-five years or so, with much of it focusing on defining the tasks and responsibilities undertaken by young carers, and the impact of caring on their physical and mental health, development and educational attainment (Aldridge and Becker, 1993; Frank *et al.,* 1999; Dearden and Becker, 2000; Thomas *et al.*, 2003; Warren, 2007; Cheesbrough *et al.*, 2017).

Indeed, the ‘young carers’ perspective has become the dominant framework through which children who have disabled parents are viewed and their needs considered. However, this portrayal is an over-simplification of a complex reality and offers only a limited insight into the lives of these young people and their families. By definition, ‘young carers’ research does not take into account the views and experiences of children who do not identify in this way: this includes children whose parents use PA support to meet their identified needs. Although ‘young carers’ research has limited direct applicability to this study, it seems likely that children and young people who have disabled parents may have common concerns and share some experiences with those contributing to ‘young carers’ research; key elements of this literature are therefore included herein.

Early studies concerned with families led by disabled parents were frequently impairment specific (Collis and Brant, 1981; Westgren and Levi, 1994; Blackford, 1999) and, as Olsen and Clarke (2003) contend, primarily concerned with the perceived risks of disabled parenting in connection with child development. This section of academic literature inevitably reflects the concerns and interests of the times in which they took place. The issues facing disabled parents and their children have evolved over the intervening period, and whilst adopting a narrow, impairment-focussed approach is considered unhelpful in reaching a deeper understanding of the complexities and dynamics of present-day family life, valid questions raised by studies drawing on impairment-specific groups of participants are explored within this review. Overall, however the focus is on studies which have taken place since the introduction of the key legislation which guides current social work practice with children and families, namely the Children Act 1989.

This chapter will analyse relevant strands of the literature, drawing out issues of significance to the experience of children and young people whose parents use regular PA support. The first sections will briefly chart the developing interest in carers' issues and provide an overview of the current context relating to disabled people and their families. The literature relating to children who have disabled parents, or who have other direct experience of personal assistance is also set out, before a summary of the 'young carers' literature is presented.

Careful reading of this literature illuminates themes which are relevant and useful to this study – both to provide context and to identify key questions which remain unanswered about aspects of family life for children whose parents are disabled. Important issues and ideas about 'difference' and 'normality' and how these concepts relate to and are understood by children are raised. These themes may also be detected within the wider literature which this review draws upon to provide insights into the lives and feelings of young people who have disabled parents. Research demonstrates that children and young people whose lives are affected by personal or parental impairment often experience complex emotions and may resent what they see as an invasion of their family privacy. Some positive aspects of experiencing non-normative family life are also evident.

‘Young carers’ research frequently highlights concerns about the prospect of ‘parentification’, a term which is used to describe a harmful process whereby children, in the absence of functioning parental figures, take on significant caregiving tasks (Olkin, 2000). Negative consequences and outcomes of caring are frequently reported; however, these findings have been contested from a disability rights perspective, and from a holistic, ‘family focussed’ standpoint. This chapter highlights these counter arguments and points of disagreement with the aim of providing a deeper insight into the complexities of family life and disability.

Throughout, the focus will be to establish what can be learnt from the existing literature in order to identify the gaps in knowledge about the experience of growing up with PA support. The discussion is arranged to examine key themes within the wide range of literature which this review takes in, ending with a formulation of important questions which this study aims to address.

Developing interest in carers’ issues

The identification of ‘young carers’ as a sub-group within the broader category of ‘informal carers’ was the result of wider research inquiry, occupied with exploring and measuring the impact and contribution of carers to the delivery of care and support within families and the community. The explosion of research into carers issues in the 1980s (Thompson and Doll, 1982; Fadden *et al.,*1987; Nolan and Grant, 1989; Zarit, 1989) was conducted against the backdrop of the increasingly dominant theme of care in the community, which commentators note has formed a central plank of government policy since the 1960s (Twigg and Atkin, 1994), culminating in major reforming legislation, the National Health Service and Community Care Act 1990. Empirical studies examined the impact of caring upon individuals’ lives, highlighting the ambiguous position occupied by carers operating on the margins of the social care system, together with the financial, social, physical and emotional costs of caring (Finch and Groves, 1983; Parker, 1985). In this way, research played a significant part in the development of legislation, policy and services for carers (Stalker, 2002), embodied within the Children Act 1989 – section 17 of which provides duties and powers to support families as a whole and promotes the upbringing of children within their family unit – the Carers (Recognition and Services) Act 1995 and 'Caring About Carers: A National Strategy for Carers' (Department of Health, 1999).

Ongoing political interest in carers' issues and commitment to funding specialist services has ensured continuing academic attention, with research studies into informal caring by children and young people eliciting vigorous debate involving academics, policy makers, service providers and disabled people (Keith and Morris, 1995; Aldridge and Becker, 1996; Olsen, 1996; Olsen and Parker, 1997; Newman, 2002). As this review will show, this debate centred on the relative benefits of delivering greater support to disabled parents to enable them to fulfil their parenting role, versus providing specialist services for young people who assume a caring role against a background of disadvantage, poverty and social exclusion. This study aims to explore that contention and to examine the impact of personal assistance to enable and support parenting. Findings demonstrate that while many disabled parents and their children agree the provision of PA support prevents children from 'falling into' caring for a parent, living with personal assistance is by no means straightforward.

The current context relating to Disabled People and their families

Following the implementation of the Children and Families Act 2014 and the Care Act 2014, disabled parents, young carers, young adult carers and their families have stronger rights to be identified, offered information, receive an assessment of their needs, and be supported using a whole-family approach.

However, these enhanced rights are set against the backdrop of a decline in local authority-provided services, ongoing since the coalition government elected in 2010 justified the retrenchment of services and restructuring of disability-related benefits by reference to the financial crises of 2007/8. Reports suggest that there is a considerable shortfall in the funding between those needing care and shrinking local authority budgets (Local Government Association, 2015), with demand for social care growing at an average rate of 3.7% a year, leading to a projected funding gap of £6bn by 2030/31, at current prices (Bottery *et al.*, 2018). It is evident that increasing numbers of people are living with long term illness and impairment, and the costs of providing community care and support have escalated (NHS Digital, 2019). This situation inevitably places systems and people under pressure.

The impact of austerity has been particularly felt by disabled people and their families, following the closure in 2015 of the Independent Living Fund (ILF), a central Government financial resource for disabled people, and the scrapping of Disability Living Allowance (DLA), a benefit which was introduced explicitly to offset the extra costs of disability. The replacement of DLA with the new, less generous, welfare benefit known as Personal Independent Payment (PIP) has caused a great deal of concern for disabled people (Cross, 2013), not least because this follows the strong downward trend in the real level of spending resources available to English local authorities, with the overall average cut amounting to 27% in real terms (Hastings *et al.*, 2015). Cuts in services and benefits are disproportionately felt by disabled people who are more likely to be reliant on health, social care, housing and transport services. Furthermore, as a result of low employment rates for disabled people, together with the additional costs associated with living with an impairment, they and their families are more likely to live in poverty and/or rely on benefits (Wood and Grant, 2010).

The meaning of poverty is a subject which has attracted thorough investigation and discussion; it is beyond the scope of this account to examine the complexities of this literature, suffice to state that the experience of poverty goes beyond basic physical or economic need and encompasses disadvantage, lack of opportunity to participate fully in society and loss of hope (Hirsch, 2019). Disability and poverty have a close connection (Palmer, 2011), with research evidencing the higher costs related to disability (Snell *et al.,* 2015; John *et al.,* 2019). Disability also has a negative impact upon life opportunities, both for the individuals directly affected, and those closely associated with them. Figures show that 21% of children in families with at least one disabled member live in poverty, a significantly higher proportion than the 16% of children in families with no disabled member (Office for Disability Issues and Department for Work and Pensions, 2014). A report by the Joseph Rowntree Foundation (Tinson *et al.*, 2016) found that disability is increasingly linked to the changing nature of poverty in the UK. Poverty has also been identified as a significant barrier to effective parenting (Russell *et al.,* 2008) and a key stress factor on children whose families are in long-term receipt of benefits due to sickness and disability (Ridge, 2011).

Having briefly set out the backdrop against which the current study is set, this review will now examine what may be discovered within the literature about children's views of family life and parental disability.

Children's views: searching within the literature

There is limited academic literature which focuses directly on how children think and feel about having disabled parents, and the quality of their relationships with them. These are potentially sensitive subjects to discuss directly, posing a challenge to research, given evidence suggests that children find talking in depth about their personal lives and families difficult (Clay *et al.*, 2016). Nevertheless, researchers can use their experience, creativity and skills to engage children and young people in focused and meaningful conversations about emotive issues, as with Cossar *et al.'s* (2016) study examining children's views on their participation in the child protection system in England.

Our understanding of children's views and experiences of parental use of personal assistance is also incomplete; indeed, a comprehensive search of the literature returned only one small scale study which has direct relevance to this research topic. Selandar's (2015) doctoral study of parenting with PA support provides very useful data from interviews conducted with eight families led by disabled parents. Between them, these families had 17 children, nine of whom participated in this small-scale qualitative study based in Sweden. The young people involved with this research all viewed PA support as a natural, or 'normal', part of their everyday life, and something they did not think a great deal about. Nevertheless, findings point toward some complex and conflicting feelings. For example, participants expressed that while PA support can help the smooth 'flow' of everyday life, it can also give rise to feelings of insecurity and concern, depending on the member of staff who is working. Children in this study especially felt their parent's vulnerability when new or inexperienced PAs were employed and often arranged to be on-hand to support parents in this situation. While the level of support provided by PAs to parents meant these children did not take on practical caring responsibilities themselves, they nevertheless remained prepared to take action: both mentally and physically 'standing by' for any unforeseen circumstances.

This research provides fascinating insights into the experience of growing up with PA support, however in order to understand more about the lives of children and young people with disabled parents, it was necessary to take a more adventurous and creative approach to the literature search. Children's views are reported within a wide range of published material, and can be found in various sources, including books and collected writings on family life (Beazley and Moore, 1996) and disabled parenting (Wates, 1997; Booth and Booth, 1998; Olsen and Clarke, 2003; Llewellyn *et al.*, 2010; Jones-Garcia, 2011). In addition, there are a limited number of personal accounts from children which are published online by disabled parents' groups, for example Disability, Pregnancy and Parenthood International. These short stories in children's own words demonstrate that they are aware of issues of difference in relation to 'other' families – they report 'noticing' things their peers do not, such as where kerbs are dropped, the availability of accessible community amenities, the width of doors etc. In these narratives, children often describe ‘having’ to do certain chores which their parents are unable to complete, albeit this is placed within the context of loving their parents and accepting the situation. Some children also speak insightfully and sensitively about recognising and admiring their disabled parent’s individual qualities and characteristics, such as emotional strength or determination (Disability Pregnancy and Parenthood International, 2016).   While these contributions can provide helpful insights, caution needs to be used when drawing upon personal narratives and testimonies as they often focus on non-representative samples or stress extreme situations.

A search was also made to assess what children and young people have to say about their experiences of other paid in-home care workers such as a nanny or au pair. Here again, there is very little published data. However, a study commissioned in 2003 for the Department for Education and Skills (Mooney and Blackburn, 2003) incorporates a literature review of published material concerning children's views on childcare provision in the UK; this revealed only five studies which fit their criteria for inclusion. Analysis of these publications demonstrated that children value childcare workers who are: “caring, friendly, helpful and playful, who will join in with them, give them freedom and responsibility, treat children with respect and fairness, take them seriously, be their friend, listen and talk to them” (Mooney and Blackburn, 2003, p. 22). Continuity was stressed as an important factor to children, who talked about the value of having adults in their life who stayed with them and whom they could get to know well.

The broad range of research outlined above certainly reveals valuable insights and themes of relevance to this study. However, a search of the literature relating to children who have disabled parents clearly demonstrates that they are most often represented within research concerned with ‘young carers’ issues. There is also a substantial ‘grey’ literature relating to ‘young carers’ which take the form of surveys, reports and evaluations of projects frequently contains brief descriptions of young carers’ lives and responsibilities with short quotes from children themselves (Jones *et al.*, 2002; Clay *et al.*, 2016; Cheesbrough *et al.*, 2017; Mesie, 2018). In addition, there is a sustained interest in young carers from the print media (Williams, 2016), and stories about their lives and experiences are reported in the press, often published to coincide with ‘young carers’ awareness events or the publication of an official report or survey.

Unquestionably, the majority of published research which examines the intersection of disability and parenting stems from the ‘young carer’ perspective. Understanding the contributions and limitations of this highly influential area of research, which has shaped current policy and practice, therefore provides essential background and context to this study. Analysis of the ‘young carers’ literature reveals that disabled parents are often presented as problematic; this is commonly based on the proposition that children whose parents are disabled are at increased risk of ‘parentification’. This is a persuasive notion when considering the needs of families led by disabled parents, as ideas about what children ‘should’ or ‘should not’ be doing as part of their everyday lives have shaped the support and services available to them. This review will now turn to examine key points within the ‘young carers’ literature.

Problematising families led by disabled parents: the emergence of ‘young carers’

Academic interest in the wellbeing of children who provide regular care started to develop in the early 1990s; this can be linked to both the United Nations Convention on the Rights of the Child (1989), and the Children Act of the same year which drew into sharper focus the importance of understanding the lives and views of children and young people. Building on wider research into the role of ‘informal carers’, early work undertaken by Aldridge and Becker (1993) identified that child carers were excluded from the existing literature, wider policy, and debates on community care. In their initial study, the authors completed in-depth interviews with 15 children who provided care to close family members – in most cases, parents who had ongoing health conditions. Their findings suggested that age played an important factor in terms of influence on carer lifestyle, needs, opportunities and health. This research highlighted significant concerns for children whose lives appeared to be restricted due to the impact of caring roles, with negative outcomes for their physical, psychosocial and educational attainment (Aldridge and Becker, 1993). This study was followed up with an exploration of 10 parents' views in a linked research project by the same team (Aldridge and Becker, 1994). This second study identified that parents felt their children provided better care than paid care workers, however they appeared to find it difficult to identify and articulate the impact of caring on their children. Indeed, it was found that there was clear reluctance on the part of both children and parents in talking to others about the caring role played by children, often due to concerns that this could have negative consequences and lead to family break-up.

Extensive publicity surrounded Aldridge and Becker's early research, and outputs from this and subsequent work by them, and others, was instrumental in shaping the development of UK law, policy and practice relating to carers' needs. For example, there was a significant expansion in services for young carers (Dearden and Becker, 2004). New projects aimed to support children and protect them from the problems associated with 'parentification', a concept which has its origins in theoretical orientations within structural family therapy (Minuchin *et al.,*1967), and describes the ways in which children adopt behaviour considered inappropriate for their age and role within the family.

The term 'parentification' was used by Boszormernyi-Nagy and Spark (1973) to describe the process through which children are expected to fulfil the parental role within the family system. This may involve children taking on roles such as preparing meals, caring for younger children, completing household chores etc. Children may also take on expressive parenting tasks such as responding to the emotional needs of their parent/family members, serving as parental confidant, peacemaker or mediator (Chase, 1999). Within the counselling and family therapy literature, parentification is frequently presented as a feature of "dysfunctional family systems"

(Engelhardt, 2012, p. 46) and may be considered a form of child neglect (Hooper, 2007).

Much of the early 'young carers' literature positions young people as "adults before their time" (Eley, 2004, p. 66), suggesting that there may be some degree of 'role reversal' within families led by disabled parents, and that this places children at significant risk. Disability rights commentators were quick to argue however that by constructing children as 'young carers', the question of how to address adequately the support needs of disabled parents is avoided; this serves to stigmatise families led by disabled parents and undermines both the rights of children and of disabled people (Keith and Morris, 1995). The concept of parentification has further been criticised as being a notion based upon prejudice, which provides a limited and inaccurate depiction of the lives of children who have disabled parents (Olkin, 2000). Certainly, narrow understandings of disability and family life, together with rigid assumptions of 'adult' and 'child' roles have made it difficult to understand potential risk factors or protective factors for parentification, and to explore how much care is 'too much' (Earley and Cushway, 2002, p. 170).

It is evident that family life can be complex and difficult for children who have disabled parents. However, as Clarke and O'Dell (2013) highlight, research which accentuates 'hidden' troubles can overlook the normative features of family life, obscuring important individual and family experience. They point out the need for research that presents: "accounts of disability from both disabled and non-disabled people, in relational contexts, outside of a service-led – or policy-led – frame" (Clarke and O'Dell, 2013, p. 81). Only in this way, they suggest, can we understand the ways in which intimate family life and personal experience is influenced by policy frameworks and service provision.

With these critiques in mind, this review will now examine what the literature can tell us about the effect of caring on children's lives.

The impact of caring on young people

There is a wealth of literature concerning the roles and tasks of ‘young carers’; early studies identified the wide range of responsibilities undertaken by young carers within the home, including: completing domestic tasks; providing personal and intimate care; emotional support; general assistance and childcare (Aldridge and Becker, 1993, 1994; Bilsborrow, 1993). More recently conducted studies have determined that the nature of caring tasks performed by young carers has subtly changed over time. National surveys of young carers who received support from specialist young carers projects across the UK were completed in 1995, 1997 and 2003; evidence suggests that over time, there has been a reduction in the proportion of young people involved in all aspects of physical care, including personal, intimate care. Reasons for this are unclear, however research indicates a wide range of factors affect pathways into caring, including: the nature of the illness or impairment of the person with care needs; the level and frequency of care required; the extent of personal autonomy and independence of the person with support needs; the age, gender, ethnicity, co-residency, power and status of the young carer, as well as the structure and socio-economic status of the family unit and the availability and effectiveness of informal and formal family support networks (Dearden and Becker, 1998; Frank, 2002; Aldridge and Becker, 2003). As a result of the complex interplay between these dynamic factors, the type of caring tasks undertaken by young carers is likely to be determined by their individual circumstances as well as by wider social and other external factors (Aldridge and Becker, 2003).

Alongside the decrease in children providing physical care, there has been a proportional increase - given the wider changes in the shape of data - in the amount of emotional support offered by young people (Dearden and Becker, 2004). A government-commissioned qualitative study with young carers, their families, and key stakeholders including a Young Carers Research Group (Clay *et al.*, 2016) shows that young carers continue to undertake a wide variety of caring roles and responsibilities, including providing emotional support, personal care, housework and household budgeting. This study found that younger carers typically undertake simpler tasks, such as keeping parents and/or siblings company and making drinks, as parents seek to protect them as far as possible from the effects of their impairment. Older young carers' tasks were often more involved, and included providing emotional support, food preparation and helping siblings prepare for school and to complete homework (Clay *et al.*, 2016).

There are important cultural elements to consider regarding children's involvement in completing household tasks and providing care. Research demonstrates that this varies within different contexts (Bowes *et al.*, 2001; Bray, 2003; Becker, 2007). Jones *et al.* (2002), in their report of research with black young carers and disabled or ill family members, describe the wide diversity of participants' religion, language, ethnicity, kinship networks and support communities. They highlight the concept of simultaneous oppression as being particularly helpful in understanding the experiences of participants whose lives are:

> mediated simultaneously through race, gender, disability and class. Their identities are also subject to stereotypes…which may be underpinned by racist, sexist and disablist ideologies.
>
> (Jones *et al.,* 2002, p. 7)

As many families do not recognise their children as 'carers' (Smyth *et al.,* 2011), there can be reluctance and anxiety among families in disclosing children's caring responsibilities (Clay *et al.*, 2016; Cheesbrough *et al.*, 2017), and some children and young people do not recognise or identify with the role of carer (Noble-Carr and Woodman, 2018), the picture emerging from research is complex and incomplete.

Whilst it is helpful to understand the nature and degree of tasks undertaken by children who have disabled parents, understanding the consequences of providing this support is of far greater importance. The weight of research evidence suggests that caring can lead to a range of negative outcomes for children, including: restricted access to social networks, school absenteeism and truancy, educational under-performance, psychological and emotional problems as well as compromised transitions to adulthood. For example, Dearden and Becker's (2000) qualitative study involving 60 young people caring for a parent with a long-term illness or disability found evidence of educational under-achievement, difficulties and delays for young people in leaving home due to their caring responsibilities, and made links between caring, poverty and social exclusion. It has been suggested that problems and negative outcomes are more likely to arise when the nature and extent of caring responsibilities is disproportionate to the age and level of physical and emotional development of the child. The Children's Society report (2013) drew upon data from the Longitudinal Survey of Young People in England (LSYPE) and suggests that taking on excessive or inappropriate caring responsibilities has a major negative impact on young people in their childhood; the consequences of providing care can also extend to the rest of their lives and have negative impacts in emerging adulthood (Boumans and Dorant, 2018).

The foregoing has provided a necessarily abbreviated overview of the 'young carers' literature. A reading of this, taken together with the wider literature concerning children who have disabled parents outlined above, reveals important recurring themes. These are considered further below:

Feeling different

Research shows that disabled young people, those with disabled parents and young carers frequently report feeling 'different' to their peers. This is commonly linked to the effects of social exclusion.

In some cases, young people use strong language to express their sense of isolation and loneliness, voicing that others will view them: "like a freak" (Roche and Tucker, 2003, p. 444). Roche and Tucker (2003) drew on research conducted between 1997 and 2000 in the UK, comparing the experiences of 190 young carers and 501 young people with Myalgic Encephalomyelitis (ME) and found that they share some common experiences. For both groups of young people, the idea that they or their household are 'different' was very important; this sense of difference can affect their ability to make friends and talk about their situation to others. The perception of the household being ‘different’ proved to be particularly significant for the participants identifying as ‘young carers’ who undertake roles that they understand as being unlike those of ‘non caring’ children.

Concerns regarding friendships with peers was reported by Warren (2007); this study took a quantitative approach, using brief face-to-face structured interviews to survey 390 children and young people aged 9 –18 years about their perceptions of what they do to help at home. Findings suggested that ‘young carers’ are more likely than non-carers to report bullying related to their caring roles, parental impairment or their perception as ‘different’. Other qualitative research, drawing on interviews with 13 young adult carers and 10 specialist ‘young carers’ workers (Heyman and Heyman, 2013) also demonstrates that ‘young carers’ can be bullied by peers for being ‘different’ or lose friends for not meeting peer expectations of participation in joint activities.

Ideas about ‘normality’

Closely connected to notions of ‘difference’ are ideas about ‘normality’. Within the literature, young people consistently express concern about how they perceive concepts of difference and normality, and how they feel others judge them and their families against these nebulous social standards. Findings from this study are consistent in revealing a sensitivity to these ideas, as participants reflected on growing up with personal assistance.

As part of a broader study of childhood and what are viewed as ‘atypical’ roles for young people, O’Dell *et al.* (2010) surveyed and interviewed 46 young people aged 15 – 18, nine of whom had experience as young carers. Researchers used a series of vignettes to examine how young people construct ideas about young carers and disabled parents. Analysis showed that participants expressed a strong sense of what is a ‘normal’ childhood. This was constructed as a time for limited responsibility, play and socialising; in ‘normal’ families, parents care for their dependent children to enable them to become fully independent individuals. Family life for ‘normal’ teenagers is free from disability or serious difficulty. Any transgression from this idealised view positions disabled parents and young carers as non-normative and deficient: a young carer is assumed to have ‘lost’ their childhood and their opportunity to have a ‘normal’ life is likewise lost or disrupted. The effect of this can be to marginalise young people whose parents are disabled.

As outlined above, Selander’s (2015) research into family life with personal assistance interviewed a small sample of children aged 8 – 18. Most of these participants had lived with support from paid workers all their lives. They identified personal assistance as a ‘normal’ part of their lives; this provided them with security and safety and also meant that children could do more with their parents. While children looked upon workers as there to primarily help parents, they described becoming close to PAs who had been with the family for a long time and expressed that they could be another adult to talk to and learn from.

A much larger, national study was set up in the US to explore the experience and impact of being raised by a disabled parent. This mixed methods study was conducted over several years, from 2009 – 2016. Participants aged between 17 – 21 completed an optional online survey and provided a short essay about their lived experiences. Interim analysis has been reported on 551 participants who have a disabled mother (Preston and Jacob, 2014). Just under 60% of participants rated their experience overall as positive, with most talking about the ‘normality’ of growing up with a disabled mother, and the resilience and strength of their families despite the social stigma, isolation and financial hardship they often faced. Findings suggest that the stability of parental disability has a considerable impact on the entire family system – some families fragmented under the stress of unstable situations, while others pulled together more strongly. Significantly, participants underlined the most pivotal issue regarding the impact of their parent’s impairment was the quality of relationship they shared.

In a small-scale Swedish study (Hultman *et al.,* 2015), young disabled people’s experiences of everyday life with personal assistance was examined. In this qualitative study, 16 young people aged 16 – 21 with physical impairments participated in multiple individual semi-structured interviews. Participants to this study regarded ‘normality’ as a highly positive value; they considered personal assistance as a means of achieving ‘normality’ and became accustomed to the presence of PAs in their lives. Relationships with PAs were described in a variety of ways, ranging from ‘tools’ to ‘professional friends’, with factors such as the individual characteristics of the PA, the opportunity for social interaction and friendships on the part of the young person, and time affecting the emotional distance between individuals.

Difficult emotions

Another theme which emerges from the research is the complex array of difficult emotions which children and young people talk about experiencing. This includes a range of feelings including worry, concern, fear, anger and guilt.

In Roche and Tucker’s (2003) comparative study outlined above, young carers and young people with ME sought to protect themselves from what they believed would be a critical judgement of their lifestyles by concealing the reality of their lived experience. Employing this ‘defence mechanism’ can however lead to worry, a loss of confidence and frustration. These findings echo an earlier mixed methods study (Frank *et al.*, 1999) involving 66 former young carers. This study used a questionnaire and semi structured interviews to gain an insight into the lives of participants. Here, young people expressed powerful negative feelings of being ashamed or embarrassed about their family circumstances, which led them to hide their experiences from others, thereby leading to social isolation.

Cree (2003) further reports on a research study which specifically explored the worries and problems of 61 young carers in Edinburgh aged between 5 – 16 years. This study found that participants identified significant worries and problems in relation to their well-being, over and above any ‘normal’ adolescent difficulties. These problems were related to friends, sleeping, school, home, and also included issues with self-harm, suicidal feelings and drugs. At the same time, Thomas *et al.'s* (2003) qualitative study with 27 young carers in Wales used a mix of informal focus groups and individual interviews, and found that participants experienced worry and fear, both in relation to their parent's safety and wellbeing, and for themselves, for example the fear of being taken into care; young people in this study also spoke about being isolated from their friends.

The literature suggests that living with PA support can give rise to mixed feelings. For example, in Hultman *et al.'s* (2015) study, disabled teenagers who used PA support expressed some ambivalence about the level of adult presence in their lives, viewing the experience overall as one of enforced dependency.

Whilst relatively little is known about the perspectives of young people whose parents use PA support, Selander's (2015) study indicates that the experience is far from straightforward, with one young adult voicing complex and mixed emotions about his mother's use of personal assistance – while he was glad for her to be receiving support, this was also closely and negatively associated in his mind with the progression of her illness and declining strength and abilities. The young people involved with Mauseth and Hjälhmulmut's (2016) grounded theory study with 15 Norwegian teenagers whose parents are diagnosed with Multiple Sclerosis also experienced a complex range of emotions. They commonly expressed worry in terms of progression of their parent's illness, but in addition, many also felt guilty – for not behaving well all the time, not helping out with household chores as much as they ought, or for planning to move out of the family home for educational purposes. These adolescents adapted to changing situations by suppressing some of their own needs and taking on greater responsibility to support and care for their parents. This study found that participants were preoccupied with preserving control in an uncertain everyday life: this concern was resolved by constantly 'balancing needs' and required participation in four different categories of internal or outward activities including: reflecting, adjusting, taking responsibility and seeking respite (Mauseth and Hjälhmulmut, 2016). These strategies were used interchangeably in an ongoing effort to affect their personal development, with both negative and positive outcomes. The young people also expressed feelings of "uncertainty, guilt, shame, anger, sadness and fear; and at the same time felt more responsible, independent, patient and empathic than their peers." (Mauseth and Hjälhmulmut, 2016, p. 861). This study concluded that openness within the family and outwardly to the wider social support network, is essential for the well-being of adolescents, and relies on high quality support from health professionals who have knowledge of parental impairment and family functioning.

Invasion of privacy

The lives of children and young people who have direct experience of personal assistance are inevitably subject to an enhanced level of professional involvement. Either they or their parent(s) will have a social worker whose role is to assess and review their needs on an ongoing basis. Their lives may also be populated by health professionals and care providers. The literature tells us that for many of these young people, the intensity and degree of intervention in their lives from people who are not family members can be experienced as an unwelcome invasion of their private and family space.

For example, a small-scale Swedish study (Skär and Tamm, 2001) examined young disabled people's experiences of using PA support to meet their own needs. This qualitative study of 13 children and young adults aged 8 – 19 with restricted mobility, used conversational interviews to examine how participants perceived their relationships with their assistant(s). Findings demonstrate that children and young people valued the continuity of PA support relationships, expressing frustration about turnover in staff since they found it difficult and time-consuming to establish relationships with workers. Participants also considered the essential asymmetry of their relationships with PAs an invasion of privacy and complained when PAs assumed authority over them – this was likened to acquiring ‘double parents’ (Skär and Tamm, 2001, p. 928) and regarded as a hindrance to independence as well as a barrier to forming peer friendships. The teenagers in Mauseth and Hjälhmulmut’s (2016) study mentioned above echoed these findings; while participants stressed loyalty to their parents and underlined their ‘normality’, those whose parents needed care at home often considered this a significant invasion of family privacy.

The children and young people in Selander’s (2015) study also expressed strong feelings about the presence of PAs in their lives – they did not want PAs to ‘control’ them or to express opinions about them or their lives. They also found it difficult at times to have workers knowing so much about their lives and families, seeking private space to themselves to help them manage this.

Developing views of parent/child care relations

Throughout the 1990s, a body of work emerged which challenged the dominant view of children as passive, immature and incomplete individuals, positioning them instead as competent in their own right (James and Prout, 1997). The idea of childhood as a preparatory rather than participatory phase of life underpins contemporary thinking about childhood, yet this is inherently problematic, since it fails to take account of the wide variation of children’s lives, including their social and cultural contexts and individual experiences of disability (Singal and Muthukrishna, 2014).

The growing interest in children’s own experiences and understandings is reflected in the literature, for example, Gladstone *et al*. (2006) note the striking absence of children’s views from studies on disabled parents, and suggest that while children are physically vulnerable and psychologically and socially inexperienced, they are also learning how family members care for each other and how to take on responsibility. They conclude that: “expanding a conceptual repertoire to include notions of interdependence and reciprocity" (Gladstone *et al.*, 2006, p. 2547) may be a more useful way to consider the needs of the family as a whole and better support the individuals within it.

Further contributions, including from the field of counselling, suggest that when children provide care and support to parents and family members, these experiences might actively promote resilience to adversity, leading to positive coping and healthy attachments (DiCaccavo, 2006).

As outlined above, whilst parentification is considered an unhelpful and limited concept, within this field researchers have begun to acknowledge and explore the complexity of parent/child care relations, with studies finding that child care-giving does not necessarily lead to child maladjustment, in fact beneficial outcomes may result for both parents and children (Tompkins, 2007; Hooper *et al.*, 2008).

Children's rights versus Parents' needs

As touched on earlier, from a disability rights perspective, the developing 'young carers' literature was considered flawed, rooted in negative assumptions of dependency, and typically based on a medical rather than social model of disability (Shakespeare, 2014). By problematising families led by disabled parents and viewing their circumstances through the single lens of the 'plight' of 'young carers', the complexities and dynamics of each generation remain unexamined, and the everyday realities and benefits of interdependence, which for most families – whether parents are disabled or not – may include older children helping around the home, caring for younger siblings or carrying out other age-appropriate tasks, may be overlooked. Similarly, the impact of other factors such as poverty, disabling professional attitudes and services, disabling environments and disabling communities are not taken into consideration or challenged.

The rapid emergence of the 'young carers' literature polarised debates between the children's rights paradigm connected to liberalism, empowerment and giving children a voice, and the approach of the disability movement – also concerned with rights and empowerment, but with an emphasis on the needs and rights of disabled people as parents. An overview of these debates is outlined below.

The expansion of services for young carers was strongly condemned for being implemented ahead of any robust research about the specific needs and circumstances of young carers (Olsen, 1996; Olsen and Parker, 1997). Olsen (1996, p. 41) further contended that the research into young carers was skewed and “tended to involve the search for the negative impact of an adult's disability on a child's growth, intelligence and adjustment”. These arguments were countered by the key researchers in the field, who characterised the criticism as a “backlash against the young carers paradigm” (Aldridge and Becker, 1996, p. 56). The assertion that if disabled people were adequately supported their children would not be led into caring duties (Keith and Morris, 1995) was, they argued, too simplistic since this fails to take into account: “the impact of illness/disability in and of itself on family life and the potential influence of the provision of care by children on other factors such as family structure, receipt of services, poverty etc.” (Aldridge and Becker, 1996, p. 62) as well as other factors such as power and personality variables within families and the child’s ability to exercise choice in relation to caring. As the debate continued, Olsen and Parker (1997, p. 130) opposed the criticisms levelled at their own work, and suggested that the young carer movement lacked a “critical perspective on the basic problem of parental dependence on children for care”.

Olsen (2000) sought to offer a fresh approach and broaden the perspective on these debates in his paper which reveals interesting parallels between the present-day young carers debate and the transformation of childhood in the late 19th century. He introduces an historical dimension to discussions about the appropriate involvement of children in domestic and caring work and compares the social construction of ‘young carers’ with the conflict surrounding children’s exclusion from the paid workforce in the 19th century, and the corresponding extension of formal education. Drawing upon the concept of the ‘priceless child’ (Zelizer, 1994), Olsen discusses the parallel ways in which the quality of childhood for some children became problematised without sufficient recognition of the limited choices that some families – especially those in poverty, or lacking sufficient support – face. Newman (2002) also called for a change of direction, stating that where legitimate concerns arise for families led by disabled parents, they are often related to poverty, social exclusion, and unsupported parenting, with no direct relationship to impairment.

An attempt was made to bridge the gap between these two perspectives when academics from both sides of the divide opened up a dialogue to “move the debate on” in a discussion paper which explored the commonalities and differences between those involved in developing services for disabled parents and young carers (Aldridge and Wates, 2004, p. 81). Here, the authors draw upon their own experiences to express their disparate views, providing the reader with two very different perspectives. Whilst seeking to diminish the differences between the two sides, this paper serves to highlight the distance yet to travel, as Wates expressed her enduring concern that ‘young carer’ research reinforces “unspoken question marks over the parenting capacity of disabled adults” (Aldridge and Wates, 2004, p. 82).   Whilst acknowledging that improved services for disabled parents may reduce the need for their children to provide care, Aldridge argued that young people often have subjective reasons to continue caring; this might include feeling needed, helping to contextualise and understand their parent’s illness or impairment, and to “cement” their relationship (Aldridge and Wates, 2004, p. 89).

In later work, Aldridge (2008) acknowledges the complexity of the lived experiences of many disabled parents and their children, and advocates the need to move away from prevalent and over-simplistic representations of children with caring responsibilities as:

> victims of their parents’ illnesses, as ‘little angels’ whose caring work is condoned through rewards or as (exploited) informal domestic workers whose childhoods are inevitably compromised by the caring activity they undertake. (Aldridge, 2008, p. 253).

Nevertheless, research suggests that families with disabled parents continue to be constructed as “non-normative” and “deficient” (O’Dell *et al.*, 2010, p. 643), highlighting the risks of over-simplifying complex family systems when evaluating the experience of young carers against the ideal of a hypothetical ‘normal’ childhood.

In a summary paper which looks back over twenty-five years of research, policy and practice, Aldridge (2018) explores the current picture and offers her assessment of the situation. She acknowledges that the increased focus on the needs of ‘young carers’ has created dilemmas and challenges for health and social care professionals which play out in the context of cuts to youth services and the cumulative impact of austerity measures. Noting that: “elements of a ‘moral crusade’ are evident in contemporary young carer discourses” (Aldridge, 2018, p. 159), she observes that children’s caring responsibilities are often presented as being a likely, even inevitable, outcome of living in families where there is parental disability. Fear of disclosure of caring has been shown to deter children and parents from self-identifying and/or seeking help or support from services. This reluctance may be based on assumptions that child protection or safeguarding issues may be triggered by professionals and result in family separations.

Aldridge (2018) further draws attention to the fact that some families actively resist children being identified as young carers, both due to the stigma associated with this term, and also because it fails to address the underlying problem, namely, families lack appropriate and effective support that would prevent children from having to provide care (Clay *et al.*, 2016). The current research sheds new light on the role that PA support has in supporting families holistically and preventing young people from becoming ‘young carers’. As findings will indicate, however, PA support can also be a complicating factor in family life and generate new roles, responsibilities and relationships for children and young people to navigate.

Summary

This chapter has provided an overview of the existing research relating to children who have disabled parents and/or lived experience of personal assistance. There are scant studies examining the specific circumstance of growing up with parental personal assistance, albeit the very limited information uncovered in the literature search provides a fascinating insight into the experience as a starting point. For example, children whose parents use PA support expressed conflicting feelings – PAs can make family life easier, but children can also worry about workers' performance, remaining 'alert' in case of unexpected problems arising. Other studies suggest that children with direct experience of personal assistance find the everyday presence of non-family members unwelcome as it disrupts the privacy of their home environment and personal life.

The research which most directly relates to children whose parents use PA support emanates from the 'young carers' paradigm. This is an area of active academic interest, and research from this perspective dominates the literature. Key studies and insights offered by this important strand of research have been summarised. These highlight significant concerns for children who provide care to family members, suggesting that their lives and opportunities are restricted by their caring responsibilities. They also highlight the negative physical, educational, social and emotional impacts of being a 'young carer'. The 'young carers' literature has been heavily criticised by disability activists and academics as offering an individualistic and simplistic view of family life, which overlooks the everyday realities of interdependence, and ignores the impact of societal factors such as poverty and disabling services, environments and attitudes. Key points of contention between these differing perspectives have been summarised within this review.

Although these studies tell us something about the experience of some young people who have disabled parents, they do not include children who do not identify as 'young carers'. It was therefore necessary to take an inclusive and creative approach to conducting this review. Consequently, a wide range of literature which explores children's views on relevant related subjects was included. Emerging threads within the broad sweep of literature reviewed reveal the complex practical social and emotional challenges that children and young people whose lives are affected by impairment or chronic health issues face. Findings from these studies tell us that these children 'feel different' to their peers, and this can make it difficult for them to form friendships and talk openly about their situation with others. Children who are perceived as 'different' can be bullied, or they may lose friends as they are unable to participate in activities due to practical issues faced by their families. Ideas about 'normality' also feature strongly within the literature, which demonstrates that young people gauge themselves and their families against the concept of a socially-accepted 'normal' childhood; feeling that they do not measure up to these standards can further marginalise them. Evidence suggests that dealing with these feelings may generate a complex array of difficult emotions which can be hard for young people to understand and express.

Although the literature provides a rather bleak outlook for children growing up in families where there is a disability, some positive aspects are acknowledged. For example, children talk about the love they have for their parents and families, express that they find satisfaction and reward in some caring tasks and point to important social and practical life skills which they have learned from their experiences.

In conclusion, there is little within the current knowledge base which explores the specific focus of this study, however the available literature sheds light on several issues of relevance, and raises questions requiring further consideration:

Does the provision of personal assistance play a role in preventing children and young people from taking on a significant caring role?

Does the presence of a PA in everyday family life affect the quality of relationships between children and young people and their parents? If so, how is this experienced?

How do children and young people experience, value and conduct their relationships with their parent's PAs?

Having examined in the foregoing two chapters the literature pertinent to this study, this thesis will now set out the methodology and the theoretical approaches adopted in the research design, including a discussion of ethical issues arising during the process.

Part Two

Methodological issues and considerations

Approach to the Methodology

This section of the thesis is set out in two chapters. The first of these will discuss the epistemological and ontological assumptions which underpin the study and inform the qualitative methodology chosen to address the research question. It will also examine underlying theoretical perspectives of understanding and researching disability issues.

The second chapter will focus on research methods used. Data were generated by means of semi-structured interviews with 11 parents, 10 children and 8 personal assistants. Various practical and ethical aspects of the project design and the rationale behind decisions taken are set out and more information is provided about the research sample. A commentary is provided of the thematic analysis undertaken.

Chapter 3: Theoretical perspectives and methodology

Introduction

This chapter focuses on the theoretical/methodological decisions that informed the research design and the methods used. As shown in previous literature review chapters, while research has explored some aspects of personal assistance relationships, there is a lack of research to date into the impact of personal assistance upon family life and family relationships. This study therefore set out to understand more about experiences of both parenting and being parented with PA support, and the significance, influence, meaning and consequences of employing a PA to facilitate family life. The following overarching research question was developed:

> *"How do disabled parents and their children experience paid personal assistance within the home, and what impact does this have upon their relationship?"*

To support this, a number of objectives were set to examine different aspects of the parent/child/PA dynamic:

(a) *Determine how disabled parents use personal assistance to support their parenting and identify significant issues influencing their experience of PA support.*
(b) *Establish children's views of growing up with PA support and their experiences of continuity and change in family life.*
(c) *Ascertain key factors shaping the level and degree of PA relationships with disabled parents and their children.*

Opening with a discussion of the researcher motivation, this chapter will go on to set out the epistemological and ontological assumptions which underpin the study and inform the qualitative methodology chosen to address the research question. Different models of understanding and issues relating to researching disability are examined, and various ethical aspects of the project design are set out.

Researcher Motivation

In my own professional practice, I have often been confronted by the social oppression and multiple barriers facing disabled people in their everyday lives. Working in a local authority community social work team frequently brought me into contact with disabled people who used social care funding to employ PA support; speaking to them about their experiences as part of the statutory review process provided me with an insight into the complexity of managing paid workers within the home environment. This built upon my pre-existing interest in disability issues, initially developed by working with and for disabled people for many years in third sector and user-led organisations and extended through academic study. Having returned to education as a mature student to complete my undergraduate degree in social work, I furthered my passion for disability issues by undertaking a Master's degree in Disability Studies alongside professional practice. Completing my dissertation gave me the opportunity to explore personal assistance relationships in greater depth, and as part of a small-scale study I met two PA users who expressed that being a parent added difficulty and complexity to the task of managing employees, suggesting that the presence of PAs in their everyday life could sometimes complicate and even disrupt family life. These findings left me with further questions and the curiosity to learn more, which I have developed through the current study.

Ontological and Epistemological Assumptions

As Gray (2014, p. 19) observes, there is a 'bewildering array' of theoretical perspectives and methodologies relating to research; this can be a challenge to navigate, especially as these are accompanied by complex terminology which is 'often inconsistent or even contradictory' (Gray, 2014, p. 19). Crotty

(1998) suggests that an interrelationship exists between the theoretical stance adopted by the researcher, the methodology and methods used, and the researcher’s underlying views and philosophical assumptions about the nature of reality and knowledge. Ormston *et al.* (2014) helpfully explain that ontology relates to the nature of reality and its characteristics, whereas epistemology is concerned with ways of knowing and learning about the world. As Bhaskar and Danermark (2006, p. 295) note, “every question or inquiry involves presuppositions of some sort”; having an understanding of research philosophy is therefore important to researchers for several reasons: it can help us understand the nature of the social world and how we can learn from it, as well as indicate suitable approaches to research design based upon different positions held (Ritchie *et al.*, 2014). Accordingly, I set out below my own perspectives and influences which shaped the design of this study.

With a strong commitment to equality for disabled people, and a firm foundation in social work principles and values, my experience of ‘reality’ is that it is a complex phenomenon which is relative, multifaceted, and strongly influenced by socially constructed meanings. In his seminal text on social work theory, Payne (2005) suggests that social work is an essentially socially constructed activity and sets out three interconnected and interlocking levels of social construction which relate to social work: the political-social-ideological cycle deals with broad societal debates about the nature of social problems; the agency-professional cycle in which employers and social work professionals interact to determine practice issues; and finally the client-worker-agency cycle which relates to the face to face encounters between client and social worker. Houston (2001) reflects the strong influence of social constructionism on social work practice and highlights critiques of this approach, pointing out the problems inherent in promoting a theory of human agency whilst at the same time taking account of the impact of social structure.

As a social worker, I believe that the key to understanding others is to listen carefully to their own accounts, as these indicate how they make sense of their lives, experiences and relationships, giving insights into how situations may be changed for the better. This illustrates the influence of inductive logic, a position which holds that knowledge about the social world is best discovered by working from the ‘bottom up’; evidence is collected from real-world observations, and from this, knowledge and theories can be developed (Ormston *et al.*, 2014). A social constructionist approach is also evident. Creswell and Poth (2018) describe this as an interpretive framework in which individuals seek to understand their social worlds. Here, individuals develop subjective meanings of their lived experiences – these meanings are negotiated socially and historically through interactions with others and are formed as a result of the cultural norms which operate in their lives. The goal of constructionist research is to listen carefully to participants, focusing on their interactions and the specific contexts in which they live, to try and ‘make sense of (or interpret) the meanings others have about the world’ (Creswell and Poth, 2018, p. 24). This framework is apparent in the grounded theory perspective of Charmaz (2014), who asserts that this approach treats research itself as a construction and requires that researchers examine how their own values and preconceptions shape the facts they identify and their analysis of these.

Whilst my thinking is shaped by these ideas and approaches, perhaps partly as a result of my social work training and background, I am also influenced by other movements such as feminism and the social model of disability. As Ritchie *et al.* (2014) observe, research findings informed by these critical approaches are often judged on their political and emancipatory effects rather than the extent to which they portray the social world of participants. Feminist approaches contend that traditional research is androcentric, providing a distorted picture of social life which either omits or misrepresents women’s experiences (Blaikie, 2007). Sheldon (1999, p. 650) acknowledges the contribution made by feminism to changing society’s rigid gender roles and expectations, but contends that this may hold little meaning for disabled women who are perceived as: “needy, dependent and passive – stereotypical feminine qualities”, noting that disabled women are often deemed incapable of aspiring to other ‘feminine’ roles, including motherhood.

While feminists and disability rights activists alike struggle against oppression caused by a socially constructed inequality based upon idealised human bodies, tensions exist between these two perspectives, including in relation to issues of ‘care’.

For example, a review of research evidence demonstrates that moving people with disabilities and mental health problems from institutions to supported living settings which enable them to express their own decisions and participate more fully in society results in improved quality of life (McCarron *et al.*, 2019). Yet, as caring responsibilities continue to fall predominantly upon women (Dahlberg *et al.,* 2007), the pressure for them to fulfil traditionally expected caring roles can limit their own relationships, leisure and employment opportunities and increase financial insecurity (Folbre, 2012). So, despite the similarities between the disability movement and the women's movement, conflict can arise between their respective agendas. Indeed, disabled women have written about their experiences of feeling alienated and marginalised by non-disabled feminists (Morris, 1991; Begum, 1992). Sheldon (1999, p. 654) suggests that the two movements can learn from and strengthen each other by recognising their shared struggles and looking “beyond the subjective experience of a select group of women”, to address more collective concerns. Given the intersectionality of this study, this was something I was mindful of throughout the research process.

Social constructionism, feminism and the social model understanding of disability (which is discussed further below) are all oppositional frameworks, in that they challenge (post) positivist research design and practice (Braun and Clarke, 2013), which was the dominant epistemological framework in the social sciences from the 1930s to the 1960s (Gray, 2014). Positivism argues that a single reality exists outside of ourselves; in order to understand this, research inquiry should be based on scientific observations, with limited interaction between researcher and subjects (Creswell and Poth, 2018). Conventional positivist approaches to research typically aim to observe and objectively measure facts and reality (Hennink *et al.,* 2011) – to separate “facts from values” as Charmaz (2014, p. 6) puts it. In this way, traditional research is assumed to be value-free, but by disconnecting the researcher from the researched in this way, it has been suggested that positivism fails to acknowledge the uniquely “interactive and co-constructive nature of data collection with human beings” (Hennink *et al.,* 2011, p. 14). In their seminal work, Lincoln and Guba (1985, p. 27) critique this approach and suggest that research produced in this way has potentially ‘produced research with human respondents that ignores their human-ness’.

Interpretivism, a major anti-positivist approach, emerged in response to the perceived limitations of positivism. Interpretivism has a number of key features: it seeks to understand people’s lived experience from the ‘inside’ perspective, emphasising the ‘importance of interpretation and observation in understanding the social world’ (Ormston *et al.*, 2014, p. 13). Social constructionism is closely related to interpretivism, as both stress that knowledge is actively ‘constructed’ by individuals rather than being passively received by them. Furthermore, both approaches reject the idea of ‘value neutral’ observations, highlighting the inherent subjectivity of participants and researchers and acknowledging the influence of these upon the creation of research data (Hennink *et al.,* 2011).

I am particularly interested in understanding the complex and sometimes messy humanity of peoples’ lives – how individuals construct and interpret their own lives, and how they make sense and meaning of their interactions with others. As a social worker, gaining this understanding can be a useful indicator for supporting positive change. Accordingly, within this research, I sought to generate knowledge through eliciting individual accounts and interpretations of participants’ social lives (Blaikie, 2007). To obtain insights into how individuals construct their reality and the meaning they give to events and experiences, a qualitative research methodology was therefore used. Padgett (2008, p. 2) explains that qualitative research seeks to represent the complex lives of participants, emphasizing subjective meanings and assuming “a dynamic reality, a state of flux that can only be captured by intensive engagement”. A more detailed discussion of qualitative research methodology is provided later in this chapter under the heading of 'Research Design', however I will now turn to a consideration of different models of understanding and researching disability.

Approaches to researching disability

The constructionist epistemology which has influenced my thinking about social work and research is congruent with a social model understanding of disability. This concept was developed by disabled people themselves (Union of Physically Impaired Against Segregation, 1976), and has been termed the 'big idea' of the British disability movement (Hasler, 1993, p. 280). This approach identifies disabled people as an oppressed social group, and rejects traditional, individualised and medicalised ways of thinking about and treating them. For example, the social model redefines disability as a two-tiered concept, the causes of which are located firmly within social organisation and responses to impairment. As such, disability is:

> the disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have… impairments and thus excludes them from the mainstream of social activities. (Oliver and Barnes, 1998, p. 18)

This 'big idea' was given authority through the work of academics including Finkelstein (1980, 1981), Barnes (1991) and Oliver (1990, 1996). According to Shakespeare and Watson's (2002, p. 12) analysis, the social model of disability was "massively important", in two significant ways. Firstly, since this explanation introduced the concept of 'disabling barriers', a new political strategy – the removal of these barriers – emerged, around which disabled people could unite. Secondly, it enabled disabled people to identify society, rather than themselves, as being flawed and in need of change. For many disabled people, this concept was truly empowering, indeed "revolutionary" (Crow, 1996, p. 55), enabling them and their allies to combat the legacy of segregation, exclusion and discrimination they faced, and supporting them to gain a positive individual self-worth and collective identity. Disabled people no longer had to feel ‘grateful’ for charitable handouts – they could instead claim their rights as citizens to be treated equally.

The social model of disability was highly influential in changing the discourse around disability, both nationally and internationally, and quickly became the dominant paradigm for thinking about and researching disability (Dewsbury *et al.*, 2004). It has played a major role in disability activism and policy development, bringing about a transformation in legislation, support and services for disabled people (Oliver, 2009). Nevertheless, criticisms of the social model emerged from within the disability studies community, notably from women. For example, Morris (1991) called for the social model to recognise personal experience, including pain, as a valid aspect of the disabled identity. French (1993) also wrote about the persistence of impairment problems which could not be remedied by social change, and Crow (1996) contended that the social model fails to address adequately the personal experience of pain and limitation which is often associated with impairment. Theorists began to call for more nuanced views of the experience of disability, with Shakespeare and Watson (1997, p. 304) arguing for a more holistic model that: ‘fully recognizes the way in which agency and structure are intrinsically knit together’. Corker and Shakespeare (2002) further suggested that the social model does not capture adequately the complex reality of disabled people’s lives, excluding important dimensions of their knowledge and experience. Academics have also argued that the social model fails to ‘see the ambiguities and rhythms with which a person relates to their environment’ (Dewsbury *et al.*, 2004, p. 155), and suggest the use of other concepts, such as resistance theories (Gabel and Peters, 2004), to explain complex phenomena.

More recently, Shakespeare (2014, p. 74) promotes an eclectic and pragmatic approach to theory, and expresses his preference for a critical realist perspective, which he finds to be: ‘the most helpful and straightforward way of understanding the social world, because it allows for complexity’. According to Bunge (1993, p. 231) critical realists believe that the way we perceive the world, particularly the social realm, depends partly on our beliefs and expectations; perception can be limited and deceptive, hence the "complete truth is hard to come by". Madill *et al.* (2000, p. 3) identify three realist epistemologies: naïve, scientific and critical, and suggest that critical realism "has much in common with constructionist positions". Sayer (2000, p. 62) concurs, asserting: "realists need have no problem with 'weak' social constructionism, that is with the idea that accounts of facts or the real are socially constructed", making this approach compatible with my own position, and something I wanted to examine further.

Shakespeare (2014) proposes that disability is an interaction between individual and structural factors, and that the unique experience of the disabled person is a result of intrinsic factors and extrinsic influences arising from the context within which the person finds themselves. Intrinsic factors include the nature/severity of impairment; the individual's own attitudes towards their impairment; personal qualities and abilities. Extrinsic factors include the attitudes and reactions of others; the extent to which the environment is enabling or disabling, and wider cultural, social, political and economic factors. People are not therefore disabled by society's reactions to them, rather they are "disabled by society *and* by their bodies and minds" (Shakespeare, 2014, p. 5). Using this interactional approach, Shakespeare acknowledges very real issues of impairment which cannot be completely eliminated simply by changes to environments and contexts, including prejudice and discrimination. This, he suggests, allows the researcher to engage critically with the complex interplay between the individual, their specific contexts and their environment. In this way, disability is defined as the outcome of interactions between diverse factors such as 'impairment, personality, individual attitudes, environment, policy, and culture' (Shakespeare, 2014, p. 77). Other commentators adopt a similar approach, for example, in writing about a young man with profound intellectual impairments who has complex communication and physical needs, Vehmas (2010) argues that initiatives such as independent living, civil rights or barrier removal will not make a significant improvement to this individual's life. Kittay (1999) makes a comparable point from her experience of being a mother to her disabled daughter.

As outlined earlier, my own perspective of disability issues, and my approach to this study, have been strongly influenced by the dominance of social model thinking and social constructionism. However, the open and pragmatic approach which Shakespeare (2014) advocates is compelling, since it allows for a closer examination of complex, multi-layered individual experience, which for many disabled parents in this study includes living with pain, fatigue, and fluctuating health conditions. I concluded that adopting a critical realist approach may lead to greater understanding of what it means to be a disabled parent in our society, and hence provide opportunities to support positive change. Whilst I take the view that people with perceived or accredited impairments can be discriminated against and excluded from becoming full citizens, based on the perception that they are ‘problematic’ to accommodate within mainstream society (Barnes, 1991), this does not fully explain the wide variation of individual experience evident from the literature (Williams, 1999; Danermark and Gellerstedt, 2004; Gabel and Peters, 2004) and apparent in my own social work practice. As Shakespeare (2015, p. 2) observes: “despite progress with disability research, gaps remain in our knowledge and understanding of what it means to be a disabled person in a particular society”. Therefore, only by developing a deeper understanding of the perspective of those with lived experience and gaining their subjective insights into the complex, diverse and multi-factorial issues they face, can improvements be made to policy and practice.

The foregoing discussion has set out the theoretical framework for this study, which fits within the interpretivist framework, informed by social constructionism and critical realist perspectives. In what follows, I locate social work research in disability study and practice.

Social work research and disability

There are close links between social work practice and research (Atkinson, 2005); certainly, many of the skills required to be a good and effective social worker, including: being able to develop a rapport with individuals, ask questions sensitively, listen actively, convey an empathic and non-judgemental demeanour, record accurately, manage large amounts of data, think critically and analytically – are fully transferable to the research task. Indeed, comparisons between social work practice and research have been explored by several authors (Shaw and Gould, 2001; Padgett, 1998) with Fuller and Petch (1995) asserting that social workers may in fact have skills which advantage them over the traditional researcher. The case has also been made that outcomes for individuals who receive social work services are improved by being strongly evidence-based and grounded in research. Social policy-making systems encourage the use of evidence-based research to monitor and evaluate social work practice (Walter *et al.*,2005), albeit the difficulties for practitioners in balancing a demanding workload with keeping up with the latest research evidence are acknowledged (Gira *et al.*, 2004). In addition, within the broad area of health and social care, the literature suggests that researching services is a core function in helping to identify improvements and increase the quality of life and care for service users (Health Research Authority, 2017).

According to a joint statement of the International Association of Schools of Social Work and the International Federation of Social Workers (2014), a leading priority of the social work profession is to combat the effects of oppression and to promote: ‘social change and development, social cohesion, and the empowerment and liberation of people’. Strongly motivated to ensure that this study would be useful and meaningful to disabled people, I was drawn to the principles of ‘emancipatory disability research’, a term coined influential disability rights activist, author and academic Mike Oliver (1992) to refer to a radical new approach to researching disability which emerged in the 1990s (Stone and Priestley, 1996; Mercer, 2002). Oliver (1992) contended that existing research paradigms were inadequate and called for a fundamental shift in the way disability research is considered and conducted, including the purpose, process and outcomes of research activities. He set out his vision for the introduction of a different set of social relations which would fundamentally change the nature of disability research production, putting control in the hands of the researched, not the researcher, thereby providing the possibility for a more enabling form of research activity which would confront social oppression. This meant that researchers should: “learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose” (Oliver, 1992, p. 111). Building on previous feminist work (Lather, 1987; Ribbens, 1990), Oliver (1992) suggested that there were three fundamentals on which this new research paradigm must be based: reciprocity, gain and empowerment. These ideas stimulated considerable debate and discussion within the disability studies literature (Rioux and Bach, 1994; Stone and Priestley, 1996; Barnes and Mercer, 1997; Albrecht *et al.*, 2001) as to whether this approach was, in Oliver’s (1997, p. 15) own words, a “realistic goal’ or an ‘impossible dream”. In considering these views, it became clear that the design of this project would have to reach a satisfactory compromise between my aspirations and the practicalities of what could be achieved, something which I shall now consider in more depth.

Research Design

As outlined above, this study adopts an interpretive theoretical perspective. Interpretive research is flexible by nature, and according to Schwartz-Shea and Yanow (2012, p. 55), this flexibility is a “conscious, intentional strategy” which enables researchers to respond to the social world of the participants and potentially unanticipated questions and answers which may develop during the research process. A strength of interpretive research is that it can react, reflect and adapt in the moment to changing situations.

According to Blaikie (2010), a research design is an integrated statement of the research project. Its formation involves anticipating and planning all aspects of the process to achieve consistency and control in the research procedure. Research design therefore requires careful preparation and attention to detail. As a developing researcher, I found this process somewhat daunting, but also helpful in organising and structuring my thinking as well as managing the resources and choices available to me. The decisions made enabled me to develop a viable project, underpinned by sound research principles, which would answer the research question and provide insights which could lead to recommendations for improvements to practice and in turn make a positive difference in the lives of disabled parents and their children.

Barnes (1996) asserts that it is not possible to adopt an ‘impartial’ stance when researching issues of oppression: researchers must make their allegiance clear – with whom do they stand? As a non-disabled person drawing on Oliver’s (1992) call to take a more radical approach to disability research, and building on more current research approaches that have involved service users, I felt it was important to involve key ‘stakeholders’ – disabled people, disabled parents, children and PAs – as much as possible within the design of this project. This approach ethically positioned the study in alignment with the needs and interests of disabled people, by demonstrating my commitment to user involvement (Barnes and Cotteral, 2012), enabling me to more clearly define the aims and scope of this study before embarking upon the project. By putting my ‘knowledge and skills at the disposal of disabled people’ as (Barnes, 1992 p.122) suggests, I sought to highlight and critically analyse the structures and processes in our society which disadvantage disabled parents and their families.

Conversations with staff from user led organisations, leads from ‘young carers’ organisations, and a number of disabled parents who engaged in advisory meetings and provided feedback from pilot interviews have informed the development of the research question and interview schedules, as have reflections from my previous social work practice and discussions with social work professionals. Detailed discussions were also held with my supervisory team, other academics and experienced researchers regarding the research strategy and final design of the project. I describe these in more detail below, turning first to a discussion of ethical considerations.

Ethics

Undertaking any research with human participants involves careful consideration of ethical issues. Within the literature, it is widely accepted that four principles of autonomy, beneficence, non-maleficence and justice provide the foundation for ethical conduct and should apply equally to all types of research (Gorman, 2007). In their guide to research with children and young people, Greig *et al.* (2007) draw upon Hart's (1992) eight-stage scale of participation and provide a summary of good practice guidelines to encourage researchers to consider all ethical implications of their study. Butler (2002, p. 241) emphasizes the close link between social work practice and research, arguing that 'the ethical foundation for a code of research ethics for social work research is to be derived from the ethics of social work itself'; to avoid any potential for complacency however, I followed Creswell and Poth's (2018) guidance on considering ethical issues throughout all phases of the research process including prior to conducting the study, beginning to conduct the study, during data collection, analysis, reporting data and publishing findings.

A full consideration of research ethics was essential, both to ensure good practice and to meet with relevant guidance (British Association of Social Workers, 2014; British Sociological Association, 2017). These principles were addressed fully in applications to the University of East Anglia's School of Social Work's Research and Ethics Committee (see Appendix 1). Contact was made with other Local Authorities in which the research took place, where research governance processes were not required, to provide them with full details of the study (see Appendices 3 and 4). Informed consent has been acknowledged as an "ongoing and negotiated" process in qualitative research (Waldrop 2004 in (Padgett, 2008, p. 65); issues of consent, including the right to participate and the right to withdraw are discussed in more depth later in this chapter with matters of recruitment.

Risk assessment addressed both participant and researcher perspectives. I took steps to ensure my own safety as a lone researcher making home visits. Here again, my training and experience from social work practice and previous research was useful. Initial contact was generally made via phone or email, following which participants were sent more detailed information about the project in a format accessible to them. In all verbal and written communication, the right to withdraw was made clear. This initial exchange acted as a screening process to check potential participants met the criteria. Individuals were given time to absorb the information provided, and to ask questions prior to arrangements being made for interview. This process enabled me to encourage participants to start thinking about their experiences prior to our meeting, and gain a sense of their commitment to involvement, overall situation and possible preoccupations or concerns. All meetings were arranged at a time to suit participants during daylight hours, and a ‘buddy’ system was in place to ensure that my whereabouts were known by a trusted individual. This ‘buddy’ was contacted immediately prior to and following interviews to confirm my whereabouts and safety. I determined that should I feel uncomfortable, threatened or in any way concerned about my personal safety, I would immediately invoke an exit strategy to remove myself from the situation as quickly as possible, however no such situation arose.

Recognising that potential participants to this research are the experts in their own lives, and that those labelled as ‘vulnerable’ are often extremely resilient, I wanted to involve them as much as possible in the whole process. However, due to the constraints of this project, I was unable to promote active participant engagement at every level of the research process as advocated by Aldridge (2014). I was though strongly committed to finding ways to “bring previously unheard voices into scholarly and associated professional conversations” (Thomson, 2008, p. 3), using creative methodological tools and techniques to facilitate this. This was particularly important to me, mindful of the power I held in the research process and given my professional standing and status within an academic setting ostensibly placed me as an ‘expert’. Power is a contested and complex phenomenon, and issues of power, care and control are an inherent part of the unpredictable nature of both family life and social work. The power imbalance between ‘professional’ and ‘service user’ evident in the social work role – and vehemently condemned by Illich (1977) – can be readily replicated in the dynamics of the researcher/ participant relationship (Dominelli, 2005) and this was something I sought to minimise.

Several factors placed me as an ‘outsider’ in this study: I am not disabled, nor are any of my immediate family, so my own experience of family life differs from that of the parents and children involved with this research. Nevertheless, as a parent myself I share many interests, concerns and experiences with parent participants, and I was able to build on this commonality. There are many arguments for and against both ‘insider’ and ‘outsider’ research, which Corbin Dwyer and Buckle (2009) address and expand upon in relation to qualitative research with specific parenting groups. They conclude that the constructed dichotomies of ‘insider’ and ‘outsider’ are unhelpful, and that by embracing the notion of the ‘space between’ these entrenched perspectives, qualitative researchers can fully explore the complexity and richness which exists, suggesting that:

> the core ingredient is not insider or outsider status but an ability to be open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience.
>
> (Corbin Dwyer and Buckle, 2009, p. 59)

This ‘space’ was something I hoped to inhabit in my research. I believed this approach would also enable me to move beyond insights based on my own ‘outsider’ perspective of the phenomena I was exploring, to develop a greater understanding of the participants’ lived experiences and perspectives. This process of gaining a deeper, subjective, level of understanding is a key feature of interpretive research and relates to the concept of ‘Verstehen’. This term refers to ‘studying people’s lived experiences which occur in a specific historical and social context’ (Ormston *et al.*, 2014, p. 11). Hennink *et al.* (2011, p. 18) helpfully summarise the distinction between understanding and ‘Verstehen’ and explain that ‘Verstehen’ refers to comprehending the issues from the “interpretive framework of the study population, or from the ‘insider’s perspective”.

Having examined the theoretical and ethical issues relating to this study, what follows is a discussion of the research methods used, the decisions behind this, and more detailed information about the research sample. The nature of the research data generated has implications for its analysis – accordingly, detailed discussion of data analysis is also provided.

Chapter 4: Research Methods

Introduction

This chapter sets out various practical issues relating to the study. Solely qualitative methodology has been used for several reasons. As demonstrated by the literature review, this study addresses a specific gap in the current research. Studies which explore the experiences of disabled parents – primarily mothers – are however evident (Thomas, 1997; Farber, 2000; Grue and Lærum, 2002; Traustadottir and Sigurjonsdottir, 2008), and there is a strong tradition of using qualitative methods to explore this topic; indeed, the aforementioned studies all generated data by means of participant interviews. Drawing on this tradition to build on the existing body of research informed the decision to use qualitative methodology in this study, as did my own perspectives on the nature of ‘reality’ and knowledge which were set out earlier. Other factors, such as the scant attention hitherto paid to the intersection of disabled parenting and the use of PA support, as well as the neglect of children’s views on this aspect of their lives, meant that insufficient was known about the study group to reasonably determine the main issues that may emerge. Therefore, the “open and generative nature” (Ritchie *et al.*, 2014, p. 37) of qualitative methods is suited, to allow the realities of those living the experience to be expressed and heard.

The complexity of the relationships being studied was another determining factor in using a solely qualitative mode of research enquiry, since this gives participants the time needed to reflect on the issue and to express their thoughts and feelings. I felt that, since I would be asking individuals to share sensitive details of family life and intimate support tasks with me – a situation which could make them feel vulnerable to criticism, or subject to intense ‘professional’ scrutiny – the best way to build the trust and develop a rapport would be to use an approach based upon participant’s own perspectives. For these reasons, qualitative research is most suitable for this study. This approach requires a small study population, and the in-depth nature of qualitative research is well suited to generate the rich, deep detail required to answer the research question (Silverman, 2013).

Research sample

Sample size and criteria

Qualitative research is guided by concepts from the interpretivist paradigm and seeks to understand or explain participant's behaviour and beliefs and the contexts of their experiences. As the purpose of qualitative research is to achieve depth rather than breadth of information from participants, relatively few study participants are required. Sample sizes are therefore typically small in qualitative research (Ritchie *et al.*, 2014), and the question of sample size, and how many interviews is sufficient, has been considered by a number of authors, with Baker and Edwards (2012, p. 6) concluding, somewhat ambiguously, that 'it depends'. In this study, a criterion-based purposive sample (Davies, 2007) consisting of thirty participants was sought to answer the research question from a range of perspectives. Patton (2002) outlines several different strategies for purposefully selecting information-rich cases, including criterion sampling. The logic here is to study all cases that meet a predetermined criterion of importance: in this case, the criterion was broad, and included those who have direct experience of parenting/being parented with or providing PA support to disabled parents in the last ten years. According to Patton (2002, p. 230), a strength of qualitative inquiry is that it typically focuses on relatively few "information-rich cases" for in depth study; in this way, the most effective use of limited resources can be made. These information-rich cases are highly productive for research purposes, since they can provide detailed insights which illuminate the questions under study.

According to Creswell and Poth (2018), validation is critical to evaluating the quality of qualitative research; they describe eight strategies to validate research, recommending that at least two of these are used in any given study. They advocate member checking as being reasonably easy to conduct and cost effective. In line with this, data including transcripts, analyses, interpretations and conclusions were taken back to participants to check the accuracy and for any gaps in understanding. Interviewing individuals with a range of perspectives on the research topic was both consistent with the underlying epistemology, and important to gain an understanding of how people with differing perspectives construct and interpret their lives, and the meaning they make of this. This supported another validation strategy – triangulation, whereby data from field notes and interviews from different participant groups were examined to look for patterns or contradictions beyond the individual experience.

The size and nature of the sample was determined by several factors including the selection criteria, the data collection method chosen, the available budget and other resources. The guiding principle was that the sample should be sufficient to generate high quality data which would provide a rich and detailed picture of participants' experiences and allow commonalities and differences of experience to emerge. As Mason (2010) observes in his analysis of five hundred and sixty PhD studies using qualitative interviews, very few guidelines exist on sample size for new researchers. Nevertheless, Charmaz (2006, p. 114) suggests that "25 [participants are] adequate for smaller projects", while Ritchie *et al.* (2014, p. 118) state that qualitative samples involving individual interviews "usually lie at under 50". Based upon these suggestions, a goal of 30 participants was set. It became apparent that this was a suitable sample size to answer the research question and provide a compelling and in-depth account, revealing a range of diverse experiences and important themes.

An overview of participants' details is given in Table 1 below.

Group	Pseudonym	Age/range	Gender	Ethnicity
PARENTS	Andrea	30-44	F	White British
	Naomi¬	45-59	F	White British
	Amber**	45-59	F	White British/ Turkish
	John++	30-44	M	White British
	Gina^	45-59	F	White British
	Cathy~	65	F	White British
	Jane#	60	F	White British
	Lydia	45-59	F	White British
	Frank	45-59	M	White Welsh
	Phoebe^^	52	F	White British
	Sofia*	30-44	F	British Asian
CHILDREN	Chloe+	26	F	White British
	Alina^	20	F	White British
	Ellee^	14	F	White British
	Lucy~	28	F	White British
	Katie#	26	F	White British
	Leo¬	11	M	White British/ Black Caribbean
	Mollie**	25	F	White British
	Tom^^	22	M	White British
	Ajay*	11	M	British Asian
	Jasmine*	8	F	British Asian
PERSONAL ASSISTANTS	Kirsten	30-44	F	White British
	Jodie	45-59	F	White British
	Jenny+	30-44	F	White British
	Sarah++	30-44	F	White British
	Erica#	34	F	White British
	Lizzie^	30-44	F	White British
	Becky^	38	F	White British
	Vanessa^	38	F	White British
Symbols * + # ^ etc indicate connections between participants				

Table 1: Participant details

A decision was made to populate three roughly equal study groups as follows:

– disabled parents who are currently, or have within the last ten years, directly employed PAs to support with identified parenting tasks;

– children aged over 8 (including those who are now adult), whose disabled parent has made use of paid PA support during their childhood;

– people who have within the past ten years worked as a personal assistant to a disabled parent with child(ren) under the age of 18.

Gaining the views of others closely involved with family life, for example the ‘other’ biological parent, step-parents, grandparents, extended family members, close friends etc would also have been valuable in addressing the research question and the gap in the current knowledge base. However, this was considered beyond the scope of this study, which aimed to focus closely on the perspectives of the individuals most directly affected by PA involvement in parenting support.

Recruitment

The initial focus of recruitment was on disabled parents as they were considered essential to accessing children and young adults who met the research criteria, however due to the anticipated challenges in identifying suitable participants, as many routes to recruitment and participation as possible were initiated. Participants were recruited using a range of strategies, including formal networks such as locality-based user-led organisations of disabled people who acted as ‘gatekeepers’ by controlling access to prospective participants, providing links to disabled parents. Three such groups actively supported this study, and shared regular research updates with their members via social media and news forums. National groups with an interest in disabled parents’ issues were also approached, however it was soon discovered that many of these were no longer active due to a loss of funding. A professional networking website provided a useful ‘shop window’ for the project and interacting with people who share an interest with disability issues enabled me to identify several potential participants, albeit this extended the geographical area covered by the study and increased travel to complete interviews. I also made use of existing connections with a local authority social work team supporting disabled people and formed links with a University-based research team involved in a separate study about the relationships between disabled people and their PAs who identified a potential participant.

PAs were sought via the same user-led organisations, since they also run payroll services for direct payment users and engage with PAs directly in this way. Other online forums were also used to attract PAs. I decided not to recruit children via specific ‘young carers’ groups, since I was keen to speak with young people who did not self-identify in this way, to capture experiences which are not already evident within the existing research literature.

It was evident that to succeed in recruiting sufficient numbers of participants, I would need to adopt a flexible and persistent approach and proceed at the participants’ own pace. In some instances, this meant initial contact to interview was relatively quick, in other cases the timeframe was several months.

In total, 11 parents, 10 children (this group including a retrospective sample of individuals who are now adult and grew up with their parents employing a PA) and 8 personal assistants were successfully recruited Interviews were held between July 2016 and December 2017. Participants were recruited through several different sources, as set out in Table 2 below:

Participant recruitment methods					
‘Professional’ involved with family	Research colleague	User-led organisation	Public speaking event	Online networking site	Recommendation from another participant
2	2	2	2	6	15

Table 2: Recruitment methods

Recommendations from existing participants were an important source of recruitment – this was especially the case when it came to recruiting children/young people, whose parents acted as ‘gatekeepers’. This technique, known as ‘snowballing’ can be a useful strategy when seeking a ‘hard to reach’ group of people (Hennink *et al.,* 2011), however the importance of building trust and being honest and reliable in communication is essential (Greig *et al.,* 2013). Following completion of interviews, participants were asked to identify other people they know who fit the research criteria, and many were happy to provide introductions or information to potential participants.

It was originally envisaged that PAs would be recruited entirely separately, as this would avoid the perception of an overly intense focus on the family, which may be experienced as uncomfortable or intrusive for parents and their children and could deter some from participating. Nevertheless, several parents suggested their PAs as prospective participants, and this resulted in an array of complex interconnections between participants, as illustrated in the diagram labelled Figure 1 below, where the blue arrows indicate relationships between participants and the orange arrows demonstrate introductions made.

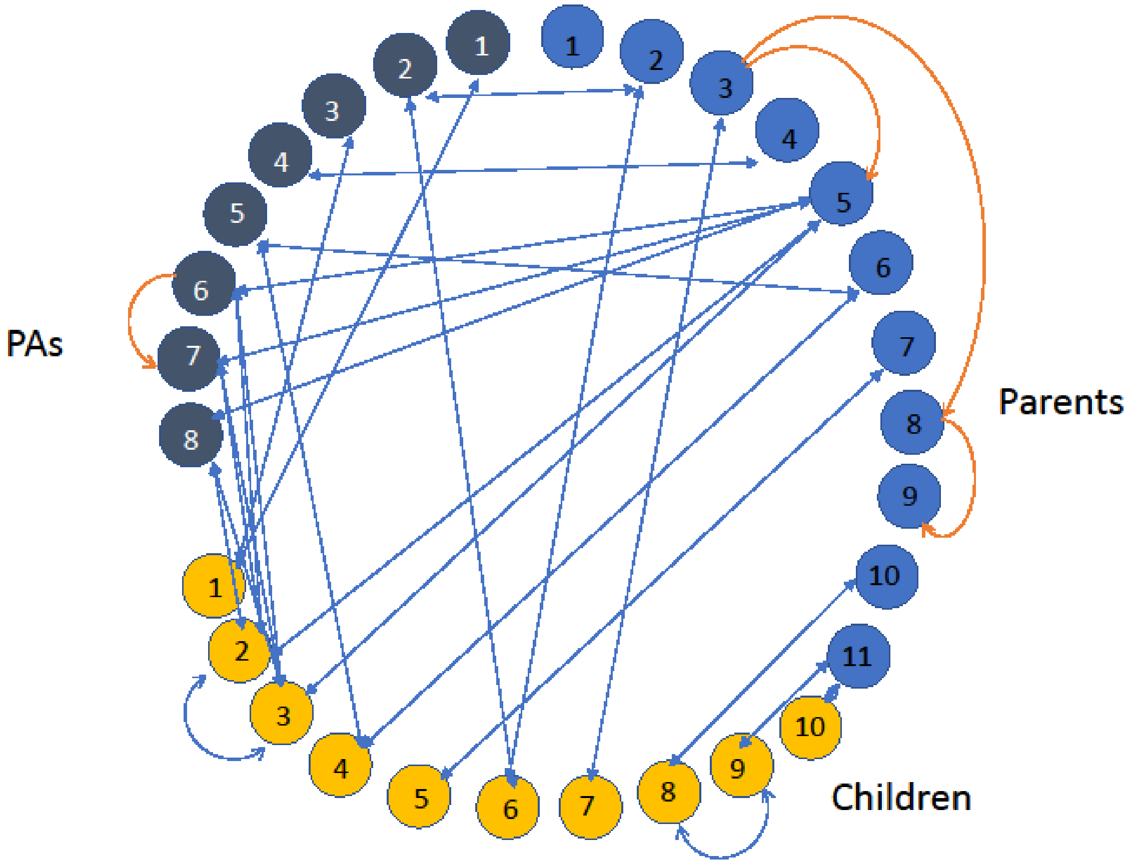

Figure 1: Participant connections

In what follows, further information about the disabled parents involved with this study is set out together with reflections on experiences of the recruitment process in relation to the different participant groups.

Disabled parents

Disabled parents proved the easiest to recruit, since they were better connected with the user-led groups linked to the study and to each other. They were also perhaps more open to the idea of engaging with research, and aware of its importance in raising the profile of hidden aspects of life and bringing about change. Disabled parents were key to accessing children, and as illustrated above, some were also happy to pass on information to their PAs about the project and to encourage their involvement. Caution was used with this approach, and individuals were asked to consider possible consequences to working relationships before taking action. As shown in Figure 1 above, there are numerous complex interconnections between participants to this study; this adds an extra dimension to findings as in some instances, individuals spoke about the same event from a different perspective. By examining the data generated in this way, it is possible to see where findings resonate with each other, and where tension or conflict exists. This serves to demonstrate the rich complexity of family life with PA support; however it was not used as an exercise to verify information given.

The parents interviewed all have physical impairments; some also have sensory impairments, and several have experienced mental health problems, however in all cases their eligibility for social care is linked to their physical impairment and their associated needs. Attempts were made to recruit parents with a wide range and experience of impairment, however I was unable to recruit parents with learning difficulties or those whose primary reason for receiving social care support is linked to mental health issues; this is reflective of the lower take up of PA support by people with mental health problems (NHS Digital, 2013), as well as the range of obstacles that people with learning difficulties face in receiving support with identified parenting needs (Tarleton and Ward, 2007).

Four participants were born with physical impairments; three of these have complex needs and use high levels of PA support throughout the day and night. Of those who have an acquired impairment, one became disabled as a teenager; one as a young adult before having children; two acquired impairments linked to health conditions around pregnancy; two became disabled while their children were of primary school age, and another when her daughter was a teenager. This meant that for some, the period of adjustment to parenthood was accompanied by other significant role changes in their lives, as they gained new identities as disabled people and employers. More information on parent participants is provided in Table 3 below.

Name	**Experience of disability**	**Current support**	**Family composition**
Andrea	Acquired impairment during pregnancy, permanent wheelchair user, affected by fatigue and pain.	Daily agency support around lunchtime and children's bedtime, regular workers provided.	Divorced mother + 2 children aged 6 and 8. Little contact with children's disabled father.
Naomi	Born with complex physical and health needs, permanent wheelchair user.	24/7 support comprising 2 live-in PAs + 2 additional PAs.	Single, lesbian mother + child aged 10 who shares time equally between parents.
Amber	Acquired impairment when daughter aged 5, permanent wheelchair user.	2 regular PAs provide flexible support when required.	Mother, disabled husband + child (now adult).
John	Spinal cord injury acquired as a teenager, permanent wheelchair user.	1 regular PA works daily from 7.30am until lunch time.	Father, non-disabled wife + child aged 2.
Gina	Born with complex physical and health needs, permanent wheelchair user.	24/7 PA support provided by 6 workers on shift basis.	Mother, non-disabled husband + 2 children (1 adult, 1 teen).
Cathy	Acquired impairment affecting mobility when children in teens.	1 regular PA works daily. The same PA also works for both of Cathy's adult children and her mother.	Mother, non-disabled husband, 2 disabled children (now adult) + disabled grandmother.
Jane	Acquired impairment affecting mobility, cognition and vision when children aged 6 and 8.	Does not currently use PA support.	Divorced mother, 2 children (now adult). Estranged from children's father.
Lydia	Born with complex physical needs linked to maternal use of thalidomide.	Does not currently use PA support.	Divorced mother + child (now adult). Mother re-married, regular contact with child's father.
Frank	Born with complex physical and health needs, permanent wheelchair user.	24/7 PA support provided by 6 workers on shift basis.	Parents divorced, both disabled. Teenage child resides with mother and step-sibling.
Phoebe	Acquired impairment during pregnancy. Permanent wheelchair user with sensory impairment.	2 PAs work flexibly over the week, according to needs.	Mother + non-disabled father + child (now adult).
Sofia	Acquired impairment as young adult. Permanent wheelchair user with sensory impairment, affected by fatigue and pain.	1 regular PA visits daily + agency support each morning + informal care evenings / weekends.	Divorced mother + 2 children aged 8 and 10. Daily contact with father, who provides regular informal care.

Table 3: Parent participant details

Children

Given the gaps within the existing literature, I recruited children/young people whose parents used PA support, but where the participants did not necessarily identify as 'young carers'. A key strategy was to recruit children via their parents, which meant they acted as 'gatekeepers', with control over my access to potential participants. Some children whose parents were interviewed for this study were too young to fit the eligibility criteria. In other situations, parents reported that their children were not interested in getting involved, and it was not possible to follow this up further and check whether this was indeed the case.

It was decided at the proposal stage that gaining the retrospective views of children who grew up with PA support but are now adult would be valuable, since they would be close enough to the experience to recall their feelings and emotions, but also have the distance to enable them to reflect on the overall experience. As a result, the age range of participants in this group ranged between 8 years and 28 years, with four children and six adults making up the cohort. It was difficult to recruit young adults via their parents, as in many cases they were living away at university or busy with important examinations which meant their parents wanted to protect them from distraction. This was a little frustrating, however the strategy was successful overall, as the majority participants in this group were recruited via their parents, the few exceptions being three adults who had grown up with PA support. This included one participant who was identified via a PA who used to work for the family; one who expressed interest via a user-led organisation; and another who approached the researcher directly following a presentation about the research project to a group of university students (helpfully also introducing her mother to the study).

There are ethical implications of recruiting children through their parents: these relate to issues of privacy, confidentiality, consent and choice of participation. A more detailed discussion of these factors is provided below, however these issues were fully considered as part of the recruitment strategy to ensure that children and young people were not coerced into participation, that their confidentiality was respected, and that their rights to participate and to withdraw from the study were made clear.

The aim was to hold individual interviews where possible, as these would enable participants to focus on their own experiences and express their views, uninfluenced by others. It was anticipated that to access the interview process, children may wish to be accompanied by a parent or another trusted individual. Certainly, this was the case for several participants, especially where younger children were involved and requested that their parents were present. Where the participants were adult, interviews were primarily held on an individual basis, although some joint parent/child and sibling interviews were held at the participants' request. No three-way or joint parent/PA or child/PA interviews took place. Although I had some initial reservations that holding joint interviews may inhibit participant engagement, the data generated by sibling and parent/child groupings were rich and detailed, often providing insights which would have been unlikely to arise in one-to-one interactions with the researcher. Overall, the experience was very rewarding as I was able to facilitate conversations which had never before been broached within some families; feedback from participants was positive, with some remarking that previous barriers to communication were broken down by the experience of talking openly together about their family life and the role of PA support in this, and they were better able to understand the other's perspective. As Finch *et al*. (2014) note, paired interviews and triads can be an effective hybrid of in-depth interviews and group discussions, especially among people who know each other well. This technique is also being used by the ESRC Centre for Corpus Approaches to Social Science (CASS, 2017) in a joint project in partnership with the BBC and the British Library, building upon the BBC Listening Project, which records intimate conversations between families and friends on various topics.

As explained earlier, the decision was taken to include adults with disabled parents who had grown up with PA support within the sample group of 'children'. The rationale was that these young adult participants would be able to accurately recall their feelings and emotions and to reflect upon their experiences with some emotional ‘distance’ from past events. In a similar way, disabled parents whose children have now grown up were also interviewed. Accordingly, the study was able to capture a breadth and depth of data which illuminate the entire experience of family life with PA support. Whilst it is recognised that memory can be fallible, and events may be interpreted, reconstructed and rationalised by participants post-event (Ritchie *et al.*, 2014), these retrospective accounts were powerful, compelling and richly detailed. Encouraging participants to tell their stories in this way enabled them to reflect on the whole experience of either parenting or growing up with PA support and important new insights were gained into this under-researched topic.

Personal Assistants

There were several obstacles to recruiting this group. PAs are not required to be registered with an organising body, and the majority do not choose to belong to a union. By the very nature of their employment, PAs work on a one-to-one basis; even where more than one PA is employed by a disabled person, PAs seldom ‘overlap’, which means they are often not well connected with others in a similar employment situation in the way that carers working for an agency are. Advice to employers is that PA contracts should address issues of confidentiality (Skills for Care, 2009; Sheffield City Council, 2016; Purple, 2019); this means opportunities for PAs to speak about their work are limited. Furthermore, whereas disabled people have long recognised the need to provide training for their PAs (Glendinning *et al.*, 2000), recent research suggests that PAs often have few opportunities to undertake training or qualifications, and that they commonly have no colleagues (Porter and Shakespeare, 2019); this can lead to PAs feeling isolated in their working environment (Spandler, 2004). These factors combined can result in PAs being somewhat difficult to find for research purposes.

As stated earlier, after completing their own interviews, disabled parents were asked to consider introducing their PAs to this study, having first considered any potential difficulties that may arise as a result. While most disabled parents did not provide a link with their PAs, as illustrated in Figure 1 above, three parent participants were happy for their PAs to be involved with the study, and as a result six PAs were successfully recruited to the study, three of whom worked for the same parent. Due to these close connections between participants, possible ethical issues around confidentiality were discussed with PAs prior to their involvement, and I was careful to ensure that I did not disclose any information to participants about the perspectives, views and experiences of others already interviewed.

Due to the difficulties of recruiting PAs, although an equal balance was sought between cohort groups, the PA group is slightly smaller. However, the data from PAs were especially rich; several participants had worked for multiple families led by disabled parents; others had worked within families for many years and were able to reflect upon the changing needs of both parents and children over the duration of their employment. As a result, information saturation was met within a smaller group. Whereas 11 parents were directly involved with this research, data were generated on 20 families led by disabled parents.

Limitations of the sample

Maximum diversity within the study sample was sought, however there are acknowledged limitations as to how diverse and representative the participants are of the general population; this is not considered problematic since it was never the intention. Of note however is the strong gender bias within the sample, which has only five male participants: two disabled fathers and three children. Three other female participants (two PAs and one young adult) all share a connection to a disabled father who is deceased, and their reflections and memories of their relationships with him were the focus of their interviews. This bias towards women’s experiences reflects the existing literature relating to disability and parenting, which primarily is concerned with experiences of mothering (Thomas, 1997; Farber, 2000; Grue and Lærum, 2002; Prilleltensky, 2003; Malacrida, 2009). However, the data generated from a male perspective within this study provide valuable insights into the role of PA support and fathering and how this may differ from the support mothers need; findings also support other research which suggests that disabled fathering differs from the experience of non-disabled fathering, and indicate further research into this area is required (Kilkey and Clarke, 2010).

Also noticeable is that participants come from a predominantly White British background. Despite this narrow ethnic range, the group of parents in particular is widely diverse in terms of their experiences of disability and impairment – including the place this fits within their lifespan as well as the specific impairment experience – parenting and family life, partnership status, age, sexuality and economic status, see Table 3 above.

Several of the parent participants have a history of activism and involvement in disability rights groups; this may be somewhat unusual, and partly attributable to the recruitment method of 'snow-balling' used within this study. Again, this is not necessarily problematic, but rather it may be a reflection that disabled people who have overcome several barriers to becoming parents link their individual struggles to wider structural factors and understand the importance of sharing their experiences through research as a way of countering negative stereotypical views about their lives and families.

Informed consent

As part of the process of gaining informed consent, I sought to be as inclusive as possible in my research materials and devised accessible information about the study to share with potential participants. On first contact the purpose of the study was outlined, and where individuals remained interested in participating and agreed, a copy of the leaflet and tailored participant information was sent to them. The informed consent letter covered the following:

- The purpose and scope of the study
- Why it is important
- What was involved in participation – benefits and disadvantages
- What would happen on interview
- What would happen after the interview – receiving a transcript and report/summary of findings; receiving a £10 store voucher as a token of thanks.
- Confidentiality, anonymity and data storage
- Participants' right to withdraw within an agreed timeframe
- Circumstances in which confidentiality would be broken

Please see Appendices 13 – 15 for copies of the informed consent form, tailored to the needs of different participants.

Contact was followed up within a few days and where individuals were happy to proceed, an interview was arranged. Verbal and written consent were taken as part of the preliminary discussion to the interview. All adult participants were deemed to have capacity to consent, however as this study involved seeking views of children and young people, parental consent was also required in some cases, as well as consent from the young person themselves. Where parental consent was required, it was made clear that the consent of any children/young people was independent from their parent's participation. Accessible, 'child-friendly' participant information sheets and consent forms (see Appendices 10 and 15) were devised to provide full details to children and young people, and to record their written consent. Good practice guidance on this process was followed (Shaw *et al.*, 2011), and the documentation made clear that individuals had the right to end their interview at any point or withdraw from the study without any need for explanation or negative consequences. There was, however, a time limit within which participants were asked to notify the researcher of their wish to withdraw from the study; this was for practical purposes around transcription, data management and data analysis. This was made clear to all participants and is in line with research ethics guidance from the Economic and Social Research Council (2020) regarding transparency and integrity of research processes. The deadline for this was within three weeks of the research interview taking place; no one chose to withdraw from the process.

Anonymity and data storage

Issues of privacy, confidentiality and anonymity were discussed with all participants, who were made aware that everything they shared would be used solely for agreed research purposes, unless this was contraindicated due to safeguarding or child protection concerns. Consent was sought to use direct quotations; these have been sensitively selected, and if necessary, changed in such a way that participants cannot be identified externally. However, given the sample size and close connections between some participants it was not possible to guarantee that individuals would not be able to identify each other, and this was something I discussed with contributors. For this same reason, in all interviews I was mindful not to discuss details of others involved, or to seek confirmation or clarification of their experiences.

In accordance with the Data Protection Act 2018 and the General Data Protection Regulations (Information Commissioner’s Office, 2018), to respect confidentiality, participants have been given pseudonyms within this thesis to protect their anonymity. Chosen pseudonyms are completely different to individual’s names. These pseudonyms were created following interviews, and used throughout transcription, analysis and discussion with supervisors. As stated previously, all geographical details given, and names of other individuals mentioned have also been removed or changed.

Methods of data collection

Semi-structured interviews were used to generate data. This included face to face and telephone interviews. Interviews are a core qualitative research method due to the level and detail of data they generate in comparison to other methods of data collection. Commonly described as a form of conversation (Kvale and Brinkman, 2009), research interviews have a clear purpose and require focus and active involvement from both parties (Holstein and Gubrium, 2004). The sensitive nature of qualitative research – including the subject of this study – means that deeply personal and emotionally-laden topics are discussed; as such, the interview encounter can create a unique dynamic between both parties, and it is important to build a relationship of trust between interviewer and interviewee. The idea of the interview as a reciprocal interaction is an important element of critical and feminist research approaches which seek to be reflexive and interactive, placing an emphasis on the interview as a collaboration (Yeo *et al.*, 2014). This approach also fits well with emancipatory research methods championed by disability studies academics (Barnes, 2003; Barton, 2005), which seek to redress the power imbalance between researcher and the researched present within traditional research processes. Interviews have been commonly used in research into disability issues, including studies which focus on parenting (Tarleton and Ward, 2007; Malacrida, 2009; Rosenblum *et al.*, 2009; Bergeron *et al.*, 2012), those exploring the employer/employee relationship relating to personal assistance (Ungerson, 1999; Stainton and Boyce, 2004; Ahlström and Wadensten, 2010; Porter *et al.*, 2020) and research into the experiences of children with disabled parents (Aldridge and Becker, 1999; Cheesbrough *et al.*, 2017); I concluded that interviews would therefore be a suitable approach for the current study.

In the early stages of research design, I considered using focus groups for the PA cohort. Both methods of data generation are based upon verbal communication and spoken narratives, which can provide an insight into participant's lives and views of their situations. My rationale was that, unlike with parents and children, I would not gain any useful environmental insights from meeting PAs in their home environment; PAs may be willing and able to travel a reasonable distance as they are likely to have a commute to their work; additionally they are typically isolated in their work environment, and may see a benefit in sharing a confidential group discussion about their work with others in a similar situation. It seemed that this approach could be productive.

However, from speaking with an experienced researcher who was at that time interviewing PAs for a separate study, the difficulty in identifying people who would meet my criteria was apparent. Asking potential participants to retain their interest and defer the interview exchange until a suitable group meeting could be arranged would therefore risk losing them to the project. The availability of PAs to interview around their work and family commitments, as well as their geographical grouping also meant that arranging even small groups would be impracticable. For these reasons, I did not use focus groups however PA interviews were handled differently than those with parents and children, in that telephone interviews were completed with this group of participants. Issues relating to this method of data generation is discussed further below.

Semi-structured interviews provided a number of advantages for this study; they are a flexible option to researchers, allowing open-ended questions to be prepared, yet permitting the interviewer to follow up with probing questions and to ask questions out of sequence where this may be helpful (Fielding, 1994). Standardisation of some questions can increase consistency, however interviews can be tailored to each participant, allowing researchers to explore more dimensions of their topic, and providing participants with the feeling that their unique perspective is being considered and responded to (Fielding, 1994). Although semi-structured interviews can be time consuming and resource intensive, generating large amounts of data to be analysed, they are considered to be a highly effective way of exploring the ways in which participants construct their lives (Yeo *et al.*, 2014). Semi-structured interviews also require careful planning and preparation on the part of the interviewer. In this study, ‘open’ questions were used to stimulate “conversations with a deliberate purpose that is accepted by the participants” (Kadushin and Kadushin, 2013, p. 17); these encourage thoughtful and considered responses and can be used to ‘get beneath’ the surface of the everyday interactions explore positive and negative aspects of these in more depth. More sensitive questions were positioned later in the interview, to allow time for a rapport to develop between myself and participants, which may promote greater confidence and openness (Dempsey *et al.*, 2016).

I developed four interview schedules tailored to the needs of the three different participant cohorts (see Appendices 16, 17, 19 and 20); questions were developed for disabled parents, PAs, and I also took into consideration the different approaches required for children currently living with PA support in their family, and participants who were now adult, reflecting on their childhood experiences. Although this proved to be a time-consuming task, detailed preparation for research encounters with participants who have different needs and different experiences of the topic allowed me to ‘think my way into’ the subject on a deeper level. To ensure my research was accessible, I prepared materials, questions and resources suitable for participants with learning difficulties, including ‘easy to understand’ participant information sheets. I also prepared specific questions and materials for children and young people, to ensure that they could engage with the experience in a meaningful and positive way. In line with good practice guidance *(Shaw et al.*, 2011), I planned to hold shorter conversations to facilitate the meaningful engagement of children and young people, and developed a range of person-centred activities using finger-puppets, pens and flipchart paper which I hoped would be fun for participants and enable them to express their views and opinions (see Appendix 17 for children’s interview guide and activity matrix). This enabled me to build a rapport with younger participants and create a safe and positive environment which would be conducive to sharing information. When planning interviews, I took into careful consideration ways of reducing stress to participants, and especially young people, including:

- Informing participants beforehand about the areas for discussion, so they knew what to expect.
- Using child friendly/accessible resources and activities to build a rapport with the researcher and to create a positive environment.
- Informing participants during the consent process that they can refuse to answer questions, take a break or stop the interview at any point. For younger children, ‘stop’, ‘go’ and ‘question’ cards were devised to address the power differential and make it easier for them to avoid questions they do not want to answer (see Appendix 18).
- Ending the interviews with a non-emotive topic.

It was impossible to exclude the risk that interviews may trigger difficult feelings for participants, however the research questions were anticipated to present a low risk of harm. Nevertheless, the topic of family life is highly personal and sensitive, and it was possible that discussions could bring up issues which may affect emotional well-being, or cause participants to question their own or others’ behaviour. Where necessary, participants were offered a break from the interview; they were also advised that they could refuse to answer questions and pause or cease their participation at any time. For all participants I considered the possible need for follow-up support at the end of the interview, and researched information about local and national organisations and sources of support or information which might be useful. All participants were made aware prior to interview (through the participant information sheet and verbally) of the duty to share information if issues arose regarding safeguarding.

Conducting interviews

Face to face and telephone interviews were conducted, all of which took place in participants' homes. Each interview lasted between 40 – 120 minutes; the majority fell between 60 – 90 minutes. Shorter research exchanges took place with children and longer interviews met the communication needs of participants with speech impairments. With consent, all interviews were digitally recorded as an mp3 audio file and transcribed verbatim by the researcher. As discussed above, interview schedules and planned activities were used to guide the process. These were designed to take participants through the discussion in a logical sequence, moving progressively from gathering basic factual information towards exploring topics which required more in-depth, thoughtful or emotional responses and observations. These schedules could be used as a tool to refocus participants if they diverted from the primary topic and I found them a useful 'aide memoire', especially in the earlier interviews. Slight changes were made to the schedules as the result of participant feedback and learning in the early stages of the research process.

In the preliminary stages of each interview (including prior to interview, during the initial contact and interview-planning phase), time was spent building a rapport with participants, explaining details of the project, and answering any questions which arose. I went through the participant information form, discussed issues of confidentiality, and gained informed consent. This process ensured that people felt 'prepared' for the interview to begin and that participants felt able to speak freely

Face to face interviews

For face-to-face interviews with parents and children, the location of interviews in participant's homes provided additional contextual/ environmental information about how family life might work in each household, and what impact the parent's impairment may have on daily tasks. I also considered the home as the setting in which children and young people would feel the safest in which to complete a research interview – something which I anticipated many may find a new and perhaps slightly intimidating experience. I felt privileged to be invited into the family home as a researcher, however the experience was not always unproblematic, as I sometimes had to contend with multiple interruptions and unexpected events; this occasionally led to a feeling of tension between my identity and aims as a researcher and my status as a guest in the family home.

In most cases, interviews took place with just the researcher and participant present, however some participants had requested joint interviews with their child for reasons of practicality and accessibility, and in other instances the participant’s spouse, PA or child, were present in the property, occasionally entering the room. Issues of confidentiality were discussed prior to the interview taking place, however no concerns arose, although some conversations were suspended for a short while when others were present, or essential care tasks were completed.

Joint interviews were initially a cause for some concern on my part, in that individuals may self-censor or cast their situation in a different light due to another person being present. In fact, these encounters often resulted in very rich detail coming to light, with participants themselves at times acting as interviewers, probing each other’s emotions and feelings, questioning situations which they had observed, and thereby eliciting information which may not otherwise have been generated. Joint interviews also provided further insights into interpersonal relationships and dynamics. This experience fits with the literature on group interviews, which highlights primary advantages as being the more relaxed atmosphere it provides (Stewart and Shamdasani, 1990), spontaneity of discussion (Krueger, 1994), and jogging each other's memories (Valentine, 2011). Children who may be more likely to be daunted by an interview situation may find these benefits particularly helpful (Punch, 2007), however it is possible that children may find it difficult to overcome power relations when others, especially adults, are present, and find it hard to express opinions and perspectives where these may be perceived as negative and upsetting to others.

Telephone interviews

Data were generated from PA interviews, in all but one instance, via telephone interviews. The use of telephones as a medium for conducting quantitative research is well established (Barriball *et al.*, 1996; Carr and Worth, 2001), however the use of telephone interviews as a data collection tool in qualitative research has only become popular more recently (Block and Erskine, 2012). Interviewing face-to-face and over the telephone share several common features: both centre on a verbal exchange between parties, they can be adapted to a range of styles from conversational to formal and provide an opportunity for follow-up and in-depth questioning with relatively low refusal rates. Studies which have used semi-structured interviews to conduct both face-to-face and telephone discussions demonstrate that the information gathered was equally robust (Sturges and Hanrahan, 2004), and this technique has been used successfully in research exploring personal assistance relationships (Porter *et al.*, 2020).

More used to conducting face-to-face interviews as part of my social work role, I was initially unsure about using the telephone to generate research data. I was also mindful of certain challenges specific to telephone communication, for example in establishing a rapport and a shared understanding, as well as the difficulty in gauging responses without the benefit of visual clues such as body language, gesture and eye gaze. Potentially important environmental information about the participant is also lost. Yet despite these possible drawbacks, telephone interviews have several advantages; they are effective and efficient, typically take less time than face-to-face interviews to complete (Block and Erskine, 2012), and offer convenience for both researcher and participant. So, although I elected to interview disabled parents and children face-to-face, speaking with PAs in this way offered several benefits, and seemed appropriate, since the aim was gathering information about participants’ working role. This proved to be the case, and with the exception of one participant who preferred to be interviewed face to face in her own home due to her access requirements, all PAs were happy to speak at length and in detail about their experiences over the telephone. Interviews were arranged around childcare and work rotas, with several discussions taking place during evenings or weekends. One interview was completed in two separate calls a week apart to fit in with her busy weekly routines.

Ending interviews

Ritchie *et al.* (2014) offer helpful guidance on conducting research interviews, including how to manage potentially difficult transitions such as endings. They advise clearly signalling the approach of an end to the interview, ideally around five to ten minutes in advance. This, they suggest, can help re-focus a tiring participant who may have something important as yet unsaid to contribute, and help to return the interviewee to the level of everyday social interaction.

I followed this advice, and at the end of the interview, I explained to participants what would happen next with the data generated, and how findings would be reported. I also thanked participants for their time and gave them a £10 shopping voucher. This token gesture of thanks was mentioned on all promotional material, however most participants expressed surprise and pleasure at the gesture, suggesting that this was not a strong motivation for their involvement. Careful consideration was given to the amount of the voucher; it was also decided that all participants should be treated equally, although this may have appeared more generous to younger participants. Guidance suggests that paying participants for their involvement in research supports inclusion is a tangible way to acknowledge the value of their contributions and can lead to more effective and equitable involvement in research of people who use services (National Children’s Bureau, 2010). Branfield and Beresford (2006) also make the case for overcoming financial barriers to involvement in research as a means of ensuring diversity and making user involvement in research work, however paying participants is not entirely unproblematic; consideration needs to be given to the ethics of consent, and there may be consequences in terms of recruitment of research participants and for the data subsequently generated (Head, 2009).

The interview was not my final contact with participants, since there was subsequent communication around sending out transcripts and updating those who opted to receive updates about progress and research findings. For example, some participants asked questions about the research process, others asked about emerging findings, and some queried what other participants 'did' in terms of managing PAs around family life.

In what follows, the processes undertaken on completion of interviews is detailed.

Data Analysis

This study used a thematic analysis, which involves the discovery, interpretation and reporting of patterns and clusters of meaning within data (Ritchie *et al.*, 2014). Thematic analysis is not allied to any particular theoretical construct, making it a versatile approach, and one which is an appropriate technique for exploratory research such as the current study. Thematic analysis is a widely used qualitative analytic method, which enables researchers to work with a variety of information in a systematic manner that 'increases their accuracy or sensitivity in understanding and interpreting observations about people, events, situations and organisations' (Boyatzis, 1998, p. 5). According to Braun and Clarke (2006), the benefit of thematic analysis lies in its flexibility, however due to the absence of clear guidelines around this technique, qualitative research is open to criticism on the basis that 'anything goes' (Antaki *et al.*, 2003). Seeking patterns in data is the shared aim of many other analytic methods, notably grounded theory, a method which emerged from the work of Glaser and Strauss (1967) and quickly grew in importance as an accepted qualitative research method (Urquhart and Fernández, 2006). Certain aspects of this methodology were 'borrowed' within this study. For example, during the coding process, I compared data with data to find similarities and differences. Charmaz (2014) describes this process as being important to make analytic sense of the data, to generate and test ideas and to bring new insights. I also undertook memo-writing, which Charmaz (2014, p. 162) recommends to create “an interactive space for conversing with yourself about your data, codes, ideas and hunches”. I found keeping a log of my thoughts and developing ideas helpful in staying connected with the data; the notion of ‘conversing with myself’ in this way was also useful in other ways – having previously worked in front-line teams where I enjoyed the interaction and support of colleagues in thinking through complex situations and generating ideas, in common with others, I found the experience of being a doctoral student isolating at times (Janta *et al.,* 2014) . The use of these techniques ensured that the data analysis process was clear, rigorous and strongly evidence-based.

Analysis was conducted in accordance with Braun and Clarke’s (2006) definitive guide which involves working systematically through the data in several stages including: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and production of the report. These stages are described below:

Familiarisation with the data

The analytic process began with immersion in the data – this commenced with transcription. Interviews were fully transcribed, with all names anonymised and place names removed. Transcripts were shared with adult participants as part of a ‘member checking’ process to ensure that data were captured accurately, and to allow for clarification of any details. Trustworthiness of results is vital to high-quality qualitative research. Member checking, also known as respondent validation, is a technique used to strengthen credibility of results (Birt *et al.*, 2016), and asking participants to check transcripts for accuracy and resonance with their experiences is one way to do this (Carlson, 2010). However, Long and Johnson (2000) suggest that caution is used with this approach, highlighting that participants may not fully recall their interviews, or that their rapport with the researcher may influence their responses. Using examples from her own work, (Carlson, 2010) warns that miscommunication between researchers and participants can arise during the member checking process, threatening researcher/ participant relationships and even the stability of the study. Mindful of potential pitfalls, I discussed the technique with participants to manage their expectations of the process. Full interview transcripts were offered to children aged over 14 years, however none requested them. For those aged over 8 years but under 14 years, an interview summary was offered which would outline key points discussed and the views expressed. This information was offered in accessible formats as required and adapted for young people; again, these were not requested by participants. Where artefacts (such as drawings or word-clouds) were created as part of the research process, photographs were taken of these and sent to the maker. This information was offered direct to the children; it was left for them to decide if they wished to share with parents. Parents were informed about this at the consent-gathering stage to allow for discussion and for the arrangements to be modified if agreed.

The primary purpose of the member checking process was to promote more active participation in the study, to facilitate transparency, and to elicit further reflections/insights from participants on the subject which may occur to them following the interview. Admittedly, some participants expressed mild embarrassment at seeing their words or frequently-used turns of phrase written down, however this was expressed in terms of amusement and gentle self-deprecation, and all agreed the accuracy of the data. In several cases, sharing transcripts led to further discussions (by email and/or telephone) to clarify points or address issues which arose subsequent to the interview. For example, one PA talked a great deal during the interview about her feelings and the emotion of the work she undertook; on reading her transcript, she wanted to explain some of her practical tasks in more detail to set this information in a clearer context. One parent wanted to expand on some of the ideas she expressed about setting clear boundaries for her PAs, for example how she sought to maintain a positive working relationship which did not become a friendship, and the rules she imposed about PAs not giving her children gifts. These additions provided another ‘level’ of information which was invaluable to the study, aiding the generation of more nuanced, in depth data.

Transcription is a fundamental process in qualitative research; whilst it may initially seem simply a practical task, theoretical issues and methodological implications arise out of decisions relating to transcription (Lapadat, 2000). The act of verbatim transcription is to capture and convert speech – a fleeting, vocal expression – into something static, tangible and manageable to the researcher. Transcription is therefore a complex undertaking, much more than capturing or representing talk, but a constructive and interpretive act in itself (Green *et al.*, 1997). Whilst the assumption was that the interviews were co-constructed, the main focus was not on how this was achieved, but on the shared understanding that was created. Being primarily interested in the content of the interviewees’ speech, data were selectively transcribed with a focus on spoken utterances; however, mindful of Jenks’ (2011) advice that it is good practice to include some interactional and paralinguistic features to ensure the written transcription remains close to the data recording, some additional information was detailed. This included speaker stress and intonation, significant pauses in speech and sudden stops; other communication such as laughter, sighs or tears, were noted to contextualise the conversation and provide a nuanced picture of the interaction for the purposes of analysis. Punctuation was used to represent changes in the pace or flow of speech, and where there were interruptions, these were noted. All transcripts were checked and corrected for accuracy against the original audio. In addition, field notes were recorded shortly after each interview, and sometimes also later, when thoughts arose. These were not used as data, rather they helped remind me of the interview context and to stay ‘close’ to the experience.

Transcriptions were typed manually at first, however this proved to be an extremely time-consuming process; I later acquired voice-to-text software and this helped speed up the process. I found that speaking the words of participants, rather than merely typing them, accelerated the process of familiarisation with the data; it also enabled me to begin to gain an insight into the subjective experiences of participants and the meaning they attach to these.

Particular challenges were experienced when accurately transcribing interviews held with participants who have speech impairments, and where joint interviews were held. These issues were discussed with participants as part of the preamble to the interview, and participants offered to read through the texts provided and give feedback or make corrections as necessary.

Following transcription, I read through transcripts and listened to the audio recordings several times, engaging fully with the data, annotating transcripts to highlight key points, and generating an initial list of ideas about what was in the data. Here I also made links to themes identified in the literature review findings and from practice observations.

Generating initial codes

The next stage was concerned with initial coding of the data. This was originally conducted manually, as a natural extension of the familiarisation process, and involved writing notes on transcripts and using colour coding to indicate potential patterns. Encoding data is an integral part of thematic analysis; in this study, an inductive approach was taken, meaning that the codes and themes identified were derived from the data. This fits with the underlying epistemological approach of this study which involves building knowledge from the “bottom up” (Ormston *et al.*, 2014, p. 6). Line by line coding was used to analyse individual interviews. Braun and Clarke (2013) describe this process of ‘complete coding’ as working systematically through each interview to search for data which relate to the study’s research questions. This process enabled me to identify recurring themes and issues of importance to each participant. Over 1000 provisional codes were identified as part of the initial process. Organising such a large body of data felt somewhat overwhelming at times, however I loaded information onto Nvivo 11, a computer software package widely used in qualitative research, and this proved a helpful tool in managing the data set, enabling me to ‘tag’ and name selections of text and to collate codes.

Searching for themes

Once all data had been coded and collated, I was able to review and merge codes, looking for similarities and differences (Charmaz, 2014). This process is widely used in qualitative analysis, with Glaser and Strauss (1967 p. 105) describing their method of “constant comparison”, Braun and Clarke (2006, p. 90) terming the process a search for “candidate themes” and Ritchie *et al.* (2014, p. 278) referring to a process of “indexing and sorting”. This process enabled me to collate themes grounded within individual participant’s accounts, and to merge these with codes from other participants. This was a challenging process, and during this stage I used memos to record my developing ideas, as well as visual techniques to map thoughts about themes (see Appendices 21 and 22).

Themes were selected due to their importance to participants, not simply because they appeared frequently within the data set. In this way, the analysis bears a close relation to grounded theory. This stage of analysis ended with the development of candidate themes and sub-themes.

Reviewing themes

Braun and Clarke (2006) describe this phase as involving two levels of refinement, the first of which is to review the coded data extracts. Here, I read the candidate themes and sub-themes to see if they formed a cohesive pattern. This process required some re-thinking about where the data ‘fit’ and involved some reworking of themes. The second level of refinement involves applying this process to the entire data set, which was re-read to check that the themes identified worked and to check for any omissions. This was another time-consuming and somewhat daunting process; at times I felt overwhelmed by the amount of data to be managed and the challenge of coming up with a coding frame which would fit the data and enable me to tell an articulate ‘story’.

Defining and naming themes

This next phase involved identifying the essence of each theme. At this point, themes were defined and further refined, and the data within them analysed, which is to say interpreted and made sense of, as opposed to simply being described. Writing about the themes which had been identified and discussing these within supervision helped me to gain a deeper insight into the data. By using this systematic method of analysis, I was able to identify similarities and differences across the data set, summarizing key features but also getting into the rich detail of what participants had to say.

Production of the report

In this final stage, Braun and Clarke (2006, p. 93) explain the task of the researcher is to tell the “complicated story of your data in a way which convinces the reader of the merit and validity of your analysis”. The aim is to provide a concise and coherent account of the data within and across themes, drawing on evidence which captures the essence of key points. This enables the analysis to be grounded firmly within the data, however Braun and Clarke (2006) stress the importance of seeking a deeper level of understanding; by critically analysing the data and making links to existing literature, thematic analysis can reveal unexpected insights which in turn may generate new contributions about the topic. These techniques ensured that the data analysis process was clear, rigorous and evidence-based.

Figure 2 below provides an audit trail of the data analysis processes used:

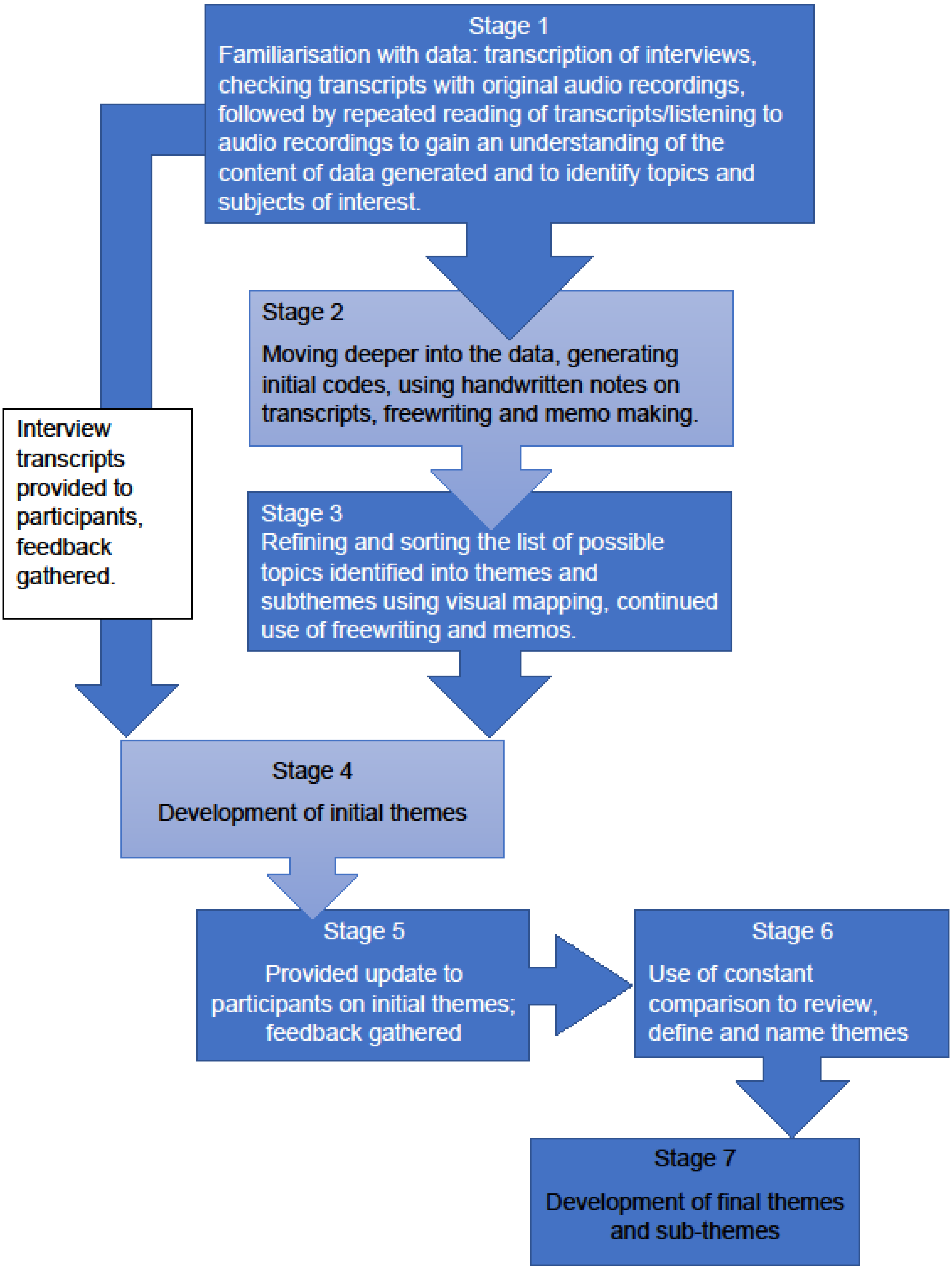

Figure 2: Audit trail of analysis and code development

Reflection

The interpretive approach adopted in this study acknowledges both subjectivity and the fact that participants and researchers bring their own particular influences and views of their social world to bear upon the research process. This contributes to the co-construction of reality during the interview process (Finlay and Gough, 2008). Given the researcher's own background, role, emotions, behaviour and beliefs must inevitably influence the research process, reflexivity and sensitivity are vital. Therefore, throughout the research process I engaged in reflexivity to examine what Weiner-Levey and Popper-Giveon (2013, p. 2177) term the 'dark matter' of my own experiences, understandings, and orientation to this subject which have shaped my interpretation and approach to the research. This involves conscious and on-going self-reflection and keeping in touch with one's own positioning and subjectivity. In this way, I was able to consider actively how my own experiences and assumptions may influence the research process and data generated, an activity which Hesse-Biber and Leavy (2006, p. 146) describe as "the process through which a researcher recognizes, examines and understands how his/her own social background or assumptions can intervene in the research process". Using interpersonal reflexivity, I was also able to think about the dynamics created between researcher and participant and how these influence knowledge creation (Hennink *et al.,* 2011). As a qualitative researcher, interpretive epistemology framed my thinking and inspired this study which aimed to better understand how participants experience their social worlds. In order to be transparent, I tracked my own thoughts, feelings and developing understanding throughout the project via field notes, in a reflective journal, and through discussions with my academic supervisors and other researchers.

I am extremely grateful that people were willing to share their insights and feelings with me so generously in this research. This was an exciting experience, in that I was provided with confirmation that the subject of my research was indeed a 'real' issue for families led by disabled people. Yet at the same time, I felt the weight of responsibility to participants in sharing their accounts accurately and 'making something' of the research which would be helpful to families led by disabled parents. The pressures I felt as a developing researcher were to some extent balanced with my experience as a social worker, since I was able draw upon my practice skills in managing fieldwork, gathering information and analysing complex situations.

I had anticipated that talking about the intricacies of family life, which we can all find difficult at times, within the confines of a one-off individual research interview might generate strong expressions of emotion. This proved to be the case for several interviewees, most notably three disabled mothers, however I was able to manage these research encounters sensitively, acknowledging and respecting their feelings and allowing time for them to compose themselves. Where I felt it would be helpful, I made limited contact following interviews to ‘check in’ with participants to ensure they did not need any further emotional support, encouraging them to speak with a friend or relative if this could be useful. The thoughts and feelings expressed powerfully within these interviews provided me with new insights into the realities and complexities of parenting with PA support. In this way, the interpretive research design employed by this study enabled me to respond in the moment to the needs of interviewees and to the sometimes unexpected answers generated by certain questions, and to gain a greater understanding of how participants construct their social worlds.

While some difficult emotions were expressed during interviews, as one might expect when talking about family life, a full range of emotions and feelings were shared by participants. Laughter was a feature of many interviews, including with the three mothers mentioned above, as people shared family stories, memories and anecdotes. Several participants expressed that they had found being involved in the research positive, with many saying that it had been helpful to discuss a subject which they had previously ‘taken for granted’ and had not fully examined or discussed with close family members. In this way, I believe participants gained some personal benefit from taking part in this study.

In my view, the qualitative research methodology used was wholly appropriate to this study, in that rich and detailed data were gathered to answer the research question. By conducting in-depth interviews, I was able to engage directly with a range of people with different perspectives of parenting with PA support, and to listen to their powerful and unique stories. To me, the use of qualitative techniques in seeking answers to questions about complex human emotions, processes and actions ‘makes sense’. Although at times I felt inundated by the amount and complexity of data generated in this way, I thoroughly enjoyed the field-work aspect of the project. The use of semi-structured interviews suited my existing skill set and met my needs as a developing researcher, enabling me to pursue different strands of enquiry with participants while retaining an overarching structure to guide the discussion. Recruiting participants was sometimes challenging, and there were times when I was not certain I would find enough individuals with lived experience who would be willing to speak with me; using semi-structured interviews gave me confidence that I would be able to maximise the opportunities that each encounter provided.

My memories of interviews remain with me vividly; this may be because I have been so immersed in the data for an extended period, however reflecting on the overall experience, my strongest recollections are of face-to-face interviews. Although telephone interviews generated high quality information and had many advantages in terms of time and cost management, as an individual and a social worker, I am perhaps more oriented to direct work. While I am happy to use the telephone as a tool to gather information, for me, interacting with other people on a face-to-face basis is more powerful medium; it also provides a wealth of other information and non-verbal cues which may be difficult to detect using technology, and it is easier to establish clear communication and a shared understanding.

My interviews with children were challenging at times, but also enjoyable. I found these more difficult to conduct, perhaps as I am more experienced in working with adults, and the focus of younger children was more difficult to engage and often fleeting. The adults involved in this research understood that the relationships at the heart of this study are unique and complex, however for the younger participants, they were simply a matter of fact and not something they had previously considered. The materials I had prepared for children and young people worked well in encouraging them to think about their lives with PA support, perhaps for the very first time. Being flexible, creative and positive with interviewees proved the best approach to enabling them to engage with the research process and share their views.

Summary

Part two of this thesis has examined the methodological issues and considerations relating to the current study. Together, the two chapters have provided an account of the research methods and methodology used in this study including what influenced the methodological decisions made. Qualitative methodology was used to explore the research question, and semi-structured interviews were conducted with a sample of 11 disabled parents, 10 children or young adults who have grown up with PA support, and 8 personal assistants who have worked with families led by disabled parents. The chapters set out theories underpinning the approaches used and provided the rationale for decisions made about data generation. Thematic analysis was used, and a commentary was provided on how this was undertaken and the issues arising out of this.

This research fits within the interpretive paradigm, which seeks to understand people's lived experience from their own perspective. This paradigm recognises that reality is socially constructed, and that sense and meaning are made within the broader social, cultural, historical and personal context within which these experiences are set. The constructivist epistemology which informs this study is congruent with a social model understanding of disability, a concept which is central to the relationships at the heart of this research. As demonstrated within the earlier literature review, personal assistance as a model for support emerged due to the demands of disabled people; however, the social model itself has attracted some criticism for failing to address adequately the nuanced experience of living with disability. While strongly influenced by the social model perspective, drawing from the principles underpinning critical realist ontology has proved helpful in developing my thinking about the complex interactions which exist in the lives of disabled parents who employ PAs, and their children.

Part three of this thesis will now turn to examine key findings, which are set out in the following chapters. The first chapter illustrates how personal assistance is used by the families in this study to meet their identified parenting needs. Factors which shape the level of PA involvement in family life are discussed, and children’s views and understanding of the role of PA are examined.

Part Three:

Findings

Introduction

The accounts of participants in this study provide a compelling and detailed picture of the experience of family life with personal assistance. Interview data are rich and nuanced, providing insights into the complexity of relationships which develop as a result of this model of support. These were inevitably informed by individual circumstances and experiences of disability, impairment and family composition. Despite these differences of experience, consistent themes emerged, revealing the complex reality of parenting with, and growing up with, personal assistance. These findings are examined over the following three chapters, which are set out as follows:

Chapter five, ‘Sharing the Tasks of Parenting’, provides an overview of how participants use personal assistance in their daily lives. This chapter introduces the participants involved in the study, setting out how families use personal assistance to support daily life. Findings demonstrate that while the performance of practical tasks is central to the role and function of the personal assistant, the support provided goes far beyond this and almost always also includes some degree of emotional support. The data presented enrich our understanding of family life with PA support and provides important contextual information about how parents’ and children’s lives are shaped by the presence of workers.

Chapter six explores in more depth the complex relationship dynamics which develop between parents, children and personal assistants, and how these are experienced by individuals. Findings reveal the diversity of these support relationships and suggest that there is an active spectrum of PA involvement: on one end, PAs provide an important function to support family life, but as individuals, they play only a minor role. By contrast, some PAs become almost a part of the family unit and have deep emotional connections with parents, children and wider family members. In these relationships, the PA becomes immersed in family life and their role is blurred and harder to define. Positions along this spectrum of involvement are not static; in fact, findings shed light on the complex reality of constantly shifting and changing interpersonal relationships. Data indicate that individual personality and preferences, family composition, age of children, and the number of PAs employed can all influence how deeply immersed in family life individual PAs become. Parental experiences of impairment and support needs can also shape the level and degree of family/PA relationships. Time is another key factor, as the longer PAs are employed within families, the more complex and entwined these connections become.

Finally, chapter seven presents participants' experiences of the varied ways in which they seek to influence, control or in other ways 'manage' the behaviour of others. These findings are important as they provide new insights into the energy that parents, PAs and children put into these relationships and shed light on complex and shifting issues of power and control. It might be expected that disabled parents may sometimes need support from PAs to reinforce 'family rules' or to help 'discipline' their children. This is certainly the case in many participant families, and it turned out to be a contentious subject for all groups, most especially the children. To support a more detailed consideration of the range of views expressed, findings in this chapter are set out in relationship dyads.

Throughout the following chapters, verbatim quotations from participants are included. To indicate where participants themselves added emphasis to their words, italics have been used.

Chapter 5: Sharing the tasks of parenting

Introduction

The shift in lifestyle which the transition to parenthood brings about is a major developmental period in the life-cycle of any family, with research demonstrating that adaptation can be problematic for many (Deave *et al.*, 2008). All parents, whether disabled or not, need support with managing this significant change in their lives, and may struggle to adjust to their new responsibilities and routines, which can be physically and emotionally overwhelming at times. To begin to understand the impact of PA support upon relationships between parents and children, and to appreciate the ways in which the presence of personal assistants can shape interactions between family members, it is first necessary to gain an understanding of the broader context in which these experiences are set. This chapter will therefore provide an overview of the ways in which personal assistance is used by the families in this study to meet their parenting needs as they change over time, both due to the constantly evolving needs of parents and children, and the development of mutual understanding and trust between parents, PAs and children as emotional ties strengthen. It will also examine other issues which arose through the data, including factors which shape the degree of PA involvement in family life and reveal children's views of living with PA support.

Practical Support

Support prior to becoming a parent

The majority of parents in this study – seven of the eleven interviewed – used paid PA support in their child(ren)'s pre-school years. Five of this group (Gina, Naomi, John, Frank and Sofia) had used personal assistance for several years prior to becoming parents. These participants had always expected to use paid support with the tasks of parenting; indeed, for many, the reliability and stability of support provided by personal assistants was an important factor in their decision to become parents. For example, Naomi's close relationships with two regular PAs whom she had employed for many years provided a valuable source of encouragement and support, enabling her to consider seriously a future as a single disabled parent:

> We talked about me getting pregnant and they said to me: "But, you could still have a child, just because you haven't got a partner, doesn't mean…" And I was like: "Well, yeah…". I did really sit and think about that. (Naomi)

For John, too, having the 'right' support in place was essential for him and his wife when planning their family; indeed, they decided to share their plans with Sarah at their very first meeting, when she interviewed to become John's PA. For John, the decision to introduce this intensely private matter at such an early stage in the relationship was a pragmatic one, as he explained:

> We thought having a child was an important thing to say, because we knew it would be something that I needed help with. (John)

John's choice to share this information is a stark reminder that disabled people, and those closely associated with them, do not have the luxury of privacy that non-disabled people take so much for granted.

As events transpired, Sarah was the first to be told that John and Freya were expecting a baby. Sarah explained that this was because she was present as part of her usual working hours when the pregnancy test was taken, rather than due to the nature of their relationship. However, as Sarah only worked part time hours, it would have been easily possible for the test to be taken at a more private moment. This example reveals how readily PAs become witness to – and a part of – intimate moments in family life.

It might be expected that those already used to employing personal assistants would benefit from the consistency this provides in managing the challenging transition to parenting, and that their experience would put them in a position of strength in adapting to a new lifestyle. However, some parents in this group spoke about additional barriers they had to overcome, including the negative attitudes of medical professionals, as well as family opposition or concern about the prospect of parenthood, which caused a great deal of tension in some families:

> My mum was very convinced I wasn't going to survive the pregnancy. My sister flew down to tell me to have an abortion. I told her to get out of the house. That was quite a big row, that was. (Naomi)

> I don't think my family ever expected me to get married and be a mum. So that was a bit of a shock. I mean, I had always wanted to be a mum, and for me it wasn't a big deal. It was just a natural process in my life. Mum and dad found that quite hard. They just didn't believe that I could do it. (Gina)

Disabled people clearly need to be resourceful and highly determined individuals to overcome deeply entrenched barriers to their becoming parents, and to deal with the complex emotions that perhaps well-intentioned expressions of concern from loved ones can give rise to. As findings will show, personal assistants may become valuable allies to disabled people, supporting them to overcome these barriers and express their parenting choices. In addition, as discussed below, some parents spoke about the power and sense of liberation which came from locating their individual experiences within a broader, politicised understanding of societal attitudes towards disability and impairment.

Changing concepts of self and the perceptions of others

Several parents spoke about how they had developed a strong political identity as a disabled person prior to becoming a parent and reflected on how their sense of self had evolved as a result. These parents aligned themselves with the social model perspective of disability, and some of them had taken on active leadership roles within user-led organisations. Having this strong positive disabled identity was very important to these parents, yet it was apparent that other roles and identities were also highly valued, enabling them to express their individuality and reject being ‘defined’ by their impairment; this was something which Naomi strongly expressed:

> Because my impairment is significant, and I need a lot of PA support, it can really take over your life. I’ve *accepted* it. I’ve always been severely disabled. I’m not *bitter* or angry, or whatever about it. But I didn’t want it to be the thing that defined me. Ever. So, I was always really proud that as a disabled person, I *worked*, and that I got my *degree*, and that I was quite a good trainer. (Naomi)

Whilst acknowledging the importance of varied roles including: wife, husband, friend, sportsperson, entrepreneur, employer, cook, many disabled participants identified most strongly and proudly as parents, seeing this as their most important and meaningful achievement. Naomi reflected on how her concepts of self have changed over the years; as a young woman, she had fought against the expectations and definitions of others to carve out her own independent identity, but now she is happiest being characterised purely in relation to her son:

> I think it’s quite nice being just mum… And that’s kind of *normalising*. And actually, that feels quite *empowering*. I really like that. And talking to people, they go: ‘What’s your name?’ and I go: ‘It’s Naomi, but just call me ‘Leo’s mum’. (Naomi)

For parents like Naomi, unable to ‘pass’ as non-disabled, having an obvious impairment and being a parent can challenge the negative assumptions held by others who believe them to be inherently dependent or passive. By simply enacting their status as parents, individuals can set a powerful and positive example of what disabled people can achieve in their lives. This was generally seen by parents in this study as a welcome ‘by product’ of being engaged actively with their child’s life. For example, John, who uses a wheelchair to mobilise, talked about how his role as a disabled father challenges other people’s views and expectations when they see him interact with his daughter in public:

> We don’t really have a buggy for her, because she just sits on my lap. She’s like a little meerkat, looking round at people. People think it’s really cute. It softens the outline of a disabled person, I think. It makes you more approachable. More normal. I think it challenges people’s assumptions. The looks I used to get were curiosity looks. Whereas now, you get people looking and smiling, which is really nice. (John)

Here, John echoes Naomi and Gina’s expressions about parenting being a ‘normal’ and ‘natural’ human process, common to disabled and non-disabled people alike, providing a shared experience and greater opportunities to connect with others on this level. Yet, whilst challenging the preconceptions of others can be a positive and affirming experience, just going about the activities of everyday life can place disabled parents and their children in difficult social situations:

> People don’t always realise I’m mum. Especially if I have a female PA with me. In shops, they always assume the PA is the parent. I think some people are surprised. Some people take it in their stride. Now Leo’s 10, they assume that I had him before I became disabled. And some people are quite *shocked* when they find out I was *as disabled* when I had him. People like to think that there must have been some *tragedy* that happened to me, and I happened to have a baby at the time. D’you know what I mean, and it would be even more of a tragedy? And they quite like that story. (Naomi)

The personal tragedy model remains a powerfully compelling narrative for some individuals when considering the intersection of disability and parenting, and Naomi’s experience of being overlooked as a likely parent was not uncommon within this study. Several participants – parents, PAs and children alike – spoke about their experiences of PAs being mistaken for parents. Ellee, aged 14, talked about her frustrations at this happening, including on repeated occasions at her school:

> Every single parents’ evening. I’ve had the same teachers since year 7, and they still go to shake the carer’s hand. And I say, ‘No. That’s my mum.’ Or, when we go somewhere, and my mum goes: ‘These are my two daughters’ and like, some people are surprised or something. Or they’re surprised, but they hide it, by like acting all jolly. (Ellee)

Vanessa, a PA for Ellee's mother, also found this experience awkward to deal with at times, describing a situation which had recently arisen when she accompanied both mother and daughter to attend a meeting:

> The man assumed that I was mum. Not Gina. And when he realised that it was Gina, he was taken aback, but it was a bit too obvious that he was taken aback – like: 'Ooh, you mean *you're* her mum?' You know what I mean? And I'm not sure if Ellee was a bit embarrassed by that. She never said anything, but you know, I think if that was me, that would have affected me. (Vanessa)

Incidents such as these can have an impact upon the relationship dynamics between parents, children and PAs; this is discussed in more detail in subsequent chapters. Despite this common experience of misidentification and apparent surprise, confusion or disquiet expressed by some in the face of families led by disabled parents, there was no evidence of children being confused or in any way uncertain about the parental role.

The evolving nature of support

For some participants, PAs were not merely present and supportive during pregnancy, but also closely involved throughout labour and childbirth. Frank and his ex-wife both have physical impairments, and at the time their son was born, they had a small 'team' of PAs working for them on a 24/7 basis. Frank could vividly recall his feelings as a new father when his wife was recovering from her planned caesarean:

> I was there for the baby. Well, a lot of PAs were around as well. It was amazing. It was very scary. The first few hours and days I was actually quite involved. The PAs were a bit less sure. There's no handbook, so you're not only dealing with your own stuff as a new dad, but also, you've got a PA there. You're having to make a lot of decisions off-the-cuff. (Frank)

It is evident from what Frank says here that, even when caught up with the strength of emotion around the birth of his son and his concerns for his wife recovering from an operation, he was mindful of the needs and feelings of his

PAs, and thinking about the decisions he had to make as their employer to help them adjust to his family's changing needs. This demonstrates how disabled parents constantly monitor and balance their own, their child's and their PA's needs in this dynamic relationship.

The (non-disabled) wife of one of the parent participants also spoke about the important role her husband's PA played in supporting her around the birth of her child, and to adjust to the physical and emotional demands of early motherhood:

> When I gave birth – you know, horrific birth – there was blood everywhere. And Sarah kind of washed my pants. And we did encapsulating the placenta, and Sarah helped with that. And breastfeeding, you know, it's really hard to start with. I had my boobs out all the time. (Freya)

Being privy to and sharing such intensely intimate, meaningful and emotionally-charged moments can have a significant impact on individuals and the relationships between them. This can lead to the boundaries between workers and employees becoming blurred and difficult to define. For some families and PAs, the development of close personal bonds which extend beyond the working relationship is welcome, even if not actively sought. However, where individuals become heavily reliant upon a PA, this can give rise to feelings of indispensability for workers, which can prove an overwhelming responsibility and be difficult to manage. Erica works as a PA for several individuals, including two families led by disabled parents, and spoke about the dilemma she feels in discussing her own future plans with them:

> I'm thinking about having children now, so then I'll have to cut my hours right back. I don't quite know how I'm going to do that, which is why I'm trying also to convince them to get someone else in. But I haven't really had that chat with them yet. I am dreading it, because I know that it's going to affect them quite a lot. But I can't live my life for them, you know, I have got to live my life still. (Erica)

Erica is highly attuned to the needs of the families she works with, and mindful of the impact any reduction in her working hours could have upon them; this makes it difficult to share her aspirations to become a parent herself, albeit she knows they would be pleased and excited for her. As set out in the next chapter, complex and often mixed feelings about PA relationships are common to participant groups in this study, with parents and children in particular, expressing worry and anxiety about the prospect of change or ending of PA relationships.

For parent participants, the role of the PA during their child(ren)'s early years was dominated by meeting the child's needs, and with the completion of a wide range of household tasks such as: cleaning, laundry, cooking, essential shopping and so on. This was echoed by PA participants who described their routine involvement with activities such as feeding, changing and bathing babies, and helping to manage sleeping and waking routines. A factor which can have a major impact upon the nature of tasks undertaken is the age and stage of development of the child(ren). Where babies and preschool children are part of the family, the role of personal assistant can be very 'hands on', as one parent reflected:

> At the very first, it was more to assist with the children, because I was just too sick. I really needed a lot physical help with them. Whereas now, it's more helping me to be able to do things with the kids. (Andrea)

As Andrea observes from her own experience, the PA role is one which necessarily evolves over time. This is something which Jodie exemplified in her description of supporting a disabled parent with her child's bedtime routines:

> When he was very small it meant a lot of me picking up and putting him in the cot. I was sometimes there overnight. There was an intercom which mum could press from her environmental controls, and I would go down, and do whatever it was that he needed. When he became a bit older, and more capable of getting in and out of bed himself, then we had a different routine. I mean, it got a bit fractious between everyone trying to actually get him in his pyjamas. Mum would do the last little chat, and the door would be open, but then I was obviously on hand in case anything was needed. (Jodie)

As children become older and more physically mobile, PAs commonly provide support with, oversee, or otherwise get involved with playtime activities. As part of this, they are frequently present when children are injured through minor accidents and may need to administer first aid or reassurance. As a parent, Andrea described her pragmatic approach to dealing with these types of incidents when they arose:

> From my very first one, I said: 'You're my support. I am the mother. If they fall over and graze their knee, they come to me first. I might need your help to bandage it up or whatever, but you know, for them to have their little cry and stuff like that, that's with me'. And I don't remember having any issues over that at all. (Andrea)

PAs can also become involved with caring for a sick child, as Amber recollected the invaluable and unflappable support provided by her PA, Mandy, when her daughter was ill:

> I can remember I'd just had a shower. I was on my syringe pump thing, and I had to give Mollie some medicine, and she didn't take too well to it, and threw up. All over me, all over my pump, and Mandy was here, and she was absolutely brilliant. Yeah. "I'll deal with Mollie, you sort yourself out. Go in the shower, I'll come and see you in a minute". And she cleared up all the sick and everything. Thank God for that! (Amber)

Potty training is another aspect of a child's development which PAs can find themselves actively supporting parents and children with. Sarah explained her role in supporting Eva's father to manage this, not taking the lead herself in these interactions:

> It's like: 'Do you need a pee?'
> 'No'
> 'Are you *sure*?'
> 'No, I'm fine'
> And then all of a sudden, you're like: Arrghh! But that's up to John then. He'll say: "Eva, you *knew* you needed a wee, why didn't you go?" [sigh]. And she's like: "Oh, I forgot". "OK, well Sarah is going to have to help you now - clean you up". He's the one telling her and I just back him up. (Sarah)

As children grow, inevitably their needs change; all parents therefore utilise different parenting skills and strategies across the course of childhood. For the participants to this study, this resulted in changing tasks and priorities for PAs; many became less involved with children when they reached school age. Contact between children and PAs became even less frequent as children reached their teenage years, when a refocussing of support upon the parent often took place.

Emotional Support

Parent/child relationships

Parent participants tended to focus initially on the practical support they received from PAs. However, it was quickly evident that PAs routinely go beyond the provision of basic hands-on tasks and become involved with emotional aspects of parenting. In this way, PAs can support and promote the development of strong parent/child relationships. For example, Gina, who is a permanent wheelchair user with a 24/7 support package, described how she and her PA, Jo, neither of whom had previous experience of a newborn baby, learned together the best ways of dealing with the practical challenges she faced as a new parent, whilst foregrounding the parent-child connection:

> It was little things, like when we changed the baby's nappies. We did it on the table, so the Health Visitor had kittens, but it was best for us. It meant that I was the one interacting, she was looking at me, not Jo. Jo was cleaning her up, but it was me that the baby was connecting with. And that was important. (Gina)

Although parents and PAs did not necessarily talk explicitly about developing emotional attachment and parental bonding, it was apparent that both participant groups were alert to the importance of promoting a strong relationship between parent and child, and their respective roles in this, especially in the early years. This does not mean to say that all parent and

PA partnerships managed to achieve this without significant effort or making mistakes along the way; certainly, some parents had to remind PAs that their role was to support and prioritise the parental attachment, as Naomi explained:

> I think I got really upset the first few times one of my PAs, when Leo was a baby, and he'd be crying, they'd automatically pick him up and go to comfort him. And I'm like, "No, you have to pass him to me". At that point I think I realised actually, you've got to do that differently. Because anyone's natural instinct, if a baby's crying, you pick it up and hold it, don't you? You don't pick it up and pass it on! Yeah. So, a couple of them needed reminding about that. (Naomi)

Whilst some parents needed to 'remind' their PAs of their role in the family, and to reinforce their primacy as parent when boundaries were over-stepped, PAs also spoke about their commitment to facilitating a strong parent/child bond:

> There would be story time, and that would be on [mum's] bed, and some of the big books, she could turn the pages herself. I would just sort of be in the background a bit. So that was their time. I think I was just very respectful of that time. I knew that it was special bonding time for them. Mum did as much as she was physically able to do. And I made it clear that mum was the reference point, and not me. (Jodie)

For Naomi, whose family life is supported by the constant presence of PAs, having as much private time as possible with her son helped developed the close emotional relationship they share to this day. Naomi spoke about the importance of PAs respecting her need for as much time alone with her son as possible:

> There are times when actually you don't want anyone else to be there really, so silence is much appreciated [pause]. Yeah. And now, if he's upset about something, he does go: "I need my mum". He loves his cuddles. Quite soppy [laughs]. It's what makes you a mum, not an accessory that just happens to be hanging around. (Naomi)

For Gina, another mother who needed practical support with all aspects of child-care, breast feeding was an important way for her to develop a bond with her baby. This nurturing act powerfully expressed her connection with her child and underlined her unique ability to meet her daughter's needs. This performance of motherhood was something she felt so passionately about that she refused to express milk to allow others, including her husband, to feed the baby:

> I was determined to breast feed because I had everything that the baby needed. That was the one thing that only a mum could do. And that was so, so important. I fed my daughter for a year. That was wonderful. That was really special for me, and very important. They would say: "Why don't you let Ben give her a bottle?" "No. No, it's my job. It's the only one that I can do. Everyone else can bath her and change nappies and everything else. But I'm doing that". (Gina)

PA involvement or detachment?

As set out within the earlier literature review, while the original Independent Living model of personal assistance pays little regard to the interpersonal relationships created by this system of support, the developing literature increasingly acknowledges the complex and fluid emotional connections which are brought into being. This study reflects this growing body of research, with the majority of participants reflecting upon various emotional aspects of the personal assistance relationships with which they were involved.

Although many saw benefits in developing warm and involved assistance relationships, some participants actively sought to limit their emotional engagement. This included Lydia, who was born with an impairment which affects her reach, dexterity and mobility, and causes constant pain. She had lived independently, without the need for any formal support, until a serious car accident left her struggling to manage personal care in a now inaccessible home environment, and to take her daughter to primary school. Lydia was clear about what she expected when interviewing any prospective PAs:

> This is what I want, this is what I don't want. "You are my arms, and you are my legs. You're not taking over, you're enabling me to live my life." It's not a good idea to be getting that close to them. You can get on with them. You can scratch each other's backs, but you don't start letting them sit down and tell you their worries. I don't want that, however lovely they are. I had one that worked for me for nine years, and when she left, I've not had contact with her since, but it's like that was a working relationship. I wouldn't normally have made friends with her in the outside world. (Lydia)

For Lydia, PAs performed an important function and had a clearly defined role to complete; they were needed and valued, but whilst they were present within the day to day activity family life, they remained entirely separate from it.

Two PAs within this study also saw their role as essentially outside the family system they supported. Although their presence was a practical reality of family life, they sought to limit their impact upon the lives and relationships of the parents and children they worked with:

> I was there as a facilitator of that person's impairment, and a facilitator of the relationship with her child. So, it was always, you know, that I was the arms and the legs of the person, rather than anything else. (Jodie)

Jodie mirrors Lydia's language here, where she talks about being the 'arms and legs' of her employer. Her physical presence is apparent and necessary, but she seeks to limit her use of 'self'. Kirsten takes things a step further – she attempts to 'disappear' as far as possible in this role which she considers both hard to define and undervalued:

> You are this kind of 'ghost', this 'shadow', it's not really seen as a proper role. It's not really valued. Apart from by that person. But only if that person really understands it. (Kirsten)

Rather than operating on an emotional level, these PAs spoke in depth about the cognitive processes they engaged with as part of their role. They described carefully watching their employer for verbal and non-verbal guidance and instruction before reacting to certain situations and appeared less likely than other, more emotionally involved, PAs to act without clear direction from the parent. Unlike other PAs in this study, they did not talk about this role fulfilling, either fully or partly, their own needs. The PA role for them was complex and political, in the sense that they aligned themselves in solidarity with their employer, albeit in a subordinate position, whilst taking a rights-based approach. They purposefully kept their feelings in check, even though they talked about admiring their employers, and felt some warmth towards the families they worked for, they attempted to maintain a clear emotional distance from the children they worked with, as Jodie explained:

> As much as I quite liked Billy, that was work. And it does kind of have to be a bit like that. So, I didn't fall in love with him as a baby. He was quite cute when he was a baby, but - no. I think I did that deliberately, because it wasn't about me, it was about the PA user. (Jodie)

Despite seeking to limit the pull of emotions in their work, these PAs acknowledged that the role necessarily generates strong emotions and feelings:

> There were definitely situations and frustrations where I knew what my gut was saying to do as a mum, but I didn't know whether that was what the PA user wanted me to do. And she wasn't actually telling me. (Jodie)

For both these PAs, performing the role eventually became untenable, and they moved on to other jobs which were professionally challenging and personally fulfilling in other ways. As Kirsten observed:

> It takes, you know, quite a person to keep doing that all the time. And you burn out a little bit. (Kirsten)

It may be that individual personalities and preferences of parents and PAs play a large part in determining the degree to which PAs become absorbed in the fabric of family life. However, children, and those who had grown up with PA support, highly valued, and talked fondly of PAs who had, in their opinion, demonstrated their commitment to and regard for the family. This included workers who remembered their birthdays, popped by to see them on a non-working day if they were unwell, sent postcards from holiday destinations, bought them Christmas presents, remembered important events in their lives, and wished them luck with exams, as well as in other ways, proved to be authentic and reliable in their dealings. This was taken to demonstrate a genuine commitment to the family, as Chloe observed:

> Although there was just one job, there was definitely two roles. I think some people definitely didn't like children as much as others. Definitely. Whereas others would be more like: "OK, I've got 10 minutes, what are you doing?" From my opinion the ones that are more involved make better PAs, because they are such a massive part of your life. (Chloe)

For the most part, children spoke in broadly positive terms about their interactions with PAs, but for others, they were an unwelcome intrusion. This was the case for Katie and her brother, whose mother employed PAs for the first time when they were teenagers. The family had used paid domestic support in the past, as au pairs were employed to care for the children when their mother's work took her abroad. Katie remembers positive relationships with the au pairs, but she and her brother had very different thoughts and feelings about their mother's PAs:

> They didn't like us at all. And we didn't like them because they were so anti-us. Like, well, we'd get home and they'd almost like stop talking. They'd make themselves and mum a cup of tea – they'd never offer us one. Or, if we were at home, and the PA was there, she'd only make lunch for herself and mum. She was lazy. She was really lazy. (Katie)

More than ten years on, Katie still has strong negative feelings about one particular PA, albeit she did acknowledge that, as teenagers, she and her brother found it difficult to appreciate their mother's perspective of the situation and on reflection felt that in expressing rebellious feelings, they could have exacerbated the situation. This left her with some feelings of guilt which she found difficult to resolve.

Whereas some children appeared to value close relationships with their parent's PA(s), there were others who expressed strongly they did not want to engage with PAs on any level and found them to be an unwelcome intrusion into their lives. This was most often expressed by older children and teenagers who identified strong negative feelings of resentment, annoyance and frustration. For example, Katie would avoid contact with her mother's PA as much as possible:

> Like, if I was in my room and I knew she was there, I just used to try not to come downstairs, because I knew that I wouldn't want to be there. (Katie)

In a similar way, Mollie, who had generally liked her mother's PAs when she was younger, sought to minimise her involvement with them in her teenage years, finding it hard to express her true feelings at the time:

> When I got older, I just kind of wanted to be on my own. Yeah, when I got to be like 14, I was like: "God, there's too many people in the house, I hate it!" So, I would just go up to my bedroom, but I would never be rude them (Mollie)

For these young people, where the presence of PAs had become an unwelcome and unavoidable part of their lives, the more distant style of PA support was preferred over one which involved a higher degree of interaction and engagement.

In fact, the majority of PAs within this study were significantly involved with family life. Here, whilst the contractual nature of the relationship was clearly understood, intense relationships developed – sometimes very quickly – between parents, children and PAs. PAs who become a part of family life in this way can sometimes remain in their employment for many years and take on a quasi-familial role. These PAs typically become involved with activities outside of their working hours, and it can be difficult to for all parties define the difference between 'work' and 'not work'. For example, some PAs perform an informal 'babysitting' role, and participate in social events or family functions on an unpaid basis. In this way, they develop relationships with wider family members, and in some situations, the PA's own family is introduced. Where this works well, ever-closer ties develop. Lizzie, who had worked for Gina for nearly 17 years at the time of her interview, explained how she and her son shared family holidays with her employer for many years:

> The kids were young, at this point they'd got a baby and Alina, who was five. She had met my son Carl and idolised him, and he'd been to a few little family things along the way. So, they said: "Would you like to work on the family holiday? Go away with us and bring Carl. We're thinking that if you bring him, then he'll distract Alina while we're caught up with the baby stuff". He was an extremely undemanding child, and it worked perfectly. We tried it with this first holiday and it just worked so well. And that happened for, what, eight years. (Lizzie)

Where the PA employment ends, PAs who have become absorbed in family life typically stay in contact and continue to participate in activities with parents and children in the capacity of 'family friend'. In these relationships, emotions are fully involved, and many participants spoke about the love, admiration and commitment they felt for each other.

Although, as described above, Lydia was the most emotionally-distant employer in this study, many other parents recognised the virtues of maintaining clearer boundaries in their relationships with PAs and appeared to value the idea of low-emotional intensity, practical support. This fits in with the Independent Living ideal of personal assistance relationships being highly boundaried. However, many of these same parents talked very positively about their experiences with PAs who became deeply engaged in family life. They described warm and affectionate personal relationships shared with PAs who had supported their family for many years – in several cases for over a decade, in one family, for two decades. They talked about appreciating the commitment shown to them as individuals, as well as to their children and families, and spoke about seeing PAs as 'part of the family'. These parents described reciprocity in their relationships – some disabled parents 'helped out' with childcare over school holidays, having the

PA’s children round to play, and there were occasions when parenting and other life problems were discussed, and advice sought and given on both sides.

Disabled parents were pleased when PAs formed strong emotional attachments to their children, often regarding this as evidence of their child’s positive qualities, and not a threat to their own relationships.

> I think it’s really nice that she’s had other people play a part in her upbringing. I don’t think it ever destroyed the closeness that Mollie and I’ve got. (Amber)

Parents also appeared to view this emotional bond between PA and child as a protective factor, as they felt that PAs with a strong emotional commitment to the family are more likely to provide reliable, higher quality care and support, and remain attached to the family for longer. This means less likelihood of disruption to family life caused by PAs leaving their employment and replacements being sought and trained.

Children mostly preferred the experience of family life with PAs who engaged with them on a personal level – they felt able to form warm and affectionate relationships with these PAs, and often spoke about ‘love’ for particular workers, especially those who had been part of family life for many years. They talked about appreciating individuals who ‘made an effort’ and who weren’t what they described as ‘complacent’ or ‘too comfortable’ in their role. Children valued the long-term nature of these PA relationships, which provided stability, security and connected them with their earlier lives, with PAs often being included as key figures in family stories.

Some PAs held a more significant meaning, since they held precious memories and knowledge for children about events or people they were too young to remember. For example, Chloe, whose father died when she was a teenager, remained in touch with his former workers, and was able to hear from them stories about his younger life, before she was born. She was also told about events from her younger years as a small child, which they had witnessed or been part of. Whilst some of this history was held by family members, contact with PAs provided Chloe with a wider range of information, helping her to keep his memory alive; she was also able to understand her father as a more rounded individual through the lives of people that worked for and been inspired by him.

Children’s perspectives:

The children participating in this research had a clear understanding that personal assistance is a necessary part of their family life; they could readily describe various tasks which the PAs undertook to support their parent, such as helping with personal care, housework, cooking and shopping. Some PAs also played a significant role in the lives of the children, helping them with practical tasks like bathing and hair washing, making their dinner, helping with homework, as well as playing and talking with them. Additionally, PAs often provide support to children outside of the home environment in the wider community, for example taking them to and from school, clubs and activities. Just over half the children interviewed had never known a time without PA support; their parents had been disabled since before they were born and had employed PAs before starting a family. For these children, PAs were an essential part of making their family ‘work’. For other participants, their parent’s impairment – and the associated need for PA support – was something which they had to adjust to later in their childhood.

Jasmine, aged eight, was the youngest participant; her mother has used PA support since before she was born. Jasmine unhesitatingly identified several PAs past and present, describing them simply as: “the people that help mummy”. Jasmine and her older brother, Ajay, live with their disabled mother who uses regular PA support which forms part of a complex assemblage of care. This also includes paid agency support each morning, and unpaid care from friends and family members, including the children’s father who visits each evening to help his ex-partner into bed for the night.

Former PAs who had ‘moved on’ from their role to take on other jobs, but remained living locally, also formed part of this extended network of support, which included family members (mothers and daughters) of existing or former PAs who could be called upon to ‘help out’ if required at short notice. This range of formal and informal support resulted in a fluid support system which both children described with confidence, with Ajay reflecting:

> I never have known anything different – it’s just kind of normality. (Ajay)

Leo, aged eleven, shares his time equally between his parents who live in different households in the same town. In this way, he experiences PA support in one home, and not the other. Leo took a pragmatic view of PA support and its place in his family. He described the PA role as generally being:

> To help mummy. And me sometimes. (Leo)

Leo’s mother has used PA support for many years and needs 24/7 support; she has employed the same two primary ‘live in’ PAs since before he was born. This deep and long-standing connection is important to Leo, who smiled as he observed:

> I’ve probably known them since I was the tiniest cell in mum. (Leo)

Whilst he appeared to have positive relationships with all his mother’s PAs, and could recognise the skills he valued in each individual – for example, describing who was ‘good at finding things’, and who was a ‘good cook’, Leo explained that these two regular PAs felt to him like:

> Family. Friends. They kind of border on family and friends. Like, on that ‘no man’s land’. (Leo)

Alina and Ellee, aged 20 and 14 respectively, have also grown up with PA support throughout their entire childhoods. They live with their parents, and their mother employs a small team of PAs who provide her with 24/7 support; as part of this significant package of care, a worker sleeps over each night in the family home. Lizzie has worked for their mother since before Ellee was born, and understanding her place in the family was something Ellee, who had always called her ‘Aunty’, found confusing as a young child:

> She’s been with us for 16 years. That’s why I thought I was related to her, because she was here every day. And then I finally found out that she wasn’t my aunty. She was in the carers’ room, and I said: ‘Aunty Lizzie’, and she went ‘No. I’m not your aunty’. Because I thought that her son was my cousin. And I cried. And I was really angry with her. (Ellee)

This story was recounted almost as a family legend, something which had been told many times before, and although Ellee talked about powerful feelings of being angry and upset, there was laughter from her sister as she spoke about her misunderstanding. Part of Ellee’s upset could have been linked to the fact that other family members clearly understood Lizzie’s role in the family, whereas she did not, perhaps feeling ‘left out’ of this knowledge by virtue of being the youngest child. Certainly, the situation could be confusing, as noted above, Lizzie and her son frequently accompanied the family on holidays. However, although Ellee now has a full understanding of Lizzie’s role and place within the family as a paid worker, it is evident that she does not view her as simply another one of her mother’s employees, as she reflected:

> She was *Lizzie.* And then, Lizzie became family. (Ellee)

In a similar way to that described by Ajay and Jasmine, Ellee and Alina’s family’s support network has grown over the years, with several PAs who no longer work for their mother forming part of a complex and extended system. This includes a PA whose employment ended around twelve years ago, but who remains closely involved in the life of the family:

> Lauren’s really local. I see her a few times a week. She knows who I work with, she got me the job. She’s more like an aunty. She was there from when I was 6 months old, so I’ve never known a time

> without her. She worked here for about eight years, so it's a long time. And then even when she left, she only lives up the road, so we see her quite a lot. And her family. She remembers every birthday. And every bonfire night we go round. (Alina)

It seems that the boundaries in several families involved with this study are permeable and flexible, and that PAs can be welcomed in one capacity, but are not defined solely by their original role or connection.

For other children and young people, personal assistance was something which became part of family life, following the onset of parental illness or impairment. Tom is the only child in his family, and many of his earliest memories are of accompanying his father on visits to see his mother in hospital; she was very ill for the first five years of his life and employed PAs from when he was around three years of age. Tom finds it difficult to remember a time without PAs, but even from this young age, he understood they had a different role and place in his family:

> It was mostly my dad bringing me up. And we had help from PAs, but even back then, there was still quite a divide – a boundary – in the sense that, it was definitely dad and mum were the parents, and she was a PA rather than being a third parent, as it were. She would sort of 'entertain' me. (Tom)

When Mollie was about three years old, her mother became ill, spending a lot of time in hospital. For a while, the family managed with informal support from grandparents and other family members, but when she was around the age of six or seven, Mollie's mother started using regular paid support. Mollie cannot remember meeting the PA for the first time, but she does recall having a distinct understanding that her life was different from her peers, and what signalled this was not her mother's impairment, but the presence in her life of PAs:

> It must have been explained to me, but I don't remember it. But I remember knowing it was different to my other friends' set up, because they just lived at home with their mums and dads. I think we

> just had to kind of make it work for all of us, we all had to get used to it, but it's a whole other dynamic, yeah. It's a different way of life. (Mollie)

Parenting roles and expectations

As set out in the methodology chapter, most participants to this study are female. The data therefore are highly gendered, with girls or women reflecting on the role of mothers and the support they receive to fulfil this role from female carers. This reflects the highly gendered nature of the existing literature, which predominantly concerns the intersection of disability and motherhood, and perhaps also more widely, the gendered way in which parenting roles and expectations are attributed and valued within the culturally dominant social construction of motherhood within the Western world (Fox, 2015).

One disabled mother who had been born with a significant impairment, spoke of the powerful negative assumptions about her ability to parent, which she first encountered as a child, and even became the subject of a family 'joke':

> I'd always assumed I wouldn't have any children. Partly because I was disabled. Being one of four girls, I remember one of my mum's friend's joking once that: "Oh it will be Naomi, the one that produces the children!" You know…hahahaha…D'you know what I mean? A real joke. Not the other three. Very funny. (Naomi)

This same parent also faced negative assumptions from the health professionals responsible for supporting her during pregnancy:

> I was referred as the midwife was a little bit concerned that I might not manage. So, I got a visit from a social worker from the children's and families service. I tried to be really positive about it. All my PAs came, and the social worker was like: "Well, what's the issue? The child is not going to be a child in need". (Naomi)

Another mother also experienced discrimination from medical professionals, based upon assumptions that disabled women are inherently asexual:

> One time, I'd gone to the doctor's with a stomach problem, and I said: "Do you think I ought to have a smear test? Because I've never had one". And the doctor said: "Oh, well you don't need a smear, because you don't have sex." (Gina)

At her postnatal check-up, Gina had to challenge the medical 'opinion' that the most responsible thing for her to do would be to become sterilised:

> They didn't really ask me "How are you? Is everything alright?", nothing like that. She sat there and said: "So, you've already had one baby. How are you going to stop it happening again?" And she actually made an appointment, and I got a letter to say I'd got to go and see a gynaecologist. I mean, I wanted more children. They said: "Well, we thought we ought to get you sterilised". Well – why? (Gina)

Despite this gender bias within the data, male voices and perspectives are present, including directly, from three sons of disabled mothers and two fathers who use PA support, both of whom have experience of employing male PAs. Data were also generated indirectly via a participant whose father employed personal assistants throughout her childhood, from three PAs who have worked directly with disabled fathers, and from a mother who employed a male PA. The presence of non-disabled fathers is also apparent within the data, as mothers, children and PAs reflect upon the impact of PA support on their role within the family.

Differing expectations about the role of mothers and fathers is evident. For example, most disabled mothers talked about the importance of PA support within the setting of the domestic sphere, whereas one father spoke of PA support primarily in terms of meeting his personal care needs and facilitating his working role. His wife is their child's primary carer, and when she goes out to work, his PA supports him to have a 'daddy day' with their young daughter, which generally involves an outing to a local park or activity centre. John spoke about his frustration at not being able to access the support he needed to physically engage with his newborn daughter – this left the family to come up with their own solutions. For example, his mother fashioned a ‘snuggle bundle’ which enabled him to pick Eva up and hold her, without fear of dropping her. John reflected on the frustrations he sometimes felt at being ‘left out’ as a disabled father, but also on a recent breakthrough which held a great deal of meaning for him:

> I’ve always wanted to be as involved as possible. Because I can’t transfer myself that restricts how close I can get to Eva, and I struggle with that little bit, because I’m not as close to her as I would like to be. But last week I took her out, actually outside, on my own for about an hour. That’s the first time we’ve been out together on our own. My worry was that she would just go off and I couldn’t get to her. So, I had a little talk with her before we went out, and she was perfect. That was very special. Really quite a big moment last week, so I’m hoping that’s going to lead to more times on my own with her. (John)

John’s wife, Freya, who was present during his interview reflected on the impact of his impairment on her role as a mother and how Eva is parented:

> I have quite an intense mother role, because I’ve always breastfed. But I’m also doing part of the dad’s role in the sense that I chuck her about the bed, so she has the physical play side. I think that makes John kind of more excluded because not only am I breastfeeding and doing the mummy bit, but doing the kind of thing dads often do. (Freya)

There is limited research into the specific needs of disabled fathers at present, so the suggestions within the data generated by this study are illuminating and reinforce the need for further research into the role of the PA relating to fathering. In a similar way, the impact of PA support upon co-parents is little understood and would benefit from further research.

Summary

This chapter has provided an overview of participants' situations and explored the ways PA support is used in everyday life by families in this study. From this, it is apparent that personal assistance involves both practical and emotional tasks, and further, that the nature and degree of this support fluctuates both predictably and unpredictably over time according to a range of factors. These factors include the changing physical needs of parents and children, as well as the development of understanding, trust and emotional warmth in the relationships between parents, children and PAs.

The views of children are also provided: given the limited information within existing literature about the lives and experiences of children with disabled parents who do not identify as 'young carers', these represent important findings in their own right.

The next chapter will go on to examine in more depth what participants have to say about the complex relationships which develop through this model of personal assistance, and the ways in which boundaries can become blurred.

Chapter 6: Relationship Dynamics

Introduction

This chapter looks more closely at the varied and complex relationships which develop between disabled parents, PAs and children. As the previous chapter set out, study data evidence the wide diversity of relationships which exist between these groups. If we think about this as being a spectrum, on one end, there is an amicable but limited relationship between individuals, where the focus is on outcomes of the tasks or functions to be performed. Here, although the presence of the PA is important to ensure the smooth running of the family, PAs themselves are essentially interchangeable and peripheral to family life. On the other end of the scale, PAs are almost a part of the family; they have long term, meaningful bonds of affection with parents and children. These relationships are sometimes described as being family-like, or friendships, and the PA role appears blurred and harder to define, despite the existence of a formal, contractual employment relationship.

Factors such as individual personality and preferences, family composition, ages of children, and the presence of other PAs appear to play a part in determining how deeply involved individual PAs become. Parental experiences of impairment and specific support needs can also influence the shape and style of PA involvement in family life and the relationships which play out. Time is identified as another key factor which impacts upon relationships, as the longer PAs are employed within families, the more complex and entwined these connections become. Time plays another part in these relationships, linked to the stage of development of the child. As will become apparent, even where parents set out with clear aspirations and intentions of how they wish to use PA support, these relationships inevitably evolve over time, creating fluid bonds and patterns of attachment.

Aspirations about the PA role

Parent participants commonly reflected on their early hopes, prior to employing PAs, and how they envisaged personal assistance would best fit around family life. For many, these aspirations centred on creating an environment which fostered mutual respect, a degree of emotional warmth and where clear boundaries were maintained; whilst these may seem reasonable enough objectives, participants' experiences showed they were sometimes hard to achieve.

Respect and emotional warmth

In common with findings from research discussed in the earlier literature review (Romer and Walker, 2013), respect was something which many participants spoke about as being a major component of the personal assistance relationship. Developing mutual respect may be easier to achieve where values or experiences are shared, however significant differences might occur and need to be accommodated; managing this requires a high degree of commitment and discipline, as O'Brien (2013, p. 197) observes, personal assistance calls for "a wider zone of indifference than most relationships do".

Sharing a clear understanding of boundaries can help promote a positive, safe and loving home environment for children, and this was something which Sarah, a PA participant, expressed was central to her relationship with her disabled employer and his wife. Sarah felt strongly that she should take the lead from the family, and give priority to their wishes and instructions. At the same time, feeling respected and valued by them gave her confidence to offer her own experience, or to give advice, where this might be construed as relevant and helpful:

> I think they understand that I just respect how they do things. I remember telling Freya about my little brother teething, little things like that. I think she'd asked: "Did you give him gripe water?" I think they do listen if I say: "Oh I remember this is a good tip" or whatever. (Sarah)

Another PA, Erica, who was employed by several members of the same family, including a co-habiting disabled mother and her disabled daughter under two separate contracts, also spoke about the central importance of respect in her work:

> Because you're going into someone else's home, you have to be respectful of what their wishes are, and I think a lot of people find that hard. It sounds like an obvious thing to say, but some of the PAs that have come in try to do things in the way that *they* think it should be done. Well no, you have to do it *their* way. Not everyone can *do* that. Also, I've noticed a lot of people don't like asking questions. You have to ask questions, even though it *can* feel like you're being annoying. If you don't *ask* you don't *know* how they like it done. It's just trying to be aware of how someone else might be feeling. (Erica)

Here, Erica describes good communication as being the foundation for forming respectful relationships, but in her experience, to be a 'good' PA also requires imagination and empathy – that is, emotional intelligence. For some PAs in this study, the role of PA was complex and had to be approached mindfully, with a degree of 'professionalism' and some level of detachment. Whilst some PAs saw the role in simplistic terms, 'almost like a friend helping out' as one put it, others sought to minimise the impact of their presence as far as possible. As described in the previous chapter, Jodie spoke about how she actively monitored her relationships with her employer and her son, seeking to maintain an appropriate emotional distance, as she considered her most valuable contribution to the family was to promote the bond between mother and child. For her, understanding and separating out her own needs and emotions helped her to fulfil her role as a PA:

> I think if you have got quite a clear understanding about what is your stuff, and what is *their* stuff, then that makes it a lot easier. Well, understanding *yourself* actually. You've got to understand yourself quite a lot in that role. (Jodie)

Kirsten also talked at length about the emotional side of her PA role with regards to working with two different families. Having grown up with a disabled sibling, Kirsten described 'falling into' a part time PA role for a disabled father, and how this had been a huge ‘turning point’ in her life. She picked up more PA work when her employer recommended her to a disabled friend, who later became a parent. Working for these two employers presented her with a challenge – both had similar physical needs, but very different ways of working with their PAs:

> Paul liked to be in control. He very much liked to set the tasks. Jen struggled with that more. Not that she wasn’t a good boss in any way, but I do think she found it more challenging to ask PAs to do things. She’s more sort of subtle. (Kirsten)

This highlights how adaptable PAs need to be and provides an illustration of how working in these two families required Kirsten to work at different points along the ‘spectrum’ of PA relationships set out above. As we saw in the previous chapter, Kirsten’s own preference was to limit her use of ‘self’ and act on a more peripheral and transactional level. This was a good match with her employer Paul, however Jen’s more ‘subtle’ approach to managing staff and ‘relaxed’ style of family life required flexibility and more active engagement from Kirsten, perhaps leading to some frustration on her part as she compared their differing approaches. For Kirsten, who grew up in a family affected by impairment, dealing with the relational aspects of the PA role made her feel guarded at times, and could be emotionally draining:

> It’s a real, real tricky balance. You’re a friend but you’re not a friend. You’re a member of the family, but you’re not a member of the family. You know, it’s a very, very fine line that you walk as a PA. It was tiring, being involved with the family. You had to be careful not to overstep the mark with [Paul’s wife]. And I don’t think I did. But I was very, very wary of that. (Kirsten)

Whilst many adult participants involved with support relationships – both parents and PAs alike – talked about the misgivings they sometimes felt about becoming emotionally over-involved, the children and young adults who had grown up with personal assistance in the family did not appear to welcome the attempts made to create or impose emotional distance in their relationships with PAs. Instead, they valued and talked warmly of workers who had demonstrated a genuine interest and commitment to them. Chloe reflected on this as she observed:

> It is really strange, thinking that there's people that were huge parts of my life that I will never ever speak to again, I don't even remember their name. And that's fine. I'm totally fine with it, but I'd never want to be that person. I'd never want to be the person that had invested all that time and just wasn't remembered. I guess some PAs made you feel like family. *They* then felt like family. (Chloe)

Chloe's expression here, about the blurring of boundaries between workers and family members, mirror Ellee's earlier reflections on her relationship with the PA she knew as 'Aunty Lizzie'. Alina also echoed Chloe's experience of appreciating close positive relationships with some PAs, but lacking a connection with others, who she regarded as simply there to perform a function for her mother:

> As a whole, I wouldn't say that I would just go to the carers, 'cos my mum is really, like, *easy* to talk to. But yeah, I think it depends on the *person*, doesn't it? Like, me and Becca were really close. When Becca was here, I loved Becca... and it wasn't that I couldn't *talk* to mum, it was just that I didn't mind telling her what I was telling her, d'you know what I mean? And she was easy to talk to. We're really close. I loved sitting with Becca. A lot of them, I *wouldn't* tell anything. They're just carers. They just help mum; I don't really say a lot to some of them. (Alina)

The quality of the emotional connection between PAs and children – whether, and how much, they simply 'like' each other – can have a significant impact upon the whole household and indeed the sustainability of the employment relationship. This is something which some parents and children talked about trying to evaluate at an early stage. For example, Jasmine and her mother recollected very strong feelings connected to one PA who worked for the family for a very short period when Jasmine was less than two years old. More than six years later, the experience was lodged vividly in both of their memories:

> Sofia: I think we've identified the moments where we had a PA where it didn't work, and that was Lillia. And I learnt a *lot* from that. [To Jasmine] You were still in nappies, so you must've been really small.
>
> Jasmine: I was either two or one. Yeah, I *really* didn't like her. I just didn't like Lillia. And I would hide from her.
>
> Sofia: That was the Christmas before I went into hospital. You would have been about 16 months old. She was here for about four weeks. She was just desperate to get out, and I think she just needed to go as well, as it really wasn't working.
>
> Jasmine: Yeah, I used to run away from her. I *literally* hated her.
>
> Sofia: One thing I learned from that, is that whenever I employ somebody now, the children do have to meet them. Because I'm soon going to get a gauge on whether this is going to work or not. I think maybe the children could tell things that maybe I can't, and sense something that's not right. So, they are my gauge – my Geiger counter, when it comes to the children.

Using this experience to inform the recruitment process, the family now have a PA who they all spoke very fondly of.

Boundaries and authenticity

Received wisdom suggests that boundaries are an important factor in the development, growth and maintenance of positive interpersonal relationships; these are generally viewed as positive, enabling healthy functioning and preventing unwanted conduct or interactions. However, boundaries can have paradoxical effects, and may obstruct growth, prevent relationships from working well, or even bring about the end of relationships (Ryder and Bartle, 1991). It was perhaps to be expected that the subject of boundaries would feature strongly in this research; certainly, this topic is often raised in literature about PA support (Glendinning *et al.*, 2000; Ungerson, 2005; Williams *et al.*, 2009; Porter *et al.*, 2020) and it was something which many participants, across all groups, spoke about as being central to their experience of family life and PA support.

Several different aspects of boundaries were discussed; these covered setting, maintaining or re-negotiating them, as well as the possible merits and disadvantages of going beyond agreed boundaries. Perspectives varied, with parents, PAs and children often understanding, responding to and reflecting on boundaries in different ways.

For parents, working with PAs can present dilemmas in determining the ‘right’ degree of friendliness vs formality, closeness vs distance, flexibility vs stability in relationships. Some deal with this by creating clear emotional distance in the employer/employee relationship, prioritizing and emphasizing practical tasks to be completed, as we saw with Lydia in the previous chapter. Whilst Lydia was notable within this study for creating and consistently maintaining the most distance in her relationships with PAs, she was certainly not alone in wishing to stay ‘in control’ of relationships with PAs. Nevertheless, many parents appeared to accept, and sometimes welcome, that relationship dynamics change over time, and interpersonal connections between individuals can strengthen and change.

A difficulty which all employers have to navigate is the unpredictability of these interpersonal connections. Frank, a disabled father, went through an extremely difficult experience, caused by an affair which developed between his wife and one of his PAs. This took place in the early years of his son’s life and resulted in emotional turmoil and family breakdown. It also had an impact on his subsequent management of PAs, leading him to adopt more formal/distant relationships with his workers. Frank reflected on his inexperience in managing PAs and setting clear boundaries at this earlier stage of his life:

> When you’re younger, it’s far more fluid, and they’re more like a friend. Whereas I think what I’ve learned the older I get, you will still develop relationships with PAs, but you’re far more aware of boundaries. (Frank)

Frank felt he had to manage boundaries with his workers differently as a result of his experience, and in fact he went on to employ his mother as his primary PA for many years, thereby creating the most complex relationship with an employee of any parent in this study. This had some tangible benefits: having complete trust in his mother, Frank could rely totally upon her commitment to him at a time when he felt emotionally vulnerable and betrayed; he also benefitted from his mother's intuitive understanding of his complex needs – another employee could have taken years to acquire this level of expertise, if at all. Furthermore, Frank felt that paying his mother for her regular support gave their relationship greater reciprocity, as the employment arrangement gave her a degree of financial security which she previously lacked. Frank had experienced a distant relationship with his mother during his marriage, so having regular support from her at this difficult time helped them to reconnect; it also served to develop and strengthen the relationship between grandmother and grandson. Nevertheless, this situation created a complex and intertwined relationship which brought significant emotional risks. As Frank reflected, the situation and family dynamics changed over the years, becoming increasingly stressful and ultimately unmanageable:

> It all goes fine when Scott was little, and my mum was relatively young and able to sort me out as well. But we all get older, and the dynamics changed. Scott became a teenager, and I went up to see him more and more, and I preferred it. Whereas the weekends here became more about what my mum wanted to do. So, tensions began to crop up, and a lot of course when I then became involved with another partner. That's when it really kind of changed. Scott's no longer a child, he can do what he wants. It's become obvious that it's no longer suitable for my mum to carry on working for me, and she will be 70 soon. She's going to feel pushed out again. I think financially she will find it quite hard, but more than that, it's about her not feeling that she's needed. [sigh] (Frank)

Co-parents and wider family dynamics

It is clear from the data that the presence of paid personal assistance within family life can set up a range of potentially problematic situations. Some of these can be reasonably anticipated, whereas others may be completely unforeseen. However, findings suggest that family/PA relationship dynamics typically create an environment in which ‘predictably unpredictable’ problems arise.

As indicated in the previous chapter, the degree to which PAs become involved with family life depends on a wide range of factors, including the needs of the parent, the age of the child(ren), individual preferences and personality, as well as the availability of informal support. Whilst some parents required PA support both day and night, it was typical for the families involved with this study to use a mix of ‘natural’, family and paid PA support. In this way, PAs can find themselves present at family events and occasions, and some of them found this to be socially uncomfortable and even isolating at times:

> Some of the people I wouldn’t have chosen to hang out with. So that was all a bit intense. It’s just sometimes you’ve got to be friendly to people that you wouldn’t really want to be friendly with. (Jodie)

> I always found those situations more awkward. I was more of a spare part. I mean, like, what do you do? It’s not really your place to be joining in discussions, because you’re only there to facilitate. So, I’d leave them to it.   But they were [pause] quite awkward. It can be quite a lonely role. (Kirsten)

PA users can also experience negotiating these boundaries difficult, as this conversation between John and his wife illustrates, when discussing his PA’s presence at a social occasion:

> Freya: She was sat on her own at one point, and I said: “Oh Sarah, sit next to me”. Because you do care, you don’t want her to, you know, be ‘Billy-no-mates’.
>
> John: But that was her being respectful, wasn’t it? Just keeping herself a little bit distant. Giving us a bit of space. But we got her to come in, and she was fine.

This exchange reinforces the importance of respect in the personal assistance relationship. It also reveals that individual family members can interpret the behaviour and interactions of PA differently. While this is not necessarily problematic, as this chapter will go on to demonstrate, disagreements between family members about PAs can certainly create friction. PAs can also find it difficult to deal with family members, as Lizzie discussed in relation to her employer's husband:

> That's a very delicate area. Probably more delicate than dealing with the kids actually [laughs]. Well, over the years, he's upset a few carers. He can be a bit blunt sometimes. I mean, he gets tired, and he's had his own illnesses and things like that. And he can be grouchy. I don't tiptoe around him, but I am [pause] aware of his moods. Like, in the morning, I know he likes it quiet. I say: "Good morning", and then leave him be, you know. The amount of times I'd be walking towards the kitchen and do an about turn to get out of the way just for a few extra seconds, so that I'm not walking in on them when he's kissing her goodbye. Just little things like that, to give them that space. (Lizzie)

Another PA, Sarah, spoke at some length about her relationship with her employer's wife (Freya), describing the ways in which she sought to minimise her impact on the mother/daughter relationship:

> If I can hear Freya's coming, I'll just kind of make myself scarce and pretend I'm not there because I think - I feel - that that's the best thing I can do for them really. One time she was crying, and Freya was in the shower or something. I remember thinking 'Shall I pick her up?' and you kind of don't want to. But it's second nature, I think: 'Oh, there's a baby crying, let's make it feel better'. But I don't want her to ever feel that I'm taking over. (Sarah)

Whilst this study did not specifically address the needs or experiences of wider family members, the limited data available concerning the 'other' parent demonstrate that PA support has a significant impact on their lives, perhaps most especially where these individuals are non-disabled, and as such have not previously been closely involved with personal assistance relationships.

For most PAs in this study, using their skills of listening, observation and empathy enabled them to understand what their employers required of them. By moderating their actions and expressions, they communicated their respect for their employer and their home environment, whilst at the same time remaining essentially ‘themselves’. The authenticity this provided was an important element of their working role and was highly valued by families. Indeed, most parents in this study were positive about their children developing relationships with PAs, feeling that they would benefit from the attention of additional positive and supportive adults in their lives. Amber strongly expressed this, when she reflected on her daughter’s upbringing, which involved PA support throughout much of her childhood:

> I think it’s really nice that she’s had other people play a part in her upbringing. In some ways it’s enhanced life. It’s brought a different sort of an aspect to it. I mean, when you think about it, in your children’s life there are people – they might be friends’ mums, or whoever – people who are quite important. But these PAs are people who’ve been very much involved, part of her growing up. (Amber)

Other parents however took a more ambivalent view about encouraging relationships between their children and PAs. For some, this was a response to feelings of being ‘let down’ in the past, and wanting to protect their children from emotional upset and rejection, something which Phoebe had experienced:

> One of Linda’s main roles was taking Tom to and from school. He really, really bonded with Linda, yeah, he really, really liked her. Unfortunately, she left because she moved, and she told Tom she was going to stay in touch, and she didn’t. And he was really upset, because she left in the July, and his birthday was in August, and she didn’t send him a birthday card. So, he was quite upset, yeah. He would have been about 12 at that time. (Phoebe)

Chloe looked back on her own experience of PAs being involved with family celebrations:

> It was cool, because like at Christmas and birthdays they [PAs] did tend to buy us presents. I remember one year one brought me a card

> with an age on, and it was a year wrong! She wasn't somebody that I knew very well, and I remember hiding all the other cards. So, I'd put that one at the front, and I'd hidden all the others with numbers so that they didn't realise. I was quite young, but I remember thinking: 'Oh no, I don't want them to feel bad and they'll be here all day.'[laughs]. My mum laughed at me and said: 'Oh, that's really sweet' and left it at that.   (Chloe)

Ellee and Alina, who have grown up with PA support, also shared their feelings about workers coming and going in their life, and how they tried to manage their emotions at times of transitions, which could be especially difficult:

> Ellee: A lot of the time, like (pause). I don't know. Like, you get close to them, but then one day they do leave.
>
> Alina: You know they're going, don't you? So you do keep a little bit of a boundary.
>
> Ellee: If you know that they're here for just like temporary work, or if you know that they might be leaving, then you can't get more upset by it.

Naomi, a mother with a 24/7 support package who employs several PAs, acknowledged the tension she experienced in bringing new workers into her son's life. This was something she felt increasingly aware of as her son became older, as she recognised she could less easily 'regulate' his relationships with PAs. Naomi recalled the difficulties which arose when one of her PAs left their employment quite suddenly, and how this had affected Leo:

> I had a right drama with one PA. Leo thought she was lovely [laughs]. Well, we, disagreed really, me and her, at the end of the day, and she said: "You don't want me here, do you?" and I was: "No, I'm sorry, I don't". And she went. And he was quite upset about that. Because obviously, it happened in front of him. (Naomi)

Leo was interviewed with his mother present on another occasion, and independently recalled this same incident, saying:

> Mum kind of snapped and yelled at her. (Leo)

This led to a discussion between Leo and his mother about their current PA situation, and whether she would need to employ somebody new soon:

> Leo: So, are you going to have to find another PA?
>
> Naomi: Well, John's working at the moment.
>
> Leo: But are you going to find another one?
>
> Naomi: Not at the moment.
>
> Leo: But soon?
>
> Naomi: Well, it's in the back of my mind to find one, but it's quite hard to find a good PA isn't it? You know.

Leo's anxiety about new PAs coming into their life, led Naomi to consider how she might involve him in PA recruitment as he becomes older, which she later discussed with the researcher:

> I think in his head, the four [PAs] that I've got are always going to be there. I don't know if that's true or not. No-one knows that. Um (pause), but it is something I'd definitely talk to him about now, and I've even thought to myself that I would involve him more in the process of recruiting. Give him more say, and actually that would be good for him. (Naomi)

Whilst some parents are cautious about developing close emotional ties with PAs, others embrace PAs – metaphorically and sometimes also literally – within the family, creating fluid and open structures in which PAs may arrive in one capacity, subsequently leave their employment, but then stay connected, sometimes for many years. The evolution of relationships in this way can be a positive and affirming experience for those involved, but it can also lead to uncertainty, and a blurring of the lines between 'work' and 'not work', which can be difficult for individuals to navigate, as set out below.

Blurring of Relationships

Several participants described their experiences of formal support relationships becoming close, even intense, very quickly; this may be due to a combination of factors which can ‘push’ people together, including the intimate nature of many PA tasks, the informal domestic setting, and the amount of time spent in each other’s company. The individual circumstances and needs of parents can also affect how relationships form and develop; for example, some parents in this study relied very heavily on PAs, especially where they had significant physical needs, or where they experienced fluctuating or ongoing ill health. This changed the dynamic of employer/employee relationships, and sometimes resulted in parents experiencing a conflicting range of emotions about their PAs – grateful for the assistance they received, yet feeling disadvantaged and disempowered by their dependency and concerned about the sustainability of their support arrangements.

PAs also talked about the complexity and fluidity of emotions which they experienced. Jodie spoke about this at length, highlighting the reciprocity of the PA/ employer relationship, and the possibilities this can offer both parties for personal growth:

> In my experience, a lot of people who work for PA users are going through something, a life changing event, themselves. And if you find yourself working with someone who has got a lot of wisdom, which my PA user *did*, then they quite like the reciprocated role that goes on. You know, whilst the PA is going through something that they may want to *share*, the PA user could be a bit of a guide, sort of a mentor. And that is exactly what happens. And the house that I worked in was very, very like that. It’s beautiful that it’s that way. (Jodie)

Here Jodie draws our attention to the unique and mutually helping relationships that can develop within the formal support arrangement; these have the power to re-shape the lives and futures of those involved and extend the boundaries of the PA relationship beyond those initially envisaged. The dynamic relationships which are created in this way often have permeable boundaries which may be crossed, redrawn or even removed wholly or in part. The ebb and flow of these connections may bring mutual benefits and result in deeply satisfying and meaningful relationships which can lead to personal development. However, the intensity may be hard to sustain, and a breakdown in such a connection could lead to conflict and disharmony which could in turn have negative consequences for individuals and children within the family.

Some parents, mindful of the difficulty of recruiting suitable PAs, reflected that they spent a great deal of time and emotional energy on building and maintaining relationships with workers in the hope of establishing high quality, long-term support. Other factors such as stability and reliability were also important to parents, especially when thinking about the impact on their children of employing individuals who were previously unknown to the family.

For young people who have grown up with PA support, having clarity around the role of the PA was raised as an important issue: we heard from Ellee in the previous chapter how upset she became when she learned that her mother's PA was not a member of the family. Ellee's mother employed PAs before she and her older sister were born, and they have not experienced family life without PA involvement. Alina reflected on how this differs from the experiences of school friends, whose parents are not disabled, and the assumptions which they made about her family lifestyle and household:

> It took a while for people to understand, like at school and stuff. You know, that *talk* you had when you'd speak to someone *new?* I explained the situation with carers, and they were like: "You've got *maids* and stuff" and I said: "They're not". I had to really correct them before it got any further, because I didn't want people to think of me like that. And I remember someone going: "Isn't that *weird?* What if someone was a murderer?" And I'd never thought of it like that before when I was younger, because I was so used to it. And then, from then on, I used to worry. (Alina)

Worry was something which other young people also talked about feeling. Children can be sensitive to others' perceptions of them or their family being considered different, and this was something Mollie clearly recalled from her teenage years. Mollie's mother started employing PAs soon after she started primary school:

> When I was younger, I didn't mind it, but as I got older, and especially when I was a teenager and I started secondary school, I remember being a bit emb - not *embarrassed*, but thinking like, how am I going to explain who this person is? I guess I'd never had to explain it before, my schoolfriends had grown up with it. I think when I went to secondary school I kind of had to say to people like "You can come round, but this person will be at my house…" And it was *fine,* but I do remember feeling a bit - I suppose I *was* a bit embarrassed that my life wasn't normal. But, then, what is normal?" (Mollie)

From what these young people have said, it seems that teenagers whose parents use PA support may feel especially sensitive about how to explain this relationship to their peers, and this has the potential to form a barrier to friendships. The impact of temporal factors such as this are discussed later in this chapter.

Jenny was in her early twenties when she started working as a PA to a disabled father with five children. She talked about her experiences of what she felt to be a very positive relationship with the family which has strengthened over the years and continues to this day. Now a healthcare professional, Jenny reflected on the nature of this relationship and whether boundaries may have become blurred:

> I think sometimes maybe – not that I would do it any differently – but if somebody else was looking in, they would say to me; "You maybe got too close to the family in your role". I think it did get to the stage with us all where [pause] I *know* I worked for them but that kind of got lost a bit really. They paid me, yeah, but I did just sort of become part of the furniture really. (Jenny)

During her time in this employment, which lasted around three years, Jenny also undertook additional tasks beyond the PA role, including babysitting. This was arranged and paid for separately to her PA contract and meant that her employer and his wife could go out together socially, while she 'hung out' with the children at home. Jenny is still in contact with the family, although she has not worked for them for over 12 years, describing her current relationships with them in terms of warm affection and friendship. Her employment ended suddenly when her employer died, and her role was no longer funded by the local authority. After she moved on to new employment, Jenny and the family made efforts to keep in touch. This was important to Jenny, however the contact initially caused her to experience some mixed emotions:

> After Paul had died, Chloe, bless her, wrote this essay for school, and Steph gave me a copy of it. And she actually wrote in there that she always saw me as a sister, an older sister. Yeah. Which was lovely. Um, really, really nice. I think that kind of added to my guilt actually. I didn't – I wasn't quite as around as much after his [death]. I was around initially, like after he died, but obviously, that was not possible [to continue]. (Jenny)

For Jenny, her relationships with the family gained a new significance and emotional depth following her employer's death and the abrupt termination of her working contract, which had been her primary source of her income. It is perhaps not surprising that she and the family stayed in touch, at least initially, for mutual comfort and emotional support following such a traumatic event, however it is notable that they have maintained close contact for so many years. It may be that their relationship is now experienced and interpreted through the prism of their shared loss, perhaps even somewhat idealised in the light of this event, but it is clearly important to all parties that they remain connected. Certainly, Chloe reflected on the importance of maintaining links to Jenny and other PAs who hold memories of her childhood:

> They [PAs] were like part of the family. They were there for us. And it's nice to have those people around that remember not just my dad, but us. And I do think some family memories are really shared. (Chloe)

Temporal Factors

The longer PAs are employed within the family, the more attached and complex relationships can become. As individuals become more invested in these relationships, there is a greater likelihood of boundaries becoming blurred, and of individuals being taken for granted. Whilst participants described many positive and supportive interactions, they also all shared some negative experiences, including some details of unhealthy and enmeshed relationships. This was something that Andrea, mother to two children aged six and seven had been though at a time when she was physically unwell and wholly dependent on PA support as a single parent. She observed:

> You’re so vulnerable, you know, and they know that you’re vulnerable. I mean, I think with the last PA, I created the monster myself. Because she helped me through some rubbish with social services, and through the divorce, and she knew a lot – that gave her power. And I’d also said that I would always fight to keep her whenever the [personal] budget was reviewed. Obviously, she knew that, and then she had control over me. And she could say things, and she could be nasty, and she could go around making the atmosphere feel *uncomfortable*. (Andrea)

Andrea was reliant upon PA support at this stage of her life, but a combination of factors including her ongoing ill health, high levels of fatigue, lack of family support, and the rurality of her location meant that she had little choice but to continue to employ an individual about whom she had real concerns, as this at least provided some stability for her and her children.

Other parents also talked about their worries relating to continuity and change from the perspective of what would happen if they ‘lost’ a valued PA who has been with the family for some time, as we saw from Naomi, Leo and Phoebe’s comments previously in this chapter.

Another temporal factor affecting relationships is associated with the amount of experience parents had in employing PAs before having their children; this is closely linked to parental experience of impairment and within this study, there were a range of perspectives. For example, some parents had long expected to use personal assistance if they were to become parents – these participants were already used to living with PA support, in some cases having several years' experience of managing paid workers within the home. These parents had had the opportunity to carefully consider how the PA role would need to change once their child(ren) were born, and saw the role primarily as enabling and supporting their parenting. They took a proactive role in planning and discussing with workers how they wanted them to interact with their children to ensure that they retained primacy as the parent. However, as Gina explained, this was a flexible learning process for both parent and PA:

> It was my home. The PAs did what I wanted them to do. I was mum. Not that they couldn't cuddle the baby, but it was: "Let me have her, let me do that". Little things, like when we winded her after a feed, it would have been easy for anyone to do that, but I had my way, and I was actually better at getting her wind up than anyone else. Luckily, I had a fantastic PA, she was very determined to help me find a way through, so that I was coping. (Gina)

Other parents had to adjust to significantly changing needs around pregnancy, or in their child's early years. Understandably, this was often a very difficult time, and some parents experienced feelings of guilt due to the impact of their impairment on their child's early life opportunities. Phoebe in particular looked back with real regret on her son's younger years:

> He didn't have many friends. This is something I feel really guilty about, because I was so unwell when Tom was young. I was in and out of hospital for the first five years of his life. So, I didn't go to the mother and toddler group, I didn't go to Tumble Tots, I didn't go to any of those places. I very rarely had people round here, because my care package was so small in those days. So, I didn't form friendships with other mums, and he didn't get to be friends with their children. And because I don't think he learned the social skills, he has always struggled with friendships and was bullied at school. And I feel really guilty about that. (Phoebe)

Adjusting to using PA support in the home was difficult for these parents and their families; whilst some had experience of managing staff within a work setting which may have been useful, they found it hard to translate this to handling employer/employee relationships within the home. On occasion, some parents even actively sought to avoid their PAs:

> The thing was, because I didn't get on with this girl, and she was the first person I'd employed, it was very much like: "Right. Here's your list, I'm going out." I actually would go out to avoid being in the house with her. (Lydia)

Phoebe also recalled an occasion when, following a disagreement with her PA, she avoided returning home until their shift had ended:

> I was really upset. I was meeting my friend, and I said: "I don't want to go back home while she's in my house." And I *sat* there with my friend, and she sat with me in town for hours and hours and hours. I mean, it was literally gone six before I would go home because I didn't want to be here when she was here. (Phoebe)

Where parents' first involvement with social care services occurred when their children were teenagers, this was often very difficult for both parents and children. Young people spoke about finding the presence of PAs within their home an unwelcome intrusion, and parents found it particularly challenging to balance their own needs with those of their children. Mother and daughter Jane and Katie spoke together about the tense relationships which developed within their household. Jane's response to this difficult situation was to separate her PAs from her children as much as possible, even though this arrangement did not necessarily suit her own needs:

> Jennifer was tricky. She wasn't terrible. She was a good person to have *around* sometimes. But I'm not sure she ever got to know you enough as people. I don't know whether she liked you or not, but I think she *judged* you. It's very hard to get into a confrontational relationship with someone who is in your house *all* the time. I mean mostly, I had her there when the kids were at school, that's how it worked, because I kept them separate, and that was quite a choice. I just knew it was going to go bottom-up if she had too much to do with the children. (Jane)

Time plays a part in these support relationships in another way, in relation to the age or stage of development of the child. This has a major impact upon both parent and PA, since the tasks of parenting, and therefore the support that disabled parents need to care for their children, change significantly throughout childhood. Participants tended to discuss the changing needs of children in three broad timeframes – pre-school, middle childhood, and teenage years. Gina, whose children are now aged 20 and 14, reflected on how the dynamics in her household have altered over the years:

> It's changed since the girls have got older. When they were very young, it was *all* about the kids. And they'd got to get on with the PAs, they'd got to like them, because if not, it won't work. But now they're older, and they're more independent themselves, then sometimes I just have to say: "Look, *you* might not like them [the PAs], but they're here for *me*. And I need them." (Gina)

Summary

This chapter has provided a deeper insight into the dynamic and complex relationships which the employment of PAs brings about between disabled parents, their children, and paid workers. Whilst parents aim to work with PAs to create stable and nurturing environments in which they can express their parenting choices and their children will thrive, not all of their aspirations are realised. Complicating factors can arise which create barriers to positive communication and the development of mutual respect and understanding.

Nevertheless, all participants reported at least one positive PA relationship; indeed, some spoke of warm attachments which have continued for many years beyond the ending of the employment contract and clearly hold deep meaning and importance in their lives. Where PA relationships exist for several years, it is more likely that PAs become immersed in the life of the family, and that boundaries become increasingly blurred; this can develop gradually and incrementally, however some participants also shared experiences where a level of intensity developed very rapidly between individuals.

Whilst PA support can be positive and enable parents to express their wishes and choices, some parents find the challenge of managing paid staff within the home a tiring and frustrating task, especially where they have fluctuating health needs. Parents of teenagers also spoke about the difficulties of balancing relationships within the home, in particular where they felt ‘torn’ between meeting their own needs, and those of their children.

Data suggest that parents and PAs need to employ different skills and strategies across the course of childhood. Perhaps the area that this becomes most apparent is in relation to setting and managing family rules, something which will be examined in greater detail in the next chapter, which sheds light on how all parties in the support relationship seek to manage one another’s behaviour.

Chapter 7: Managing Behaviour

Introduction

The often-sensitive subject of responding to and ‘managing’ others’ behaviour was raised by all participant groups within this study and emerged as a strong theme within the data. This dialogue often commenced within the context of how children are taught the rules of family life, and the role of personal assistants in supporting this. Certainly, the involvement of PAs in the often-contentious area of upholding and reinforcing family rules links directly to the question at the centre of this study about how the relationship between disabled parents and their children is affected by the presence of personal assistants in their lives. Findings suggest there can be significant consequences for parent/child relationship dynamics, however individual reflections frequently extended to include the challenges of dealing with unwanted behaviour from paid workers, and indeed from parents, and it was apparent that all participants sought, in a variety of ways, to influence, control or ‘manage’ the behaviour of others in the parent/PA/child relationship triad.

This chapter is therefore given over to examining participants’ views and experiences of managing others’ behaviour. Within the data it was powerfully evident that all parties to the support relationship are highly attuned to the sense of being closely observed by others. Following a discussion of how this is experienced, the findings are arranged using relationship dyads to allow for more detailed analysis of the interactions between participants and what they reveal about the relationships between individuals. Relationships between parents and PAs are considered first, since the formation and ongoing development of this relationship establishes the character and tone of paid workers’ subsequent interactions with family members.

Support and surveillance

Within certain parameters, how non-disabled parents discipline their children is primarily a matter of individual choice, most likely discussed and agreed with co-parents and with the support of other close family members who may provide advice or guidance from their own parenting or life experience. However, for disabled people reliant upon paid PA support, expressing their parenting choices is likely to be a much more broadly collaborative and negotiated experience, directly involving those from outside the close family circle.

Parents within this study frequently talked about feeling ‘judged’ as parents – by relatives, the ‘professionals’ working with them, their PAs and even by individuals with no link to the family who nevertheless believe they are justified in intervening or expressing an unsolicited opinion. Disabled parents were acutely aware that their every action or inaction is observed by ‘strangers’ in their own home, and some expressed concern that PAs could report them to the authorities if they considered them to be ‘bad’ parents. Gina summed up her feelings:

> As a parent, you constantly feel like you’re being judged, but even more so as a disabled parent. No one thinks you’ll be able to do it, they don't expect you to cope and it feels as if they’re waiting for you to fail. I worried that a PA could easily misinterpret things and possibly report me to social services. It’s a very real fear for disabled parents, that our children could be taken away. (Gina)

The concerns Gina and others voiced about judgements being made about their capabilities as parents tended to be most strongly felt in the early years of their children’s lives, when the adjustment to becoming a parent can be a difficult transition, and at a time when parenting can be an intense and unpredictable activity.

Parent participants also felt they did not have the same freedom as non-disabled parents to get things ‘wrong’ and to learn from their mistakes. They sought to minimise the potential for any confusion about their choices and decisions by firmly establishing their authority, and ensuring that PAs understand and respect their approach to managing children's behaviour. This ensures that PAs act within the agreed parameters of their role; it also fulfil the secondary function of helping parents to manage anxiety about the possibility of unwelcome interest and intervention in their family from social services.

Children shared parental feelings of being under scrutiny and spoke about living under a degree of surveillance beyond that of their peer group – this was most frequently discussed in relation to the number of adults present in the home environment who could 'tell them what to do'. Children expressed strong, mostly negative, views about the intervention of PAs in disciplining them, with some expressing resentment at workers being involved with what they considered a purely parental role. Some children talked about 'pushing boundaries' with PAs whose authority they did not recognise, however they also reflected on situations when PA involvement had been helpful, and even preferable, to parental intervention. In some cases, this led to an increased respect for PAs and signalled the start of developing deeper relationships with them. `

Leo, aged 10, revealed that he feels heavily monitored by the adults in his life and experiences some pressure to 'behave'. Leo's parents do not live together, and since he shares his time equally between both their homes, he is in the position of being able to compare his mother's household which uses 24/7 PA support, and his father's home, where no personal assistance is required. Leo pointed to the additional scrutiny he is subject to in his mother's home:

> There's *many* more eyes watching me here, so I can't be naughty. (Leo)

Although Leo spoke about his feelings in a somewhat light-hearted way, this was clearly something he wished to share and felt strongly about. Being watched was something other children were also very sensitive to. Alina and Ellee discussed together how they perceived the overly-scrupulous attention of PAs increasingly irritating as they got older:

> Alina: It was like: “Let me live my life in my house without you *always* watching me.” Just stop watching me all of the time.
>
> Ellee: Exactly, it was like if you’d had a packet of crisps before dinner, even like that, you’d get told off. So what? You know?

This powerful sense of being watched and judged was also shared by PAs, mindful of accurately gauging their role in determining when – or frequently more of a challenge – when not, to intervene in interactions between parents and children. Some PAs felt ambivalent about having direct involvement in this aspect of family life; they spoke about struggling to engage with children who were being ‘uncooperative’ and perceived that they lacked authority in enforcing family rules and boundaries of behaviour. The issue of power and control was also raised by some PAs who had experienced children assuming the same level of authority over them as that of their parent(s), thereby presenting them with a dilemma and potential conflict of interest.

Some PAs saw their interventions with children as a purely functional aspect of their role and considered their actions simply as enacting the instructions of their employer. By acting as the ‘arms and legs’ of the parent, for example by placing children on the ‘naughty step’ or imposing ‘time out’ as instructed by the parent, these PAs minimised the engagement of ‘self’ in the disciplinary process. Nevertheless, PAs agreed they found it easier to support discipline regimes if they shared similar values and had a parenting style in common with their employer, and some spoke about the challenges they felt when seeking to ‘upwardly manage’ their relationship with parents.

Parents and PAs

The level of PA involvement in family life naturally varies according to the identified needs of the parent as well as the age and needs of the child; while some aspects of this can be predicted in line with broad ‘milestones’ of child development, others are hard to foresee and may need to be worked out ‘in the moment’ as the situation demands. All parents involved in this research stressed the careful consideration given before employing a PA to the role that they would be expected to fulfil with regards to interacting with and managing their child(ren)'s behaviour. Discussions about this typically took place as part of the interview and selection process, with parents using these conversations as a gauge to determine candidate suitability. Notwithstanding these efforts, parents often spoke about problems they experienced with PAs acting beyond the agreed role, as Naomi explained:

> I *definitely* discuss with people that they aren't there as the childminder, they are there to help me be a parent to Leo. But some people just assume they would be the babysitter. Or make the *decisions* even. I had one PA who was very surprised that I kept telling her what to do. She wanted to be the one in *charge*. (Naomi)

In Naomi's experience, it is not uncommon for PAs try to assume authority over her – in fact, she described this as a 'common theme' of employing personal assistants. Yet despite experiencing such frequent resistance, Naomi reflected that overall, it is easier for her to instil her values and manage PA interactions with her son than to manage family members' behaviour. This may be a natural consequence of the power dynamic in the employer/employee role, as well as the weight and 'history' of complex familial relationships which can inhibit effective communication and prove a barrier to change. PAs play an important role in enabling Naomi to be an active and involved parent to her son; while she places an emphasis on practical support due to the level of her impairment, she also recognises and values the sensitivity and intuition some workers develop over time, and the way this 'wisdom' as she terms it, can support her developing relationship with her son. For her, finding the right balance between assistance and autonomy as a parent is key to achieving an effective working partnership:

> That's one of the biggest things, if I was to say anything to PAs, it's to know when to keep out of it. And that's much more than you'd realise. Yeah. As I put it to my PAs, it's a team effort, it's not just me, I couldn't do it without them, obviously. But they couldn't do without me *either*, you know. (Naomi)

Having met the challenges of pregnancy, child birth and living with a new baby, parents quickly move on to dealing with active toddlers. This can be a testing time for any parent. Lizzie, one of Gina's PAs, talked about her role in managing toddler behaviour and recalled a typical experience:

> If Ellee was having a paddy on the floor and Gina wanted her in her bedroom, I would do that. I would just pick Ellee up. Screaming her head off, wriggling around. I always used to pick her up so she was facing away from me, and I would stand and hold her under the arms, as un-affectionately as I could, at Gina's eye level until Gina had told her what she wanted to say. And then she was like: "Right. Bed." And I'd walk to the bedroom and put her down. I would not say a word. I really, literally, was the hands. I didn't offer an *opinion*, I didn't back Gina up, I didn't back Ellee up. Nothing. Just nothing. (Lizzie)

It is noticeable how Lizzie deliberately sought to limit her use of 'self' in dealing with the child, regarding herself in this moment as a physical extension of the parent and doing her utmost to remove her own involvement in the situation, including the withdrawal of eye contact. In a similar way, another PA spoke about intentionally limiting her involvement of 'self' in situations where she supported a parent to implement a 'naughty chair' behaviour management strategy with her son:

> I would be the one that would have to put him *on* it, so I would be looking to mum about when I needed to do that, because the instructions were all coming from her. And then she would tell him what the issue was, and she would go back and tell him when to come off. (Jodie)

Jodie was clear that her role was to enact the instructions of the parent and not operate under her own authority. On this occasion, Jodie felt her partnership with the parent worked well, however there were situations which triggered feelings within her of frustration at her employer's lack of explicit direction. This led to an internal conflict for Jodie, who faced a dilemma when the parent made decisions which either did not align with her own values, or where she felt forced to act of her own volition due to the parent's indecision. As a PA, Jodie was strongly motivated by her rights-based understanding of the role; consequently, she felt she had failed when she encountered situations which led her to act in a way she considered disempowering to her employer; this left her with difficult to resolve feelings. She reflected:

> I do try very, very hard to weigh up the pros and the cons, and to not be intrusive or judgemental. But then, there are some things where, in your heart, you just go: 'Argh, that can't happen!' And she would leave me hanging [pause]. That was one of the really uncomfortable things. There would be something that I would feel like I needed to do, but she wouldn't give me permission to do it. And then it had to be my decision, rather than hers. And that's actually really very disempowering. (Jodie)

Being so closely involved in everyday family life obliges PAs to think and act as the parent requires in a wide range of different and often changeable circumstances. This demands imagination, empathy and emotional intelligence. Clear communication between parents and PAs is therefore vitally important. In Jodie's example given above, she felt that her employer had not provided this. She also appeared to feel unable to ask for the guidance she required in the moment, or to discuss it with her employer at a later time. This failure of communication between them led to feelings of frustration and dissatisfaction for Jodie.

For Sofia, a disabled single mother with two primary school age children, investing time each day to share information with her PA enables her to stay in control, and ensures the PA understands the family's plans and becomes attuned to their changing needs:

> It's the first thing we do every morning. Sit down and have a bit of a 'team talk', about what's *happening* that day, what *needs* to happen and what *could* happen. What we're doing the next day, and what's going to be happening generally over the week. Flashpoints, things that are going to be tricky. (Sofia)

While these and other examples of open and positive communication suggest there are grounds to be optimistic about parent/PA relations, there were many occasions when parents in this study felt actively undermined by their PAs. For example, Naomi's authority to limit her son's computer time was outwardly accepted by her PA, but then weakened by his actions:

> Sometimes it's like: 'Why do I *bother*?' D'you know what I mean? [laughs]. [speaking quietly to avoid being overheard] It's like, really *bad*. [pause] I'm saying: "No more computer time" and he [the PA] gets his *tablet* out, and the next thing, him and Leo are watching it

> [pause]. And I'm like: "I said he couldn't go on his *game*!" What on earth's that all about? (Naomi)

Although she laughed when sharing this account, Naomi was plainly annoyed at how this situation had developed. Equally, she appeared to feel unable or unwilling to tackle her PA on the issue, evidenced by her talking quietly to avoid being overheard by the PA who was present in the house at the time of interview. Albeit from a different perspective, this mirrors Jodie's experience, and in a similar way, Naomi also expressed frustration and a degree of failure. She provided this narrative as an example of just 'one of those things' she had to live with and 'put up with' as a consequence of using PA support. Naomi has a large package of support and employs several workers to provide assistance around the clock; she acknowledged that managing relationships with all the people in her life can be 'exhausting', but also spoke positively about how PAs can sometimes enable her to see things from another perspective. She felt that having a divergence of opinion at times can be positive if it challenges her to reflect differently on her parenting choices and enables her to do things better:

> Pippa and Kirsty are very good at pointing out, very nicely – *very* nicely, actually – things where I could actually *do better*. It's fair comment. Sometimes I might not *agree* with them. But sometimes I go: "Yeah, you're *right".* So, I think that's quite good. (Naomi)

Being able to discuss choices and decisions can obviously be helpful where the connection between parents and PAs is positive and there is respect between individuals with a shared understanding of the boundaries of their relationship. This is not the case for all parents. Unlike Naomi, who accepts the occasional frustration and annoyance at PA behaviour as an inevitable part of the flow of any human interaction, including those with employees, Phoebe felt that this 'push and pull' dynamic in the working relationship was both unacceptable and preventable. She recalled an incident which centred around an experience many parents may recognise as a stressful situation – taking an unwilling and bored child shopping for new school shoes:

> Sally, my PA at the time, had a right go at Tom in the shoe shop. He *was* mucking about, you know. But I was *so* embarrassed because:

> one, I didn’t want to make a scene; and two: that she was shouting at my son. I mean, really and truly looking back on it, I shouldn’t have allowed it, but at the time I just didn’t have that much confidence. (Phoebe)

It was interesting to note that while this situation appeared to evidence poor performance on the part of the PA, the parent in fact blamed herself for ‘allowing’ the incident to develop, commenting that her own lack of confidence was a barrier to handling events more effectively, leading to the escalation of events. In listening to Phoebe describe her struggles with managing the behaviour of both her son and her PA in a very public arena, it was evident that she experienced a real conflict in attempting to be both a good mother and a good employer; there were times when she could simply not be both, and in these moments, she felt a failure on both accounts. This left her with enduring negative feelings of guilt and self-doubt.

Gina also reflected upon her initial reluctance to tackle PAs about their performance at work, before reaching the conclusion that no-one, not even the ‘best’ PA is ever indispensable. Her efforts to adjust to the challenges of a growing family – managing an active young child and understanding the needs of a new baby – were further exacerbated by the unhelpful attitude of her PA, with whom she had hitherto enjoyed a positive relationship. A seemingly innocuous instruction to the PA about making up a bottle of formula led to a much wider confrontation and eventually the termination of their working relationship. Tiredness, anxiety, stress and other personal factors may have all played their part in the developing disagreement which culminated in the unravelling of a seemingly strong 8-year connection, but as Gina exclaimed to the PA:

> At the end of the day, you get to go *home*. I don’t! (Gina)

Gina’s expression of frustration here locates the point where the perspectives of parents and their PAs diverge – PAs become privy to all the intimate secrets and details, the emotional highs and lows of their employer’s lives, leaving families open to a certain degree of vulnerability. However, while this risk is predictable, it may be difficult for parents to control, as the relationships are fundamentally asymmetrical – PAs do not share their lives and confidences with their employers in the same way, they can retain their own counsel and guard their privacy. This can lead to tension developing within the relationship.

By contrast, although Amber initially felt reticent to seek formal assistance after acquiring an impairment as a mother, once support was in place, she felt confident to express her views and instructions to her PAs. This may be because she already felt secure in her parenting role before employing a PA. Nevertheless, she too experienced frustration and anger when her directions were not carried out by her PA and her authority was undermined. Although Amber had mostly positive experiences of receiving PA support, she distinctly recalled an event which still rankled many years later:

> Well, she'd totally *ignored* what my *instruction* was. And I'm *sorry*, but when I'm paying someone, they should follow out what *I* ask them to do, in the *way* I ask them to do. And it reflected upon *me* as a *parent*. I just had to let it go. Because there wasn't anything you could do about it. She wouldn't say *sorry*. Because as far as she was concerned, the job got done, so what's the problem? (Amber)

In this situation, Amber felt angry at her instructions being ignored and thwarted in her attempts to exercise control over the PA. She was also concerned that her PA's actions may have put her in a bad light and worried that this would provide others with a negative view of her as a mother and affect her reputation as a 'good' parent. Yet, despite the legitimate power she held as employer, Amber felt powerlessness to change the situation and ultimately concluded there was 'nothing she could do' to change the PA's attitude. In other ways, the PA had proved reliable and performed as required, so on balance, Amber felt she had to let things stand.

For single mother Andrea, the realities of struggling to deal with the impact of fatigue and fluctuating ill health alongside family life, as well as the challenge of finding suitable PAs in a rural area, were yet other barriers to dealing effectively with unwanted behaviour from PAs, as she described:

> When you're sick and you're scared of people walking out of their job, asking them to do something slightly different is difficult because of

> the response you might get. You're dependent on them, so if they don't like what you said to them the day before, they can withhold care from you. I had one PA that would leave early because I'd fallen asleep. So, they got away with a lot because I was just too sick to deal with it. And there was no-one who could help me. I felt they were taking advantage, but I couldn't tackle it. (Andrea)

Another single mother, Jane, also talked about the impact of her particular circumstances and their effect upon her relationships with PAs. Jane identified that her social isolation had shaped her relationship with PAs, particularly the power dynamic between employer and employee:

> I don't think she [the PA] felt superior, I think she felt equal. I think she just saw herself as a friend, so an equal. And it's very hard for it not to be a friendship, when you're spending time together doing social things. And it's *hard* as a single parent in that role *not* to sometimes share your concerns with the person you're with, the other adult that's around a lot. (Jane)

Participating in a quasi-friendship with her PA created difficulties for Jane when her authority as an employer was challenged. For example, when Jane asked her PA to facilitate her teenage children's transport, this was flatly refused. This left Jane with the dilemma of how to ensure her children's safety whilst also promoting their growing independence, at the same time as having to work out how to respond to this direct confrontation from her PA. Jane reflected on the sense of guilt, frustration and failure which this left her with:

> I would have set-tos with her, and I'd say: "This is what I want you to do today." And sometimes she would just say: "No." And then what you do? Do you say: "I fire you"? It's a very difficult thing. I'm very bad with confrontations as well. I'm really not good at it.   (Jane)

PAs and Children

All participants recognised that PA involvement in maintaining family rules and managing children's behaviour could be a sensitive and sometimes controversial issue. Perhaps unsurprisingly, by far the strongest views on this subject were expressed by children, many of whom questioned the legitimacy and authority of personal assistants to exert control over them. Alina discussed this in a shared conversation with her mother and her younger sister:

> Alina: I was at that age where Lizzie [the PA] was allowed to discipline me. So, we had our moments. Oh my God, Lizzie's such a *snitch.* Because they're just in my house and that was just how it was. So, *now*, it's nothing. But you can see the differences in the relationships you have with different carers. [to Ellee]: Like, I remember at the time when *you* were young, with different carers that you didn't like because they were telling you off. But they're *allowed.*
>
> Ellee: It's not their job.
>
> Alina: Mum made it their job. Because mum said: "'If I'm not there, you can say something".
>
> Mum: Only if I'm not there.
>
> Alina: But that is different for the child.
>
> Researcher: Did that make you feel a bit resentful?
>
> Alina: Yeah. Go and get my mum and get her to tell me off!

Both young people expressed strongly that PAs should not be involved with managing their behaviour, despite knowing that their mother gave her PAs permission to intervene in her absence. This can present family members and workers alike with something of a dilemma, where there is no common acceptance of the PA role and involvement in what may be termed 'discipline' of children. The consequences of this are that children can feel aggrieved, as Alina experienced:

> I could never take it that seriously when they told me off, because I really had that in my head [*with emphasis*]: 'You are NOT mum or dad'. I think when I was young, I just wanted them to know *that.* I just used to get annoyed about it: 'Don't tell me what to do'. (Alina)

Jasmine (aged 8), appeared readier to accept the understanding which exists between her mother and her PA, Jessica, about managing family rules:

Researcher: So, who makes the rules around here?

Jasmine: Jessica [the PA] and Mummy.

Researcher: OK. You said Jessica first? Is there a reason you said it that way round?

Jasmine: [laughs] No.

Researcher: So, is Mum the ultimate boss in the house?

Jasmine: No, it's what Jessica and Mum says goes.

Researcher: OK, how does that work?

Jasmine: Well, Jessica tells Mum what she *thinks* would be good, and then Mum says yes or no. And then if she says no, they will keep it like that, but change it, like slightly.

Jasmine does not question or reject the appropriateness of being disciplined by her mother's PA, however it may be that for her, the PA role is blurred. In this family which has constructed a fluid network of support, Jessica fulfills several roles: in addition to working as a PA, she teaches Jasmine at the local dance school. On weekends, Jasmine will sometimes stay overnight at Jessica's house so that she can attend dance competitions and events around the country. This arrangement may make it difficult for Jasmine to differentiate between the various functions Jessica performs.

Leo (aged 10), found it difficult to express his views on the things he didn't like about having PAs involved in his life, but with encouragement from his mother, he was able to give his views on being 'told off' by PAs:

Mum: So what's not so great about the PAs?

Leo: When they tell me off.

Researcher: Do they tell you off sometimes?

Leo: Yeah.

Researcher: Is that unreasonable?

Leo: It is reasonable, but not nice.

Researcher: That's understandable. Do you think it should just be your mum and dads that tell you off?

Leo: [Nods]

Chloe, who grew up with PA support throughout most of her childhood (from birth to her mid-teens when her father died), talked about the understanding in her family that discipline would be handled by parents, but PAs could directly intervene with minor issues, such as siblings being unkind to each other, or playing music too loudly. Like other children in this study, Chloe felt that her behaviour was closely observed and monitored by her father's PAs. Although for the most part, PAs did not get involved with 'disciplinary' matters, there was one occasion which Chloe recalled from her teenage years, when the PA picked her up from a night out at a roller disco:

> I had a massive love bite. And the *whole way* home she shouted at me. Properly shouted at me: "If your parents see that, you'll be in so much *trouble*. I'm *disgusted*. *How* could you let somebody do that to you? *Don't* let your dad see that. It's not worth it. *This* time, I won't tell him." And obviously she *did.* She obviously told them and said: "Look. I don't think she's going to trust me if you tell". But I was like: 'Oh, I can't believe she's told me off. She should be cool with it. She's young'. I just sat there and took it. And actually, it was fine. I just thought: 'What do *you* know? You're not cool'. (Chloe)

Although Chloe was angry and annoyed at the time that her father's PA felt entitled to voice a strong opinion and make value judgements about her behaviour, she accepted the 'telling off' on the basis that her parents would not be informed. With the benefit of hindsight, Chloe believes that the PA did speak to her parents, and that they agreed between themselves to let the matter stand, since it had been sufficiently dealt with, and that to broach the subject further could damage relationships between Chloe, the PA and her parents. This situation highlights the complex issues of trust and shifting allegiances between parties, which can be difficult for all individuals to manage, but may be especially hard for children and young people to understand and navigate.

As demonstrated in the previous findings chapter, while some PAs occupy a mostly functional, peripheral, position in family life, many others become completely subsumed within the family unit and develop complex and multifaceted relationships with members. These PAs acknowledged the challenge they experienced in managing children's behaviour, sometimes feeling caught between parents and children in knowing how to react 'in the moment'. On occasion, they can find themselves weighing up issues of confidentiality and trust and attempting to predict how their response to a young person may affect their own future relationships with both parent and child, as well as those between parent and child.

Dealing with unexpected events can be challenging for PAs to navigate, especially where they are caring for children in the absence of a parent. One PA experienced this when accompanying her employer's teenaged daughter on a shopping trip. This involved the PA being present with the young person in a changing room, when she noticed a 'love bite'. Unsure of how to react, she texted her employer for advice and instruction. Summarising the situation as she saw it, this PA identified the key issue of trust, and to whom she felt she owed it:

> It sort of went across that your mum's going to find out about this, even though I'd already told her, because I'd asked her how she wanted me to handle it. So, I've not broken my trust. Well, I *have*, but she doesn't know that I have, sort of thing. But ultimately, my trust is with mum. (PA)

Another PA, Erica, found it particularly challenging to manage her employer's young daughter. Although she understood the 'family rules' and had full parental permission to implement these, Erica did not feel that she had legitimate power or authority to direct the child and was concerned that she may be accused of acting inappropriately. She struggled to maintain control, and in her view, the child sensed this hesitation, testing her at every opportunity:

> [Sighs]. She wouldn't do as she was told. She would listen to her mum, but I think she *knew* she could get away with things with me. You know, children are like animals, they just know. They sense the weakness [laughs]. You know the 'naughty step'? She just wouldn't sit. She wouldn't even sit on the step for me! [laughs] And you can't physically move her, because, you know, I might get told off for hurting her. So, it was very difficult. (Erica)

Another PA recalled dealing with a young child who misunderstood the extent of her parent's – and her own – authority over the PA:

> She used to say: “You work for my mummy, you have to do what *I* say.” (Lizzie)

Eventually, the child developed an understanding of the PA as an individual and came to realise that the PAs working for the family were not always subject to the express control of her parent. She also began to understand that her parent’s authority over the PA did not extend to include herself. Lizzie felt this was a ‘breakthrough’ moment in her relationship with the child, which led to them building greater respect for each other, and ultimately the positive relationship they enjoy to this day.

Another participant who had grown up with PA support recalled his own finely-tuned understanding of who could – and who could not – discipline him as a child. Tom’s mother employed a PA, but he would also sometimes go to a childminder before school. He talked about his understanding of these two different roles and his perception of the authority invested in them:

> In comparison to the PAs, I would say that [the childminder] had a lot more ability to give discipline. But that could have been the fact that I was in *her* house, rather than them being in *my* house, and I think that can actually make a big impact. Because it was *my* house, and they were just PAs in my house, I didn’t quite feel the same, that they had that level of authority over me. I’d wait until mum or dad told me off. (Tom)

For Tom, the location of the support being provided made a significant difference to how he understood the dynamics of power: at home, the workers were merely his mother’s assistants and had no meaningful control over him. When he went to the childminder’s house, different rules applied, and he was subject to, and accepted, her authority in this environment.

Other young people also spoke about how the presence of PAs in the home environment changed the atmosphere. For example, Katie recalled how she and her brother used their home differently when PAs were there:

> I didn’t feel like I could relax if she was there as much, because if we did, she would judge us. So, we didn’t go and watch TV, or make ourselves food or anything like that because if we’d do anything, they’re was a criticism it seemed. (Katie)

Siblings Alina and Ellee also expressed how the mood and energy of their home changes with the presence or absence of PAs:

> Ellee: When they're not here at all, that gets weird.
>
> Alina: That's dead eerie. If there's no-one walking, scuttling all around, pottering about. Every noise is like – it's weird, isn't it?
>
> Ellee: Completely.
>
> Alina: Proper weird. I used to hate it. If you would go down to the kitchen when you were younger, or you were in bed and you couldn't hear someone walking up and down the corridor, it was like 'Why's the house so quiet?' Other times, the house can be dead busy.
>
> Ellee: Wherever you go, they seem to be there. Like one minute they're in the kitchen, one minute they're in the bathroom.

As the data set out above show, children and PAs share unique and complex relationships, which are often only partly overseen or supervised by their parents. Shifting power dynamics and personal perceptions are key factors in shaping how individuals experience their understandings of each other and the areas of tension which arise between them.

Children and Parents

All parents and children within this research talked in positive terms about their relationships with each other. Since some interviews involved parents and children who chose to talk together about their experiences of PA support, the close and loving relationships which they shared was clear to see. While it is accepted participants may have wanted to present a positive view of their lives to the researcher, they also spoke openly about some of the difficulties in their relationships.

Following on from the conversation set out earlier in this chapter, Jasmine (aged 8) considered the differences she perceived in being disciplined by her mother, and by her mother's PA, Jessica:

> Researcher: Does it feel different being told off by mummy, to being told off by Jessica?
>
> Jasmine: Yeah.
>
> Researcher: What's different?
>
> Jasmine: I don't know. [laughs]
>
> Researcher: Who do you feel most told off by?
>
> Jasmine: Jessica, because she tells me off properly. Because mummy is a softie. She doesn't want to tell us off really. She goes like this: "I'm really, really sorry about that, but I'm just disappointed". Yeah.

Jasmine makes a comparison between her mother and her PA's interactions with her; this may be due to a range of factors, including the different personalities and preferred communication styles of the adults involved. Jasmine's perceptions of these differences could also contribute to her interpretation of the situation.

Leo, who had found it difficult to talk about PAs disciplining him, was much more comfortable with sharing that his mother was the person in his life who told him off the most, quickly turning this into a light-hearted conversation about how embarrassing she could be. Perhaps this served to deflect the unease Leo had felt earlier when asked to discuss feelings which he found hard to express, yet it also highlighted that what he found most embarrassing about his mother was not her impairment, or the fact that she needs constant support, but what he considered to be her 'bad' singing.

Leo's mother had participated in a separate interview with the researcher which took place several weeks before this shared conversation. In this earlier interaction, she reflected on how her role in managing her son's behaviour has evolved over time. Aged 10 at the time of interview, Leo understands what is expected of him; together with his increased independence, support with parenting requires less direct PA intervention, providing both Naomi and Leo with valuable space to develop and enjoy their relationship. As previously established (see Chapter 5), Naomi identifies very strongly with her role as a mother – she feels a sense of empowerment by both becoming and being Leo's mother. Nevertheless, squaring her responsibilities as a parent with the uncertainties and realities of living with a chronic health condition can be emotionally demanding:

> I've had a lot of ill health, the last two years. It's a biggy. Um. I think that [pause as she is tearful]. Oh, sorry, I didn't expect that. I was actually thinking it's time to have a conversation about getting a Living Will made, and all of those kinds of things. And I've never really thought about it so much before. But I've been so ill recently, it has – cemented it really. (Naomi)

Amber and her daughter Mollie, now aged 24, spoke about having a very strong emotional bond; they have daily contact even though Mollie now lives in a nearby town with her boyfriend. Amber considered the involvement of PA support as an 'enhancement' to their lives; she also identified another benefit of the family's situation, which led to her husband developing a closer bond with their daughter than he might have otherwise, since he took on a more active role caring for her as a young child. Amber's health fluctuated unpredictably when Mollie was a young child, and she was frequently in hospital. She remembered the impact this had on her thinking about the role she could play in her Mollie's life:

> I think it made me concentrate an awful lot upon her emotional development and wellbeing, more than perhaps so much the practical, physical needs. Yeah, much more concentrated on making life as normal as possible for her, making sure she was emotionally coping with what was going on. (Amber)

Amber acknowledged that Mollie's behaviour growing up was shaped in some ways by her worries and concerns about her mother's health. For example, she recalled that, as a child, Mollie was excited by the prospect of staying overnight with friends, however later in the evening she would always become tearful, and her father would have to bring her home. In her separate interview, reflecting on the impact her family circumstances had upon her childhood, Mollie recognised the part it played in shaping her behaviour, especially as a teenager. When many of her peers were asserting their growing independence from parents, Mollie was mindful of her family's situation and the impact any 'misbehaviour' on her part might have to unsettle this:

> I don't consider myself to be an angel. But I don't think I was the most difficult daughter in the world [laughs]. I don't think I gave them hell! I obviously had my cheeky moments, but I wasn't a tear-away, or throwing tantrums left, right, and centre. So yeah, I think I was quite responsible. I stayed out late occasionally, but not too late. I *was* very sensible. I think there was always so much else going on, that I think I just thought I can't put anyone through anything else. (Mollie)

Tom and his mother, Phoebe, independently described their close relationship, which they both believed had been strengthened by dealing with and overcoming the problems Phoebe has more recently experienced in managing – and dismissing from her employment – two longstanding PAs. As he became older, Tom recognised that the relationship between his mother and her employees was becoming increasingly difficult. His loyalty towards his mother brought about a change in his behaviour towards the PAs:

> I think that once I realised the impact they were having on her, I started beginning to resent the PAs a little bit. Because they would make sure that they were really nice to *me,* but then go and be sort of sometimes quite mean to mum. Quite manipulative. Towards the end, I would actually be so resentful that I would start making it *more* difficult for them to do their job. (Tom)

Phoebe credits Tom for motivating and supporting her to address the employment issues she had previously found so difficult to manage:

> He said to me: "Mum, how many times are you going to let her do this to you before you are going to do something about it?" Which was quite confronting for a 19-year-old to be telling his mum. Well, he said: "I'm sick and tired of hearing you upset because of the way they're treating you." And I thought 'I can't let this carry on'. I hadn't even realised he'd noticed. And I thought 'he's my *son*, these are meant to be the best years of his life, and he's worried about me.' (Phoebe)

Other teenage children also expressed feelings of frustration or annoyance in their behaviour towards to PAs, especially where they did not like or approve of them. In some cases, their feelings may have been an expression of support or solidarity with their parents, however this behaviour could be interpreted as unhelpful by parents. For example, from Katie and her mother Jane's shared reflections, it was evident that there had been animosity between the children and one particular PA. Jane responded by rearranging her PA hours to fit around times when the children would be at school, keeping them all apart as much as possible. However this did not address the cause of the problems, and feelings of tension and frustration remained. Now in her twenties, Katie has developed new insights into this time in her life; she expressed feelings of guilt at not supporting mother more, but also regret that her mother had not been more emotionally available at the time, providing the support and guidance she and her brother both needed:

> It's really hard looking back, because I know that I didn't do as much as I wanted to, to help her. But then, I was only a kid. I think the problem was because she was so focused on trying to keep the house together, we almost got a bit lost. We didn't really think about what we wanted to do – she didn't have enough time to focus purely on, like: 'What are you going to do? How is your schoolwork? How's this? How's that?' (Katie)

This highlights the nuanced and complicated feelings which can develop for children whose parents use personal assistance.

Lydia promoted friendly but distant relationships with her PAs. In this way, she avoided emotional entanglements with her employees, and found it easier to maintain her primacy both as parent and employer. PA support enabled Lydia to use her time and energy more efficiently, however she acknowledged that her desire to be 'in charge' may not always have been helpful in her relationship with her daughter, Summer:

> Having a PA is a huge invasion of privacy, however much you like the person. I think perhaps I could be a bit selfish sometimes. In that, well, this person's for me, not a friend for Summer. It was important to me that Summer got on well with the PA when she was little, but I

> don’t think she was upset [when they left]. Well, I’ve never asked her. (Lydia)

It seems that the experience of employing a PA can sometimes add to the stresses of family life and may not always be as helpful and supportive as parents anticipate. Certainly, having reflected on her experiences throughout her son’s childhood, Phoebe strongly expressed that PA support had been a barrier to her parenting and limited her options as a mother. She felt that having regular PA support led her to rely too heavily upon paid workers to meet her practical and emotional needs and stopped her from forming sustainable ‘real’ friendships with other parents of young children in her local community. Although she acknowledged that PA support was undeniably helpful in the short term, overall, she felt it had disempowered her and left her extremely dependent upon her PAs. Phoebe described the unhelpful and enmeshed relationships which developed with two of her PAs, who worked for her for many years, gradually gaining power within the family environment and influencing her decision making. She was left with overriding feelings of guilt that her relationships with these PAs were a distraction from her parenting role and ultimately, from her relationship with her son, concluding:

> It didn’t enhance my relationship with Tom at all. It did the opposite - it *didn’t* enable me in my parenting role really. It took my attention away from Tom. So, actually, I’m not sure having a PA *was* that successful for me, being a parent, if I’m honest. (Phoebe)

Despite reaching this conclusion, Phoebe continues to use PA support, whereas Andrea, who also experienced problems with managing her PAs decided that the only way she could take back control in her life was to stop being an employer. Andrea feels that switching to using agency support has freed her to take on a new challenge of home-schooling her daughters:

> I tell you, I feel so much better. I was a *shadow* last year, you know. But making the choice *not* to be the employer, *not* allowing them to have that hold over me any more, has really released me. So, now I’m a ‘home-ed’ mum and I love that identity, it’s so amazing that I am able to be part of my children’s *learning*. (Andrea)

Summary

This chapter has examined the interactions between parents, children and PAs in the context of managing behaviour within the parameters of family rules. Relationship dyads have been used as a means of examining these relationships more closely, and this approach to the data has helped to shed light on a range of factors which influence and shape both individual relationships between PAs, their employers and their families, as well as the relationships at the centre of this study, those between parents and children. Factors such as: quality of communication, power, control and confidence can directly affect the parent/PA relationship, which in turn establishes the character and tone of PA/child interactions. Data show that a strong common theme, shared by all participant groups, relates to feelings of being observed and judged by others, with children expressing their views on this aspect of family life most emphatically.

The power of place is a significant factor in these relationships, as the intimate space of the family home both physically shapes the ways in which individuals encounter and relate to each other and conveys meaning and power to those who ‘belong’. For many parents in this study, using PA support not only provides them with the assistance they need to live independently, but it also frees them from possible dependence on their children for care. However, it is evident from the data that the lived reality of family life with PA support is far from straightforward, and there are complex layers of worry, concern and inter-dependence which parents and children must traverse. This can leave some families with enduring negative feelings of guilt, frustration and self-doubt.

Part Four:

Discussion and conclusions

Chapter 8: Discussion and recommendations for policy and practice

Introduction

This study set out to understand parenting with PA support and the relationships between disabled parents and their children, exploring the significance, influence, meaning and consequences of employing a personal assistant to support family life. Through speaking directly with those with lived experience, specific insights into the role of the personal assistant in shaping and supporting parent-child relationships have emerged, and a deeper understanding of the consequences – both positive and negative – of employing a PA has been gained.

Whereas the literature review situated the topic of this dissertation within what is currently known about disabled parenting, personal assistance and children's views, it also exposed the gaps in our knowledge about these experiences. This prompted several questions which this study has shed additional light and new perspectives on. For example, data evidence the wide range and variability of tasks which PAs undertake to support disabled parents and their families; more is known about how parents, PAs and children experience their interactions and the effect of these on the parent/child relationship. A greater understanding has been gained of the role of personal assistance in preventing children and young people from becoming 'young carers', and new insights have been gained into the inherently complex dynamics of these relationships.

The empirical material presented in the foregoing chapters has shown the tensions and challenges which exist in the interpersonal relationships between disabled parents, children and personal assistants. They described how these three groups interact together as part of everyday family life, to share the tasks of parenting (chapter 5), revealed the complex and dynamic nature of these relationships (chapter 6) and examined the ways in which individuals seek to ‘manage’ each other’s behaviour (chapter 7). This discussion chapter reviews key themes and insights which have emerged from this study, considering them further against the existing body of knowledge explored within the literature review. It also provides an evaluation of the study as a whole, ending with a discussion of implications and recommendations for future policy and social work practice.

Overview

Findings from this study highlight the complexity, intensity and fluidity of relationships which exist in families using PA support, and reveal the dichotomies and tensions deeply embedded within these.

Parents identified that having ‘good’ PA support had enabled them to be the parents they wanted to be: with this in place, they were able to make real choices about how they raise their children, and to effectively manage the practicalities of family life alongside living with impairment. Within this study, parents used PA support to meet a wide range of practical needs, including support with feeding, bathing, dressing their children and putting them to bed, managing transport to attend school, family events and extra-curricular activities, support to play and interact with their child(ren) and to manage behaviour and instil family rules and discipline. In addition, parents spoke about the emotional support provided by PAs, with whom they may discuss concerns about the social, emotional and educational development of their children. PAs can also provide important emotional support to children; sometimes, as findings from this study suggest, simply ‘being there’ to care for the parent enables the child(ren) to focus on school or other activities outside of the home, supporting them to learn new skills, participate in hobbies and interests and develop friendships. PAs may also offer a supportive but ‘impartial’ listening ear and advice to children.

In these different ways, ‘good’ PA support can reinforce and support the development of close relationships between parents and children and enhance a loving and stable home environment. This is an important finding, and one which supports the limited literature available on this topic (Wates, 2003; Olsen and Tyers, 2004; Commission for Social Care Inspection, 2009; Selandar, 2015). These findings are also consistent with literature reporting favourable outcomes to users of direct payments, including high levels of satisfaction, increased control, improved self-esteem, enhanced relationships, and new opportunities for interpersonal, vocational and lifestyle development, as a result of greater flexibility and freedom of choice (Glendinning *et al.*, 2000; Stainton and Boyce, 2004).

Within this study, most participants spoke about their support relationships as being positive and helpful; factors these relationships share are mutual commitment, open communication and a degree of emotional warmth or regard. Yet while creating and maintaining these relationships is a joint endeavour, they contain various aspects of asymmetry which creates potential for conflict. For example, PA users have the power to set the tasks and terms of their workers' employment: they can 'hire and fire'; yet in reality, disabled parents are often uniquely dependent on the support of their PA to manage daily life, which may include living with and managing fluctuating pain and fatigue, alongside the demands of caring for children and other family commitments. Parents can sometimes feel undermined by their PAs, leading to further tension, frustration and weighing up difficult decisions: Will attempting to discipline the PA make any difference, or will it make matters worse? Would it be possible to find another, better PA? Or should they just 'put up with' the PA they have and accept their shortcomings? Compromise and cooperation are essential to make these relationships work, but this is not necessarily easily achieved nor equally felt. Previous research demonstrates the importance to disabled people of being able to select the person they want for the job (Stainton and Boyce, 2004), however the experience of making 'mistakes' in recruitment is common (Christensen, 2009, p. 127), as this study also showed. For disabled parents, the consequences of hiring the 'wrong' worker are felt by the whole family.

In their study of personal assistants based in Sweden, Ahlström and Wadensten (2010) describe the dilemma which PAs face in maintaining a balance between professionalism and friendship. The lack of differentiation between the professional sphere of the PA role and the private arena of the disabled person can lead to what the authors term “incomplete mutuality” (Ahlström and Wadensten, 2010, p. 185) in relationships, whereby PAs include the disabled person in the relationship, but this is not fully reciprocated. This can make PAs feel unappreciated, depersonalised and insecure in their role. Conversely, findings from this study demonstrate that PAs actively managed or limited the level and degree of personal information they shared with their employer. This supports findings from a more recent UK study (Porter *et al.,* 2020). The position of teenagers and young people was somewhat contradictory: they did not wish to include PAs in their lives, preferring to maintain a clear physical and emotional distance – yet they spoke in terms of affection of PAs who made a difference in their lives and did not blur into the anonymity of being ‘just another worker’.

Previous studies have demonstrated the tensions and ambiguities that are inherent in personal assistance relationships which operate on a number of different levels: they are personal yet professional; practical and emotional (Woodin, 2006; Christensen, 2012; Porter *et al.*, 2020). Certainly, findings suggest that the involvement of a PA in everyday family life inevitably adds a layer of complexity to what may already be a difficult or uncertain situation. This can create a constant note of anxiety which forms a dissonant accompaniment to family life: parents and children alike spoke of their worries about the long-term sustainability of support relationships, and the disruption to their lives should highly valued (or even not-well-liked) PAs leave their employment. Families in this study felt their lives were open to scrutiny and a level of judgement which families led by non-disabled parents are not subject to: they are unable to ‘edit’ what the PA sees and hears while they go about their duties in the heart of the family home, as they might with visitors by appointment, or those present for shorter periods of time. For example, PAs may work for several hours each day and be on hand at stressful times, such as when children are tired or unwilling to co-operate with morning routines, school runs, mealtimes, and bedtimes.

The crucible of family life can create an environment in which intense relationships quickly form between individuals. This can be experienced as positive, however it can also be an unwelcome development, and lead to unpredictability and instability; given the speed with which these relationships can develop, they can become difficult to manage and boundaries which parents had intended to set in place and maintain may soon become overstepped and blurred as everyday life unfolds. Some parents and PAs described a feeling of ‘just clicking’ with each other and rapidly reaching a mutual understanding in their relationship. Not all participants experienced this however, as some PAs spoke about how difficult they found it to gauge what their employer might want from them, and they admitted to finding it emotionally and mentally draining at times to work out how they should respond. Parents too, spoke about how tiring it can be to constantly manage various aspects of their life: dealing with a PA was just another variable to consider amongst many others. This supports earlier research on direct payments which reported difficulties and dissatisfaction among direct payment users regarding levels of responsibility and commitment (Clark *et al.*, 2004).

PAs in this study conveyed mixed feelings about their role, even where they were happy in their work at present – on the one hand, some gained satisfaction from providing high quality support and of reaching the stage of ‘just knowing’ how to respond to different situations they encountered in their working role. Yet at the same time, their feelings of loyalty to parents and their children, as well as awareness of their ‘expert’ status, ‘tied’ them to the role more than they would like, making it difficult for them to contemplate leaving to take up alternative employment which may actually suit them better. Although there can be beneficial flexibility when being employed by an individual, some PAs found it extremely difficult to broach a conversation with their employer about altering terms or conditions of their employment, for example reducing their hours. One PA even expressed guilt about the possible impact her own longer-term plans to start a family might have on the family she worked for. This finding supports earlier research, where PAs expressed feelings of guilt at the prospect of leaving their role (Ungerson, 2005), and reflected that being so closely involved with family life was a "double edged sword" (Leece, 2010, p. 202). Conversely, some PAs expressed that the low status of their role, which had no prospects of career development or even a pay increase, was not a long-term option, but something they considered as being a helpful transition to a new career, or something which suited their life only at present and not in the long-term.

Most parent participants spoke broadly positively about their experiences of employing PAs. Nonetheless, all had at least one – sometimes many – difficult or stressful encounters to relate. Indeed, conflict can frequently occur within the unregulated relationships which exist between disabled people and their personal assistants, and examples were reported of exploitation, manipulative behaviour and criminality (including theft) by PAs. Similar findings are evident in the literature, which show that 'trouble', involving emotional dilemmas and inter-personal conflict, is often found in direct payment relationships between disabled employers and their personal assistants (Porter and Shakespeare, 2019). The development of negative relationships can be extremely damaging to individuals and families; these have the potential to be disempowering and can even create a barrier to parenting. Where strained dynamics exist between parent and PA, parents may become concerned about being judged negatively by their PAs, fearing they may 'report' them to social services. This concern adds to the pressure that many disabled people already feel about being viewed negatively by society, as individuals and as parents – certainly, research suggests that children with disabled parents are over-represented in the looked-after system (Wates, 2002).

Living lives which are populated and heavily monitored by a range of professionals, many disabled parents seek to manage their anxieties and mitigate risk by investing emotionally in the PA relationship, building warm connections with workers in the hope that they will remain on friendly and 'loyal' terms with them. These parents also explain at length their parenting choices and decisions in the hope that PAs will understand and respect their choices. Not all parents take this approach however, as some prefer to adopt a more distant style, defining and maintaining a clear role within the family for PAs which is based on the completion of defined practical tasks rather than broader, less structured, outcomes.

During the analysis process, I became interested to understand how or why parents interacted with their PAs in these different ways, and the effect this had upon parent/child relationships. I considered that factors such as personality styles and preferences could be operating in different situations, as could earlier experiences of managing working relationships with others. However, it became apparent that individual experiences of both acquiring impairment and parental identity have a significant impact on parent/PA relationships, as detailed below.

The impact of life stage

On examining the data closely, it is evident that whether parental impairment is lifelong, or acquired at a later stage, can have a significant impact on parental views, expectations and experiences of using personal assistance. Although Selandar’s (2015) research indicates that life stage has an impact on interactions between parents and PAs, elsewhere within the literature, the influence of this dynamic on support relationships has not been widely examined nor fully appreciated. However, there is a literature more broadly on disability and the life course which reflects the barriers disabled people face relating to choices and expectations around the socially valued role of parenting (Priestley, 2003; Shah and Priestley, 2011).

Findings from this study support Olsen and Clarke’s (2003) analysis which highlights the significance of change for disabled parents and their families, both in terms of individual experiences of transition to parenthood, and broader changes in family composition. They emphasise the need to understand the experience of disability in relation to changing experiences of parenting, changing demands of the parenting role and set this within the wider context of relationships (Olsen and Clarke, 2003).

This study also provides new insights into the complex intersection of impairment, life stage, parenting and personal assistance, indicating that greater attention and prominence needs to be given to the combination of these factors. Similarly, findings suggest that children and young people respond differently to PA support dependent on their age, with teenagers especially finding personal assistance difficult to adjust to and accept. Within these perspectives, there are subtly different views; further research is required to refine this transitional model, which is discussed below, starting with a consideration of parental views.

Transition from disabled adult to disabled parent: (John, Frank, Naomi, Gina, Sofia, Lydia)

These parents had either been disabled from birth or had acquired an impairment in childhood. Most of them were long-term PA employers and many had always expected to use paid assistance if they were ever to become parents. In some instances, individuals had been told in no uncertain terms they would ‘never’ become a parent, and yet they overcame various barriers to achieving this, including layers of negative attitudes from medical and other professionals and family opposition or concern about their ability to ‘cope’ as parents.

Notably, the study participants in this category identified strongly as Disabled People in the political sense, aligning themselves with social model perspectives. Literature highlights the important contribution made to research by disabled experts by experience (Boxall and Beresford, 2013; Fox, 2016), and many in this group were actively involved with user-led organisations, concerned with promoting the rights of disabled people to bring about equality and social change. As well as having a strong positive identity as a Disabled Person, these participants reflected on other roles and diverse and positive identities (including sportsperson, student, writer, entrepreneur) which were important to them at this earlier stage in their lives, seeing these identities as a way to both to express their individuality and reject being ‘defined’ by their impairment.

Having become parents, there was a shift in self-perception, with former identities being somewhat set aside as the parental role assumed primacy. Naomi exemplified this attitude, reflecting on how her ideas of self and identity have evolved over the years. Although she described herself simply, as being ‘just mum’, it was evident that achieving this identity was by no means straightforward as it held within it many layers of complexity. For Naomi, becoming a mother was her greatest achievement and she recognised both the power invested in this role and the challenge she presented to the world.

Becoming a parent is undeniably a life-changing event, and one which can create a seismic shift in identity, whether we are disabled or not. This may be especially so in the earlier years, when family life is structured around the needs and routines of a baby or young child, and parents can feel overwhelmed at times by the physical and emotional demands placed on them. Although participants in this group spoke about their willingness to be a role model for others, and to challenge negative assumptions about the perceived dependence or passivity of disabled people, this was considered a positive by-product of being an actively-involved parent to their child(ren). Being focussed on their child and providing a nurturing and stable family life sets a powerful and positive example of what disabled people can achieve, and is an example of the ‘personal being political’ (Hanisch, 1969).

Data indicate that the transition to parenting for mothers and fathers is very different, suggesting that society places different expectations upon disabled men and women. Findings from earlier research indicates that the experience of impairment and disability can both constrain the performance of fathering and provide opportunities to father differently (Kilkey and Clarke, 2010). Further research is required to fully understand the experience of fathering with personal assistance, and how relationships between fathers and their children can be best supported, however there were interesting insights from this study. John and Frank were the only fathers who participated in this research; although they have very different lives and individual experiences, they appeared to create more formal and ‘compartmentalised’ relationships with PAs than most other parent participants. For example, John uses PA support each day with personal care tasks and to access his work environment. In addition, once a week, when his wife is at work, he has a ‘daddy day’ with his daughter. On ‘daddy day’, the focus of PA support is caring for his daughter, and they visit soft play centres, local parks or amenities. John’s PA is therefore present in many areas of his life, from the intimate setting of his home, to when he is delivering professional presentations. This echoes literature which describes some workers ‘sharing the inner circle’ (Marquis and Jackson, 2000) of the disabled person’s life.

Another participant’s experiences suggest that there may be a difference for individuals in making the transition from being an independent disabled parent (that is, someone with no formal support needs), to one who requires personal assistance. While limited data is available on this, Lydia’s perspective was unique within this study: of all the parent participants, she created and maintained the most emotional distance between herself and her PAs. Lydia had been fully independent throughout her childhood and adult life and managed without support for several years after her daughter was born. However, having sustained multiple injuries in a serious car accident, she needed additional support with personal care and to get her daughter to/from school. Lydia found this transition a difficult one and struggled to negotiate successful relationships with her PAs, even avoiding being in the house with them at times. Over time, she found a way to accommodate personal assistance alongside family life by developing clearly-defined and business-like relationships with her employees, fostering a friendly atmosphere, but limiting any emotional involvement. Lydia’s PAs may facilitate her parenting, but in no way do they become a part of family life.

Transition from non-disabled person to disabled parent: (Phoebe, Andrea, Amber, Jane, Cathy).

These mothers became affected by impairment issues either during pregnancy or after becoming parents. Temporal factors are again apparent, as the data indicate subtly different experiences for parents, depending on when they become disabled.

For the two participants who become disabled during pregnancy, parenting with PA support was a something they spoke about in highly negative terms: while other parents also shared some adverse experiences of using PA support, this was most strongly expressed by Andrea and Phoebe. Becoming affected by impairment issues whilst pregnant meant that they had the simultaneous experiences of adjusting to parenthood, becoming a disabled person, and having paid support in their lives for the first time. These mothers both concluded that PA support with parenting did not work for them, reaching this decision for different reasons and at different stages of their children's lives.

Andrea, whose children were aged 6 and 7 at the time of interview, first employed PA support when she was pregnant with her eldest child. This was a difficult time for both her and her husband, and looking back, she felt their relationship deteriorated from this point due to the pressures of change in their lives. Andrea is now raising her children as a lone parent. Despite several experiences where she found PAs to be unreliable and manipulative, she continued to use PA support following her relationship breakdown, feeling she had no alternative for the safety of her children. Over time however, Andrea's health has slowly improved, and although she still requires regular paid support, she now chooses to use the services of a regular childminder and a care agency, putting the time and energy she previously used managing staff into home-schooling her children. She finds this much more fulfilling and rewarding.

Phoebe has used PA support for over twenty years. She continues to employ PAs, however she expressed strong negative views about having

PAs so closely involved in family life. Over the course of her son's childhood, Phoebe employed several PAs, many of whom stayed with the family for several years. Having reliable, regular support from a small team of workers would seem a positive solution to meeting the needs of disabled parents and their families, yet despite this level of support – in fact, *because* of it – Phoebe reflected that the experience left her feeling socially cut-off and disempowered:

> I've been isolated. Having direct payments, being an employer as a disabled parent has been an extremely lonely existence. It *was* a very difficult time. I *resented* having people in my house when Tom was younger. And it was very, *very* difficult for me to make friends with other mums. I think that's down to having PAs. Everywhere I went, I had a PA with me. They get in the way, they do. (Phoebe)

Despite her experiences, Phoebe feels that directly employing PAs remains the best of the limited options available to her, although she stated she would not recommend using PAs to other disabled parents. Having carefully considered how to best use PA support, she has changed her approach, measuring her achievements rather than simply the hours of support provided.

Other parents in this group became disabled later in their lives, experiencing the onset of illness or impairment once parenthood was more established. This meant their transition was from non-disabled parent to disabled person/parent. Amber's first PA started working for her when her daughter was 6, whereas Jane and Cathy both started using PA support when their children were teenagers. In this sub-group, individuals identified most strongly as parents. Whilst they had acquired a positive identity as a Disabled Person, and were involved to some degree with user-led organisations, they were not highly politicised in terms of talking about a wider rights perspective in relation to parenthood and did not link their situation to specific models of disability. These parents initially found it difficult to accept they needed support; Amber, for example, had worked with disabled people in her career, and found it hard to adjust to being the focus, not provider, of support. For Cathy, it was not until her daughter received support for her needs as a disabled young person in her own right that she was able to identify that she, too, needed and would benefit from PA support.

Initially, parents in this group ‘got by’ with informal and/or family support before agreeing to consider longer term paid support when it was apparent that this was unavoidable. Although these participants had experience from their working lives to bring to their experience of employing PAs, they found it difficult to use these skills within their personal lives and in the home environment. So, whilst these parents had both experience and transferable people management skills, applying this within the context of PA employment proved challenging alongside adjusting to lifestyle changes which had accompanied acquiring an impairment, and the unpredictability of family life. For Jane, setting and maintaining a boundaried working relationship with PAs proved extremely difficult in the informal setting of her home; she struggled to deal with the emotional side of her interactions with her PAs, often feeling ‘caught’ between PAs and her children, who were critical of each other, and also of her. This was disheartening and frustrating and led to feelings of guilt and self-doubt.

While these parents had strong positive identities as parents, feelings of regret were also expressed, relating to their impairment and the consequences of this. For example, Amber reflected that her daughter’s experience of childhood had inevitably been changed by her illness:

> I used to feel that I wasn’t a proper parent because, you know - seeing what she’s seen in life, at a young age - me in hospital, being ill. It’s made *her* a different sort of person. I mean, she might have been a caring sort of person anyway, but I think it’s brought out that side of her. I think it’s affected her (pause) She didn’t have that sort of innocence, of being care-free in childhood. She lost that. (Amber)

Although adapting to change was practically and emotionally difficult to deal with at times, overall, parents in this group felt secure and confident in their role as parent, feeling their relationships with their child(ren) were not harmed by the presence of PAs.

Children’s views

As noted in the literature review, relatively little has been published on children’s experience of growing up with disabled parents, or their views of personal assistance. However, there is a range of relevant related material to be found within the literature which provides important insights into their lives and experiences, including a significant body of work on ‘young carers’ issues. Careful reading of this literature reveals that children whose lives and families are affected by impairment can experience a bewildering array of mixed and difficult emotions; they may be preoccupied with issues of ‘difference’ and ‘normality’ and feel judged by their peers. Additionally, those with direct experience of personal assistance may feel this is an unwelcome intrusion into their private lives. This study builds on the existing body of knowledge and demonstrates the additional complexity that living with PA support can generate.

Children had mixed and sometimes fluctuating views on the role of PA support. As with their parents, this variability seems connected to when personal assistance first became a feature in their lives. For younger children, especially those whose parents had a lifelong impairment or complex physical needs, there was an acceptance of personal assistance being part of their ‘normality’. Yet these younger participants were also conscious that their home and family lives were different from their peers whose parents did not use PA support. While some younger children resented being ‘told off’ by PAs, overall, they accepted their authority to enforce family rules, and tended to speak positively about individual workers who they liked being with, and whose qualities they valued. For example, popular PAs are good at cooking, help with homework, take children to extra-curricular clubs, give them birthday or Christmas presents, and are good at ‘finding things’.

When children became older, however, they tended to view personal assistance less positively, and for many, PAs became an unwelcome intrusion in their lives and homes. In teenage years, PA presence or direct intervention was generally unwanted and could lead to resentment and frustration, with young people tending to withdraw from the shared parts of the home to the privacy of their own rooms to avoid unwelcome interactions. Young people sometimes expressed negative views about workers, judging them as ‘lazy’. They too felt judged by PAs who compared them negatively to their own children, passed comment on their appearance, school grades or the tidiness (or otherwise) of their rooms. Unsurprisingly, this could lead to conflict within the family.

Not all teenagers and young adults expressed strong negative views about PA presence in their lives, certainly, many spoke warmly and positively about individuals who had provided them with valued support and guidance. Nevertheless, it was clear that mixed and conflicting feelings are not uncommon among children who grow up with PA support.

PA styles – a responsive continuum of involvement

Just as disabled parents and their children have shifting personal perspectives on employing and managing workers, PAs have individual preferences and styles of working which can influence their level of engagement with families. Findings suggest there is a responsive and constantly evolving continuum of PA involvement with family life. At one end, the PAs are peripheral to family life; these workers are important to the functioning of the family and have valuable roles to fulfil, but as individuals they are incidental and ultimately replaceable. At the other end of the spectrum, PAs are fully immersed within and become an integral part of family life; their relationships with parents and children operate at a much deeper level than those of more peripheral workers, and hold meaning and emotion to all those involved. Data show that the position of workers along this continuum is not static, in all relationships there is potential for change.

The different approaches and motivations of PAs are described in earlier research (Guldvik, 2003), which proposes two mutually exclusive ideal types of PA – ‘Huma’ and ‘Pragma’, each characterising different values and preferring different types of relationship. Huma PAs seek affective attachment whilst Pragma PAs focus upon instrumental outcomes; one relationship is marked by intimacy and friendship, the other by professionalism and distance. Guldvik (2003) also proposes a continuum of PA styles, suggesting that individuals remain static within this. By contrast, findings from the current study evidence a measure of fluidity, so that while PAs may have a preferred level of involvement or style of working, their position does not remain fixed, but the degree of engagement in family life can be 'dialled up' or down according to changing situations or the needs of the family.

A notable insight provided by the study sample, which included some PAs who were employed by the same disabled parent, suggests that families can accommodate and even embrace a wide range of flexibility from their workers, employing individuals who have very limited involvement with family life alongside others who are fully absorbed within it. As the sample of PAs also included those with experience of working for several families led by disabled parents, it was evident that the same worker can be fully immersed in one family unit whilst operating much more peripherally with another. This may suggest it is the employer who sets the tone and level of the relationship, with PAs responding accordingly. However, factors which appeared to influence the degree to which PAs are involved with the family include: the types of tasks required of them, the amount of hours worked each week, the degree of interaction with younger children and the length of time employed by the parent. In addition, factors such as personality, rapport, empathy and affection are also influential. This is described in more detail in what follows:

Peripheral PAs

PAs involved in this study who operated at a more peripheral level talked about being 'shadows' or 'ghosts' – on the edges of, or outsiders, to family life. Their language echoes previous studies into the experiences of nannies, who spoke about the tensions of being simultaneously needed but not necessarily wanted by families (Macdonald, 1998). These PAs described in detail the cognitive processes which engaged them; this was somewhat unexpected, given the broadly practical nature of the PA role. Peripheral workers were greatly concerned not to take control of the situation, nor to act without due consideration of the consequences. They did not invest heavily or emotionally in their relationships with either parent or child(ren), seeing the role as essential, but themselves as secondary, aiming to promote and prioritise the emotional bond between mother or father and child. These PAs were highly reflective individuals, with some describing themselves as ‘natural spectators’, not naturally comfortable in taking leading roles. Perhaps some degree of alignment between individual traits and role performance is to be expected, and that those who prefer to minimise their visibility will tend to operate in a more peripheral capacity. Yet despite the seemingly straightforward, hands-on nature of the role, PAs wishing to remain at the margins of family life saw their function as inherently complex and political – they positioned themselves in solidarity with their employer and made specific links to the social model understanding of disability.

Literature suggests that developing a sense of “interdependence and common concern” (Guldvik *et al.*, 2014, p. 58), between PAs and their employers can be an advantage to both parties in the support relationship, however Christensen (2012, p. 407) cautions against developing a “too strong” degree of solidarity as the development of a ‘companion’ role can set up a tension with the role of employee and turn into unpaid work. Evidence suggests it was not possible for peripherally-acting PAs to remove emotion from their work encounters: two participants spoke about their strong feelings of frustration, prompted by their employer failing to direct them, causing a situation where they felt they had to ‘take control’. This led to feelings of failure at acting in a disempowering way. This fits with Guldvik’s (2003) study, where both Huma and Pragma assistants experienced problems related to passivity on the part of their employer.

Peripheral PAs also described feeling ‘burnt out’ by their work experiences. This echoes findings from research which identified physical and emotional stress-fatigue among PAs who found it hard to strike a balance between personal life and work (Matsuda *et al.*, 2005). Ultimately, where the PA role was one of subservience to the employer and the unique skills and individual contributions of the PA were not recognised and valued, the job was unrewarding and unfulfilling. These PAs went on to other roles which they found challenging and personally rewarding, set in more conventional work environments. This example may demonstrate the difficulties of setting aside one’s personhood to act as a ‘tool’ for another individual.

Whilst the PA role by its very nature brings about a relationship between parties, the relationships developed here tend to be on the ‘cooler’ end of the spectrum as described by Ungerson (2005). There may be some friendly feelings between PA and parent, but these are more akin to being ‘colleagues’: there to ease the working relationship, but not significant or long-lasting in nature or degree. Relationships with peripheral PAs tend to cease once they leave their employment.

Immersed PAs

The majority of PA relationships described by participants in this study are located towards the more immersed end of the continuum. Here, while PAs were motivated to move into this work by financial reward and the flexibility this role provides, they (sometimes very quickly) formed strong relationships with parents and children, becoming firmly embedded within the family unit. These connections often endure, and PAs can remain in their employment for many years, with relationships taking on a quasi-familial character. As PAs become more deeply involved with family activities outside of their working hours, so there is a blurring of boundaries between ‘work’ and ‘not work’. The discussion of blurred boundaries is a common feature of the literature concerning personal assistance (Glendinning *et al.*, 2000; Christensen, 2012; Graham, 2015; Porter *et al.*, 2020). In the current study, some PAs participated in family functions or activities on an unpaid basis and in this way get to know close and wider family members on a social level. Emotions are much more actively and openly involved – interviews with immersed PAs contained lots of talk about ‘love’, especially in relation to children, but they also spoke of affectionate relationships with employers, whom many warmly admired. Very often, the PA’s own family is introduced to the employer’s family, sometimes their children become friends, and participate in family outings or activities in school breaks, even sharing family holidays. In this way, the blurring of boundaries between individuals and families escalates.

By contrast to PAs working more peripherally, those who had experienced a high level of involvement within their employer’s family life described their role in more practical and significantly less cognitive terms. These PAs saw their role as straightforward, hands-on, and not especially complicated; there was less reflection and consideration of what they ‘should’ do in their role. They tended to hesitate less and act more quickly to intervene with children than peripheral PAs, perhaps because they are highly attuned to the parent’s needs and wishes, or perhaps because there are fewer, and less apparent boundaries to deter them. Where the PAs employment status ends, more immersed workers typically stay in contact with the family; some continue to participate in activities with disabled parents and their children as part of their lives in the capacity of ‘family friend’ or ‘honorary aunty’.

Although many parents had previously discussed the virtues of peripheral PAs in providing low-emotional intensity, practical support in a highly boundaried relationship, these same parents talked positively about PAs who are immersed in their family life and go ‘the extra mile’ to support them. They described warm and affectionate relationships shared with PAs who had supported their family for many years – in several cases for over ten years, in one family, for two decades. They talked about appreciating the commitment shown to them as individuals, as well as to their children and wider families; parents saw these PAs as ‘part of the family’ and described reciprocity in these relationships – some disabled parents ‘helped out’ with childcare over school holidays, having the PA’s children round to play with their own. Some PAs also worked in a separate capacity as a ‘babysitter’ which enabled the parent to go out in the evenings, knowing their children were well cared for by someone they knew and trusted. There were occasions when personal problems were shared, and advice sought and given on both sides. Other informal practical and financial arrangements also developed, for example one disabled parent and her PA share a love of reading and have a joint e-book account to save them both money on purchases which they enjoy discussing together.

Although many positive experiences were shared by participants who found benefits in PAs becoming deeply involved with family life, the blurring of boundaries which follows may have unexpected consequences. Data from this study support other research findings (Leece, 2010), that the development of warm, family-like relationships can instil a sense of obligation towards their employer. This can make it difficult for workers to refuse to undertake additional unpaid work, or to request a change in their working hours or conditions. More immersed PAs certainly felt a weight of responsibility for being the cause of unwanted change in their employer’s lives, and many would defer raising an issue such as this. The findings from this study suggest that whilst the development of positive emotional attachments between PAs and families can promote longevity of employment, open communication between parties does not necessarily follow.

More complex and difficult to manage emotional situations can also arise, for example, one PA in this study struggled to manage her feelings towards her employer and wider family members when inappropriate levels of affection were expressed to her as she was providing support with intimate personal care. This placed the PA in an extremely difficult and isolated position; powerful and conflicting feelings of confusion, dismay, personal loyalty towards the employer and a wish to ‘protect’ the family from harm or upset prevented her from speaking to anyone about this situation – in fact, she had never disclosed this incident prior to the research interview which took place more than ten years later.

The close involvement of PAs in family life can bring about strong emotional, romantic or sexual feelings between employers and their workers; this can jeopardise the stability of families, as was the case for Frank, whose wife had an affair with his PA, causing the marriage to break down and the family to split. Another parent described an intense and emotionally harmful sexual relationship which developed with one of her PAs before she became a parent, which led to her feeling controlled and increasingly isolated. She was only able to exit this relationship with support from other PAs. These findings fit with earlier research which suggests that the physical proximity and intimate nature of the PA relationship can set up complicated social and personal boundary confusions which can lead to employers and their PAs becoming enmeshed in complex relationships (Saxton *et al.*, 2001).

Parent/child relationships: living with competing tensions

A wide range of factors will have an impact upon how parents and their child(ren) interact together and experience relationships, for example personality, age, family situation, lifestyle, impairment and health issues can all play a part in shaping the bond between them. Findings from this study suggest that with the right support, disabled people can overcome barriers to parenting presented by their impairment, and in this way, PAs can enhance and promote positive relationships between parent and child. However, the presence of paid workers in a family can have an unpredictable affect upon, and even undermine, the very relationships they aim to support. Data from this study contribute to existing knowledge on this topic and suggests that living with and growing up with long-term PA support can alter both the quality and nature of the parent/child relationship dyad.

For example, many disabled parents expressed pleasure and pride when discussing the warm and affectionate attachments which have developed between their children and PAs. This was generally welcomed and attributed to the child's innately lovable disposition. Although most parents did not consider these positive child/PA relationships a threat to their own position in their child's affections, some parents acknowledged more complex and nuanced feelings, especially in relation to spontaneous physical expressions of affection between PAs and their children, as Phoebe reflected:

> She was very huggy. That used to annoy me really, because I used to think: 'He's *mine*. How *dare* you hug my child?' (Phoebe)

Phoebe felt usurped by the PA's instinctive embrace of her son; perhaps as individuals Phoebe and her PA express their affection in different ways, or maybe the easy physical closeness and 'hands on' approach of the PA was particularly difficult for her to observe as a young mother dealing with physical limitations linked to her impairment and needing support for the first time in her life. Whatever the case, if disabled parents can have occasional qualms or misgivings about the quality and nature of their child's relationship with their PA(s), sometimes even experiencing hurt feelings as a result, it is clear that PA involvement in family life will inevitably affect relationships between parents and their children to at least some degree.

Another area which provoked strong feelings, certainly for children and young people, was the involvement of PAs in maintaining 'discipline' and family rules. The overriding view amongst children was that this is solely a parental role and responsibility, and they found it difficult to accept being 'told off' by PAs, even where parents had given authority for them to act in their absence. Children expressed the injustice of being 'watched' by additional adults in the private space of their home and felt additional pressure to 'be good' for PAs. They became angry, resentful and exasperated when PAs 'snitched' on them to their parents. Feelings of being 'disapproved of' had adverse consequences for how children and young people felt about themselves and for their relationships with both parents and PAs.

Dealing with this dynamic situation means that for both parents and children, the experience of paid personal assistance is to live with competing tensions, dimensions of which are outlined below:

Continuity and change

Where parents use PA support, different facets of family life are affected by issues of continuity and change: these relate to both employment staff and life circumstances. These are discussed in turn:

As in other studies on personal assistance (Glendinning *et al.*, 2000), the disabled parents involved in this research place a high value on continuity in PA relationships, often investing a great deal of time and energy in nurturing these connections, in the hope that this will lead to improved staff retention. Research suggests this can be an effective strategy; Ungerson (2005) found that the warmth of support relationships was a factor in reducing the risk of them breaking down, at least in the short term. Existing alongside this aspiration for longevity in support relationships, however is the awareness that over-dependency upon certain PAs can readily develop. The competing concern arises that should these PAs quit their employment, they would be virtually impossible to replace, causing both emotional upset and significant practical problems to the whole family. This can present parents with a dilemma – how close should their relationships with PAs become?

Parents and children alike voiced concern about the impact of staff turnover on their lives. Shared research conversations between parent and child participants highlighted that children as young as eight years old can be affected by anxiety related to PA staffing issues and the prospect of unpredictable, unwanted and uncontrollable change in their lives. This anxiety can be difficult to manage.

Parent participants who were disabled before their children were born were able to prepare for the changes in support they anticipated following the arrival of a new baby. These parents expected that the dynamics of relationships with PAs would alter as the family grew and implemented new routines and practices to ensure that the support provided was firmly centred on enabling them as parents. Although preparations were broadly successful, it can be difficult to establish new ways of working, and new babies can be captivating – for example, one parent had to remind her PAs to take her crying baby straight to her for comfort when he awoke, rather than seeking to calm or settle him themselves. Other parents had similar experiences but overall found that with practice and reinforcement, practices such as picking up a crying or injured toddler and bringing her directly to the parent to comfort whilst the PA deals with first aid soon becomes second nature.

As children grow older, so their individual needs change; adapting to this inevitably affects the PA role and relationships. In this study, older children, especially teenagers, appeared to find PA presence a difficult and complicating factor within their lives. Some felt positive about their relationships with PAs, however there were also times when they felt judged by PAs or compared negatively to the PA’s own children. The likelihood of disagreements and even conflict between parents and children regarding PAs appears to increase as children become older. Reaching a suitable compromise can be difficult for parents, who may feel ‘torn’ between meeting their own needs for support and reducing the tension in the household; in one participant family, reaching a solution to the ongoing animosity between her children and PA left the parent feeling criticised by both all parties, reflecting on this time in her life as demoralising and disempowering.

Privacy vs scrutiny

A further tension exists between the desire for privacy and intimacy in the home environment, set against the necessity of bringing ‘strangers’ into the family domain. This makes parenting, which for non-disabled parents is essentially an intimate activity which only close family members and friends are party to, into something which is conducted under the (sometimes constant) gaze of others. Living with a high level of observation can be a stressful experience for both parents and children who need time and space to nurture and develop their own relationship (Malacrida, 2007). Some parents in this study require assistance with virtually every aspect of everyday life; for those who require 24/7 support, being alone with their child, even for a very short amount of time, is a rare and precious experience.

Many parents and PAs discussed the importance of ensuring the focus of attention does not become oriented away from the parent/child dynamic and towards parent/PA interactions. Nevertheless, data suggest this certainly happens on occasion, with children expressing that PAs can ‘get in the way’ of their relationships with parents, for example if they want to talk about something important and/or confidential. This can be frustrating and upsetting for children, potentially creating a barrier in the parent/child relationship. PA presence was also mentioned as a factor in discouraging children from spending time in the shared/public spaces of the house. These findings support research into adolescent’s experiences of parental impairment which suggests that children actively “create distance” (Mauseth and Hjälhmulmut, 2016, p. 861) as a way of seeking respite from difficult aspects of their lives.

A lack of privacy in the home environment, together with the increased number of adults in the household, also proved a deterrent for some young people in bringing friends home after school. In this way, PA presence can have a negative impact upon peer relationships and socialising opportunities for children. Children and young people whose parents use PAs support – and whose lives are often already full of professionals such as social workers, occupational therapists, health workers etc – can therefore feel marginalised and isolated in their own homes. However, findings from a comparative study based on evidence from Australia and Sweden (Laragy *et al.*, 2011) suggest that while home-based support inevitably leads to some invasion of personal life, directly employing assistants can provide some degree of predictability and reduce feelings of intrusion into family privacy for parents and children.

‘Normality’ and difference

Although some children and young people spoke about accepting the level of PA support in their lives as simply being their ‘normality’, they understood that aspects of their family life were very different from the experiences of their friends. Children may be particularly sensitive to societal norms, and similar findings are evident within literature examining ‘young carers’ issues (Roche and Tucker, 2003; O’Dell *et al.*, 2010; Smyth *et al.*, 2011). For some children in this study, the difference was linked directly to their parent’s impairment, but for others, the focus of difference appeared to be associated more closely to the experience of living with PA support. Children often felt that PA presence needed to be explained to their peers, who might otherwise mistake a PA for a family member or even a ‘maid’.

While children and young people were alert to the possibility of PAs being misidentified by others, none of the children in this study in any way confused the role of PA with that of a parent. And yet, many gave examples where PAs were assumed to be their parent; this occurred in a wide range of settings, including: at school (where the teachers should have been aware of the family situation), in shops, playgrounds, at children’s activity groups and in government offices amongst others.

This misidentification of PAs was something that nearly all participants had experienced. Although these are new findings, as set out within the literature review, ‘blurring of boundaries’ in PA relationships is a common theme. For example, there is some evidence that a range of structural and contextual factors can ‘push’ employers to present their PAs as friends (Woodin, 2006). Indeed, some disabled employers actively seek PAs who demonstrate the potential for friendship (Matsuda *et al.*, 2005), while a study involving disabled adolescents using PA support (Hultman *et al.*, 2015) found that where young people have few friends, PAs can act as replacements for peers. The PAs in this study felt uncomfortable at being confused as the parent, and they sought to rectify the misunderstanding quickly and quietly where possible. Parents also felt awkward in this circumstance, but above all, mindful that their child(ren) could feel upset about any confusion. Data from this study show that children as young as eight often face dilemmas about how to deal with the assumptions and preconceptions of others about their family lives and circumstances. While evidence suggests that the awareness of difference becomes heightened with age, so does their understanding of their situation and their confidence and experience in handling difficult situations.

Dealing with these competing tensions can be hard for parents and children alike and it is evident that living with even a small amount of PA support can have a significant impact on the balance of family life and how parents and children interact together. In the worst cases, ‘bad’ PA support can lead to disharmony, conflict and even create a ‘toxic’ home environment, with children witnessing arguments between adults, including angry outbursts and swearing on the part of PAs and parents. Although this can be difficult to experience, some participants spoke about how ‘getting through’ these types of situation could strengthen their bond and sense of family unity.

PA support can certainly be an effective solution to the various challenges and barriers which families led by disabled parents may face, however the evidence clearly shows that unintended negative consequences can also result, with children being drawn into complex relationships with parents and PAs, as discussed below.

Young carers, ‘not carers’, or something in between?

As discussed in the literature review, there is active academic interest in the lives and experiences of children who have disabled parents. Within this literature however, children and young people are primarily viewed through the lens of ‘young carers’, with the result that little is known about young people with disabled parents who do not identify in this way. Data from this study address this gap in the literature and provide a new perspective on ‘young carers’ issues, offering insights into the implications and complications of growing up with personal assistance. Analysis suggests that the regular presence of PAs influences the ways in which individual family members interact together, and how families operate. This can be highly beneficial, since the provision of practical, social and emotional support to disabled parents may reduce the likelihood of their children becoming carers, a situation which has been shown to have a negative impact on children's wellbeing and life chances (Clay *et al.*, 2016).

'Caring' is an issue fraught with controversy and complexity, and as with other studies (Cheesbrough *et al.*, 2017), parent participants were sensitive to the adverse connotations of their child(ren) becoming (or being identified as) 'young carers', either for themselves, siblings or other family members. Indeed, parents actively positioned their children as 'not carers' and identified reliable PA support as a key factor in preventing children from becoming involved with care tasks. Parents saw PA support as a mechanism to promote greater choice and control in their lives and to facilitate their parenting. As one parent observed:

> Because I've got help, I can do *anything.* We can go out, we can have meals out, we can go on holiday. We can do anything else we want to do. We can make plans. (Gina)

Although parents were concerned to distance their children from the label of 'young carer', one disabled parent had sought additional support for her son from a young carers group when he was aged 15. At the time, her husband was in hospital following a heart operation; although she continued to use PA support, she felt her son needed additional emotional support. He attended a few sessions, but as soon as his father was discharged from hospital he asked to stop going, suggesting he did not feel the service had been helpful.

While PA support is commonly used to help manage and complete domestic chores, parents stressed that this was focused on their needs, and their children are still expected to 'help out' around the home. Indeed, many parents reinforced the importance of children treating PAs with respect and not as if they were 'maids', to fetch and carry for them. Depending on age and suitability of task, children might take their turn at setting the table for dinner, washing up, tidying their bedrooms, vacuuming, making drinks or snacks. None of the children who participated in this study provided intimate personal care to their parents (for example bathing, dressing or using the toilet), nor did they self-identify as ‘young carers’; this fits with Warren’s (2007, p. 140) contention that helping others with these types of tasks “most clearly distinguishes young carers from other children and young people who do not assume caring roles in the family”. However, research suggests that familial bonds of affection, obligation and reciprocity can discourage individuals from seeing their relationships as anything other than ‘normal’ (Smyth *et al.,* 2011).   Certainly, the children and young people participating in this study emphasised the ‘normality’ of their situation, whilst also acknowledging differences between their own family life and that of their friends. Additionally, in discussions about the tasks and support offered by children and young people, participants’ definitions of ‘caring’ were overwhelmingly based on practical tasks, with emotional support frequently disregarded.

Younger children did not talk about ‘caring’ or being ‘young carers’, however older participants were certainly aware of this terminology and the possible impact of providing support to family members. For example, Alina and Ellee described a family of their acquaintance where the mother is disabled and has four children. Caring became a significant issue for the two older siblings when their younger brothers were born:

> The frustration was *there*. Because their mum expected quite a lot more than our mum ever did. Tilly’s got mental health problems. Really bad. And I would say that it’s down to the pressure of being a young carer. It went from nothing to everything when the babies came along. It was just one, and then she was pregnant again. Suddenly, mum needed more help and all the stuff they were used to had gone. Their world collapsed really. It *really did* have a *massive* effect – especially on Tilly. She had a mental breakdown. (Alina)

Data from this study suggest that the employment of a PA can alleviate some of the anxieties children hold about their disabled parent’s wellbeing, enabling them to focus on important school-based learning and to participate in social activities and events away from the home. It would be inaccurate to suggest however that children did not continue to experience some level of worry or concern about their disabled parent. This is perhaps only to be expected, and fits with the 'young carers' literature (Cree, 2003). However, children also spoke about experiencing anxieties over and above this, relating to the individual PAs themselves. For example, children can worry about whether the PA is conscientious and dependable. This was something else Ellee and Alina discussed together:

> You can't tell if they're trustworthy. You can't just look at someone and trust them. Because you're basically trusting a stranger with your mum. (Ellee)

> It worries me more now than it did when I was young. When I was young, I never thought about it. (Alina)

Tom also experienced significant worries about his mother's PAs, when he noticed they were becoming increasingly 'manipulative' and 'controlling' of his mother, and she seemed unable to manage the situation. This was an emotionally difficult time for him, as he described feeling anxious about the situation, worried about his mother, angry and resentful of the PAs, and helpless in knowing what to do about it. Although not attributed directly to an issue with PA support, one parent also disclosed that her daughter had experienced mental health problems as a teenager, which she described as social anxiety linked to school attendance resulting in self-harming behaviour. Things became so unmanageable that support was provided from education, youth and health services.

Of course, all children will experience feelings of tension, apprehension or nervousness at times; those who have disabled parents may have additional worries or concerns about the health or wellbeing of their parent, or a particular PA. Certainly, as set out in the earlier literature review, research suggests that the intersection of disability and personal assistance can evoke a range of difficult emotions for young people (Cree, 2003; Roche and Tucker, 2003; Hultman *et al.*, 2015; Selandar, 2015).

All participant groups were mindful of the unpredictability of relationships set up by this support mechanism – even as they pointed to PA involvement as a helpful solution to various problems or challenges which disabled parents and their families face, they gave examples of difficult situations and experiences. Although this area is under-researched, it seems that relationships with PAs are just as complex and unpredictable as all other human interactions, and their presence in the heart of family life may bring about unintended consequences. These can be positive, with some families forming longstanding connections with PAs. Adverse effects may also be felt, for example where the arrival of a PA unsettles or disrupts existing interpersonal relationships, family routines and structures. This change may require a period of adjustment and demand compromise and negotiation between individuals to resolve.

While younger children appear not to be highly aware of the relationship dynamic between their parent and PAs, as they become older, evidence suggests that children may experience a sort of ‘apprenticeship’ in becoming a PA manager. This begins with observing how their parent interacts with PAs and learning from this; over time teenagers may become increasingly involved with various aspects of managing and supervising staff to support their parents, almost as if it were a ‘family business’. Examples of this included acting on behalf of their parent to give instructions to PAs, reporting back to parents on aspects of PA performance, checking on PA hours as part of running a payroll system, or helping to oversee staff rotas and family timetables.

Data suggest that PA support may be helpful as a means of preventing children from becoming carers in the sense of providing support with aspects of daily life such as maintaining personal hygiene or keeping a habitable home environment. However, in some circumstances, the presence of PAs in family life can increase the level of emotional and other support children and young people provide to their parents, and this too, counts as ‘caring’, even though it is not always recognised as such. Research suggests that where caring becomes long-term and disproportionate to the child’s level of maturity and understanding, this can have an adverse effect upon the child's own needs and development (Aldridge, 2006). Where children's wellbeing is affected in this way, they would be considered 'young carers' under s. 96 of the Children and Families Act 2014.

The position for children whose parents use PA support varies as much as for any other child in any other family. However, their situation undeniably gives them a level of maturity, experience and responsibility which children whose parents are not disabled do not have. In this way, whilst children who grow up with personal assistance are not 'young carers' in the traditional sense, neither are they 'not carers'. Rather, their experience is situated somewhere between these positions and requires further research to be better understood.

Personalisation, individualism and collectivism

Disabled people have certainly won the battle to receive personal budgets as a right under legislation and policy. This should be celebrated; however, the war for genuine equality goes on, and findings from this study indicate that disabled parents have become an increasingly atomised and disparate group of individuals who are now much less visible and more disconnected from each other than ever before. For example, whereas several parent participants had previously been involved with user-led organisations, some of them specifically run by and for disabled parents, these groups have now all closed. This leaves disabled parents with fewer sources of support or information – indeed, many parent participants asked for advice or guidance about their situation since they did not know any others in a similar position. Some gave permission for their contact details to be shared with other parents, and by this means, this study was able to foster new peer support relationships, albeit this was necessarily very limited within the scope of this small-scale research. Several parent participants had either had their personal budgets cut or were very concerned that this would happen at their next social care review. Some reported that their care and support had not been reviewed within the past year, but worries about the security of their funding, and the impact a reduction of support would have upon their families, deterred them from seeking social work intervention, even where this may have benefitted them. Concerns about stability of support and funding are well-founded; disabled people and their families are particularly susceptible to cuts in services and welfare (Wood, 2012; Hastings *et al.*, 2015; Tinson *et al.*, 2016).

Although this study undoubtedly indicates that there are many positives to employing PAs to support family life, evidence nevertheless suggests that the way that direct payments – the key delivery mechanism of personalistion – have been implemented presents several challenges to disabled parents and their families. This is disappointing, especially given this support system emerged from the Disabled People's Movement's successful campaign which presented PA support as a means of increasing independence and control. However, in the realisation of this vision, the difference between receiving support in the community and being a part of the community appears to have been lost, and the data reveal that many disabled parents, even when they have access to PA support, can sometimes feel isolated, overwhelmed by their responsibilities, and under intense and unwelcome scrutiny in the very place where they should feel most secure and relaxed.

During the early stages of the implementation of this policy, it was widely suggested that by providing disabled people with money to spend on meeting their needs, a flourishing 'marketplace' would emerge to meet the diverse and unique needs of individuals. This, it was argued, would create real choice for disabled people looking to employ skilled PAs. However, while personalisation has become the primary mechanism for delivering support to disabled people, driving up numbers of people holding personal budgets, all parents in this study spoke about how hard they found it to recruit 'good' PAs. Families living in rural areas faced particular difficulties, but even those residing in more urban surroundings also experienced challenges in recruiting and retaining suitable workers. Simply providing people with money is not enough to ensure they get the support they need.

The policy of personalisation can be seen as an expression of the rise of individualism in modern life (Houston, 2016). However, while this new individualism has produced some positives for those who use services, it has been argued that this increasing shift in focus and concomitant disregard of the importance and power of the collective is problematic and risks limiting, rather than extending, social justice (Ferguson, 2012). It has also been noted that the policy of personalisation and its ubiquitous narrative of empowerment fails to take into consideration: “disabled people’s collective ability to analyse their situation, voice their concerns and challenge their disablement” (Dodd, 2013, p. 262). In this way, personalisation in social care and social work could be seen as a factor in undermining disabled people’s rights and creating further isolation.

Although personalisation was embraced as a mechanism which would reduce costs, increase efficiency and empower individuals by putting them in control of their care (Duffy *et al.,* 2010), it has been suggested that the ethics of personalisation are more complex than often portrayed, and that the policy of personalisation risks negatively impacting on both social justice agendas and the autonomy of service users (Owens *et al.*, 2017). The success of the Disabled People’s Movement in bringing about change during the 1980s was made possible by the development of organisations which provided opportunities for disabled people to come together and organise collectively; in this way, their voice was stronger and clearer, and their radical actions were impossible to ignore. Ironically, with the strength of their arguments bringing about the change they demanded, the voice of disabled people was tamed; many organisations which originally challenged the paucity of state services went on to become service providers themselves. For example, many user-led organisations took on local authority contracts to provide specialist services such as payroll management and/or support planning, turning from ‘poacher’ to ‘gamekeeper’ in the process. Critiques of personalisation highlight the uneasy relationship which exists between its origins in the Disabled People’s Movement and the social model understanding of disability, and the neoliberal agendas which have become associated with it (Sims and Whisker, 2014). Certainly, personalisation has broad appeal, in that is attractive to both the political left and right; as Ferguson (2007, p. 387) observes, the term ‘personalisation’ has become a keyword of twenty-first century social work, a “warmly persuasive word” which is difficult to argue against. However, the very ambiguity of this policy has led to disillusion and conflict in its implementation (Dickens, 2016); furthermore, its introduction in a time of global financial crisis has had a disproportionately negative impact upon disabled people (Pearson and Ridley, 2017).

According to Lavalette (2017), the continuing impact of austerity politics in the UK has served to mask the transformation of welfare and public sector funding cuts. The current pandemic has placed additional strain on social services, service users and carers alike. Controversial emergency legislation, the Coronavirus Act 2020, temporarily suspends the statutory duty of local authorities to conduct detailed assessments of care and support needs and to meet these needs, replacing them with a ‘power’ to provide support and services. Within a week of this legislation passing, six local authorities suspended their duties to disabled adults, including delaying reviews, reducing care packages and deferring assessments (Reyes, 2020). This erosion of rights directly affects disabled parents and their children. At the same time, disabled people who employ PAs have gained new responsibilities to ensure their workers’ safety from coronavirus. Government guidance (Department of Health and Social Care, 2020) sets out the steps PA users should take to increase hygiene levels, reduce close contact, provide appropriate protective equipment, allow time off for sick workers and set up contingency plans to meet their needs. Yet, while advice suggests individuals can use their personal budgets ‘flexibly’ to cover the extra costs incurred additional funding and resources have not been provided.

In a paper examining the implications of Covid-19 on social care support and services (Comas-Herrera *et al.*, 2020), the authors set out the increased risks to people with social care needs as a consequence of infections. As disability scholars (Abrams and Abbott, 2020) point out however, the response to this threat reveals underlying disablist values; they argue that the phrase ‘pre-existing condition’ used in official reporting of deaths has become a shorthand for both othering and devaluing the lives of disabled people. Early indications are that the current pandemic has had, and will continue to have, enormous wider health effects which place disabled people and their children at particular risk of economic hardship, social isolation and strain on family relationships (Douglas *et al.*, 2020).

The voluntary and community sector is highly sensitive to the social, economic and political conditions in which it operates and research suggests that organisations serving the most deprived and vulnerable groups, including disabled people, have been hardest hit by funding cuts (Jones *et al.*, 2016). This has led to the decline of many ‘grass roots’ support groups, with the result that disabled people have much less opportunity to meet and are arguably more isolated than ever before (Cross, 2013). For example, some parents involved in this study were previously active members of a national user-led organisation for disabled parents which provided information and support and ran a telephone ‘helpline’. However, due to funding issues and the amount of time demanded of volunteers (all disabled parents themselves) this organisation has now closed. Another, rurally based, group of disabled parents identified as a potential source for promoting this study also closed before research ethics was gained, again due to withdrawal of funding. There are some online and social media groups with a focus on disabled parents, however these are run by individuals on a voluntary basis and are typically small, with sporadic outputs on different online platforms.

Study limitations

This study offers new insights into the impact of personal assistance in the lives of disabled parents and their children; however, some limitations must be acknowledged. While maximum diversity within the study sample was sought, there is a noticeable gender bias within the sample, which is made up primarily of women. Participants also come from a predominantly White British background. Despite these limitations in terms of how representative the participants are of the general population, the group of parents in particular is widely diverse in terms of their experiences of disability and impairment, parenting and family life.

Undertaking single interviews provided a wealth of information about the lives of participants, however as data suggest that temporal factors are relevant to the experience of parenting with PA support, a longitudinal study may have been beneficial in examining changes in family lives. The one-off interview also offered only limited opportunity to establish a rapport, making it more difficult to explore more complex aspects of participants' lives and experience. To overcome this, in the pre-interview stage, communication was established with prospective interviewees by telephone and/or email to provide information about topics to be covered. This approach worked well with adult participants however there were no opportunities to communicate directly with prospective child participants prior to interview, albeit child-focussed information leaflets were provided for parents to pass on and discuss with their child(ren).

Participatory methods and tools worked well in helping younger people access the interviews, focusing and guiding the discussions, thereby enabling participants to engage meaningfully with the process. While interview materials and resources could have been improved if they had been devised and designed in collaboration with young people whose parents use PA support, there was limited scope to achieve this within the PhD project.

It was planned for all interviews to be completed 1:1 with the researcher, however the reality of many disabled parents' lives means that they are very seldom on their own. Therefore, on several occasions, interviews were undertaken with PAs, children or other family members present or nearby. This was also the case when undertaking interviews with children and young people. This will have affected the views and experiences that participants were willing to share, and on occasion, it was clear that participants carefully constructed their answers, mindful of the presence of others. Nevertheless, visiting the family home provided a valuable insight into the daily lives of families living with PA support, and the opportunity to observe first-hand interactions between parents, children and PAs. For many young participants, for whom this was their first research experience, having a parent nearby gave them the confidence to take part, which they may not otherwise have done.

Implications for policy and practice

A deeper understanding of the complex issues brought about by living with and growing up with personal assistance has emerged from this study. As a result, implications and recommendations for changes in policy and practice have emerged. These respond to specific challenges and tensions which participants to this study have experienced, and are based on person-centred, strengths-focussed approaches to social work intervention. Recommendations designed to create positive change for families led by disabled parents are suggested for policymakers, managers and service-providers and practitioners alike. Messages for parents are also included, as are suggestions for further research.

Recommendations for policy-makers

- Promote peer-support services which enable disabled parents to make better connections with each other; in this way they can share valuable knowledge and information about living with and managing PA support.

- Further development of policies aimed at addressing the complex social causes of disadvantage, inequality and discrimination which disabled parents and their children face.

- Ensure that the needs of children whose parents use PA support are assessed, identified, understood and met.

- Current covid-19 restrictions add a new dimension and challenge to care and support services. In an era of social distancing, self-isolation and shielding, essential support may need to be provided in new ways. Consideration needs to be given to how this can be managed effectively in this, and any future, pandemic.

Recommendations for managers and service providers

- Recognise the importance and value of social workers forming lasting professional relationships with disabled parents and their children; creating positive and continuing connections with social workers will enable families to seek support when they need it whilst maintaining their independence.

- Provide joint training for staff on principles of best practice relating to working with disabled parents and any local protocols, ensuring positive communication and partnership working between relevant adults' and children's team workers to best meet the needs of families.

- Promote a risk-enabling culture which acknowledges the rights and needs of disabled parents and their children.

- Provide guidance and support for practitioners on the needs of children whose parents use PA support. Evidence demonstrates these children and their families do not consider them to be 'young carers', yet the local authority has legislative duties to these children which must be balanced against the respect for private and family life and safeguarding concerns.

Recommendations for practitioners

Messages for social workers:

- Take time to understand the specific support needs of disabled parents and discuss with them the different ways these needs could be met according to their individual situation and preferences.

- Discuss with disabled parents and their families the meaning and possible impact of personal assistance relationships; this will better prepare parents and children for their encounters with PAs, leading to more positive and enduring partnerships.

- Be aware of specific factors such as life stage and impairment; these may have a profound impact on parental responses to using PA support.

- Recognise that children and young people (and wider family members) can be ambivalent about the impact of PA support in their lives.

- Be open and honest in conversations with disabled people and parents about the potential positives and negatives of PA relationships.

- Ensure that disabled parents are provided with clear and accessible information about how to manage their PAs.

- Be mindful of the wider factors which can shape the parent/PA relationship, for example: legal and contractual structures and employment practices; social understanding of the PA role; the local 'market' in care.

Messages for PAs:

- Try to be clear about your role and tasks within the family and home. Open communication is central to the success of the parent/PA relationship, but asking for guidance may be difficult at times. Speak to your employer if you are unsure of your responsibilities and/or how these should be enacted.

- Try to develop an understanding of the family ‘rules’ and your part in in supporting parents to manage these. PAs sometimes have a role in helping parents to ‘discipline’ their children and to manage their behaviour – this can be a highly contentious area of family life, most strongly felt by children and young people. Be clear about your involvement and responsibilities.

- Families who rely on PA support have to give up some of their privacy. Respect confidentiality and be prepared to work ‘in the background’ at times so that parents and children can enjoy time together, developing their relationships without feeling closely observed.

- Expect your role to change over time, as children age and develop and parental needs change. Relationships with family members may also change as you become more familiar with one another. Be aware of and open to these natural changes, recognise and discuss any concerns, and work with your employer to adapt to the family’s needs.

- It is not uncommon for PAs to be misidentified as parents, friends or other family members. This can be an uncomfortable and upsetting experience, especially for children. Talk to your employer about how they prefer to handle these situations.

- Try to resolve any issues, concerns or disputes directly and confidentially with your employer; where possible avoid children or other family members becoming involved in these matters.

Recommendations for further research

- Further research is needed about the role of personal assistance in supporting disabled fathers with their specific parenting needs, and to examine the gendered nature of parenting and PA roles.

- The impact of personal assistance in the lives of people who do not identify as White British is not fully understood. Research into the experiences of families from the Black, Asian and minority ethnic community is therefore essential.

- Research is needed into the impact of personal assistance on close family members of disabled parents, including partners, other parents, grandparents and wider support networks.

- Further research regarding children and young people's views and experiences of growing up with disabled parents would be beneficial to examine in detail the interaction between personal assistance and 'young caring'.

- This study features qualitative methodology; research from a quantitative approach would provide a different perspective. A longitudinal study would also offer new understandings into the dynamic nature of family life with PA support.

Messages to Parents

Findings from this study indicate that growing up with PA support can have both positive and negative implications for children and young people. Parents will therefore want and need to consider how they can mitigate against adverse outcomes such as feelings of stress, anxiety, emotional upset, frustration and the intrusion of privacy which some children can experience as a result of ongoing PA presence in their lives. Literature suggests various strategies for avoiding potential difficulties that may arise in employer/employee relationships. These include careful matching of the interests and expectations of PA users with workers in the recruitment phase (Guldvik, 2003); the introduction of a probationary period to ensure all parties are happy with practical and performance arrangements, and the employment of more than one worker to reduce over-reliance on any one individual (Porter and Shakespeare, 2019). Training has also been suggested for employers and PAs to promote problem-solving and help manage the 'emotion work' in the support relationship (Matsuda *et al.*, 2005).

Porter and Shakespeare (2019) suggest that a key feature of positive employer/employee relations is mutual respect and the willingness of both parties to accommodate some degree of difference in “personality, values, or modes of practice” (Porter and Shakespeare, 2019, p. 20), although they acknowledge this may be easier to describe than accomplish.

For disabled parents contemplating employing personal assistant(s), in addition to considering implementing these strategies, other suggestions include:

- Talk with children and other family members about how it might feel to have a PA involved with family life and discuss what their role should be so that everyone shares a clear understanding of this.

- Decide whether, and to what degree, PAs will be involved with managing children’s behaviour. Make sure that children and PAs fully understand decisions about this.

- Be clear from the outset with PAs about their role and expectations for involvement in family life. Set up a contract of employment, detailing terms and conditions and how any complaints or disputes will be dealt with.

- Think through how children and young people can feel involved at an appropriate level in the recruitment process. For example, parents in this study found it helpful to arrange a meeting between their children and potential PAs to gauge reactions and judge how they might ‘get along’ together.

- Find regular private family time and space away from PA support; ensure that children feel able to approach parent(s) with any concerns or issues they may have, so that PAs do not become the focus of attention and create a barrier to parent/child relationships.

- Resolve any concerns about PA performance without involving children. Support or guidance with managing employment issues is available from ACAS; some providers of PA employer’s liability insurance also offer this.

Conclusion

This thesis has shed light on the experiences of disabled parents and their children, exploring the impact of personal assistance in their lives and the interpersonal relationships they share. The study highlights the varied ways in which PA support is used by families to support everyday life and confirms that this model of assistance can be truly life-changing and life-enhancing, enabling disabled people to make active choices in their lives, and to be the parents they want to be. Evidence shows that children can also benefit from parental use of personal assistance: where reliable and trustworthy workers become a central part of the family support system, they help to promote a stable home environment and their presence substantially reduces the likelihood of children taking on significant practical caring roles for a parent, protecting them from the negative outcomes associated with this.

Participants' accounts also illustrated the complexities and challenges of living with personal assistance and demonstrated how relationship dynamics – never static in any family – can be shaped and even considerably altered by the presence of PAs. Relationships between parents and children can be enhanced and enriched with the 'right' support, however negative interactions with PAs can prove a barrier to parent/child relationships, with the primacy of parents sometimes being undermined by the actions of their employees. This can be exasperating for parents, who, due to the difficulties of finding 'good' support may find themselves in the position of having to 'put up with' less than ideal performance on the part of their workers.

Children must also learn to compromise; however, while they may accept the necessity of in-home support, the physical presence of PAs can literally 'get in the way' of children receiving the one-to-one parental time and attention they need. This can be a source of frustration for children, with teenagers expressing most strongly their feelings of annoyance at the unwelcome intrusion of PAs in their lives. Other negative feelings can be provoked: evidence shows that children as young as eight years old can feel anxious about the prospect of PAs leaving their job, or the disruption to daily life caused by new workers joining the family unit. Where children and young people hold critical views about PAs, this can result in disharmony, create tension between parents and children and even cause lasting damage to intra-family relationships.

By addressing the gap in our existing knowledge base about the lived experience of children whose parents use PA support, this study furthers our understanding. By drawing attention to the complex reality of involving paid support in the home environment, it also raises important questions for further research. While findings demonstrate that where PA support is established in families, children are unlikely to help their parent with personal care tasks, when relationships between parents and their PAs become tense or difficult, children can provide a significant amount of emotional support to a parent. Data also reveal the extent to which young people become involved with demanding tasks relating to managing paid staff, sometimes taking on substantial responsibility for overseeing employment matters or acting as an intermediary between parents and PAs.

All families are unique, and the relationships contained within them complex, diverse and dynamic; in this regard, families led by disabled parents are much like any other. At the same time, disabled people experience layers of societal discrimination and disadvantage as well as significant and numerous barriers to becoming, and being, parents. The provision of personal assistance is often regarded as a simple and practical solution that can be tailored to each family's unique challenges and problems. However, personal assistance is by no means a panacea to the problems faced by disabled parents; as some issues are 'solved', so others are created. As this study establishes, employing a PA will inevitably have an impact on family life and the relationships between parents and children; recognising this is essential, to enable disabled parents, PAs, social workers and indeed children, to be better prepared.

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Appendices

Ethical Approval Form for Research 2013 version

School of Social Work

Research Ethics Committee

All staff and students (including research staff) must obtain approval from an appropriate Ethics Committee before undertaking research involving human participants; this includes piloting. This form is for staff and students applying for ethics approval from the School of Social Work Research Ethics Committee. Information on the Committee and links to ethical guidelines are available on the School Ethics web pages (http://www.uea.ac.uk/socialwork/research/ethics) In completing this form, it is expected that applicants will refer to the UEA ethics policy and the ethical guidelines suggested on the school ethics pages (eg ESRC, BPS, JUC-SWEC) and will follow best practice as suggested by these guidelines.

1. Principal Investigator(s) ……………Nicola Jones ……………………

Proposed start date ……………1 April 2016 ……………………….

Proposed funding source (if applicable) ………………………………..

2. The Project

2.1 Title:

The Impact of Personal Assistance on relationships between disabled parents and their children.

Please attach a ***brief*** outline of your proposal that summarises your aims, sample and methods. This should include details of how you will recruit your sample and what exactly participants will be asked to do. Data collection instruments (where available) should be appended. Where interviews, focus groups or other activities/experiments or interventions are planned an outline of the content of these should also be appended. Where the development of your research materials/strategy is not yet complete but you need ethics approval to proceed, the committee can discuss with you how these other plans can be reviewed and approved at a later date.

Background

When disability is considered in relation to children, the focus is often upon the needs of disabled children and the specialist support they and their families may need to maximise their potential. There is however a larger group of children – who may or may not be disabled – living with a disabled parent, and experiencing disadvantage and social exclusion as a result of their parent's restricted access to education, employment, health services, transport and their children's schools (Newman and Wates 2005).

Whilst a wealth of literature has highlighted the needs of 'young carers' (Meredith 1992, Aldridge and Becker 1993, Siddall 1994), the labelling of the children of disabled parents in this way has been strongly criticised in disability studies literature. For example, Olsen (1996) expresses concerns that an emphasis on the needs of children can undermine the provision of support to parents and the family as a whole. Newman (2002) further notes the difficulties brought about by applying a sometimes conflicting individual rights framework to relationships between family members. More recently, the focus has shifted to consider the unmet needs and rights of disabled parents, and how these may be more positively construed. This has coincided with the ongoing transformation of adult social care and development of new services which aim to tailor support to meet the specific needs of each individual. As a result, there has been a significant increase in the uptake of personal budgets – a sum of money allocated to an individual to pay for their eligible assessed social care needs. One of the most popular uses of this funding is to pay for the services of a personal assistant (Waters and Hatton 2014) who will undertake a range of practical tasks to support the individual within their home and community.

A study is proposed to examine the interpersonal relationships which exist between disabled parents, their children, and personal assistants who are present in the family home and may undertake important caregiving tasks to the child. The research question will focus on the impact on parents and their children of having a third party involved so intimately in their lives in this way and may be expressed as:

"How do disabled parents and their children experience paid personal assistance within the home, and what impact does this have upon their relationship?"

Please note, personal assistants are referred to throughout this document as 'PAs'.

Aims

To examine relationships between disabled parents and their children, exploring the significance, influence and meaning of the PA role in supporting family life.

To develop a guide for disabled parents, PAs and social workers, providing information on possible areas of tension/difficulty in managing the PA relationship with respect to parenting support, and how these may be avoided/handled.

Access

The initial focus of recruitment will be on disabled parents as they are essential to accessing another key participant group within this study, namely their children. Suitable participants will be recruited using a range of strategies, for example formal networks such as local user-led organisations of disabled people may act as 'gatekeepers' and provide links to disabled parents interested in engaging with this project. Three local groups, Equal Lives (Norfolk), Suffolk Coalition of Disabled People and ECDP (Essex) have all agreed to support this study. National groups such as the Working Together with Parents Network and other online forums may also be used to promote the research. 'Snowballing' of participants may prove a useful recruitment technique for this 'hard to reach' group (Hennick et al. 2011).

PAs will be recruited via the same user led organisations, which also run payroll services and engage with PAs in this way. Other online forums will also be used to attract PAs and again ‘snowballing’ techniques are likely to be helpful.

Sample, scope and limitations

The study will be based geographically in East Anglia. A non-probability purposive sample (Davies 2007) of approximately 30 participants will be sought; these will be divided into three equal study population groups – disabled parents, children (aged 8 years and over), and PAs. The cohort of PAs will be recruited separately, so in most situations they will not be ‘matched’ with the families; this is felt to be important so as to avoid an overly intense focus on the family, which may be experienced as uncomfortable or intrusive for parents and their children. This is also appropriate as the study aims to retain a focus on the wider issues involved with these unique relationships, rather than be drawn into detailed investigation of particular families. Nevertheless, there may be instances where ‘matched’ PAs may be recruited to the study, for example if the ‘child’ is now an adult, and all parties consent to involvement, valuable insights may be learned by retrospective reflection. There may also be instances where ‘unmatched’ disabled parents and children are interviewed, perhaps where parents are happy to be involved, but do not consent to their child’s involvement for any reason, or where adult ‘children’ wish to participate but their parent does not.

It would be interesting and valuable to also gain the views of other individuals closely involved with the family life of participants, for example non-disabled parents, grandparents, extended family members, close friends etc. However, the necessary limitations of this project make this beyond the scope of this study, which will focus more closely on the perspectives of the individuals most directly affected by PA involvement in parenting support. There are limitations as to how diverse and representative the participants will be of the general population, as well as to the generalisability of findings, however variation sampling will be undertaken to ensure maximum diversity. The research materials and questions are reflective of anti-discriminatory and anti-oppressive practice, and some transferability may be applicable to other similar settings. ‘Easy to Understand’ and ‘child-friendly’ summaries of the study will be produced so that findings may be disseminated to a wide range of people.

Service User and stakeholder involvement in the design

Informal discussions with staff from local user led organisations, ‘young carers’ organisations, and a small number of disabled parents who have engaged in advisory meetings with the researcher have informed the development of the research question, as have reflections from the researcher’s previous social work practice and discussions with social work professionals. Discussions have also been ongoing with the researcher’s academic supervisors regarding the design of the project, and with other experienced researchers within UEA.

Methods

Social work research tends to favour qualitative methodologies to knowledge creation (McLaughlin 2009). This study will follow this convention, adopting an interpretivist paradigm to gain subjective insights into the experiences of those involved, and understand the meaning they attach to these (Holliday 2007). This approach has been chosen in preference to using quantitative methods informed by a positivist perspective, which would not provide the rich, deep data being sought.

Utilising qualitative techniques, the views of participants will be gathered by means of conducting semi-structured interviews. Individual face-to-face meetings will be arranged at a time and place to suit disabled parents and children – this is likely to be in their own homes, a place which is the location of the relationships being studied, and where they participants are most likely to feel comfortable in sharing confidential information. Where younger children’s views are sought, short conversations lasting approximately 30 minutes will be held, and accessible materials and approaches used to facilitate engagement (NCB 2010). The researcher will be led by the needs of the child/young person – it is likely that the length of interviews will vary. The aim is to hold separate interviews to enable participants to focus on their own views and experiences and, where possible, to gather the unique thoughts of each individual, uninfluenced by others. However, it may be that to access the interview process, children may wish to be accompanied by a parent or other trusted individual. Whilst it is hoped that children will be interviewed without parents present as this may elicit more/different information about their relationships with parents and PAs and how they make sense of these, the researcher will be guided by the wishes of the child/young person and their parent; if they wish for a parent to be present for the interview, this will be respected.

Telephone interviews will be held with PAs to gain their views and experiences. Telephone interviews have been shown to produce high quality data in successful in similar studies (Schofield et al. (2011), and this approach may be best suited to engage with individuals who are likely to have a range of working roles and family responsibilities who may otherwise be unable to access this study.

For all participants, the range of topics to be discussed will be shared prior to interview. This will be provided in accessible, and age-appropriate formats. This will enable individuals to prepare for the discussion, reflecting on their experiences and perhaps ordering their thoughts in advance. It is anticipated that this may be reassuring for individuals in preparing to talk about what are private and intimate areas of their life, and may help them in setting their own boundaries about what they do/do not wish to discuss. Interview guides have been prepared for the three different groups

With consent, all interviews will be audio recorded, and later fully transcribed.

Transcripts will be shared with participants either electronically or via post, as part of a data-checking process, and to allow clarification of any points raised. The purpose of this is to promote more active participation in the study, to facilitate transparency and to elicit further reflections/insights from participants on the subject which may occur to them following the interview. This technique has worked well with a previous study into PA support conducted by the applicant. For many participants in this previous study, the research interview provided the very first opportunity to discuss their relationship with PAs; a number of them expressed that having talked about their situation, they had re-ordered their thoughts, been surprised by the turn of the conversation, or various aspects of their interactions with their PAs. Participants to this study were provided with transcripts and were able to add further detail, or to amend their viewpoint following further reflection. These additions provided another ‘level’ of information which was invaluable to the study. It is proposed that this research will follow this practice, which will aid the generation of more nuanced data, and support validity. This is not an attempt to seek a greater ‘truth’ on the subject, rather an opportunity to generate more in depth data. There will be no ‘doubling up’ of interviews – additional visits will not be made to participants, any feedback provided will be in writing or by telephone depending on the access requirements of the individuals, and this will be made clear to participants prior to their involvement.

It is proposed that children will also receive a transcript or interview summary. Full transcripts will be offered to children aged over 14 years and sent to them if they request it. For those aged over 8 years but under 14 years, an interview summary will be offered and provided if they would like it. This will outline key points discussed and the views expressed. The normal procedure will be that this information is provided direct to the children; it will then be for them to decide if they wish to share this with parents. Parents will be informed about this at the consent-gathering stage. If they have any objections these will be discussed and arrangement may be modified with the agreement of all.

3. Informed Consent and Briefing

3.1 Informed Consent and Briefing

Please explain your strategy in relation to gaining informed consent from participants. Points to consider include:

- Are there any ethical issues in relation to recruiting your sample for example unequal relationships between the gatekeepers and potential participants?
- What information (and in what form) will be given to participants about the study?
- How will consent be recorded?
- What are participants consenting to in terms of uses of the data (for example will you make it clear that the data may be used in publications or for further secondary analysis?)
- What rights will participants have to withdraw from the study during or after data collection?
- For participants under the age of 18, please detail if and how you will obtain consent from parents or guardians, and explain how the assent/consent of the child/young person will be obtained.
- Is consent required from any other persons for example gatekeepers such as teachers or social workers?
- If you do not plan to gain consent from participants, clear justification for this must be made.
- Will you be offering participants any reward/incentive?

(Append copies of information sheets and consent forms where appropriate).

This study will use qualitative techniques to generate data by means of individual face-to-face semi-structured interviews with parents and children. Individual telephone interviews will be held to gain the views of PAs.

Prospective participants will be approached via locally based user-led groups in X county, Y county and Z county. These groups have offered their support to the project, however they will not provide any confidential data to the researcher regarding particular individuals, but act as intermediaries to promote the project to their members and other local disabled people via their respective websites, newsletters and other forums. Participants will also be sought via local authority social work teams – a presentation and information will be provided to front line workers and they will be asked to pass on details of the project to individuals who form the target group of this study. Online groups for disabled parents/PAs will also be approached to promote the study. All participants will therefore be self-selecting.

As this study involves seeking views of children and young people, parental consent will be required, as well as consent from the young person.

Individuals will be asked to provide consent for the data generated by their involvement to be used in the researcher's thesis, further publications and for secondary analysis by the researcher.

Accessible, child-friendly participant information sheets and consent forms have been drawn up to provide full details to prospective participants about the study, and to record written consent from participants. These documents confirm that individuals have the right to end their interview at any point, or withdraw from the study without any need for explanation. It is also made clear that the consent of any children/young people is independent from their parent's participation.

There will be a time limit within which participants must notify the researcher of their intention to withdraw from the study; this is for practical purposes around data analysis. The 'deadline' will be within three weeks of the research interview taking place, and this will be made clear to all individuals.

As well as providing full details of the project in written format, the researcher will discuss all matters prior to involvement as part of the process of ensuring informed consent is obtained.

All participants will be provided with a £10 shopping voucher as a token reward to recompense them for their time and any out of pocket expenses incurred in connection with engaging with the project.

Full transcripts will be provided to participants as outlined above to enable them to check the accuracy of the data and to clarify any points raised. These transcripts will be provided as soon as possible, but may not be available within the 'cooling off' period; again this will be made clear.

3.2 Withholding of Information from Participants

Do you plan to withhold any information from participants about the nature or purpose of your study? NO

If YES, describe your reasons for this and your plans for debriefing participants at the end of the study.

3.3 Information for Participants on Completing the Study

Do you plan to give participants more information about your research and/or findings after they have taken part? YES

If YES, how will this information be given and what will it include? (give details or attach the information sheet)?

Participants will be provided with a summary of research findings. This information will be provided in accessible formats, and adapted for young people. This summary will also be provided to the user groups connected to the study. Participants be provided with a full (electronic) copy of the researcher's thesis upon request. The researcher will also offer to hold information sharing events, hosted by stakeholder organisations, to disseminate findings more widely.

If NO, why won't participants be given further information?

4. Confidentiality, Anonymity and Data Storage

4.1 Will the data be gathered anonymously? NO

If NO, how will you protect the identity of your participants and ensure that any personal information you receive will be kept confidential?

Names and contact details will be disclosed through the interview process. From the outset each participant will be allocated a code and pseudonym. A database linking the real name and code/pseudonym will be password protected and stored on the researcher's secure office computer based on the UEA campus. No personal data relating to participants will be stored on personal computers/laptops.

Interviews will be fully transcribed by the researcher, with all names/places annonymised as part of this process. Transcripts will be shared with participants as part of a 'member checking' process to ensure that data is captured accurately, and to allow for clarification of any details.

Care will be taken to ensure that individuals are not identifiable in any resulting written document or journal article. Consent will be sought to use direct quotations; any quotations will be carefully selected, and if necessary changed in such a way that participants cannot be identified either externally, or by each other.

4.2 How will you ensure the secure storage of data both on and off site?

Hard copy original personal data (eg signed consent forms) will be kept in a locked cabinet in the researcher's office at UEA. Wherever possible the assigned code and pseudonym will be used to identify participants during the research process.

Interviews will be electronically audio recorded on a digital device with participants' consent. Recordings will be uploaded to the researcher's secure UEA computer as soon as practicably possible, and deleted from the recording device immediately thereafter. Each interview will be given a code and anonymised, using pseudonyms, immediately after transcription. All data from participants will be stored under the given case code.

All electronic data will be stored on the UEA secure shared file drive and accessible only to the researcher. No personal data will be stored on portable devices such as laptops or memory sticks.

4.3 What are your plans for archiving or destroying the data after completion of the research?

The anonymised data will be stored in accordance with the. UEA Research Data Management policy which specifies that research data should be kept and remain available for access for at least 10 years following any publication. Thereafter the data will be appropriately destroyed

5. Risk assessment: Protection of Participants

What risks and/or inconveniences might participants experience and what steps will you take to minimize these?

Be aware that interview questions or questionnaire items might raise issues that are sensitive for individual participants or may create anxiety. Explain what steps you will take to minimise this or to help participants, for example by providing information on relevant support groups or centres in your information sheet.

Where relevant, you should detail how you plan to deal with any situations where you may uncover evidence of a risk of serious harm to the participant or another person.

Risks

This study asks participants to reflect upon their experiences of PA support in relation to family life. Participants will be divided into three groups – parents, PAs and children. Within the cohort of ‘children’ it may be that adults who experienced growing up with a disabled parent and PA support, are recruited to the study. The younger age limit for participants within the ‘child’ cohort will be 8 years. Their views are valuable and welcomed as adding a different perspective and dimension to the study.

Data will be generated by means of individual interviews lasting around 60-90 minutes. Interviews will be tailored to each individual, and may be of shorter/longer duration. Interviews with children are expected to last around 30 minutes, but again may vary in duration according to the needs of the individual. Where participants request to be accompanied/supported by others to enable them to access the interview process, this will be accommodated.

Risks – interviews with children/young people

Research suggests that families led by disabled parents face significant disadvantage. It is therefore likely that children and young people involved in interviews may have faced adversity in their lives. They will also have a range of strengths and skills.

It is impossible to exclude the risk that interviews may trigger difficult feelings for a child or young person. The researcher will need to be alert to signs of discomfort and be prepared to pause or end the interview early if necessary. If a parent feels that it would be inappropriate for the researcher to conduct a one-to-one interview with their child, arrangements will be made for the young person to be accompanied/supported to enable them to access the interview process. The researcher will always check that the child/young person is happy to be interviewed alone - if they prefer to have another person present, this will be facilitated.

Advice and guidance will be sought by the researcher into best practice when conducting research with children and young people, using the resources and expertise available at UEA within the School of Social Work.

Ways of reducing stress to young people include:

- Informing participants beforehand about the areas for discussion, so they know what to expect.
- Using child friendly/accessible resources and activities to build a rapport with the researcher and to create a positive environment.

- Informing participants during the consent process that they can refuse to answer questions, take a break or stop the interview at any point. For younger children, a ‘pass’ card may be used to balance the power differential and make it easier for them to avoid questions they do not want to answer.
- Giving participants information about how to make a complaint about the interview process.
- Ending the interviews with a non-emotive topic.

If the young person is distressed or needs follow-up support at the end of the interview, the researcher will discuss with them whether they have the support they need, eg someone to talk to about issues raised, or what other means of support they would find helpful.

Young people will be made aware (through the participant information sheet and verbally) of the researcher’s duty to share information if issues arise regarding their safety or that of another young person. If this were to occur, it would be discussed and managed in careful negotiation with the young person and in accordance with local safeguarding policy and procedure.

The researcher is an experienced social worker, and will also be able to access expertise and support from her supervisors and the team of experienced researchers within the School of Social Work at UEA. The researcher will have a DBS check completed prior to engaging with any fieldwork.

Risks – interviews with disabled parents

Disabled parents face a range of discriminatory attitudes and structures within our society and as such, they may have experienced significant barriers to parenting. Disabled parents are perhaps uniquely determined individuals, and will have a range of strengths and skills upon which to draw.

The research questions are anticipated to present a low risk of harm to participants, however the topic of family life is personal and sensitive, and it is possible that discussions could bring up issues which affect an individual's emotional well-being, or cause them to bring in to question their own or others' behaviour. If necessary, the participant will be offered a break from the interview. Participants will be informed during the consent process that they can refuse to answer questions they are uncomfortable with, and can pause or cease their participation at any time.

Where necessary, the researcher will signpost individuals for appropriate practical support via their local user-led organisation and online resources around managing staff. Examples of such support/guidance include:

ACAS Employing personal care workers

Employing your own support

Being the Boss

If emotional support is required, individuals will be signposted to other relevant local universal services, and steps will be taken to encourage participants to contact a friend/relative if need be. Limited follow-up support can be provided by the researcher by phone if the participant were visibly and notably upset as a direct result of the interview process. Any telephone call would be made the following day and is offered as a courtesy only; this will be made clear to participants. The researcher is aware of the boundaries and difference between the roles of social worker and researcher, but feels that it would be appropriate to provide very limited follow-up in certain situations. The interview is not the researcher's final contact with participants, since there will be contact around sending out transcripts and updating with findings, so some minimal interaction beyond the interview itself is expected.

In the event of an issue arising whereby risk of serious harm to the participant or another person is indicated, the matter will be dealt with under the relevant local adult safeguarding procedures and according to UEA guidance. Participant information sheets include make this clear.

Risks – PA interviews

This research will address issues which arise for PAs as part of their paid employment. As such, the process presents a low risk of harm to participants, although again it is possible that discussions could raise questions about their own or others' behaviour and cause emotional distress. If this situation arises, participants will be offered a break from the interview. Participants will be informed during the consent process that they can refuse to answer questions they are uncomfortable with, and can pause or cease their participation at any time.

Where necessary, the researcher will signpost individuals for appropriate practical support via their local user-led organisation and online resources. Examples of such support/guidance include:

Working as a PA

The PA Network Scotland

Inconveniences

All participants will be required to give up their time to take part in individual interviews. All participants will be offered a £10 gift voucher as a token to thank them for their time and to convey that their views are valued. For all participants, the researcher will ensure that interviews are held at a time and in a place convenient to them.

Possible benefits

Whilst there are likely to be only limited direct benefits for individual participants, they may find it helpful and even enjoyable to have the opportunity talk through issues which have affected their lives and to be listened to. Individuals will also be contributing to furthering knowledge and understanding of this important and under-researched topic which may be beneficial to others and personally rewarding.

6. Risk assessment: Protection of Researcher

Does involvement in the research put you at risk of physical or psychological harm, distress or discomfort greater than that encountered in your everyday life?
YES

If YES, describe the nature of the risk and the steps you will take to minimise it

The researcher is an experienced, qualified and registered social worker, experienced in conducting 1:1 meetings with disabled people in the community and private homes. The researcher has received training in lone working as part of the mandatory requirements for her previous role in a front line Local Authority social work team, and has also conducted similar field research in the past.

This research will involve lone working in participant's homes. All meetings will be arranged at a time to suit participants during daylight hours. The researcher will inform her academic supervisors of the time and place of all interviews, and will make contact with an agreed individual prior to the interview who has full details of the researcher's whereabouts. This individual is most likely to be the researcher's husband as the person expected to pick up promptly on any concerns, but may also be a nominated supervisor, another UEA PhD student or support staff from the SWK office. The researcher will not go ahead with the interview if she is unable to make contact with the agreed individual. The researcher will call the agreed individual immediately following the termination of the interview when she is off the premises to confirm her safety. If no call is made within 2.5 hours, the agreed individual will telephone the researcher. If on receipt of this telephone call, the researcher feels concerned about her safety, she will use a predetermined code to indicate help should be summoned. At this point, the agreed individual will contact the police and provide details of the researcher's location. If the researcher does not answer the pre-arranged call, the agreed individual will immediately make a second attempt, and if this call is not picked up, they will telephone the police. Where the researcher feels uncomfortable, threatened or in any way concerned about her safety, she will immediately invoke an exit strategy to remove herself from the situation as quickly as possible. If she is not able to leave the premises, she will attempt to call the agreed individual and use the agreed code word to raise the alarm. Where participants are recruited via organisations, a request will be made to check against their database for any potential risks in visiting the home.

The researcher will travel independently to interview locations by means of her privately owned vehicle. The researcher is appropriately licensed, and the vehicle is insured, taxed and well maintained.

The researcher will carry her student ID card identifying her as a member of the University of Anglia and information on the research being undertaken.

7. Other Permissions and Clearances

7.1 Is ethical clearance required from any other ethics committee?
NO

If YES, please give the name and address of the organisation:

However, research governance will be sought from relevant local authorities – they have advised a ‘light touch’ approach will be required, once UEA approval has been granted.

Has such ethical clearance been obtained yet? N/A

If YES, attach a copy of the ethical approval letter

7.2 Will your research involve working with children or vulnerable adults?
YES

If YES, have you obtained an enhanced disclosure certificate from the Criminal Records Bureau (CRB)? NO

An enhanced DBS check will be obtained immediately prior to the researcher conducting the fieldwork. A copy of this will be provided to the researcher’s academic supervisors before any interviews are held.

DECLARATION OF PRINCIPAL INVESTIGATOR

I am satisfied that all ethical issues raised have been identified and that satisfactory procedures are in place to meet the standards set out in the UEA ethics policy and to adhere to ethical best practice.

Signature .... **Date** ....

DECLARATION OF THE SUPERVISOR (for research students only)

I have reviewed and discussed with the student their ethics application and am satisfied that all ethical issues raised have been identified and that satisfactory procedures are in place to meet the standards set out in the UEA ethics policy and to adhere to ethical best practice.

Signature .....Jonathan Dickens .... **Date** ...11.02.16.....

PLEASE SUBMIT ONE HARD COPY AND ONE ELECTRONIC COPY OF THIS COMPLETED AND SIGNED FORM WITH ACCOMPANYING DOCUMENTATION TO THE SECRETARY OF THE RESEARCH ETHICS COMMITTEE.

11 April 2016

Nicola Jones
School of Social Work
University of East Anglia
Norwich Research Park
NORWICH
Norfolk NR4 7TJ

University of East Anglia

School of Social Work
Faculty of Social Sciences
University of East Anglia
Elizabeth Fry Building
Research Park
Norwich
Norfolk NR4 7TJ

Telephone
+44 (0)1603 592057
Fax+44 (0)1603 593552

Dear Nicola

The Impact of Personal Assistance on relationships between disabled parents and their children

The Research Ethics Committee has considered your application for ethical approval for the above project. The reviewers were in agreement that the ethics issues had been satisfactorily considered and addressed. I am therefore happy to confirm that ethical approval has been granted and that you can now begin your study.

It is a requirement of your approval that you should report any adverse events that may have occurred, these being defined as “any unanticipated problem involving risk to subjects which ultimately results in harm to the subject or others”.

If you plan to make any significant changes to the design of your study, you should also contact me.

With best wishes – I hope your research goes well.

Yours sincerely

G. L. Schofield

Prof Gillian Schofield

Deputy Chair of School of Social Work Ethics Committee

X County Council
Corporate Intelligence Team
Organisational Intelligence & Commissioning Delivery

Date: 13 May 2016

Dear Nicola Jones,

Research Proposal:

The Impact of Personal Assistance on relationships between disabled parents and their children

Thank you for forwarding your research proposal to the Research Governance Group.

We are pleased to accept the approval granted by University of East Anglia's School of Social Work Ethics Committee in respect of your research project – School of Social Work Ethics Committee approval letter, dated 11th April 2016. We thus confirm that your research proposal also complies with X County Council's research governance guidelines.

May I remind you that your sponsor is responsible for reviewing the quality of the research as it progresses. Should there be any major alterations or adverse occurrences during the research, your sponsor is required to notify the Research Governance Group and explain what has been done about it.

When the research is completed please submit a copy of your findings and details of any peer review to the Research Governance Group. Please submit this in an electronic form.

In the mean time good luck with your research and if you do need to discuss any aspects please contact X X direct on xxxxxx xxxxx or on xxxxxx.xxxxx@.....gov.uk.

Yours sincerely,

Organisational Intelligence
Chair, Research Governance Group

Date: 19.04.2016

Nicola Jones
School of Social Work
University of East Anglia
NORWICH
By email

Dear Nicola
The Impact of Personal Assistance on relationships between disabled parents and their children (Ref: 231)

Thank you for providing copy of the application & supporting documentation in relation to your research project as well as copy of the approval letter by the University of East Anglia ethics committee.

I am pleased to confirm that the X County Research Governance panel endorsed this ethics approval. Therefore, from the research governance point of view, the study is approved to go ahead in X County on the same terms as this approval. The panel especially welcomes this research project as it aims to increase understanding of issues affecting disabled parents and their children particularly where personal assistants are involved with their family.

We will now add this research to the database as an approved study being implemented in X County. The database is available to the public but any enquiries come through the panel chair who will pass them on to you.

As part of the approval please can you:

a) let the panel know of any major changes to the methodology or implementation
b) provide the panel chair with a copy or summary of the final report when completed so we can update our records. At that point it will be discussed with you whether or not you wish the report to be put onto our database.

The X County Research Governance panel wish you well with this work. I hope everything is clear but please contact me if you have any further queries about research governance.

With best wishes

XX
Chair of Research Governance Panel

Appendix 5 - Online promotional material

Participants Sought for Research Project

20th April 2016
By Anna Ede

Are you a disabled parent? Do you have a personal assistant? What difference has this made to your experiences of being a parent and caring for your child(ren)? Over recent years, more disabled people are becoming parents and using PA support, but so far, no-one has listened to what they, their children and PAs have to say about how this works for them.

If this issue affects you and your family, you may be interested to hear about a new research project which is being conducted locally by University of East Anglia PhD student Nicola Jones. She is interested to learn more about what works well for disabled parents who use PA support, as well as find out what could be done better, so that this information could be shared with others and improve services.

If you would like to contribute to this study and can spare an hour and a half of your time to talk about your experiences, you could be helping other disabled parents, children, professionals and students, and perhaps even make a difference to future services.

All information will be treated confidentially. Your anonymity will be assured – no names or identifying information will be contained in any report.

For more information, please contact Nicola Jones by email: nicola.t.jones@uea.ac.uk or telephone: 07981 917 915; she will be happy to explain more about her project and answer any questions you may have.

Appendix 6 - Project postcard

My name is Nicola Jones. I am a PhD student at the University of East Anglia. I am trying to find out what disabled parents and their children think about having PA support in their family life.

Are you a disabled parent?

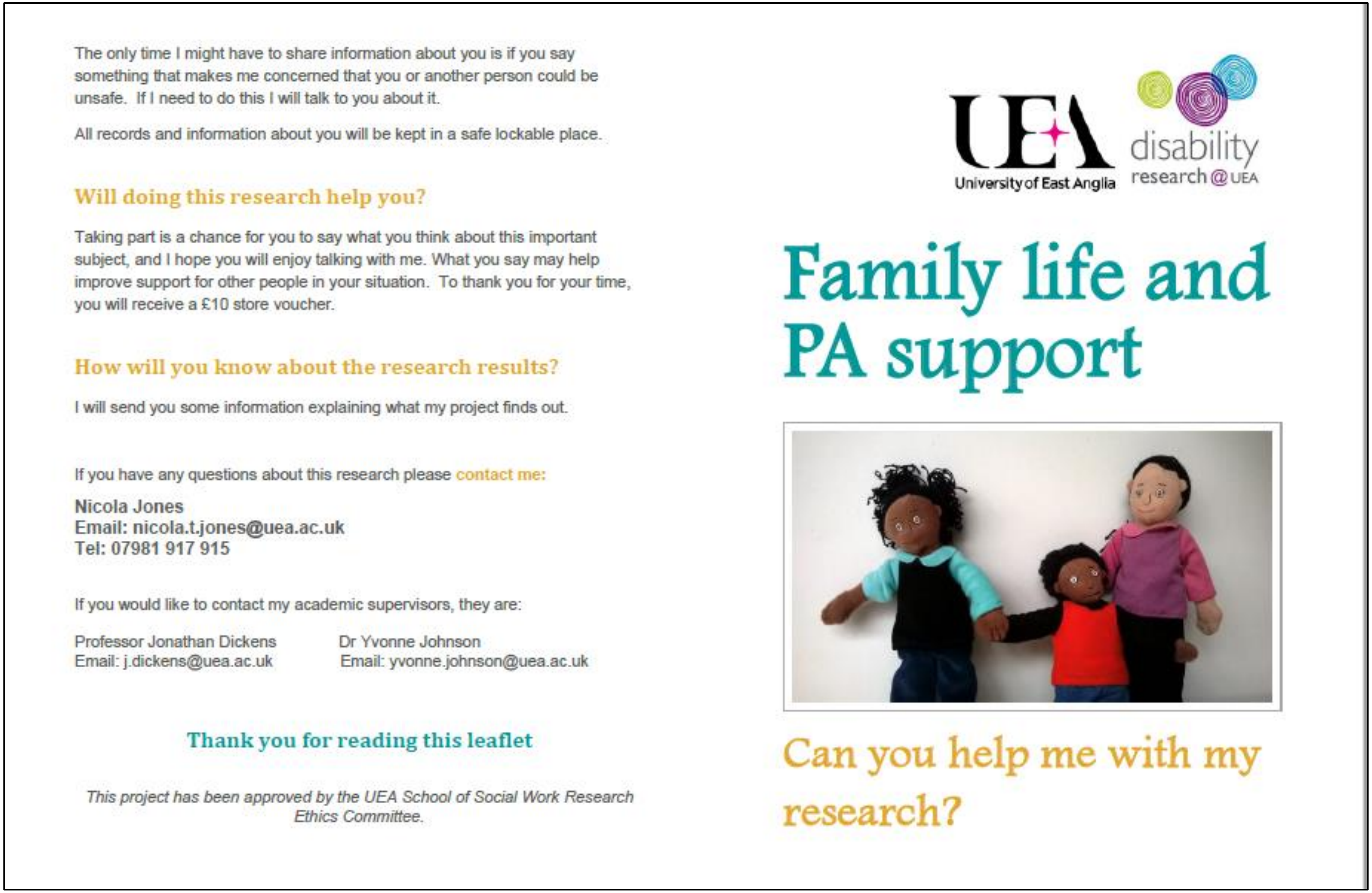
Do you have some experience of this? If so, I would like to talk to you.

So far, no-one has listened to what disabled parents and their children have to say about how PA support works for them.

All personal information will be kept confidential, and you will receive a £10 voucher to thank you for your time.

To find out more, please **contact me:**

Email: nicola.t.jones@uea.ac.uk Tel: 07981 917 915



The only time I might have to share information about you is if you say something that makes me concerned that you or another person could be unsafe. If I need to do this I will talk to you about it.

All records and information about you will be kept in a safe lockable place.

Will doing this research help you?

Taking part is a chance for you to say what you think about this important subject, and I hope you will enjoy talking with me. What you say may help improve support for other people in your situation. To thank you for your time, you will receive a £10 store voucher.

How will you know about the research results?

I will send you some information explaining what my project finds out.

If you have any questions about this research please contact me:

Nicola Jones
Email: nicola.t.jones@uea.ac.uk
Tel: 07981 917 915

If you would like to contact my academic supervisors, they are:

Professor Jonathan Dickens Email: j.dickens@uea.ac.uk	Dr Yvonne Johnson Email: yvonne.johnson@uea.ac.uk

Thank you for reading this leaflet

This project has been approved by the UEA School of Social Work Research Ethics Committee.

University of East Anglia
disability research@UEA

Family life and PA support

Can you help me with my research?

Hello.

My name is Nicola Jones. I am a PhD student at the University of East Anglia. I would like to tell you about some research I am doing.

What is it all about?

I am trying to find out what disabled parents and their children think about having PA support in their family life.

Why am I doing this research?

More disabled people are becoming parents and using PA support. So far, no-one has listened to what disabled parents, their children and PAs have to say about how this works for them. The aim is to find out what works well, what could be done better, and to share this information with other people.

Who will be involved?

I will be talking to disabled parents who have experience of using PA support, and their children. I will also be talking to PAs who work with disabled parents, and to people who grew up with PA support in their family.

Do you have to take part?

No, it's completely up to you to decide whether or not to be involved, but I do hope you will agree to talk to me. If you do, you will be given this information leaflet to keep and asked to sign a consent form. Even if you say 'yes', you can change your mind later, but please let me know within 3 weeks of your interview.

What will happen if you take part

I will visit you at your home, or somewhere else if you prefer, at a time that suits you. I will explain more about the research and answer any questions you have. I would like to spend some time with you on your own, but you can have someone else with you. We might do some activities and talk together. There are no right or wrong answers, and you don't have to answer every question, you can just say 'pass', 'no' or 'stop'. You can take a break at any time, just let me know. If you are a PA, I would like to interview you by telephone.

Could there be any problems with taking part?

Sometimes people get upset when talking about their lives, and if this happens, we can take a break. If you are worried or concerned, I can put you in touch with someone who might be able to give you some advice, and you can always talk to someone else you know and trust.

How long will it take?

The visit will take about an hour and a half, but we can take as long as we need to talk, or I can come back and see you again.

How I will remember what you say

I would like to record what we talk about rather than writing things down so that I can concentrate on what you are saying.

Keeping your information safe

What you say will be kept confidential. This means if I write about anything you say in my report I will change your name so no-one will know that it was you who said it.

PARTICIPANT INFORMATION SHEET – DISABLED PARENTS

Study title: ***'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'***

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

This project forms part of my studies at the University of East Anglia leading to a PhD. My research supervisors are Professor Jonathan Dickens and Dr Yvonne Johnson – their contact details are provided below.

The aim of this small-scale independent study is to examine the impact of personal assistance (PA) support on the relationships between disabled people and their children.

The research question will be explored by means of interviews with disabled people and their children. People working as PAs will also be asked to share their experiences.

Why have I been invited to participate?

I am interested in talking with you about your experiences of using PA support, and how this affects family life, in particular your relationship with your child(ren). This is a small-scale, locally-based project: approximately thirty participants will be involved.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to be involved, but I hope you will consider sharing your valuable experiences. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreement to participate in this research does not compromise your legal rights in any way.

What if I change my mind?

If you decide to take part you are still free to withdraw, and without giving a reason – a return slip is provided on the consent form for you to send to the researcher if you decide to withdraw. Due to the practicalities of analysing the research data, the deadline for withdrawing from the study is three weeks from the date of your interview; the exact date will be confirmed with you.

What will happen if I take part?

The interview will take approximately one and a half hours of your time, and will be arranged at a time and a place convenient for you. I would like to audio record the interview to avoid having to take detailed notes while we talk and so that I can transcribe it accurately afterwards for the purposes of analysis.

What are the possible benefits of taking part?

Although there are likely to be only limited direct benefits for individual participants, you may find it helpful and even enjoyable to talk through issues which have affected you. You will also be contributing to furthering knowledge and understanding of this topic which may be beneficial to other disabled parents and their families, PAs, social care professionals and students. This topic is currently under researched and it is hoped that findings from the study will influence future practice developments. To thank you for your time in taking part, you will receive a £10 store voucher.

Are there any disadvantages or risks to taking part?

No significant harm is likely to happen to you as a result of participating in this research. However, it may be that talking about your experiences could bring up some difficult emotions. If this happens, you can pause or stop the interview. For your information, I have an enhanced Disclosure and Barring Service (DBS) check.

Will what I say in this study be kept confidential?

All data obtained during the study will be treated confidentially. Your anonymity will be assured - no names or identifying information will be contained in any verbal or written report. Effective protection against inadvertent identification will be addressed.

The issue of confidentiality will be discussed with you during the recruitment process and at the beginning of the interview. All information given during the course of the interview will be treated confidentially with the exception of any details that indicate a risk to your safety or the safety of another. Should any such issue arise, I would discuss this fully with you and make an informed decision about the appropriate passing on of such information.

All data will be stored according to strict University guidance and held electronically on a secure server. The data will not be put to any use other than that specified in the research proposal, which is available for your information. All digital audio recordings will be uploaded to a secure location and erased on completion of the full research process. You will be provided with a full transcription of your interview to check the information recorded is correct, and if you want a copy of the audio file, you will be provided with this.

What should I do if I want to take part?

Please contact me so we can arrange a suitable time to meet for interview.

What will happen to the results of the research study?

The results of the study will form the basis for a thesis which will be submitted in partial fulfilment of my doctoral studies at the University of East Anglia in 2018/19. I will inform all participants of the completion of this and provide a digital copy if requested. A summary of findings will also be produced – a copy of this will be provided upon request.

Other publications may arise as a result of the study, to which anonymity of participants will continue to apply.

Who is organising and funding the research?

I am conducting this research as a student in the School of Social Work, within the Faculty of Social Sciences at the University of East Anglia.

Who has reviewed the study?

The research has been approved by the University of East Anglia's Ethics Panel and has received Research Governance approval from Essex, Suffolk and Norfolk County Council.

Contact for further Information

If you have any questions about any of the above, or about anything I have not included, please feel free to discuss this with me prior to the interview. My contact details are:

Nicola Jones
PhD Student, University of East Anglia
Email: nicola.t.jones@uea.ac.uk
Tel: 07981 917 915

If you wish to discuss anything with my academic supervisors their contact details are as follows:

Professor Jonathan Dickens
Email: j.dickens@uea.ac.uk
Telephone: 01603 59 3634

Dr Yvonne Johnson
Email: yvonne.johnson@uea.ac.uk
Telephone: 01603 59 1437

Thank you for taking time to read this information sheet.

January 2016

Dear Parent/ Carer

Family life and PA support: a research project

My name is Nicola Jones. I am a research student at the University of East Anglia. My project is trying to find out what disabled parents and their children think about having PA support in their family life. More disabled people are becoming parents and using PA support, but so far no-one has listened to what they and their children have to say about how this works for them. The aim is to find out what works well, what could be done better, and to share this information with other people to improve things.

To learn more, I would like to speak with disabled parents and their children. I also plan to speak separately with PAs who work with disabled parents and their families, and to people who grew up with PA support in their family. I would like you to consent to me speaking with your child.

If your child takes part I will:

- Talk to you both about the project to explain things fully and check you are happy to get involved.

- Spend some time with your child to find out their views. This might involve doing some activities and talking together. This will take about an hour of their time, and they will receive a £10 voucher as a thank you.

To find out more, please read the enclosed leaflet and information sheet with your child.

If your child would like to take part, or if you have any questions, please contact me on **07981 917 915** or by email: **nicola.t.jones@uea.ac.uk**.

Thank you for the taking time to read this letter.

Nicola Jones

INFORMATION SHEET – CHILD/YOUNG PERSON

Study title: ***'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'***

What is this all about?

Hello. My name is Nicola Jones. I am a PhD student at the University of East Anglia. I want to tell you about a research project I am doing

I am trying to find out what disabled parents and their children think about having PA support in their family life – the good things and also if sometimes this is not so good. I will also be speaking to PAs about this separately to find out what they think. **I would like to speak with you about this.**

Do I have to take part?

No, it's completely up to you to decide whether or not to be involved, but I hope you will talk to me. If you want to take part, you will be given this information sheet to keep and asked to sign a consent form.

What will happen if I take part?

If you decide to take part in the project I will:

- Visit you and your family at your house, or somewhere else if you prefer.
- Talk to you and your parent or carer to explain more about the project and answer any questions.
- Spend some time with you on your own. We will do some activities and talk together. If you do any drawings, I would like to take them away with me to copy, and then send them back to you.

Can I change my mind, stop or take a break if I want?

It's your choice whether or not you want to take part in the project, and you can change your mind at any time.

There are no right or wrong answers, and you don't have to answer every question. You can take a break or stop at any time, just let me know.

How long will it take?

The visit will take about an hour, but we can take as long as we need to talk, or I can come back and see you again.

How will you remember what I say?
I would like to record what we talk about rather than writing things down so that I can concentrate on what you are saying. The recording will be typed up and then deleted. If you don't want to be recorded, that's OK.

Who will you tell what I've said?
What you say will be kept confidential. This means if I write about anything you say in my report I will change your name so no-one will know that it was you who said it.

The only time I might have to share your information is if you say something that makes me concerned that you or someone else is not safe. If I need to do this I will always try and tell you first, but sometimes I might not be able to.

What's in it for me?
Taking part is a chance for you to say what you think about the support you get in your family and what things are like for you. I hope you will enjoy talking with me.

What you say may help improve support for other young people and their families.

You will receive a £10 store voucher to thank you for your time in taking part.

If you would like to have one, I will send you a leaflet explaining what my project finds out.

If you have any questions about the research please contact me:

Nicola Jones
Email: nicola.t.jones@uea.ac.uk
Tel: 07981 917 915

Thank you for taking time to read this information sheet.

January 2016

PARTICIPANT INFORMATION SHEET – NOW-ADULT CHILDREN

Study title: ***'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'***

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

This project forms part of my studies at the University of East Anglia leading to a PhD. My research supervisors are Professor Jonathan Dickens and Dr Yvonne Johnson – their contact details are provided below.

The aim of this small-scale independent study is to examine the impact of personal assistance (PA) support on the relationships between disabled people and their children.

The research question will be explored by means of interviews with disabled people and their children (some of whom may now be adults). People working as PAs will also be asked to share their experiences.

Why have I been invited to participate?

I am interested in talking with you about your experiences of using PA support, and how this affects family life, in particular your relationship with your parent(s). This is a small-scale, locally-based project: approximately thirty participants will be involved.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to be involved, but I hope you will consider sharing your valuable experiences. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreement to participate in this research does not compromise your legal rights in any way.

What if I change my mind?

If you decide to take part you are still free to withdraw, and without giving a reason – a return slip is provided on the consent form for you to send to the researcher if you decide to withdraw. Due to the practicalities of analysing the research data, the deadline for withdrawing from the study is three weeks from the date of your interview; the exact date will be confirmed with you.

What will happen if I take part?

The interview will take approximately one and a half hours of your time, and will be arranged at a time and a place convenient for you. I would like to audio record the interview to avoid having to take detailed notes while we talk and so that I can transcribe it accurately afterwards for the purposes of analysis.

What are the possible benefits of taking part?
Although there are likely to be only limited direct benefits for individual participants, you may find it helpful and even enjoyable to talk through issues which have affected you. You will also be contributing to furthering knowledge and understanding of this topic which may be beneficial to other disabled parents and their families, PAs, social care professionals and students. This topic is currently under researched and it is hoped that findings from the study will influence future practice developments. To thank you for your time in taking part, you will receive a £10 store voucher.

Are there any disadvantages or risks to taking part?
No significant harm is likely to happen to you as a result of participating in this research. However, it may be that talking about your experiences could bring up some difficult emotions. If this happens, you can pause or stop the interview. For your information, I have an enhanced Disclosure and Barring Service (DBS) check.

Will what I say in this study be kept confidential?
All data obtained during the study will be treated confidentially. Your anonymity will be assured - no names or identifying information will be contained in any verbal or written report. Effective protection against inadvertent identification will be addressed.

The issue of confidentiality will be discussed with you during the recruitment process and at the beginning of the interview. All information given during the course of the interview will be treated confidentially with the exception of any details that indicate a risk to your safety or the safety of another. Should any such issue arise, I would discuss this fully with you and make an informed decision about the appropriate passing on of such information.

All data will be stored according to strict University guidance and held electronically on a secure server. The data will not be put to any use other than that specified in the research proposal, which is available for your information. All digital audio recordings will be uploaded to a secure location and erased on completion of the full research process. You will be provided with a full transcription of your interview to check the information recorded is correct, and if you want a copy of the audio file, you will be provided with this**.**

What should I do if I want to take part?
Please contact me so we can arrange a suitable time to meet for interview.

What will happen to the results of the research study?
The results of the study will form the basis for a thesis which will be submitted in partial fulfilment of my doctoral studies at the University of East Anglia in 2018/19. I will inform all participants of the completion of this and provide a digital copy if requested. A summary of findings will also be produced – a copy of this will be provided upon request.

Other publications may arise as a result of the study, to which anonymity of participants will continue to apply.

Who is organising and funding the research?
I am conducting this research as a student in the School of Social Work, within the Faculty of Social Sciences at the University of East Anglia.

Who has reviewed the study?
The research has been approved by the University of East Anglia's Ethics Panel and has received Research Governance approval from Essex, Suffolk and Norfolk County Council.

Contact for further Information

If you have any questions about any of the above, or about anything I have not included, please feel free to discuss this with me prior to the interview. My contact details are:

Nicola Jones
PhD Student, University of East Anglia
Email: nicola.t.jones@uea.ac.uk
Tel: 07981 917 915

If you wish to discuss anything with my academic supervisors their contact details are as follows:

Professor Jonathan Dickens
Email: j.dickens@uea.ac.uk
Telephone: 01603 59 3634

Dr Yvonne Johnson
Email: yvonne.johnson@uea.ac.uk
Telephone: 01603 59 1437

Thank you for taking time to read this information sheet.

January 2016

PARTICIPANT INFORMATION SHEET – PAs

Study title: ***'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'***

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

This project forms part of my studies at the University of East Anglia leading to a PhD. My research supervisors are Professor Jonathan Dickens and Dr Yvonne Johnson – their contact details are provided below.

The aim of this small-scale independent study is to examine the impact of personal assistance (PA) support on the relationships between disabled people and their children.

The research question will be explored by means of interviews with disabled people and their children. People working as PAs will also be asked to share their experiences.

Why have I been invited to participate?

I am interested in talking with you over the telephone about your experiences of working as a PA and supporting disabled parents and their children. This is a small-scale, locally-based project: approximately thirty participants will be involved.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to be involved, but I hope you will consider sharing your valuable experiences. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreement to participate in this research does not compromise your legal rights in any way.

What if I change my mind?

If you decide to take part you are still free to withdraw, and without giving a reason – a return slip is provided on the consent form for you to send to the researcher if you decide to withdraw. Due to the practicalities of analysing the research data, the deadline for withdrawing from the study is three weeks from the date of your interview; the exact date will be confirmed with you.

What will happen if I take part?

The interview will take approximately one hour of your time, and will be arranged at a time and a place convenient for you. I would like to audio record the interview to avoid having to take detailed notes while we talk and so that I can transcribe it accurately afterwards for the purposes of analysis.

What are the possible benefits of taking part?
Although there are likely to be only limited direct benefits for individual participants, you may find it helpful and even enjoyable to talk through issues which have affected you. You will also be contributing to furthering knowledge and understanding of this topic which may be beneficial to other PAs, disabled parents and their families, social care professionals and students. This topic is currently under researched and it is hoped that findings from the study will influence future practice developments. To thank you for your time in taking part, you will receive a £10 store voucher.

Are there any disadvantages or risks to taking part?
No significant harm is likely to happen to you as a result of participating in this research. However, it may be that talking about your experiences could bring up some difficult emotions. If this happens, you can pause or stop the interview. For your information, I have an enhanced Disclosure and Barring Service (DBS) check.

Will what I say in this study be kept confidential?
All data obtained during the study will be treated confidentially. Your anonymity will be assured - no names or identifying information will be contained in any verbal or written report. Effective protection against inadvertent identification will be addressed.

The issue of confidentiality will be discussed with you during the recruitment process and at the beginning of the interview. All information given during the course of the interview will be treated confidentially with the exception of any details that indicate a risk to your safety or the safety of another. Should any such issue arise, I would discuss this fully with you and make an informed decision about the appropriate passing on of such information.

All data will be stored according to strict University guidance and held electronically on a secure server. The data will not be put to any use other than that specified in the research proposal, which is available for your information. All digital audio recordings will be uploaded to a secure location and erased on completion of the full research process. You will be provided with a full transcription of your interview to check the information recorded is correct, and if you want a copy of the audio file, you will be provided with this.

What should I do if I want to take part?
Please contact me so we can arrange an interview.

What will happen to the results of the research study?
The results of the study will form the basis for a thesis which will be submitted in partial fulfilment of my doctoral studies at the University of East Anglia in 2018/19. I will inform all participants of the completion of this and provide a digital copy if requested. A summary of findings will also be produced – a copy of this will be provided upon request.

Other publications may arise as a result of the study, to which anonymity of participants will continue to apply.

Who is organising and funding the research?
I am conducting this research as a student in the School of Social Work, within the Faculty of Social Sciences at the University of East Anglia.

Who has reviewed the study?
The research has been approved by the University of East Anglia's Ethics Panel and has received Research Governance approval from Essex, Suffolk and Norfolk County Council.

Contact for further Information
If you have any questions about any of the above, or about anything I have not included, please feel free to discuss this with me prior to the interview. My contact details are:

Nicola Jones
PhD Student, University of East Anglia
Email: nicola.t.jones@uea.ac.uk
Tel: 07981 917 915

If you wish to discuss anything with my academic supervisors their contact details are as follows:

Professor Jonathan Dickens	Dr Yvonne Johnson
Email: j.dickens@uea.ac.uk	Email: yvonne.johnson@uea.ac.uk
Telephone: 01603 59 3634	Telephone: 01603 59 1437

Thank you for taking time to read this information sheet.

January 2016

University of East Anglia

disability research @ UEA

PARTICIPANT CONSENT FORM

Title of Project: ***‘The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study’***

Name, position and contact details of researcher:
Nicola Jones
PhD Student, University of East Anglia
Email: nicola.t.jones@uea.ac.uk
Tel: 07981 917 915

Please initial box

1. I agree to take part in the above study. I confirm that I have read and understand the information sheet (attached to this form). I understand my role in this research and have had the opportunity to ask questions. All my questions so far have been answered to my satisfaction. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and without prejudice. ☐
3. I have been informed that the confidentiality of the information I provide will be safeguarded. ☐
4. I understand that if I raise issues about a child or vulnerable person being hurt or abused, someone will contact me to talk about it before taking further action. ☐
5. I have been provided with a copy of this form and the participant information sheet. ☐

Please tick box

	Yes	No
6. I agree to the interview being audio recorded	☐	☐
7. I agree to the use of anonymised quotes in publications	☐	☐

Data Protection Act 1998: I agree to the researcher processing personal data that I have supplied. I agree the processing of such data for any purposes connected with the research project has been outlined to me. I further agree to the researcher processing personal data about me described as sensitive data within the meaning of the Data Protection Act 1998.

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

If you wish to withdraw from the research, please complete the form below and return to the above-named researcher BEFORE *(insert date)*

……………………………………………………………………………………………………

Title of Project: ***'The Impact of Personal Assistance on relationships between disabled parents and their children– an exploratory study'***

I WISH TO WITHDRAW FROM THIS STUDY

Name: ___________________________

Signed: ___________________________ Date: _____________

Send to: Nicola Jones, University of East Anglia, School of Social Work, Elizabeth Fry Building, Room 2.27, Norwich, NR4 7TJ

Appendix 14 - Consent form (easy read)

PARTICIPANT CONSENT FORM

Title of Project:

'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'

If I talk to Nicola Jones about my experiences

- I understand that the interview will be recorded.

- I understand that the interview will be private.

- I understand that I can stop the interview at any time.

If you understand the statements above, you now need to decide whether you would like to take part in the project.

Please put a circle round No or Yes.

No Yes

_______________________________ ________________ ________________

Name of Participant Date Signature

_______________________________ ________________ ________________

Name of Researcher Date Signature

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

If you wish to withdraw from the research, please complete and return the form below BEFORE *(insert date).*

……………………………………………………………………………………………...........................

Title of Project: ***'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'***

I WISH TO WITHDRAW FROM THIS STUDY

_______________________________ ________________ ________________

Name Date Signature

Send to: Nicola Jones, University of East Anglia, School of Social Work, Elizabeth Fry Building, Room 2.27. Norwich, NR4 7TJ

YOUNG PERSON'S CONSENT FORM

Title of Project: ***'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'***

Name, position and contact details of researcher:
Nicola Jones
PhD Student, University of East Anglia
Email: nicola.t.jones@uea.ac.uk
Tel: 07981 917 915

Please initial box if you agree with the following;

☐ The research has been explained to me.

☐ I would like to take part in the project.

☐ I understand I can stop the interview or take a break at any time.

☐ I understand I can leave the project if I change my mind.

☐ I understand that my name will not be used and I will not be identified in any way in the report.

☐ I would like to receive a summary of the report.

Please tick box

	Yes	**No**
I agree for my interview/s to be recorded.	☐	☐
I agree to the use of anonymised quotes.	☐	☐

Data Protection Act 1998: I agree to the researcher processing personal data that I have supplied. I agree the processing of such data for any purposes connected with the research project has been outlined to me. I further agree to the researcher processing personal data about me described as sensitive data within the meaning of the Data Protection Act 1998.

I have read this consent form and I understand what is being requested of my child as a participant in this study. I freely consent for my child to participate. I have been given satisfactory answers to my questions. The researcher has provided me with a copy of this form.

☐ I give consent for my child to be audio taped during their interview (parent's initial)

Name of Parent/Guardian	Date	Signature
Name of Participant	Date	Signature
Name of Researcher	Date	Signature

YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

If you wish to withdraw from the research, please complete and return the form attached BEFORE *(insert date).*

Title of Project: ***'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'***

I WISH TO WITHDRAW FROM THIS STUDY

Name (please write clearly) ……………………………………….

Date ………………………….

Signature …………………………..

Send to: Nicola Jones, University of East Anglia, School of Social Work, Elizabeth Fry Building, Room 2.27. Norwich, NR4 7TJ

INTERVIEW GUIDE – Disabled Parents

Study title: *'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'*

Research Question: *'How do disabled parents and their children experience paid personal assistance within the home, and what impact does this have upon their relationship?'*

1. First of all, can you tell me a little about yourself?
age category:

18–24	25–29	30-44	45-59	60-64	65+

What is your ethnic group?
Which best describes your ethnic group or background:

White
1. English / Welsh / Scottish / Northern Irish / British
2. Irish
3. Gypsy or Irish Traveller
4. Any other White background, please describe

Mixed / Multiple ethnic groups
5. White and Black Caribbean
6. White and Black African
7. White and Asian
8. Any other Mixed / Multiple ethnic background, please describe

Asian / Asian British
9. Indian
10. Pakistani
11. Bangladeshi
12. Chinese
13. Any other Asian background, please describe

Black / African / Caribbean / Black British
14. African
15. Caribbean
16. Any other Black / African / Caribbean background, please describe

Other ethnic group
17. Arab
18. Any other ethnic group, please describe

What is your impairment/disability?
This study adopts the 'social model of disability', which challenges the traditional/medical assumption that having an impairment will inevitably lead to individual difficulties. The social model was devised by disabled people themselves and defines disability as the disadvantage or restriction placed upon disabled people by wider society as a result of their impairments. The difference between these two ideas is about where the 'problem' lies – with the individual, or with society.

What is your marital status…?

Single, never married
Married/civil partnership
Co-habiting with partner
Separated
Divorced
Widowed

Please describe your household composition (genogram/ecomap?):

What is your highest level of educational qualification?

What is your work history?

Are you currently…?

Employed for wages
Self-employed
Out of work and looking for work
Out of work but not currently looking for work
A homemaker
A student
Retired
Involved in voluntary work
Unable to work

Are you currently in receipt of benefits?

2. My primary research focus is on how having PA support affects your relationship with your child/ren, but before we talk about that, it would be helpful to have some background information about your experience of PA support generally.

- When did you first employ a PA? What made you do this?
- How did you go about it? Do you have contracts/person specifications in place?
- What experiences have you had of agency support/services – did this have an impact upon your decision?
- What kind of support did you have in terms of understanding your responsibilities before employing staff?
- Do you manage your own payroll or have support with this from an individual or service?
- Have you changed how you do things? Have your criteria for employing staff changed?
- Do you offer training to your PAs? What essential skills must they have?

3. So, thinking about things generally, what difference has having PA support made?
- Practically? Socially? Emotionally? – can you give me some examples?
- What does having PA support mean for you?
- Has having PA support made you change the way you live your life, or the decisions that you have made?
- Have your confidence levels changed as a result of having PA support? How?
- Have your skills developed? Which/how?

4. Focusing now on family life, can you tell me more about how PA support works for you?
- Again, practically? Socially? Emotionally? – can you give me some examples?
- What is it like to have a PA around in day to day life? Can you describe how it feels?
- Who does what to help make family life work? How do you decide who does what?
- Can you describe what an 'average day' looks like for your family? What makes it a good day or a bad day?
- What are the good things about having a PA in the family?
- Are there sometimes difficult situations? Can you give me some examples (perhaps around discipline/treats/family rules)? How have you resolved these and stopped them happening again?
- What would you say are the key skills for PAs in supporting disabled parents and their families? (name 5)
- How do you think other people understand your family life and how it works for you? Do you feel you have to explain your family situation to others?
- What do other close family members make of your situation? Does having PA involvement impact upon your relationship with your partner/your child's other parent? How? Do they have positive relationships with your PAs? How do these relationships affect you?

5. Thinking more closely now about your relationship with your child(ren)
- How would you describe yourself as a parent?
- What do you think your child understands about your family situation and having a PA? How has this changed over time?
- How have things changed for you as a parent as your child(ren) gets older? Have things been easier or harder for you at different stages of your child's life?
- What impact does your impairment have upon your parenting? Is your child(ren) aware of difference/disability? Do you talk about this with them?
- How does having a PA around affect your relationship(s) with your child(ren)? In the past? Now? In the future?
- Does having a PA around affect your parenting style? Do you ever act differently when a PA is around? Do you act differently with different PAs?

- Have you ever sought parenting advice from your PA? Have you ever given your PA parenting advice?
- How do you stay in control as a parent? Are there ever differences of opinion with your PA? Has this ever made you upset or angry? Is this something you talk about with your PA? How do you resolve any difficulties – in the moment/after the fact?
- Does your child ever seek out you/your PA for different things? Comfort? Practical help? Guidance? Homework help? How do you feel about this?
- How do you observe your PA's relationships with your child(ren)? Have these changed? If so, how? Have you influenced how these relationships have changed? In what ways?
- How do you feel about your PAs relationships with your child(ren)? Do they always get on? Are there ever tensions? How do you manage these?
- How do you explain to your child when a PA is leaving your employment?

6. Do you think improvements could be made to support to disabled parents who use PA support?
- What support would you have found helpful when you first thought about having a PA involved with your family life?
- What would you say to a disabled person thinking about becoming a parent?
- Do you know any other disabled parents? What would you say to them about having PA support in family life?
- What would you say to someone thinking about working as a PA for a disabled parent?
- What would you say to professionals working with disabled parents - how can they provide the best support?
- What would you say to children who have disabled parents?
- If you could go back in time, what advice would you give yourself? What would you have liked to have known?
- Have you changed how you manage your PAs since becoming a parent?

7. Is there anything else you would like to say or add?
- Reflecting on your experiences and our discussion, is there anything you will now do differently? If so, what?
- What would you say have been the critical incidents or key turning points for you as a disabled parent?
- What are your hopes and plans for the future?

THANK YOU VERY MUCH FOR TAKING PART IN THIS RESEARCH – DO YOU HAVE ANY QUESTIONS TO ASK?

Children's interview guide and activity matrix

Interviews with children will be facilitated by a range of participatory activities aimed at putting them at ease with the researcher and the situation whilst eliciting information about the research topic. The matrix below outlines a number of activities which have been developed with this in mind. The researcher will bring a supply of resources along to interview, and depending on the individual child, some of these activities will be introduced and used where appropriate. Not all activities will be used as this may be experienced as overwhelming and distracting.

Task/Question	Activity
Explaining study aims	Talk through and check understanding of information sheet.
Gaining consent	Discuss and complete consent form with parent/carer and young person.
Agreeing/Setting ground rules	Discuss and agree ground rules – listening to each other/respect/confidentiality/having a break. Familiarise participant with stop/go/pass cards and recording equipment.
Getting to know you	Discussion/selecting and completing template: All about me/One page profile/ What I like best about myself/What's important to me / My day
How does this child/young person see themselves within their family?	Who's in your world – what's special about your family? Discussion and production of genogram using stickers/finger puppets/drawing.
How does this child/young person view and understand their support network?	Important people in my life/ Who's who. Development of discussion and production of ecomap using stickers/finger puppets/drawing techniques.

How does this child/young person view their relationships with the people in their family/support network?	Who helps me? Who does what? Development of discussion around important relationships using helping people cards/finger puppets/role play. Finishing a sentence – “It’s great when….”/ “It’s not so good when…”
What are this child/young person’s views and experiences of having PA support in their family?	Tell me 5 things about your PA/s – using outline of hand/points of a star. This might include their name, how often they see them, what they do with their parent, what they do with them, what they think about them.
What does this child/young person understand about PA support? What does this mean for them?	Development of discussion; asking them to explain to someone else (using Martian picture card/finger puppets/role play) what having PA support is like. Name 5 good things/5 not so good things (as activity above).
What would this child/young person like to be different in their lives?	Children/young people will be asked to identify things about their lives that they would change if they had three wishes.
Conclusion	Children/young people will be thanked for their participation, and asked if there is anything else they want to say or add. In recognition of the value of their time they will be given a thank you card and a £10 store voucher.

Appendix 18 - Stop/Go cards for children's interviews

Appendix 19 - Interview schedule (adult children)

INTERVIEW GUIDE – Adult children

Study title: *‘The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study’*

Research Question: *‘How do disabled parents and their children experience paid personal assistance within the home, and what impact does this have upon their relationship?’*

1. First of all, can you tell me a little about yourself?
a) age category:

18–24 25–29 30-44 45-59 60-64 65+

b) How would you describe your ethnic group or background?

c) Do you have impairment/disability?
This study adopts the ‘social model of disability’, which challenges the traditional/medical assumption that having an impairment will inevitably lead to individual difficulties. The social model was devised by disabled people themselves and defines disability as the disadvantage or restriction placed upon disabled people by wider society as a result of their impairments. The difference between these two ideas is about where the ‘problem’ lies – with the individual, or with society.

d) What is your marital status…?
Single, never married
Married/civil partnership
Co-habiting with partner
Separated
Divorced
Widowed

e) Please describe your current household composition (genogram/ecomap?):

f) Do you consider yourself to be:

Heterosexual or straight
Gay or lesbian
Bisexual

g) What is your work history?

h) What is your current work status?

2. My primary research focus is on how having PA support affected your relationship with your parent(s), but before we talk about that, it would be helpful to have some background information about your family.

- Can you describe your family background - ecomap/genogram?
- Who are the most important people in your family?
- Siblings? Extended family networks?
- Experience of parental disability/impairment? Acquired impairment or prior to your birth?
- What impact did your parent's impairment have upon your family life?
- How do you reflect on growing up with a disabled parent – do you think it has influenced your life choices or opportunties?

3. Focusing now on the time when PA support became a factor in your family, can you tell me more about how that worked for you?

-Can you recall when a PA was first involved in your family life?
-What did you understand about the role of the PA?
- What was it like to have a PA around in day to day life? Can you describe how it felt?
- Practically? Socially? Emotionally? – can you give me some examples?
- Who did what (tasks, rituals, routines) to help make family life work (your mum/dad/other family members, you, the PA)? How was it decided who did what?
- Can you describe what an 'average day' looked like for your family with PA support? What made it a good day or a bad day? Did the PA have any bearing on this?
- What were the good things about having a PA in the family?
- Were there ever difficult situations? Can you give me some examples (discipline/treats/family rules)?
-If things went well, why do you think that was?
- How do you think other people understood your family life and how it worked for you? (friends, school staff, members of the public)
- Did you ever feel you have to explain your family situation to others?
- What did other close family members make of the situation?
- Did having PA involvement impact upon your relationship with your siblings? How?

4. Thinking more closely now about your relationship with your parent

- Did you have a sense of your family being different? What this due to your parent's impairment, or the fact of them using PA support?
- How have things changed for you in terms of your relationship with your parent as you have grown older? Have things been easier or harder for you at different stages of your growing up?
-Did having a PA around affect your relationship(s) with your parent – did you/your siblings/parent behave differently around the PA?
- Were there ever times when you felt the PA was particularly supportive of you?
- Were there ever times when you felt the PA was particularly unhelpful?
- Did you ever seek out support from the PA for things such as Comfort? Practical help? Guidance? Homework help?
- Did you ever experience a PA moving on from their role with your family – how did you understand this? Did your parent explain? Did the PA talk about it with you?
- Did you ever develop friendships with the PAs – have these been maintained over time?
- Were there ever tensions within the family regarding the PAs? How were these managed?

5. Do you think improvements could be made to support to disabled parents who use PA support?

- What support or information would you have found helpful when you first thought about having a PA involved with your family life?
- What would you say to a disabled parent thinking about using PA support?
- What would you say to someone thinking about working as a PA for a disabled parent?
- What would you say to professionals working with disabled parents - how can they provide the best support?
- What would you say to children who have disabled parents?
- What would you say are the key skills for PAs in supporting disabled parents and their families? (top 3)

6. Is there anything else you would like to say or add?

THANK YOU VERY MUCH FOR TAKING PART IN THIS RESEARCH – DO YOU HAVE ANY QUESTIONS TO ASK?

INTERVIEW GUIDE – PAs

Study title: *'The Impact of Personal Assistance on relationships between disabled parents and their children – an exploratory study'*

Research Question: *'How do disabled parents and their children experience paid personal assistance within the home, and what impact does this have upon their relationship?'*

1. First of all, can you tell me a little about yourself?
a) age category:

18–24	25–29	30-44	45-59	60-64	65+

b) How would you describe your ethnic group or background?

c) Do you have an impairment/disability?
This study adopts the 'social model of disability', which challenges the traditional/medical assumption that having an impairment will inevitably lead to individual difficulties. The social model was devised by disabled people themselves and defines disability as the disadvantage or restriction placed upon disabled people by wider society as a result of their impairments. The difference between these two ideas is about where the 'problem' lies – with the individual, or with society.

d) Do you have personal experience of parenting?

e) What is your highest level of educational qualification?

f) Do you consider yourself to be:
Heterosexual or straight
Gay or lesbian
Bisexual

g) What is your work history?

h) What is your current work status?

2. My primary research focus is on how having PA support affects the relationships between disabled parents and their child/ren, but before we talk about your experiences of that, it would be helpful to have some background information about your work as a PA generally.
- When did you first become a PA?
- What attracted you to this role?
- Can you outline your career as a PA. Have you worked for a number of different disabled people as a PA? If so, have there been different expectations of you? How did you manage this?
- What in your experience are the differences between being a PA and working for an agency or other organisation in a caring role?
- What formalities regulate your working relationship with your employer? ie contracts /person specification/ supervision arrangements?
- Do you have a CRB/police check/disclosure?
- Have you ever had training in your role as a PA?
- What is your understanding of the social model of disability?
- Can you give examples of some work you are proud of doing as a PA?
- Are there any times when being a PA has been especially difficult or challenging for you? Why was this?

3. Focusing now on your work with disabled parents and their families and thinking of specific examples, can you tell me more about your experiences?
- What is it like to be present in day to day family life as a PA? Practically? Socially? Emotionally?
- How do you balance being supportive and available with letting the parent take control?
- Who does what to help make family life work? Who decides who does what?
- Can you describe what you might do in an 'average day' with the family?
- What do you think are the good things about having a PA closely involved with family life in this way?
- Are there sometimes difficult situations? Can you give me some examples of this (perhaps around discipline/treats/family rules)? How have these been resolved? What stopped them from happening again? Did this cause ongoing tension?
- How do you think other people understand family life for disabled people? Have people ever questioned your role perhaps if you are out with the family socially, or at the school gates? How have you explained it to others?
- How have you experienced relationships with other close members of the family – for example the other parent/grandparents/others?
- What would you say are the key skills for PAs in supporting disabled parents and their families? (name 5)

4. Thinking more now about working with child(ren)
- What do you think the child(ren) understands about their family situation and having a PA? How has this changed over time?
- How have you observed things changing in the family as the child(ren) gets older? Have things been easier or harder in your role at different stages of the child's life? How so?

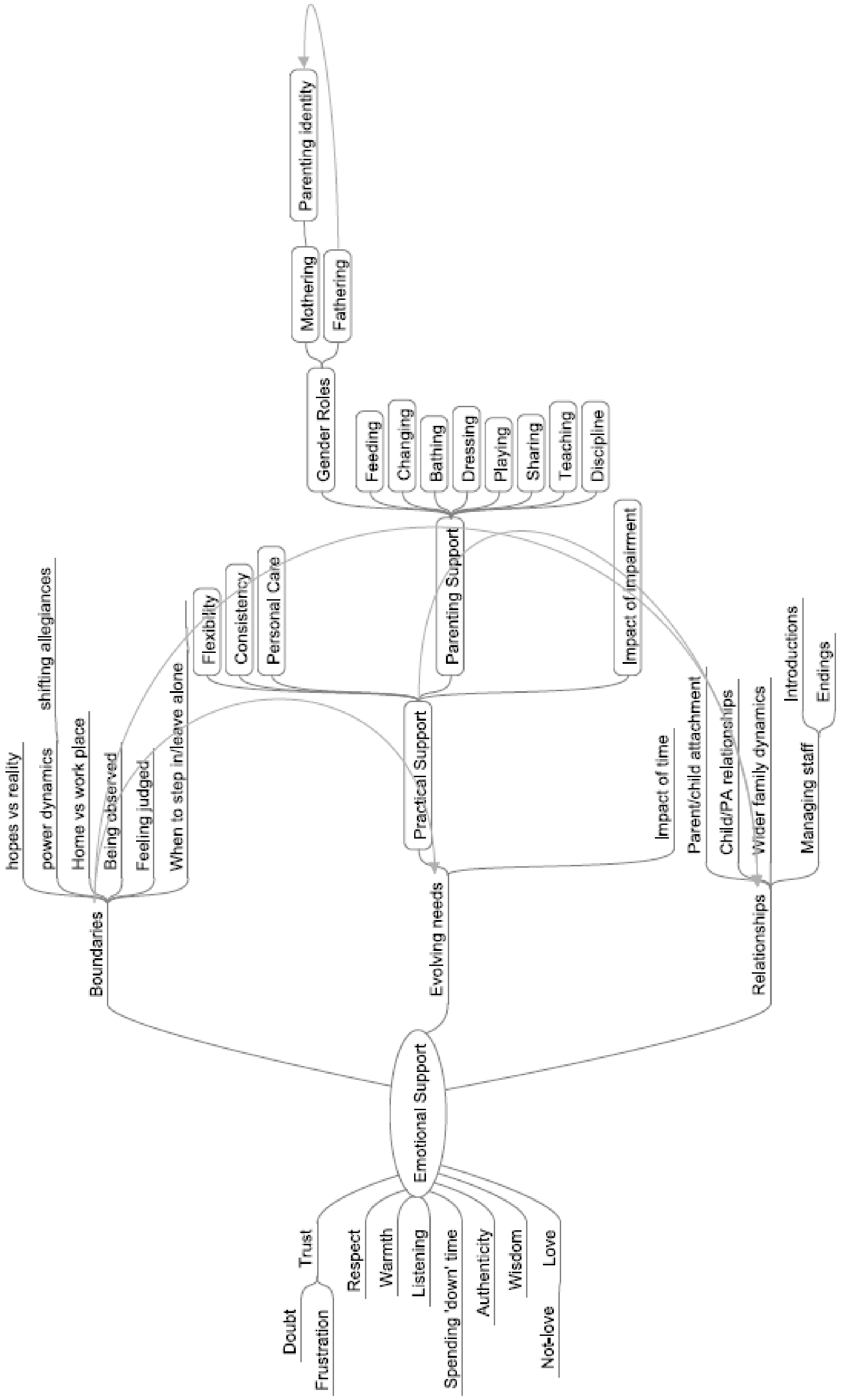
- Is the child(ren) aware of difference/disability? Does their parent talk to them about this? Do you?
- How do you think PA support affects the relationships between disabled parents and their child(ren)? Can you give some examples? In the past? Now? How do you see things changing in the future?
- Do you think having a PA around affects how disabled parents act towards their children? Does your interaction with the child change when different members of the household are present?
- Is it always clear to the child(ren) who is in charge? How do you deal with any differences of opinion with the parent? Has this ever made you upset or angry? Is this something you talk about? How do you resolve any difficulties – in the moment/after the fact?
- Are there times when you have been asked not to intervene with the children? How did this make you feel?
- Are there times when you have been directed to do something that you have disagreed with? How did you deal with this?
- Have you ever given any parenting advice to your employer? Have they ever given you parenting advice?
- Does the child ever seek you out for comfort? Practical help? Guidance? How do deal with this? What do you feel about it? Is this ever a cause for tension with the parent/family?
- How would you describe relationships with the child(ren)? Have these relationships changed over time? If so, how?

5. Do you think improvements could be made to support to disabled parents who use PA support?
- What support do you think parents would find helpful if considering using PA support?
- What would you say to a disabled person thinking about becoming a parent?
- Do you know any other disabled parents than the one(s) you work for? What would you say to them about having PA support in family life?
- What would you say to someone thinking about working as a PA for a disabled parent?
- What would you say to professionals working with disabled parents - how can they help get things right?
- What would you say to children who have disabled parents?
- If you could go back in time, what advice would you give yourself about supporting disabled parents? What would you have liked to have known?

6. Is there anything else you would like to say or add?
- Reflecting on your experiences and our discussion, is there anything you will now do differently? If so, what?
- What have been the critical incidents or key turning points?
- What are your hopes and plans for the future?

THANK YOU VERY MUCH FOR TAKING PART IN THIS RESEARCH – DO YOU HAVE ANY QUESTIONS TO ASK?

Appendix 21 - Visual mapping of themes



Appendix 22 - Theme development