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Where is the Person in Personalisation?

Experiences of People with Learning Disabilities and their Families in Glasgow

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Abstract

The shift towards the personalisation of social care ostensibly aims to enable people to exercise choice and control over their support. However, its implementation is taking place at the same time as the effects of austerity and welfare reform are being felt by disabled people and their families. Most notably for this thesis, the restructuring of learning disability services alongside the implementation of the Social Care (Self-directed Support) (Scotland) Act 2013 in Glasgow has resulted in the widespread closure of day centres for people with learning disabilities.

This study sets out to explore how policy change played out in the lives of disabled people and their families. It focuses particularly on the experiences of people with learning disabilities aged 30 and over, living in Glasgow. The formative experiences of this group took place before anti-discrimination legislation, and several participants had attended day centres for much of their adult lives. Additionally, many family carers were becoming less able to provide support themselves, adding further complexity to care arrangements.

It was very clear that policy change had affected daily lives and relationships of this group. There was little evidence of the values and principles underlying SDS in practice. Participants generally had negative experiences of interaction with services and professionals, and found SDS to be stressful and time consuming. Closure of day centres in Glasgow was a key issue for many families and had resulted in major changes to routines and relationships, as well as contributing to feelings of not being listened to and a lack of trust in powerful professionals.

Whilst budget cuts are an issue for local authorities and for families, this thesis suggests there are additional barriers to achieving the transformation of social care in Scotland. The key findings relate to the vast gap between SDS policy and practice, and the importance of collective spaces for people with learning disabilities and their families. As the ten-year strategy for SDS approaches its end, and the Scottish Government develops a programme to reform adult social care (Scottish Government, 2018a: 21), this thesis makes an original and important contribution to knowledge in this area.

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List of Abbreviations

AAC	Augmentative and Alternative Communication
ACSP	Adult Carer Support Plan
BASW	British Association of Social Workers
BCODP	British Council of Disabled People
CIL	Centre for Inclusive Living
COSLA	Convention of Scottish Local Authorities
DLA	Disability Living Allowance
DPO	Disabled People's Organisation
EHRC	Equality and Human Rights Commission
ESA	Employment and Support Allowance
EU	European Union
GCC	Glasgow City Council
GDA	Glasgow Disability Alliance
GDPR	General Data Protection Regulation
ILF	Independent Living Fund
IQ	Intelligence Quotient
IRISS	Institute for Research and Innovation in Social Services
LAC	Local Area Co-ordinator
LDAS	Learning Disability Alliance Scotland
LDSS	Learning Disability Statistics Scotland
NPF	National Performance Framework
PA	Personal Assistant
PIP	Personal Independence Payment
RAS	Resource Allocation System
SCLD	Scottish Commission for Learning Disability
SCSWIS	Social Care and Social Work Improvement Scotland
SDS	Self-directed Support
SEQ	Self-evaluation Questionnaire
SLDO	Scottish Learning Disabilities Observatory
SSSC	Scottish Social Services Council
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UPIAS	Union of the Physically Impaired Against Segregation

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This thesis is dedicated to the memory of my dear friend and feminist sister,

Mhairi McDonald

15th August 1965 – 1st November 2019

Author’s Declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature:

Printed name: Karen Young

1. Introduction

This qualitative study set out to explore the experiences of people with learning disabilities[1] and their families at a time of considerable change to social care policy and service provision. The research was concerned with understanding how policy change played out within family lives, and focused on the experiences of people with learning disabilities aged 30 and over and their families, living in Glasgow.

The topic emerged from my personal experience of family care, professional experience as a social care worker and volunteer with a carers' organisation, and academic interest in disability and policy. When I began the PhD process, my plan was to explore the experiences of older parent carers and their disabled adult children; I was interested in understanding ageing, caring and support, and hoping to document the challenges faced by parents and their children as they both grow older. Following initial engagement with relevant literature and informal discussions with disabled people, family carers and care workers, it became clear that social care policy and service provision was a pressing issue for this group.

The shift towards the personalisation of social care ostensibly aims to enable people with assessed needs to exercise choice and control over their support arrangements, thus empowering people to make decisions about their own lives. The introduction of the Social Care (Self-directed Support) (Scotland) Act 2013 placed a duty on all local authorities in Scotland to offer self-directed support (SDS) to eligible people with effect from April 2014. However, the implementation of SDS is taking place at the same time as public spending cuts and welfare reform associated with austerity (Pearson and Ridley 2017), and

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[1] The term 'learning disabilities' is used throughout the thesis as this is the language used in policy and services in Scotland, and which participants identified with. Academic literature also uses the terms 'learning difficulties' and 'intellectual disability', but these were not used by participants in this study.

constrained public sector budgets have contributed towards policy implementation taking longer than expected (Scottish Government, 2019a; Audit Scotland, 2017).

Several commentators have argued that SDS has been seen as a means to reduce social care spending at a time when local authority budgets were facing substantial cuts as a result of austerity measures (Pearson and Ridley, 2017; Ferguson and Lavalette, 2014; Smith, 2014). Furthermore, there is a body of evidence which suggests that Glasgow City Council adopted this approach in learning disability services (Main, 2014: 34; LDAS, 2016: 2; SCSWIS 2011: 9). Presenting SDS as the fair way to allocate scarce resources, one of the ways in which the local authority set out to achieve cost savings was through the closure of day centres for people with learning disabilities (Main, 2014).

Glasgow has the highest population of all local authorities in Scotland (NRS, 2019), and is both the most deprived city and local authority area in Scotland (Glasgow Centre for Population Health, undated). Census data suggests that people with learning disabilities are disproportionately represented in the most deprived areas in Scotland (NRS, 2016), however it is not possible to accurately ascertain the number of adults with learning disabilities living in Glasgow as there are apparent anomalies in the official statistics, illustrated below.

Local authorities are required to report annually to SCLD about all people with learning disabilities known to them (SCLD, 2019). SCLD use this data to publish national statistics, noting that this is an underestimate as it does not include people with learning disabilities who are not known to the local authority (ibid.). In 2017, Glasgow City Council reported that there were 2,190 adults with learning disabilities in receipt of a service funded by the local authority, equivalent to 4.2% of the population (SCLD, 2017). At this time, GCC reported that they were unable to report the number of people with learning disabilities known to them as this data could not be extracted from their Management Information System (ibid.), and in 2018, no data for Glasgow was reported due to GDPR issues (SCLD, 2018). In 2019, there were reportedly 2,171 people with learning disabilities known to the local authority in Glasgow, equivalent to 4.1% of the population (SCLD, 2019). This raises questions about the reliability of the published data; not only is this lower than the number of people who were receiving a service two years previously, it is also substantially lower than the national average of 5.2% (SCLD, 2019). Within the context of deprivation and the disproportionate representation of people with learning disabilities noted above, this data needs to be treated with caution.

Day centres are a highly contested issue; on the one hand, they are critiqued for their role in the segregation of disabled people from 'mainstream' society, whilst on the other hand, they are highly valued by many people with learning disabilities and their families who have strongly resisted closures (Needham, 2014). Notwithstanding these important critiques, for people who attended the day centres and their families, the programme of widespread closures has resulted in substantial changes to daily lives and relationships.

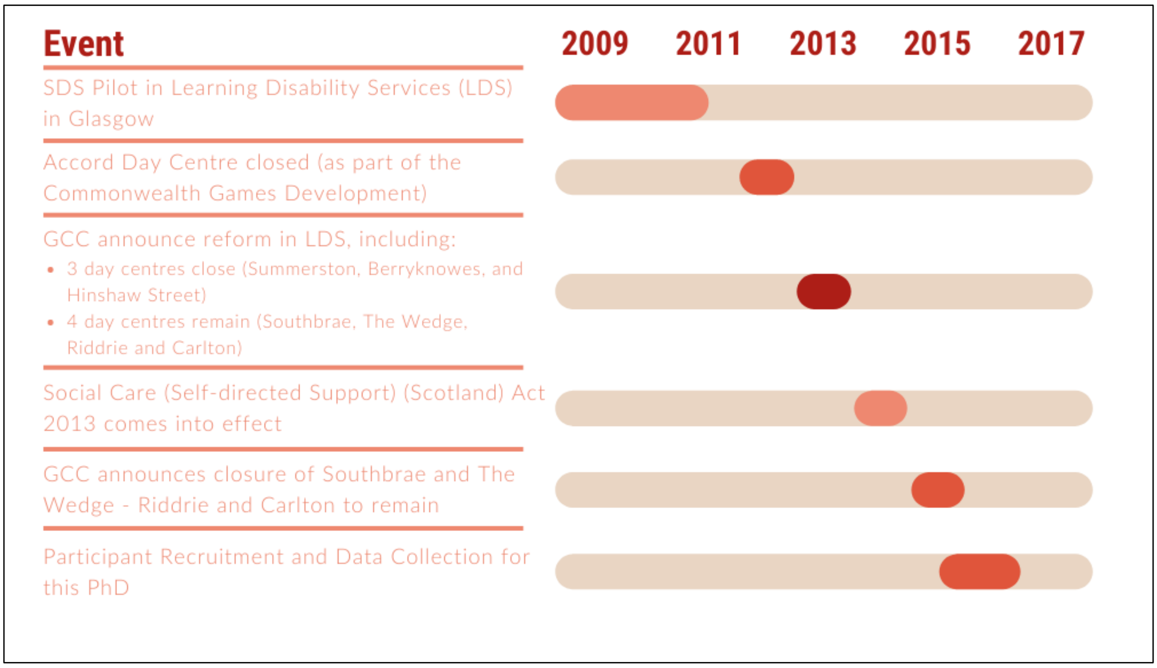
Having realised that the implementation of SDS and restructuring of learning disability services were major issues for people with learning disabilities and their families in Glasgow at the time (see figure 1, below) I revised my research proposal accordingly. Thus, this study set out to explore the experiences of people with learning disabilities and their families within a shifting policy environment, focusing on people with learning disabilities aged 30 and over, living in Glasgow. The main research questions were:

- In what ways have changes to social care policy affected the day-to-day lives of people with learning disabilities and their families?

- How does the dominant policy discourse of Personalisation reflect the needs and wishes of people with learning disabilities and their families?

- In practice, does self-directed support policy increase choice and control for people with learning disabilities and their families?

Figure 1 - Timeline



I chose to focus on this particular age group for several reasons. First, as noted above, one of the main changes within learning disability services in Glasgow was the closure of day centres. My knowledge of relevant policies and experience of working in the sector meant that I understood that this change would mainly affect people who had been attending day centres for many years. The Same as You (Scottish Executive, 2000) had sought to introduce alternatives to day centres, and the number of people attending day centres had declined since its implementation (Scottish Government, 2013). Whilst the number of people attending day centres is reported at the national level (SCLD, 2018), it is not reported by age, therefore it is not possible to ascertain the impact on different age groups. Nonetheless, it was clear from the national learning disability strategies (Scottish Executive, 2000; Scottish Government, 2013) that day centres were no longer the default option for people leaving education and entering adult services

Further reasons for choosing to focus on people aged 30 and over related to ageing and life trajectories. People with learning disabilities experience extended transitions to adulthood (Riddell 2009; Pascall and Hendey 2004), and often live in the family home, supported by parents and/or other family members (Williams, 2013). Importantly, the increase in life expectancy for people with learning disabilities, together with the ageing population and dependence on family care, means there are increasing numbers of older parent carers (Walker and Ward, 2013), adding further complexity to the experiences of this group.

There is little existing evidence in relation to SDS implementation and the experiences of people who require social care support. This study contributes towards addressing this gap, providing an in-depth critique of SDS implementation and illustrating the impact on the daily lives and relationships of participants.

This thesis is structured in three parts. The first part, chapters one to four, explains the context of the study. This introductory chapter has outlined the emergence of the research topic and provided some background information. In the first of two chapters that review relevant literature, chapter two provides an overview of literature and debates relevant to disability and families, including models of disability, care and support for people with learning disabilities, and ethics of care. In chapter three, the focus turns to the emergence of personalisation as the dominant narrative in social care policy, and the discussion draws on academic, policy and ‘grey’ literature to present current debates. Chapter four explains my approach to carrying out the research, discussing theoretical and practical issues as well as critical reflections on the process.

The second part of the thesis, chapters five to seven, present my analysis of the interview data in relation to participants’ experiences in three main areas. Chapter five discusses participants’ experiences of the policy shift in social care, focusing on the assessment process and local implementation of SDS. In chapter six, the discussion turns to participants’ experiences of support services, and is structured in two parts. The first part of chapter six considers the closure of day centres and the impact this has had on the lives of participants, while the second part looks at participants' experiences of alternative services. Chapter seven continues the discussion of the interview data to show how private sphere experiences were related to changes to policy and service provision, highlighting the emotional context of family care and the importance of friendships and support networks.

In the third and final part of the thesis, chapter eight draws the discussions in the previous two parts together. It returns to the key research questions before setting out the main findings of the study and what this means for policy and practice. The thesis concludes with some brief reflections on the research process, and an overview of the key findings and potential ways forward.

2. Literature Review I - Disability and Families

2.1. Introduction

This study set out to explore the experiences of people with learning disabilities, as well as the experiences of their families, at a time of considerable change to social care policy and service provision. As noted in chapter one, this thesis focuses on the experiences of people with learning disabilities aged 30 and over, and their families, and there are several factors which are particularly relevant in framing the experiences of this group. These factors include: extended transitions to adulthood for people with learning disabilities; the important role played by families in the lives of people with learning disabilities; increased life expectancy and ageing of people with learning disabilities and family carers; and experiences of various disability policy developments over the life course.

The four interrelated factors set out above provide the context within which participants experienced changes to social care policy and service provision, discussed further in this chapter. The first section in this chapter provides a brief overview of the medical and social models of disability through the lens of disability studies literature. In the second section of this chapter, the discussion moves on to consider learning disability and the life course, highlighting issues related to transitions to adulthood, life trajectories and living arrangements, as well as ageing and life expectancy. The third section looks at care and support provision for people with learning disabilities, outlining the major policy developments that have determined daily lives and living arrangements, from deinstitutionalisation and normalisation, to community care, and, now, personalisation. The fourth and final section discusses the contested nature of care and introduces the ethics of care as a tool to understand the complex and messy lived reality of interdependent family lives.

2.2. Models of Disability

The first section in this chapter provides an overview of the medical and social models of disability – with a particular focus on learning disability. In Scotland, disability policy is underpinned by the social model of disability, while the medical model is explicitly rejected (Scottish Government, 2016). For example, the Scottish Government delivery plan ‘A Fairer Scotland for Disabled People’ states that it is ‘based unequivocally on the social model of disability as opposed to the medical model’ (Scottish Government, 2016: 4). Policy development is explored in-depth in chapter three, but it is relevant to briefly outline the various ways in which disability has been framed in policy here as these are directly related to models of disability.

UK governments have dealt with the ‘problem’ of disability though policies concerned with the segregation, compensation, rehabilitation, and, more recently, citizenship of disabled people (Drake, 1999). These approaches were successive but overlapping; from Victorian policies where disabled people were ‘contained’ within institutions, to compensation for injuries sustained in war or industry, as well as the growth of welfare and social services, and more recent rights-based policies (Drake, 1999). Throughout the various policy approaches, it is evident that some groups of disabled people would fare better than others, as Glasby (2017: 60) notes; ‘of all community care user groups, people with learning difficulties may well be the most neglected and excluded’.

2.2.1. The medical model

For most of the twentieth century, disability was understood in terms of a medical model and was conceptualised as a problem residing in the individual. As a result, medical intervention was needed to correct 'deviant' bodies and make them more like 'normal' bodies (Drake, 1999). Disability was therefore seen as an individual failing and this provided justification for the social disadvantage experienced by disabled people. This social disadvantage was exacerbated by public attitudes which viewed disabled people as victims of circumstance who needed to be looked after and pitied (Drake, 1999). The medical model also provided justification for health and welfare services to intervene in the lives of disabled people, as evidenced by the emergence and development of social policies (Drake, 1999). As noted above, the Scottish Government’s current approach to disability claims to reject the medical model, and is instead informed by the social model and independent living values (Scottish Government, 2016: 4).

2.2.2. The social model

The emergence of new social movements and political activism in America and Europe in the 1960s paved the way for a challenge to the medical model of disability (Barnes and Mercer, 2001). In the UK, many disabled people were becoming increasingly aware that political parties and traditional disability organisations, which were usually run by non-disabled people, were not representing their needs (Barnes and Mercer, 2001). The disabled people's movement sought to de-stigmatise disability and challenge assumptions that disabled people were tragic victims, and advocated an alternative to the medical model, which came to be known as the social model of disability.

The original ideas in the social model are attributed to the Union of the Physically Impaired Against Segregation (UPIAS). UPIAS was founded in 1972 by a group of disabled activists – most notably Paul Hunt (Finkelstein, 2006). Driven by their experiences of residential homes for disabled people in the UK, the group aimed to have control over their own lives and create alternative forms of support in the community (Finkelstein, 2006). UPIAS produced an important statement which drew a clear distinction between impairment and disability by identifying society, not physical impairment, as the cause of disability:

> *It is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society.*
>
> *(UPIAS, 1976: 3)*

This statement presented a radically different perspective on disability to the medically dominated understanding of disability which was prevalent in Britain at that time. During the 1980s, UPIAS's statement was developed further by disability activists who argued that disability was socially produced, and that society is the source of disability (Oliver, 2013). The key tenets of the social model are: disabled people are an oppressed group; impairment and disability are distinct phenomena; and disability is social oppression, not impairment (Watson, 2004).

The social model gained momentum during the 1980s and began to impact upon professional practice as it was adopted in training programmes on disability equality and in the training of social workers (Oliver, 2004). However, the academic discipline of disability studies did not emerge until the 1990s. Sociologists had previously paid little attention to disability, perhaps because of the dominance of the medical model narrative or the sociological focus on other inequalities such as: class; gender; ethnicity; and sexuality (Barnes, 1998).

Crucially, the social model served as a rallying call for disabled people to join together and create a political movement in order to challenge exclusion and discrimination, and campaign for policy change. This was liberating for individuals who came to understand that their disability was not a personal ‘problem’, but one which had been caused by society (Barnes and Mercer, 2001).

The social model showed that disabled people were ‘disabled by society, not by our bodies’ (Shakespeare 2006: 33), thereby transforming the relationship between disabled people and society from gratitude to entitlement.

The influence of the social model is evident in policy development – most notably in relation to the concept of independent living. Importantly, the drive for choice and control in social care services was instigated by disabled people themselves, who were dissatisfied with existing paternalistic social care services. They campaigned for independent living by way of cash payments which would enable them to arrange their own support instead of receiving local authority services. These issues will be discussed in more detail in chapter three.

Notwithstanding the profound impact of the social model, and its significance in policy development, it is important to briefly note that the social model has been contested by many writers within Sociology and Disability Studies (Thomas, 2004). Many of the critiques are related to the separation of impairment and disability within the social model. Notably, Thomas (1999) introduced the concept of ‘impairment effects’ and proposed an alternative social-relational model of disability which acknowledged that the effects of impairment and illness contributed towards restricting the activities of disabled people. Proposing that the social model is an ‘outdated ideology’, Shakespeare and Watson (2001) argued that the social model neglects impairment. Shakespeare and Watson (2001) highlighted embodied experiences of disability and called instead for a social theory of disability which would recognise multiple bio-psycho-social factors. In contrast with the social model explanation of disability set out above, Shakespeare and Watson (2001: 17) argue that ‘people are disabled both by social barriers and by their bodies’.

2.2.3. Learning disability and the social model

The relationship between the social model and the experiences of people with learning disabilities is highly contested. Whilst Williams (2013: 13) describes the social model as ‘a strong and useful tool with which to approach the issues facing people with learning disabilities’, the discussion here will show how it has been critiqued by other writers for neglecting the experiences of people with learning disabilities.

Williams’ application of the social model focuses on the disabling barriers experienced by people with learning disabilities, arguing that the barriers experienced by this group ‘relate primarily to attitudes of other people, and the lack of ordinary opportunities to live a fulfilled life’ (Williams, 2013: 13). Furthermore, Williams highlights interactions between social barriers and impairment-related barriers; for example, barriers to having a job might include other people’s negative attitudes and behaviours as well as being unable to read or manage money (Williams, 2013).

However, Chappell argues that people with learning disabilities have been marginalised within the social model, proposing that although it can, and should, include people with learning disabilities, learning disability has largely been neglected within social model analyses (Chappell 1998, Chappell et al, 2001). This is related to understandings of impairment and focus on the body, as well as the absence of people with learning disabilities in researching and theorising about disability (Chappell 1998, Chappell et al, 2001). Importantly, Chappell et al (2001) note that the usefulness of the social model is dependent on disabled people, allies and professionals recognising and identifying with it. Thus, for Chappell, these issues have contributed towards learning disability being positioned ‘in the backwaters of disability studies’ (Chappell, 1998: 219).

More recently, Rogers (2016) critiques the social model's neglect of the difficulties associated with experiences of learning disabilities. Whilst acknowledging that the social model has 'transported disability into the public and academic sphere, to be understood as a social phenomenon', Rogers describes it as 'alien' in relation to the experiences of people with learning disabilities and their families (Rogers, 2016: 27). This is supported by observations that:

> *…certain difficult behaviours and day-to-day occurrences, whether for the intellectually disabled person or for the one caring, are not eradicated via the processes of a social model of disability.*
>
> *(Rogers, 2016: 27)*

In order to address the disconnect between the social model and the experiences of people with learning disabilities and their families, Rogers proposes an alternative 'care ethics model of disability' (Rogers, 2016). This model recognises the needs of people with learning disabilities, and those close to them, in relation to care and justice (Rogers, 2016), and is influenced by ethics of care theory, which is discussed in more detail later in this chapter.

The care ethics model of disability proposed by Rogers (2016) sets out three interrelated 'spheres', where care and caring work are carried out: the emotional caring sphere; the practical caring sphere; and the socio-political caring sphere. Importantly, the identification and analysis of these three caring spheres makes visible 'care-less spaces' within and between all three spheres, which 'damage, thwart and contest caring work' (Rogers, 2016: 35). In contrast to 'care-full' spaces, where care and caring work are carried out with care, 'care-less' spaces are settings and relationships ostensibly associated with the provisions of care, but where there is a lack of care and caring in practice

(Rogers, 2016). For example, the avoidable deaths and systemic violence experienced by people with learning disabilities and their families within institutional ‘care’ settings is evidence of ‘care-less spaces’ (Rogers, 2016).

The discussion above provides a brief overview of how the medical and social models have informed understandings of disability and policy development. The next section moves on from the theoretical understandings of disability to look at learning disability and the life course, including transitions to adulthood, life trajectories, living arrangements, and ageing and life expectancy.

2.3. Learning Disability and the Life Course

This study was concerned with the experiences of people with learning disabilities who were aged 30 and over, and their families, at a time of considerable change to social care policy and service provision. As noted in chapter one, there are several interrelated factors which are relevant to this particular group and provide the context within which participants experienced changes to social care policy and service provision. These issues include: extended transitions to adulthood for people with learning disabilities; the important role played by families in the lives of people with learning disabilities; and increased life expectancy and ageing of people with learning disabilities and family carers.

The discussion in this section on learning disability and the life course considers each of these three interrelated issues. This section will first discuss transitions to adulthood for people with learning disabilities, before moving on to look at life trajectories and living arrangements, including the important role played by families in the lives of people with learning disabilities. Thereafter, issues relating to ageing and life expectancy, which add further complexity to care and support arrangements, are considered.

2.3.1. Transitions to adulthood

People with learning disabilities experience extended transitions to adulthood (Riddell, 2009; Pascall and Hendey, 2004). As outlined earlier, this was one of the factors which contributed towards this thesis focusing on the experiences of people with learning disabilities aged 30 and over, and provides some of the context within which participants experience changes to policy and service provision. Whilst extended transitions to adulthood are not unique to people with learning disabilities, there are particular challenges for this group, which are discussed further below.

The transition from youth to the stable identity and status of adulthood is now understood as an increasingly complex process of extended transitions for young people, related to changes in education and employment (Riddell, 2009). Within the youth literature, indicators of transitions to adulthood include: financial independence; employment; leaving the family home; having a partner; and becoming a parent (Tisdall, 2001: 172). Although the experiences of disabled young people have been largely neglected within the youth transitions literature (Riddell, 2009), there is some evidence that transitions to adulthood can be particularly complex for this group (Pascall and Hendey, 2004).

It should be noted that transitions to adulthood are often non-linear, multi-dimensional and extended across all groups of young people (Henderson et al, 2007). Furthermore, measuring 'successful' transitions is problematic because the concepts of ‘adulthood’ and ‘independence’ are themselves contested (Tisdall, 2001: 167-168). Notwithstanding the debates about adulthood and independence within the disability and transitions literature (for example, see Tisdall, 2001: 167), it is important to note that disabled people 'achieve employment, economic independence, personal autonomy, independent housing and citizenship to a lesser degree and at a later stage than non-disabled adults' (Pascall and Hendey, 2004: 166). The factors which contribute towards the extended transitions of disabled people include: dependency on parents; unemployment; being in a 'loop of training'; and a lack of suitable housing (Pascall and Hendey, 2004: 168).

For people with learning disabilities and their families, normative markers of adulthood – such as leaving the family home, having a partner, and being in employment – are often not reflected in their experiences (Walmsley, 1996). This means that, rather than experiencing transitions to adulthood, the trajectories of people with learning disabilities and their families may be more accurately characterised by a 'suspended life course' (Walmsley, 1996: 329). The subsequent discussion in this chapter shows that many of the themes illustrated by Walmsley over 20 years ago remain relevant today.

The combined effects of educational, employment and economic disadvantage contribute towards the extended transitions of disabled people – making them dependent on parents and reinforcing 'the status of perpetual child' (Riddell, 2009: 85). For people with learning disabilities in particular, disadvantage in education has long term consequences that affect post-school destinations and financial dependence (Riddell, 2009). For example, training courses for people with learning disabilities tend to be related to the development of 'life skills' rather than vocational skills (Riddell, 2009). Thus, rather than education leading to employment, this group often finds themselves in cycles of training and retraining (Riddell, 2009; Pascall and Hendey, 2004), which means that people do not have the resources to live independently and are therefore forced to remain in the family home or in supported accommodation (Riddell, 2009). Relatedly, the often vital role played by families in the lives of people with learning disabilities (Williams, 2013) is discussed in the next section of this chapter.

Furthermore, the barriers to leaving the family home for young disabled people may be exacerbated for people with learning disabilities (Tisdall, 2001: 176). This can be due to parental attitudes (Walmsley, 1996) as well as the effects of cognitive impairment (Bigby, 2012). For example, one small study involving 22 people with learning disabilities found that only 4 participants, who were all mothers, had had their own homes when they were in their twenties (Walmsley, 1996). This was an exception as most participants had continued to live in the family home into adulthood (Walmsley, 1996). Whilst Walmsley proposes that the attitudes of parents are highly important in enabling people with learning disabilities to adjust to adulthood, a more recent study by Bigby (2012) draws attention to the role of impairment effects (Thomas, 1999). In her study, Bigby (2012: 427) argues that ‘the very nature of intellectual impairment adds a complex layer of issues associated with supporting independence, choice, autonomy and decision making’.

Both Walmsley (1996) and Bigby (2012) highlight issues which specifically relate to transitions to adulthood for people with learning disabilities. This is important because learning disability has been neglected in much of the disability studies literature (Chappell, 1998, Chappell et al, 2001), as outlined earlier in this chapter. Notwithstanding this critique, there are some aspects of the literature on transitions to adulthood for disabled people that, more broadly, may also have relevance to the experiences of people with learning disabilities and their families. For example, parents and families often play an important role in the lives of people with learning disabilities (Williams, 2013; Walmsley, 1996) and there is strong emphasis on the importance of families and relationships in transitions for young disabled people within the literature (Tisdall, 2001; Pascall and Hendey, 2004).

Whilst neither Tisdall’s (2001) nor Pascall and Hendey’s (2004) studies explicitly explore the experiences of people with learning disabilities, they draw attention to important intersectional issues which may also apply to this group. For example, Pascall and Hendey (2004: 172) argue that parents play a crucial role in enabling their disabled adult children to achieve independence by providing ‘material, cultural and social support’ throughout childhood and into adulthood. Importantly, Pascall and Hendey (2004) also highlight that some parents are more able to provide this support than others. In their study, which involved 72 disabled people in England and Wales, the importance of 'exceptional parents', and particularly mothers, in helping achieve independence was highly evident (Pascall and Hendey, 2004). Those parents categorised as ‘exceptional’ by Pascall and Hendey shared expectations that their child would achieve independence, and possessed the ability to negotiate, and challenge, in dealings with professionals. This group of parents benefitted from having ‘insider’ knowledge or networks related to their occupation, and there were class differences in achievement of independence (Pascall and Hendey, 2004). These were ‘relatively privileged parents in educational and economic terms – parents with skills, time and money’ (Pascall and Hendey, 2004: 174). In contrast, participants whose parents did not possess these advantages were unlikely to live independently from their families or to be in employment (Pascall and Hendey, 2004: 182).

By highlighting the role of class and privilege in achieving independence for disabled young people, Pascall and Hendey’s (2004) findings add nuance to the aforementioned factors identified by Walmsley (1996) and Bigby (2012). It has previously been argued that class, gender and ethnicity have been neglected in the literature concerning the transitions of young disabled people (Tisdall, 2001 171). As such, Pascall and Hendey’s (2004) findings suggest this warrants further enquiry.

2.3.2. Life trajectories and living arrangements

As noted previously, people with learning disabilities often live in the family home, supported by parents and/or other family members (Williams, 2013). Some of the factors which contribute to this have been outlined in the prior section. Additionally, changes to social care policy have affected the living arrangements of people with learning disabilities. For example, deinstitutionalisation and community care policies led to the widespread closure of hospitals and big institutions (Williams, 2013) and the emergence of group homes (Power, 2014). The next section in this chapter outlines changes to care and support services for people with learning disabilities and, relatedly, chapter three traces the policy journey more broadly – from disability activism in the 1970s to the current dominant narrative of personalisation.

This study is concerned with the experiences of people with learning disabilities aged 30 and over. Whilst Walker and Ward (2013) and Bigby (2012) suggest that most middle-aged and older people with learning disabilities live with family carers, the picture in Scotland appears more mixed. For example, recent national statistics suggest that people with learning disabilities aged 35[2] and over in Scotland are more likely *not* to live with a family carer, whereas those aged 34 and under tend to live with a family carer (SCLD, 2018: 29).

Across all age groups, the provisional published data suggests that 30% of adults with learning disabilities (known to local authorities) live with a family carer, and 42% do not (SCLD, 2018). For those aged 35 and over, 20% of people with learning disabilities live with a family carer, and 54% do not (SCLD, 2018). Where people are known to live with a family carer, it is most likely to be a parent; for all age groups, 73% of those who live with a family carer live with a parent, and

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[2] Although participants in this study were aged 30 and over, this data analysis is based on the age bands used in LDSS published statistics, which are: 16-17; 18-20; 21-34; 35-44; 45-54; 55-64; 65+.

for those age 35 and over, 62% of those who live with a family carer live with a parent. The substantial decrease in the proportion of people with learning disabilities living with a parent carer in the 35 and over group is likely related to the availability, age, and ability of parents to provide support as both they and their sons and daughters grow older, as well as the availability of suitable alternative living arrangements. Importantly, the data suggests that a substantial number of older parents are providing care for their disabled sons and daughters.

However, it should also be noted that the living arrangements of a substantial proportion of people with learning disabilities are not reported by local authorities (28% of all ages; 25% of 35+), and the data only includes those people with learning disabilities who are known to the local authority and reported to SCLD[3]. Thus, although SCLD report that people with learning disabilities aged 35 and over are more likely *not* to live with a family carer, this data needs to be treated with caution as the living arrangements of 25% of adults with learning disabilities, aged 35 and over, are not known.

The discussion above, as well as the earlier discussion of transitions to adulthood, illustrates some of the ways in which families often play a vital role in the lives of people with learning disabilities. As Williams notes:

> *Families have always been central to the lives of people with learning disabilities at all ages. Although not all people with learning disabilities*

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[3] SCLD (2018) official statistics state: 'The numbers of adults included in LDSS are those adults with learning disabilities known to local authorities and reported to the LDSS team. There will be adults with learning disabilities not known to local authorities and possibly some who are known but not reported. These adults are not included in the reported figures'. See: https://www.scld.org.uk/wp-content/uploads/2018/12/Learning-Disability-Statistics-Scotland-2018_1.pdf (p28).

> *have support from their families, nevertheless for many it is commonly accepted that family members are the basis onto which other support is built.*
>
> *(Williams, 2013: 71)*

Throughout this thesis, it is noted that families and relationships often play a central role in the lives of people with learning disabilities. This study takes a very broad understanding of families, drawing on sociological debates concerning conceptualisations of families. Notably, the idealised ‘nuclear family’ is no longer the reality for many families, and the shift from this outdated model is related to social and demographic factors including: birth rates; marriage and re-marriage; divorce; co-habitation; step-families; and inter-generational households (Morgan, 1996; Jamieson, 1998; Smart, 2007).

In view of the epistemological issues set out in chapter four, and recognising that the meaning of ‘families’ is contested, the relationships discussed in this study were deliberately not defined at the outset. The complexity and fluidity in defining who ‘counts’ as family in intimate relationships with others is highlighted by Sims-Gould and Martin-Matthews (2008: 1582), who suggest that paid care workers can become ‘family-like’. Whilst recognising that care relationships are complex and multi-faceted, this study did not set out to include the perspectives of those who provide paid care for practical and logistical reasons[4].

Similarly, sociological analysis has shown that the term ‘families’ cannot be understood simply in biological terms, and various alternative conceptualisations

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[4] In a few cases, paid care workers were present during the interviews, but participants were generally related to each other in traditional ways; parent/child, siblings or partners.

have been proposed; for example, ‘families of choice’, kinship and households (Smart, 2007). Notably, the re-conceptualisation of ‘families’ has also involved the recognition that family is a practice, rather than a structure (Morgan, 1996), as ‘families are what families do’ (Smart, 2007; 27).

The concept of ‘family practices’ was originally proposed by David Morgan in ‘Family Connections’ in 1996. This reconceptualization of families was part of an attempt to develop other ways of doing sociology in relation to family life and a response to the marginalisation of family sociology within the wider field (Morgan, 2011). ‘Family practices’ are actions which are performed repeatedly and regularly within families, and are therefore taken for granted and ordinary, although they may appear strange or unusual to others (Morgan, 1996). Despite their apparent ordinariness, such practices carry meaning, related to the context and history within which they take place and become legitimate; for example, ‘feeding the children’ appears ordinary, but has meaning in relation to parenting, gender and consumption (Morgan, 1996: 190-191).

Whilst recognising that models of family have changed over time, Morgan (2011) argues that family practices remain. This is supported by Smart (2007: 48), who suggests the inclusion of ‘relationality’ in ‘family practices’, to reflect that people have significant relationships with others and what they do (or do not do) is affected by these connections. The added concept of ‘relationality’ is helpful because it recognises that people are actively involved in the construction of networks with others, rather than the subjects of given, fixed, relationships with ‘kin’ (Smart, 2007).

Additionally, there is a considerable body of empirical research which highlights the diverse ways in which people experience families and relationships (Tisdall, 2001). These alternative ways of understanding families from a sociological perspective reflect the shift away from the idealized nuclear family towards more diverse and fluid forms (Smart, 2007). However, outwith academic debate, the term ‘family’ remains strongly associated with biological ties or shared living arrangements (Smart, 2007). Co-residence was not a requirement for participation in this study, and several of the people who participated did not live with their families – although they continued to give and receive familial support in various ways. Likewise, Smart (2007) notes the continuation of relationships and support when people no longer live together or have less contact, suggesting that family members may continue to support each other regardless of their living arrangements.

It is clear that families provide considerable amounts of care for people with learning disabilities throughout the life course. This may be related to normative understandings of family and beliefs that family care is the best care (Forbat, 2005), although beliefs that living with family is the best arrangement for people with learning disabilities have been strongly challenged by discourses of rights and citizenship (Walmsley, 1996: 324). The ‘problem’ of care is discussed later in this chapter, but it is important to note here that decisions concerning care and support within families are complex. For example, the moral imperative to care is associated with gender identity (Henz, 2009) and ‘legitimacy’ (Connell, 2005) for some women, and it is also related to welfare ideology and the emergence of policies which support informal care (Forbat, 2005). Additionally, there are further difficult issues to consider in relation to care for family members who have learning disabilities. Whilst Bowey and McGlaughlin (2007) suggest that some parents are reluctant to ‘let go’ of their adult sons and daughters, it is important to acknowledge that people with learning disabilities are at risk of abuse (Hall, 2011; Williams, 2013; Macdonald, 2015) and the desire for parents to protect their children from harm may contribute towards family care decisions. Crucially, there may also be no real alternative to family care for many people, as Walmsley notes: ‘It may be that families are far from ideal, but that the alternatives offered to people are not so good either’ (1996: 338).

However, although the extended transitions to adulthood and prevalence of family care for people with learning disabilities are acknowledged in the literature (as discussed above), we know little about how this group feels about these relationships (Walmsley, 1996). Walmsley (1996: 324) suggests that this knowledge and understanding is lacking because research has tended to focus on broader changes in policy; for example, deinstitutionalisation and community care, rather than families and emotions. It is noted that there are particular challenges in researching families and emotions – some of which are discussed in chapter four in relation to undertaking this study – and the neglect of emotions in sociological research (Smart, 2007), discussed below.

This sociological study set out to explore how changes to social care policy played out in the day-to-day lives of people with learning disabilities and their families. Love and emotions are inextricably linked with our experiences of relationships, yet, while much has been written on the subject of families and relationships, love and emotions have been largely neglected (Smart, 2007). Smart (2007) suggests that there is a reluctance to deal with feelings within sociology, which is partly related to beliefs that emotions are the subject matter of psychology or biology. Furthermore, the reluctance of sociologists to deal with complex issues of feelings and emotions may also be related to theoretical and methodological considerations that result in a tendency to focus on more visible aspects of relationships – such as care and commitment (Smart, 2007). However, simply focusing on the visible aspects of relationships risks producing a shallow account of lived realities. Mason (1996) draws attention to the vast difference between how care looks and feels, noting that:

> *‘there is a considerable experiential chasm between acts of care (e.g. preparing food and helping another to eat) carried out with love and those carried out without any feelings – even if the behaviour ‘looks’ manifestly the same it ‘feels’ very different’*

(Mason, 1996, cited in Smart, 2007: 60)

2.3.3. Ageing and life expectancy

Ageing and increased life expectancy are pertinent issues for people with learning disabilities and their families, given the reliance on family care outlined above. As noted earlier, one of the factors affecting this group is the ageing of both people with learning disabilities and family carers, creating further complexity in care and support arrangements.

The increase in life expectancy[5] for people with learning disabilities, together with the ageing population and dependence on family care, means there are increasing numbers of older parent carers (Walker and Ward, 2013). Thus, instead of increased longevity being seen as an opportunity for people with learning disabilities to develop life skills and autonomy, ageing has been framed as a 'problem' that creates new issues for families and for social policy (Breitenbach, 2001: 238). People with learning disabilities are now 'much more likely to outlive their parents than in previous decades' (Bigby, 2012: 426), and many parents worry about what will happen to their disabled adult children when they die or are no longer able to care for them themselves (Bigby, 2012; Walmsley, 1996). As a result, there has been increased attention to future planning in policy and practice (Bowey and McGlaughlin, 2007); however, Bigby (2012) suggests that this tends to focus on carers, whilst people with learning disabilities are framed in terms of dependency and excluded from the planning process.

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[5] Although life expectancy for people with learning disabilities has increased, there remains a gap of approximately 20 years with that of the general population (Scottish Government, 2013). The SLDO has an ongoing project to understand more about this, see: https://www.sldo.ac.uk/projects/adult-health/life-expectancy/

In contrast to the literature which presents people with learning disabilities as a burden on their families, Walmsley (1996: 334) suggests that ageing parents can sometimes be a burden on their disabled adult children. Drawing on relationships research with people with learning disabilities, Walmsley (1996) observed mutual support in families as parents aged or became frail, and responsibility for tasks – such as housework, shopping, and gardening – fell to the adult children. Whilst some participants expressed pride that they were helping their parents, others expressed resentment about the restrictions they experienced as a result; for example, they were unable to go out as often as they would have liked or were not able to move out of the family home (Walmsley, 1996).

Thus, as people with learning disabilities and their parents get older, relationships can be both a source of tension and support (Walmsley, 1996; Bigby, 2012). In Walmsley's study, for example, tensions existed in relationships where parents: required substantial support; placed restrictions on their adult children in relation to what they were permitted to do; and retained control over money (Walmsley, 1996). However, the complexity in these relationships is illustrated by Bigby (2012: 429), who notes that in addition to sometimes having restrictions placed on their social lives by dominating or dependent parents, people with learning disabilities often have shared social lives and friendships with their parents as they attend groups and events together – as well as with their parents’ friends.

However, within the context of increased life expectancy of people with learning disabilities, perceptions of ageing are complex. While seen as ‘not quite grown up’ by family and professionals, people with learning disabilities are also perceived as ageing prematurely (Bigby, 2012; Breitenbach, 2001). For example, Bigby (2012: 430) suggests that parents often retain control and treat their adult children who have learning disabilities as though they were still children.

Similarly, Breitenbach (2001: 232) notes that people with learning disabilities are often perceived as ‘eternal children’, and suggests this may be related to ‘cognitive maturity’ and lack of visibility as they grow older.

Ageing is associated with life trajectories; however, as illustrated in the discussion above concerning transitions to adulthood, normative markers do not necessarily reflect the experiences of people with learning disabilities. For example, leaving the family home is commonly presented as a normative marker of adulthood, but the living arrangements of people with learning disabilities often involve ‘institutionalisation’ or ‘lifelong co-residence with parents’ (Bigby, 2012: 427). Furthermore, Breitenbach (2001: 233) raises important questions regarding how people with learning disabilities themselves understand ageing, and the relevance of markers of age, as well as the timing of life events.

This section on learning disability and the life course set out to consider the context within which participants experienced changes to social care policy and service provision. The interrelated issues relevant to people with learning disabilities aged 30 and over, and their families, include: extended transitions to adulthood for people with learning disabilities; the important role played by families in the lives of people with learning disabilities; and increased life expectancy and ageing of people with learning disabilities and family carers. The next section moves on to consider care and support provision for people with learning disabilities, outlining the major policy developments which have determined daily lives and living arrangements.

2.4. Care and Support for People with Learning Disabilities

The previous section highlights important issues in relation to ageing and the life course for people with learning disabilities and their families, including: extended transitions to adulthood; the importance of families; and increased life expectancy and ageing. Importantly, these issues are experienced within the context of changes to social care policy and service provision. This study focuses on the experiences of people with learning disabilities aged 30 and over, and their families, a group which has seen considerable policy change over the lifetime. For example, the formative experiences of this group took place within a pre-equalities era, before the Equality Act 2010, the Disability Discrimination Act 1995, and in some cases the Education Act 1970.

This thesis explores how changes to social care policy and service provision play out in the daily lives and relationships of people with learning disabilities and their families. Thus, this section provides a brief overview of major policy developments which have determined daily lives and living arrangements for this group, from deinstitutionalisation and normalisation, to community care, and more recently, personalisation. Most notably, the shift from collective to individualised services associated with personalisation, has resulted in the widespread closure of day centres for people with learning disabilities (Needham, 2014). The emergence and development of personalisation as the dominant narrative in social care policy is discussed in detail in chapter three. This section focuses on the ways in which the daily lives and living arrangements of people with learning disabilities are determined by policy and service provision.

2.4.1. Deinstitutionalisation and normalisation

Prior to the implementation of deinstitutionalisation policies in the late 1980s and early 1990s, people with learning disabilities either lived with their families or in institutions (Williams, 2013). Although long-stay hospitals and institutions were associated with the provision of care, there were also ‘hidden motives’ of control and containment involved in the institutionalisation of this group (Walmsley, 1999, cited in Williams, 2013).

The concept of ‘normalisation’ has been highly influential in the development of learning disability services since the 1970s (Williams, 2013). Normalisation is broadly concerned with people having an ‘ordinary lifestyle’, and the support they need to achieve such an aim (Williams, 2013). This was an important development for people with learning disabilities because normalisation contributed to the recognition that this group should be able to participate in the community, have relationships and make choices (Williams, 2013). Crucially, given that support services for people with learning disabilities had been limited to long-stay hospitals and institutions prior to this time, normalisation provided a ‘tool to fight back against the dehumanizing aspects of institutional care’ (Williams, 2013 20). However, notwithstanding this important contribution to challenging the way in which learning disability had previously been framed in policy, the concept of normalisation has been subject to critiques since the 1970s and 1980s (Williams, 2013). Fundamentally, normalisation requires that people fit into ‘typical social roles’, which neglects social barriers and rights-based approaches to disability (Williams, 2013: 21).

Deinstitutionalisation policies meant widespread closures of hospitals and big institutions for people with learning disabilities, and the emergence of alternative forms of care in the community (Williams, 2013). The implementation of the NHS and Community Care Act 1990 was a key factor in this policy shift and this is discussed further in chapter three. Thus, deinstitutionalisation resulted in the creation of specialist provision for people with learning disabilities; for example, group homes, special schools, and day centres (Power, 2014). However, despite the closure of long-stay hospitals and institutions associated with deinstitutionalisation, people with learning disabilities remained largely invisible within communities (Power, 2014). During this period, there was a substantial growth in the number of day centres for people with learning disabilities (Mental Health Foundation, 1993, cited in Todd and Sheam, 1996). However, although these facilities were physically located within communities, people with learning disabilities were still largely invisible outwith the centres, and many people remained tied to their homes and families and had limited social networks (Power, 2014).

2.4.2. Community Care

The term 'community care' was initially used in relation to the policy shift from long-stay hospitals to 'community-based provision' in learning disability and mental health services, before expanding into other services – including those for older people (Means et al, 2008: 5). Subsequently, the term 'community care' has become widely used in policy narratives, although what is meant by this is contested; feminist writers have highlighted that caring is done by individuals, usually women, and not communities (Means et al, 2008). Nonetheless, 'community care', and broader rhetoric in relation to community (for example, community schools and community policing) remain popular in policy, perhaps because 'community' is associated in the imaginary with myths of 'harmonious, caring and integrated communities of the past' (Means et al, 2008: 3).

As a result of deinstitutionalisation and community care policies, many people with learning disabilities now live in supported living rather than residential accommodation (Means et al, 2008). Whilst this may be seen as progress towards independent living, which is discussed in chapter three, some studies show little difference to the level of choice or quality of life for people in supported living rather than residential accommodation (Means et al, 2008). Importantly, instead of *choosing* where they would like to live, people are often *placed* in particular accommodation (Means et al, 2008).

Thus, the closure of outdated institutions does not mean the end of institutional life for people with learning disabilities (Means et al, 2008). Many people with learning disabilities live in group homes, where daily lives are determined by staff rotas (Means et al, 2008). This is important because supportive staff play a vital role in enabling people to exercise choice and achieve quality of life (Means et al, 2008: 141). Furthermore, many people with learning disabilities living in group homes experience few opportunities for community activities (Means et al, 2008). Consequently, people with learning disabilities are often ‘living in the community but not a part of it’ (Williams, 2013: 172).

2.4.3. Personalisation – challenges and opportunities

The concept of personalisation is highly contested, and chapter three sets out current debates and tracks the emergence of personalisation as the dominant narrative in social care. For people with learning disabilities and their families, the implementation of personalisation has major implications in relation to daily lives and living arrangements; this is the focus of the discussion here. As set out in chapter three, personalisation is a ‘culmination of’ ideas associated with deinstitutionalisation and the independent living movement (Power, 2014: 168). Importantly, personalisation shifts the focus from the provision of social care services to the support people need to be independent in the community (Power, 2014). In terms of funding, this means allocating budgets to individuals rather than collective services – such as day centres. For many people with learning disabilities and their families, this presents particular challenges and opportunities, as discussed below.

Challenges for people with learning disabilities and their families

The implementation of personalisation presents many challenges for people with learning disabilities and their families. The main issues discussed here are: the impact of austerity and reductions in social care budgets; the shift from collective services to individual support; most notably, the widespread closure of day centres; the lack of suitable alternatives to day centres; skills and capacity issues; and carers' perspectives. Although each issue is presented separately, they are, in practice, largely interrelated.

Austerity and social care budgets

The impact of austerity on policy implementation is discussed in chapter three; however, it is important to note here that disabled people have been disproportionately affected by cuts to public spending and welfare reform from 2008 (Ferguson and Lavalette, 2014; Ginsburg et al, 2012; Morris, 2011). Whilst this section identifies several challenges in relation to personalisation for people with learning disabilities and their families, public spending cuts underpin many of these issues.

One of the direct consequences of public spending cuts has been an increase in eligibility criteria and a reduction in social care budgets (Pile, 2014; Needham, 2014; Hall, 2014; Pearson and Ridley, 2017), which is discussed further in chapter three. In relation to the daily lives and living arrangements of people with learning disabilities and their families, the combined effects of cuts to social care budgets and increases to eligibility criteria mean there is less support for people with mild or moderate needs (Power and Bartlett, 2018). In practice, this means that many people who have mild or moderate needs are no longer in receipt of social care services (Power and Bartlett, 2018). This puts people at risk of loneliness and isolation (Power and Bartlett, 2018), and risks people reaching a crisis situation because there are fewer opportunities for early identification and intervention when people are experiencing difficulties (Hamilton et al, 2017).

Shift from collective services to individual support

The implementation of personalisation has resulted in widespread closures of day centres for people with learning disabilities (Needham, 2014; Mencap, 2012). Mencap (2012: 6) reports that day centre closures have resulted in many people being 'stuck at home with nothing to do, isolated and scared about the future'.

Day centres, groups and projects often provide the settings for people with learning disabilities to create their own communities and develop connections with each other (Williams, 2013: 185). However, the closure of day centres has resulted in the loss of friends and workers (Hamilton et al, 2017), and fewer opportunities for social support networks for many people with learning disabilities (Hamilton et al, 2017; Power and Bartlett, 2018).

We all exist within 'webs' of relationships with others (Tronto, 1993), and the importance of inter-dependence in daily lives has been promoted by many disability commentators (see, for example, Shakespeare, 2000). Friendships and peer support are very important in the lives of people with learning disabilities (Power and Bartlett, 2018; Hamilton et al, 2017), and building these bonds can be difficult for this group – requiring time and support from others (Hamilton et al, 2017). The closure of day centres and other collective spaces means there are fewer opportunities to create and maintain these relationships (Power and Bartlett, 2018; Hamilton et al, 2017).

Consequently, Hamilton et al (2017) argue that the loss of day centres and other collective support arrangements is detrimental to the wellbeing of many people with learning disabilities. Their study found that some people with learning disabilities had become isolated and lonely, and this was detrimental to their mental health (Hamilton et al, 2017). Whilst it is well recognised that social support is important for wellbeing, changes to social care services – as a result of personalisation – means that the social networks of people with learning disabilities are becoming increasingly fragmented (Hamilton et al, 2017).

However, the widespread closure of day centres is an extremely contentious issue. Whilst there has been much resistance by people who attend the centres and their families, the closures have been welcomed by others (Needham, 2014). The disability movement is generally critical of day centres because of associations with the segregation and institutionalisation of disabled people (Needham, 2014). Thus, the closure of day centres for people with learning disabilities and others (for example, elderly people) has been framed as a 'positive consequence' of personalisation, rather than a result of austerity and the neo-liberal agenda, by supporters of personalisation and disability commentators (Needham, 2014: 94).

One powerful argument adopted by supporters of day centre closures was that day centres were no longer what people wanted, and this was supported by evidence of declining use (Needham, 2014). However, Needham points out that access to day centre places was being restricted in various ways as a result of public spending cuts, therefore declining use was not simply a result of people exercising choice (Needham, 2014). As noted above, public spending cuts have resulted in an increase in eligibility criteria, which means that fewer people are deemed eligible for social care – including access to day centre places (Needham, 2014). For people who remain eligible for social care, the cuts to social care budgets, discussed above, mean fewer hours of support and this may not be sufficient to attend a day centre (Needham, 2014). At the same time, many local authorities increased, or introduced, costs to individuals for attending day centres, which was also a prohibitive factor (Needham, 2014). For example, daily rates charged to individuals could range from a nominal fee of around £4 per day to the full cost of the service of around £60 (Needham, 2014). Furthermore, some local authorities had restricted access to day centres by not offering a day centre service to certain groups, including: young people; people who were in residential homes; and people whose care was self-funded (Needham, 2014).

In addition to contesting ‘evidence’ of declining use set out above, Needham’s (2014) analysis of the ‘recurring stories’ in personalisation reveals the powerful narratives which personalisation advocates have invoked to legitimate the widespread closure of day centres. This is an important critique because there is much support for day centres from people with learning disabilities and their families (Mencap, 2012; Needham, 2014; Hall, 2011). Whilst the narratives above contribute towards ‘de-legitimizing’ day centres as appropriate places of care (Needham, 2014), Needham’s analysis also reveals how powerful professionals discredit the perspectives of families by portraying those who argue to protect day centres as ‘special interests’ or ‘illegitimate voices’ (2014: 95-96). As will be discussed in chapter three, personalisation is associated with cost savings (Needham, 2011; Pearson and Ridley, 2017) and a shift in power from professionals to people who use services (Pearson et al, 2014); Needham’s analysis in relation to day centre closures illustrates the difficulty in reconciling these objectives within the context of austerity.

Lack of suitable alternatives to day centres

Another ‘recurring story’, which Needham (2014) identified in her analysis of personalisation narratives in relation to day centres closures, was that the closures would free up capacity for people to develop alternatives to day centres (Needham, 2014: 97). Whilst there was strong evidence of the ‘recurring stories’ discussed above, which served to de-legitimise places and people in practice, this was not the case for the ‘recurring stories’ about freeing up capacity to develop alternatives (Needham, 2014). This disconnect between policy narratives and practice led Needham (2014) to argue that narratives had been much more successful in legitimising day centre closures than they were in achieving alternatives, and she proposes several possible explanations for this, which are outlined below.

One option is that the ‘recurring story’ that day centre closures would free up capacity for people to develop alternatives was a ‘rhetorical flourish, rather than a genuine policy goal’ (2014: 101). An alternative explanation is that personalisation may have been subverted by local implementation and the financial crisis (Needham, 2014). In Scotland, there is evidence that cuts to public spending have impacted on the implementation of personalisation (Pearson and Ridley, 2017; Audit Scotland, 2017; Scottish Government, 2019a), discussed in chapter three. Further explanations related to prioritisation and timing; it may be that the closures are seen as more important, or it may be the case that alternatives have yet to be achieved (Needham, 2014).

Whilst the possible explanations set out above may each have contributed towards the disconnect between policy narratives and practice in relation to freeing up capacity for people to develop alternatives to day centres, Needham (2014) suggests that incoherent social care policy is a key factor. As noted earlier, personalisation is associated with a shift from the provision of collective social care services to individual support in the community (Power, 2014). Assumptions that day centres will be replaced by ‘community hubs’, as well as existing community facilities, are implicit in personalisation policy narratives, yet there are no clear plans or infrastructure (Needham, 2014). Importantly, personalisation does not explain how ‘new collective spaces’ – discussed later in this chapter – will come about (Needham, 2014). Furthermore, the impact of austerity and public sector cuts is discussed in detail in chapter three, but it is also relevant to note here that local authority budget cuts affect public services, for example: libraries; community groups; and leisure centres, which have been increasingly seen as alternatives to day centres (Ferguson, 2012). Thus, rather than deliberate subversion, Needham suggests that narratives around freeing up capacity to develop alternatives have been unsuccessful as a result of incoherent social care policy, as managers and staff are expected to 'achieve contradictory policy goals… more tailored services at the same time as massive funding cuts' (2014: 103).

Notwithstanding the critiques outlined above, it should also be noted that the shift from collective services, like day centres, to individual support and independence in the community may not reflect the needs and wishes of some people with learning disabilities and their families (Hall, 2011; Hamilton et al, 2017). Some people with learning disabilities do not want more independence and control in their lives (Hamilton et al, 2017), and many want to be able to attend a day centre (Hall, 2011; Mencap, 2012). As noted earlier, personalisation is associated with independence in the community, but for many people with learning disabilities, communities are hostile places (Hamilton et al, 2017; Hall, 2011; Power and Bartlett, 2018). Crucially, public places can be hostile environments[6] for people with learning disabilities, who often experience discrimination and abuse (Hall, 2011). As Williams notes:

> *Policy about inclusion within mainstream services tends to paint a rosy picture of 'community', which in reality may not exist for a person with learning disabilities.*
>
> *(2013: 173)*

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[6] The hostile environment for disabled people has been exacerbated by austerity and media reporting of disability and welfare reform, (see SCDR/GMU: https://www.gla.ac.uk/media/media_214917_en.pdf and Garthwaite: https://doi.org/10.1080/09687599.2011.560420).

Skills and capacity

For people with learning disabilities, personalisation can present particular challenges in relation to skills and capacity issues (Hall, 2011). Personalisation is associated with choice and control; as discussed in chapter three, for many people, this means managing a personal budget or employing a Personal Assistant (PA). However, Hamilton et al (2017) found that people with learning disabilities experienced managing a personal budget as difficult and stressful, and this was exacerbated for people who had PAs, as the PAs needs were often prioritised over the person being supported (Hamilton et al, 2017).

Moreover, there are also additional costs associated with personalisation for people with learning disabilities, which may conflict with implementation in a time of constrained budgets. In order to be able to participate in the planning and assessment process, many people with learning disabilities will require additional time and support (Hamilton et al, 2017). This means that there can be ‘higher costs associated with the care planning and assessment process’ for people with learning disabilities (Hamilton et al, 2017: 289).

Importantly, some people with learning disabilities are more able to benefit from the opportunities presented by personalisation than others. For example, the people who are more likely to benefit from personalisation are those who are more able (Hall, 2011; Hamilton et al, 2017), and those who are well supported and resourced (Hall, 2011). However, people with learning disabilities who do not have family support are less likely to benefit from personalisation and are at risk of isolation and exclusion (Hamilton et al 2017).

Relatedly, networks of support are extremely important for people with learning disabilities (Hall, 2011; Power and Bartlett, 2018; Hamilton et al, 2017). Personalisation is associated with the principles of independent living, discussed in chapter three, but this raises particular challenges for people with learning disabilities, as Hall notes:

> *…any degree of 'independent living' for people with learning disabilities is achievable only through the active support of families, carers and disability organisations, often in communal space*
>
> *(Hall, 2011: 599)*

Carers' perspectives

A further consideration, in relation to personalisation for people with learning disabilities, is the perspectives of family carers. As noted earlier in this chapter, families often play a vital role in the lives of people with learning disabilities (Williams, 2013), and changes to social care as a result of personalisation can be particularly difficult for parents to accept (Power, 2014). For example, being independent in the community is an unknown and unpredictable alternative to a day centre (Power, 2014), and families are required to accept that things can, and sometimes do, go wrong (Power, 2013). Whilst it is noted that parents can be over-protective (Power, 2014; Bigby, 2012; Breitenbach, 2001) and have difficulty in 'letting go' of their disabled adult sons and daughters (Bowey and McGlaughlin, 2007), as outlined earlier in this chapter, people with learning disabilities are at risk of abuse (Hall, 2011; Williams, 2013; Macdonald, 2015) and this may make change to established and known routines very difficult for families. Notwithstanding these issues, it is also important to note that there is a risk that the voices of people with learning disabilities might be drowned out by the voices of carers (Hamilton et al, 2017).

Opportunities for people with learning disabilities and their families

Personalisation presents particular challenges, as outlined above; however, for some people with learning disabilities, personalisation also means new opportunities (Hall, 2011; Power, 2014), some of which are outlined below. Chapter three discusses competing discourses in the development and implementation of personalisation policies, therefore it is sufficient to note here that personalisation is associated with people being able to exercise choice and control over their support arrangements. This, in itself, is an opportunity; personalisation means people with learning disabilities should be able to choose the support they want, instead of having to fit in with traditional services. This is a particularly significant shift in policy for this group, who have historically been marginalised and excluded by policy (Glasby, 2017), as set out earlier in this chapter.

Furthermore, within the Scottish policy context, choice and control are not dependent on having a social care budget, in contrast with personalisation in England (Hall, 2014). The Social Care (Self-directed Support) (Scotland) Act 2013, which will be discussed in chapter three, requires that people who are assessed by the local authority as needing social care are entitled to exercise choice and control in relation to how their needs are met, even if those needs are not deemed eligible for a budget. Within the context of increased eligibility criteria (Pile, 2014; Needham, 2014; Hall, 2014; Pearson and Ridley, 2017), which has resulted in a growing group of people who have social care needs but no budget (Hall, 2014; Power and Bartlett, 2018), personalisation in Scotland can be understood as an opportunity because this group is entitled to exercise choice and control in relation to how their needs are met.

Inclusion and independence in the community

In addition to the opportunity to exercise choice and control, personalisation may also mean new opportunities for inclusion and independence in the community for people with learning disabilities (Hall, 2014; Power and Bartlett, 2018). Within the Scottish context, Hall (2014: 130) proposes that the combination of public sector cuts and the Scottish approach to policymaking could potentially lead to ‘opportunities for new and progressive forms and spaces of care’ for people with learning disabilities, which are discussed below.

Notwithstanding the negative consequences of austerity and public spending cuts for many disabled people and their families, Hall (2014) suggests that cuts to social care budgets could contribute towards the emergence of alternative forms of care, within the context of personalisation and the Scottish approach to policymaking. The Scottish approach to policymaking is discussed in chapter three, but it is relevant to mention here that the policy and political context in Scotland is somewhat different to other parts of the UK (Hall, 2014). Fundamentally, the Scottish approach is associated with co-production – in both the design and delivery of policies (Cairney et al, 2016; Cook, 2017; Cairney, 2017) – while the Scottish Government’s approach to social policy emphasises public sector provision (Hall, 2014). This is evident in the development and implementation of self-directed support (SDS), discussed in chapter three, and there is a strong and consistent policy message about the importance of co-production – between individuals, families, services and professionals – in all aspects of SDS.

Relatedly, policy objectives of inclusion and independence in the community underpin the Scottish Government (2016) strategy: ‘A Fairer Scotland for Disabled People’. This is supported by ‘The keys to life’, the national strategy for people with learning disabilities (Scottish Government, 2013), and its predecessor, ‘The Same as You?’ (Scottish Government, 2000). It is also further supported by the provisions of the UNCRPD – notably Article 19, living independently and being included in the community (UN, undated).

Support networks and community connections

For people with learning disabilities, support networks are vital to fostering belonging and inclusion (Hall, 2011), and policy can actively support this, for example, through ‘community connectors’ or Local Area Co-ordinators (LACs) (Power, 2014). LACs are one example of the new forms of care for people with learning disabilities which have emerged in Scotland (Hall, 2014). Building community connections takes time, resources, and a range of individuals and organisations (Hamilton et al, 2017), and the role of the LAC includes connecting with local organisations and building inclusive communities (Hall, 2014). Power (2013) notes that ‘community connectors’ and LACs require workers with particular skills, knowledge, and resources so that they can build connections within communities, and work with others to support the inclusion of people with learning disabilities in local areas. Importantly, being connected to their local communities could help to challenge the discrimination and exclusion experienced by people with learning disabilities in mainstream society, and contribute towards a ‘sense of belonging and respect’ (Hall, 2014: 130).

Whilst the provision of LACs was a recommendation in the Scottish Government’s 2010 strategy, ‘The same as you?’, there has been considerably less focus in subsequent policy developments (Hall, 2014). For example, there was little mention in the 2013 strategy, ‘The keys to life’ (Hall, 2014), and LACS are notably absent in the refreshed national learning disability strategy implementation framework and priorities for 2019-2021 (Scottish Government, 2019c). Combined with the enduring difficulties in the recruitment and retention of skilled, experienced and qualified social care workers (SSSC, 2017), and the impact of public spending cuts on local authorities (Hall, 2014), the potential for LACs to contribute towards building inclusive communities may be limited.

Changing places and spaces of care

The discussion above has illustrated potential opportunities for inclusion related to the implementation of personalisation and the emergence of new forms of care and support. However, personalisation is also associated with changing places and spaces of care, and this has implications for inclusion and belonging for people with learning disabilities, discussed below.

Whilst the widespread closure of day centres for people with learning disabilities associated with personalisation is highly contentious, as outlined earlier in this chapter, it may also contribute towards the emergence of alternative forms of support, and inclusion, within communities. Increasingly, day centres are no longer being seen as appropriate places for the care and support of people with learning disabilities (Power, 2014); instead, care is often being provided in public places, as well as in the home (Hall, 2011). This shift to care in public spaces opens up new opportunities for inclusion, but many people with learning disabilities will need support in order to benefit from this change (Power and Bartlett, 2015).

Whereas public spaces are increasingly being seen as appropriate places of care (Power and Bartlett, 2018), having ‘spaces and relations of ‘belonging’ and wellbeing’ (Hall, 2010: 49) may be more important and appropriate for people with learning disabilities than being in mainstream spaces (Hall, 2010). Belonging and inclusion can be found in places where there are opportunities to be with other people with learning disabilities (Hall, 2010, 2011). Furthermore, spaces which are exclusively for people with learning disabilities, and the relationships formed within these spaces, can provide friendships, support and acceptance (Hall, 2010, 2011).

Importantly, spaces which are exclusively for people with learning disabilities do not necessarily exist entirely separately from mainstream society (Hall, 2010). For example, Hall (2010) discusses a theatre group where the actors all have learning disabilities, and they connect with wider audiences through performing in mainstream arts venues. Such spaces can provide opportunities to challenge assumptions and expectations in relation to learning disability (Hall, 2010).

Despite the changing spaces and places of care associated with personalisation, the personalised service landscape, where care is provided in everyday settings rather than formal settings, is framed as ‘place-less’ by policy (Power, 2014). While place is often key to experiences of inclusion for people with learning disabilities, this has largely been neglected in policy (Power and Bartlett, 2018). Similarly, as noted earlier in this chapter, Needham (2014) observed that personalisation policy narratives lacked any clear plans or infrastructure to explain how alternatives to day centres would come about.

The continued importance of place in the lives of people with learning disabilities is illustrated by the emergence of ‘safe-havens’ (Power and Bartlett, 2018). Power and Bartlett (2015 and 2018) note that some people with learning disabilities are finding their own places of inclusion within local communities and public places. Some of the ‘safe-havens’ identified by Power and Bartlett (2015: 9-12) include: places where people with learning disabilities can go to meet local people; places where they could find ‘sanctuary and safety’; and places to be with friends and go unnoticed by others. The emergence of these ‘safe-havens’ (Power and Bartlett, 2015, 2018) highlights some of the complexities and negotiations in inclusion for people with learning disabilities – these are ‘moments of inclusion’ within wider exclusion (Power and Bartlett, 2018: 8). Thus, it illustrates that (moments of) inclusion within mainstream places are possible, potentially shifting expectations of and about people with learning disabilities (Power and Bartlett, 2015). However, it also demonstrates the sustained exclusion and discrimination experienced by this group within public places (Power and Bartlett, 2018). Despite inclusionary policy narratives, people with learning disabilities had to seek out their own places of inclusion. Furthermore, as noted earlier in this chapter, networks of support are extremely important for people with learning disabilities (Hall, 2011; Power and Bartlett, 2018; Hamilton et al, 2017). Power and Bartlett (2018) note that ‘safe-havens’ were made possible with the involvement of other people – including advocacy workers, friends and families.

Inclusion is complex

The discussion above highlights the new opportunities, brought about by personalisation, for inclusion and independence in the community for people with learning disabilities. Whilst inclusion has a ‘warm ring to it’ (Williams, 2013: 120), it is important to note that *achieving* inclusion is difficult for a group who have historically been marginalised and excluded from society (Williams, 2013). Simply being in the same place does not mean people with learning disabilities and others will interact with one another (Williams, 2013). While Hamilton et al (2017) similarly note that inclusion and belonging require more than people with learning disabilities being physically present or visible to others, Hall (2014) suggests that being seen *and* doing things within public spaces can help break down barriers and contribute towards inclusion. Additionally, there is some research which suggests that inclusion and independence is not necessarily what some people with learning disabilities want (Needham, 2014; Hamilton et al, 2017).

Relatedly, Williams (2013: 120) observes that a gap exists between policy rhetoric and practice in relation to inclusion for people with learning disabilities. Expectations and perceptions that inclusion is simply a matter of ‘inserting people with learning disabilities into a pre-existing mainstream community from which they have previously been excluded’ remains a very prevalent view amongst policy-makers (Williams, 2013: 185).

The discussion above provides a brief overview of major policy developments which have determined daily lives and living arrangements for this group: from deinstitutionalisation and normalisation, to community care, and, more recently, personalisation. Key challenges and opportunities in relation to personalisation were outlined; most notably, cuts to public spending and the widespread closure of day centres for people with learning disabilities (Needham, 2014). The discussion here focused on the ways in which the daily lives and living arrangements of people with learning disabilities are determined by policy and service provision. The next section moves on to consider 'care' as a contested issue.

2.5. The 'Problem' of Care

Care research originated in feminist analysis during the 1980s (see, for example, Finch and Groves, 1983), highlighting the unpaid work carried out by women in the private sphere and making visible what was previously assumed to be natural female activity (Fine and Glendinning, 2005). This was important because it highlighted the ways in which caring carried costs for women and affected equality of opportunity, but it was also problematic because it conceptualised care as a 'burden' (Fine and Glendinning, 2005). Framing care as domestic drudgery and cared for persons as a burden is disempowering and oppressive to those who undertake care and those who receive it (Fine and Glendinning, 2005).

By contrast, this section shows that care is a moral and political issue (Barnes, 2012). The moral dimension of care is evidenced by arguments that care is necessary to achieve social justice and that society as a whole will benefit if all of its members receives the care they need (Barnes, 2012: 13). The political dimensions of care have been highlighted by the diverse perspectives and activism of the disabled people's movement, mental health 'survivors', and the carers' movement (Barnes, 2012). This section begins by discussing the feminist origins of care research, and the persistence of gendered patterns of care, before moving on to consider the rejection of 'care' by the disabled people's movement. The discussion then goes on to introduce ethics of care, an alternative way of conceptualising care, which recognises both moral and political issues.

2.5.1. Care is a feminist issue

More than thirty years ago, feminist analysis illustrated how care was associated with femininity (Graham, 1983) and culturally defined as 'natural' for women (Finch and Groves, 1983). Despite social and political change, the feminine association persists (Hanlon, 2009; Henz, 2009); care remains bound up with gender identity (Henz, 2009) and ‘legitimacy’ (Connell, 2005) for many women. These factors facilitate men's avoidance of care (Henz, 2009) and enable men to benefit from women's emotional labour (Connell, 2005). Hanlon (2009) notes that care by men remains low, even in more gender equal countries, and suggests that the link between care and feminine attributes makes care inaccessible to men.

However, it can no longer be assumed that women will undertake caring roles because social and demographic change affects the provision of family care (Fraser and Warr, 2009). McDonnell and Ryan (2011) suggest that there will be a greater role for men in future care provision. Changing social norms are an important factor here; for example, contemporary understandings of fathering mean men are expected to take more responsibility for their children (Fraser and Warr, 2009).

Although it is difficult to accurately determine the number of people undertaking unpaid care, partly because measures are self-reported and therefore rely on individuals self-identifying as carers, there is data to suggest that 41% of carers in Scotland are men (Scottish Government, 2015). However, within the context of the feminisation of care, such data needs to be interpreted with caution. Because women's care is often naturalised and perceived as ‘ordinary’ family practice, it is difficult to distinguish additional caring responsibilities from the reciprocity and support which takes place within families (Forbat, 2005), thus women may be less likely than men to self-identify as carers.

Care research has largely tended to focus on women’s experiences (Fine and Glendinning, 2005; Cahill, 2000). This may be related to the feminist origins of care research, which has often focused on critiques of the welfare state, and either views men as not being carers or proposes that men's role in care is different from women's (Fine and Glendinning, 2005). Cahill (2000) suggests that male caregiving has been overlooked because most carers are women and care research has been seen as a women's issue, undertaken by women about women. Whilst there is some research to support the proposition that men's care is different from women's (Sims-Gould and Martin-Matthews, 2008), gender is relational and dichotomising the caring experiences of men and women is problematic (Connell and Messerschmidt, 2005).

There is growing evidence that gender is no longer the most influential factor in determining caregiving (Fine and Glendinning, 2005; Henz, 2009; Dahlberg et al, 2007). Household and relationship change are key factors in determining care provision within families, including: co-residence with parent; marriage; divorce; co-habitation; and re-partnering (Henz, 2009). Age is also an important factor in patterns of caregiving. Whilst there are more women than men carers in the population, gender inequality reduces in older age groups (Dahlberg et al, 2007). In their study of UK Census data, Dahlberg et al (2007) found that, in the population aged 70+, men were more likely to be carers than women[7], and were

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[7] Across all age groups of carers, there are more women than men, including age 70+. However, the *likelihood* of men age 70+ being a carer is greater, in relation to the *population* of people aged 70+.

more likely to be undertaking the most intense caregiving[8]. Census data does not tell us who people are caring for, but Dahlberg et al's findings may be related to narrowing gender differences in life expectancy (Hearn, 2010), and the increasing number of older men caring for an elderly spouse (Fine and Glendinning, 2005).

Structural factors also affect ability to care. Segal (2007) highlighted that a lack of welfare provision contributes towards the necessity of care by women, arguing that the public and private are not connected in policy. Additionally, the relationship between care and the labour market is complex. Restricted participation in the labour market has lifestyle implications for carers and leads to long term disadvantage (Carers UK, 2018). Acknowledging that care affects labour market participation, King and Pickard (2013) argue that labour market participation also affects care; women are more likely to work part time than men and, consequently, are more likely to be considered as available for care (King and Pickard, 2013).

Recent policy initiatives in Scotland have made some attempts to enable carers to balance work and care – notably the introduction of the 'Carer Positive' employers' scheme and the Carers (Scotland) Act 2016. The 'Carer Positive' scheme recognises employers who provide supportive working environments for carers, and the Act gives carers the right to have an adult carer support plan (ACSP) while placing a duty on local authorities to provide support to carers. The ACSP records carers' needs and outcomes, including any support required to meet outcomes in relation to work or study (Scottish Government 2016). However, one of the problems with carers' policies is that they tend to frame those who provide care and those who receive care as if they are two separate groups, with opposing interests and needs (Barnes, 2011: 158). In practice, the lives of carers and the people they support are often inextricably linked (Barnes,

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[8] 50+ hours per week.

2011; Sevenhuijsen, 1998; Walmsley, 1996). Ethics of care provides a useful alternative way of conceptualising care, and is discussed later in this chapter.

The persistent association of care with the private sphere of home and families contributes towards the invisibility of care (Barnes, 2012). Paradoxically, relationships are often neglected in care research as studies have tended to focus on quantitative data and the performance of tasks (Sims-Gould and Martin-Matthews, 2008). Dahlberg et al (2007) suggest that beliefs that care is a private matter contribute towards older people being reluctant to seek support. This is important, given the ageing population and growing number of older carers, as policies which attempt to support carers will only be effective if people self-identify as carers and feel able to seek support from services.

Care takes place throughout the life course (Barnes, 2012). Everyone needs care from others at some time in their lives, yet it remains largely invisible (Barnes, 2012). Rather than being marginalised within the private sphere, care needs to be seen and discussed in the public and political realm to show that it is a universal experience, which requires collective responsibility (Lloyd, 2010). Reframing care as a 'normal' part of human experience and existence, rather than an 'exceptional' need which is limited to particular groups, challenges the binary categories of care giver and receiver, as well as the associated marginalisation of care (Barnes, 2012).

2.5.2. The disabled people’s movement and the concept of care

The concept of care has been highly contested by the disabled people’s movement – related, in part, to feminist analyses which framed care as a ‘burden’ on women (Fine and Glendinning, 2005). Furthermore, the association between care and dependency is detrimental to the disabled people’s movement’s objectives of independence and autonomy, and many activists have been critical of the use of the term ‘care’ (Hughes et al, 2005). Thus, for many in the disabled people’s movement, care is rejected as ‘disempowering and oppressive’ (Lynch et al, 2009: 114) and ‘support’ is endorsed instead (Shakespeare, 2000).

In particular, feminist writers in the early 1980s (such as Finch, 1983) provoked anger from disability writers like Morris, who identifies as being both disabled and a feminist (see Morris, 1991). Furthermore, challenges to ‘the idea that care is what disabled people need’ have largely been based on the experiences of people who have physical impairments, not learning disabilities (Walmsley, 1996: 325). Walmsley argues that care research in relation to other impairment groups cannot easily be applied to the particular circumstances of caring for people with learning disabilities because this often involves additional emotional and practical factors; for example, ‘fostering adult independence’ (Walmsley, 1996: 325).

Social policy literature and debates concerning care have undoubtedly contributed to the construction of disabled people as dependent (Shakespeare, 2000). Noting that everyone is a ‘service user’ in the broadest sense, and that we all depend on ‘good will and mutual aid’ to some extent, Shakespeare argues that:

> *The danger comes when disabled people have no choice and no alternative, and are reliant on unresponsive services or demeaning charity which renders them marginalised and dependent.*
>
> *(2000: 64)*

In an analysis of social policy literature, Shakespeare (2000) identifies some of the ways in which disability and dependency have been constructed in policy. For example, Shakespeare (2000: 12) suggests that some policy literature concerning disabled children frames them as a ‘burden’ on the family. In relation to people with learning disabilities, Shakespeare (2000: 16) argues that policy narratives portray this group as ‘childlike’, unable to make decisions and in need of protection. Furthermore, Shakespeare’s analysis highlights policy narratives which represent the perspectives of family members or professionals who speak on behalf of people with learning disabilities, rather than drawing on the experiences and perspectives of disabled people themselves (2000: 14). Shakespeare’s analysis is important because it reveals historic and longstanding issues in relation to the construction of disability and dependency. However, within the Scottish policy context, there is more recent evidence of co-production which challenges this narrative – this is discussed further in chapter three. Importantly, the Scottish Government’s learning disability strategy, ‘The keys to life’, demonstrates a commitment to involving people with learning disabilities (Scottish Government, 2013) and an expert group contributes towards the ongoing monitoring of the delivery plan (SCLD, undated). Learning disability policy in Scotland is also discussed further in chapter three.

The analysis above demonstrates the dominance of dependency in social policy literature and debates concerning disability and care – although the notion of dependency is highly contested. Fine and Glendinning (2005) suggest that dependency is wrongly assumed to be negative, and draw instead on Sevenhuijsen (2000: 15), who argues that dependency is a normal part of human existence, which serves to bind people together in a society where ‘everybody needs care and is… capable of care giving’.

2.5.3. Ethics of care

The discussion above has highlighted some of the contested issues in relation to care and dependency. This section introduces an alternative way of conceptualising care, which recognises the moral and political aspects and addresses the critiques proposed above.

The first ‘wave’ of feminist ethics of care literature emerged in the 1980s, and developed further in its second ‘wave’ from the early 1990s (Rogers, 2016). Ethics of care originated as a challenge to assumptions about abstract moral reasoning, highlighting instead gendered and relational ways of thinking about justice and moral issues (Barnes et al, 2015). The discussion here draws mainly from the second ‘wave’, which has focused on ‘the moral and ethical aspects of family lives and extending the range of contexts in which caring relations and relationships are seen to exist and are struggled with’ (Rogers, 2016: 36). The extensive range of contexts within which care and caring exist are evident in Tronto’s broad definition of caring as:

> *…a species activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web.*
>
> *(1993: 103)*

In addition to the broad definition of care outlined above, Tronto (1993) proposes four phases of care: caring about; caring for; care giving; and care receiving. Each of these has a corresponding ethical value: attentiveness; responsibility; competence; and responsiveness (Tronto, 1993).

The first phase, caring about, is associated with attentiveness. Caring about requires the need for care to be recognised and is therefore related to knowledge, since we can only care about things we know exist. Caring about is not conditional on love or affection, and does not necessarily require skills or resources; for example, we may care about issues we have seen on tv but do not necessarily act on this. The second phase, caring for, is associated with responsibility. This phase involves making decisions and taking action to meet needs. Caring for requires resources to be available - including time, money, and knowledge; without such resources, care needs cannot be met. The third phase, care giving, is associated with competence. Care giving refers to the direct process of meeting care needs; this phase involves the physical labour of providing care. The fourth phase, care receiving, is associated with responsiveness. The inclusion of this phase in Tronto's conceptualisation of care highlights the importance of recognising and understanding the experiences of those who receive care. People who receive care may have expert knowledge of their care needs, but little power over how these needs are defined or met in practice. Thus, care receiving is concerned with how well the care received meets the needs of recipients (Tronto, 1993).

The four dimensions of care, and the associated values, described above are necessarily intertwined. For example, responsibility is dependent on attentiveness; taking action to ensure needs are met requires needs to have been identified and recognised as such. Importantly, Tronto's identification of the four dimensions and ethical values provide a measure against which care can be evaluated; ultimately, good care needs all four phases to work together (Tronto, 1993).

Relatedly, Sevenhuijsen proposes a broad definition of care as a process, practice, and 'moral orientation' (1998). Sevenhuijsen's definition of care as a process and a practice further demonstrates that care is not simply about obligation or the performance of tasks. Recognition of need is fundamental to both Tronto's and Sevenhuijsen's conceptualisation of care. Like Tronto, Sevenhuijsen argues that needs can, and should, be acknowledged in an ethics of care which requires the ability and willingness to recognise needs and to take responsibility for ensuring those needs are met. Furthermore, understanding needs requires openness, and sensory and embodied knowledge, and Sevenhuijsen proposes associated values of: 'empathy, intuition, compassion, love, rationality, and commitment' (1998: 61). The 'moral orientation' in this definition of care refers to our responsibilities for others, whereby decisions are made within the context of relationship networks '…in which s/he has to find balances between different forms of responsibility (for the self, for others and for the relationships between them' (Sevenhuijsen, 2000: 10).

The discussion above shows the necessity of care and connectedness; care is concerned with maintaining relationships and responsibility for self and others (Sevenhuijsen, 1998), and the conceptualisations of care provided by Tronto (1993) and by Sevenhuijsen (1998) demonstrate that care is a fundamental part of human experience. In addition, ethics of care theorists have shown that interdependence and vulnerability are fundamental parts of human experience (Sevenhuijsen, 1998); throughout the life course, everyone *needs* care (Sevenhuijsen, 1998). This is important because it means *need* for care is not ignored or seen as negative; care is re-framed in a more positive way, associated with attentiveness and connection to others (Sevenhuijsen, 1998). Thus, ethics of care allows us to reject the care/autonomy dichotomy, which is the subject of both the disabled people's movement and feminist critiques of care, and move beyond debates about dependence/independence to an understanding of interdependence.

The concept of interdependence is useful in this study, which is concerned with family care and seeks to explore the experiences of both people with learning disabilities and those who provide support. These experiences are intrinsically related and it would be simplistic to categorise them as two distinct groups; however, despite being interrelated, they are not the same either. As such, the ethics of care takes into account that the experience and perceptions of care givers and receivers might differ (Sevenhuijsen, 1998). Fine and Glendinning (2005: 602) argue that care research needs to examine the experiences of both carer and cared for, since the 'interests, needs and perspectives' of care providers and care recipients are different aspects of the same phenomenon. Family care takes place within existing complex relationships involving people whose lives are connected; ethics of care provides a useful way of conceptualising care in this context.

Attention to lived experience and the importance of relational and situated knowledge are reflected in ethics of care (Barnes, 2012). Thus, Sevenhuijsen (1998) argues that care research must involve people who receive care from others and people who provide care to others, and places emphasis on the importance of subjective values and experience. This is supported by Barnes who argues that 'we need to consider the lived experiences of giving and receiving care, and how contexts, conflicts and power impact the difficult moral decisions as well as the practical tasks of care’ (2012: 40).

In relation to the experiences of people with learning disabilities and their families, the concept of interdependence is somewhat contested. Whilst there is a body of research which presents care as being unidirectional, and people with learning disabilities as a ‘burden’ on families (Walmsley, 1996: 325), this is contested by studies which show how these relationships are characterised by reciprocity and interdependence (Bigby, 2012). For example, increased life expectancy means there is a growing group of people with learning disabilities caring for elderly parents (Bigby, 2012), and parents often report that they value the support and companionship of their sons and daughters (Walmsley, 1996). More recently, however, Rogers (2016) argues that the concept of interdependency falls short of representing the experiences of people with learning disabilities and their families, because of the particular effects of cognitive impairment:

> *Intellectually disabled people, and their close personal ties, have a particular position where, whilst gendered, classed and 'raced' discourses have a part to play, intellectual capacity further oppresses, discriminates, and penalises intellectually disabled people and their caring practices and relationships.*
>
> *(2016: 32)*

Caring for people with learning disabilities can be particularly complex (Walmsley, 1996), as noted earlier in this chapter. Ethics of care can add value here because it highlights that care is complex and skilled (Barnes, 2011). Feminist ethics of care theorists have emphasised the emotional and relational aspects of care, illustrating how care takes place within relationships and involves unseen and difficult to measure dimensions such as: communication; negotiation; and investment of the self, as well as practical 'hands-on' labour (Barnes, 2011). However, Barnes (2011) suggests that the emotional and relational dimensions of care are neglected in policy and in academic literature, with care simply framed as activities and tasks which are performed for, or on, some people, by others. As outlined earlier in this chapter, understandings of care, and assumptions concerning independence and autonomy, have been contested by disabled people, with Barnes (2011: 153) suggesting that these critiques have contributed towards the neglect of the emotional and relational dimension of care in much of the literature. These critiques were a response to analyses (illustrated earlier in this chapter) which framed care as a burden, which is disempowering and oppressive to both those who undertake care, and those who receive it (Fine and Glendinning, 2005). By drawing attention to the complexity and skills involved, as well as the necessity of care and connectedness, ethics of care addresses critiques in relation to the framing of care as burdensome.

As well as highlighting that care is complex and skilled (Barnes, 2011), ethics of care also emphasises the value of knowledge and experience. This is important because the association between care and the private sphere of love and emotion ‘imply a naturally occurring emotional response’ which does not reflect the complexity and skilled judgements required in the provision of care (Barnes, 2012: 172). Drawing on Sevenhuijsen’s original identification of the ‘epistemological dimension’ of care, and the ‘knowing and thinking subject’ (1998: 89), Barnes (2012) emphasises the role of knowledge in ‘competent’ care giving. For Barnes, the ‘epistemological dimension’ includes the emotional responses and experiences of care receivers, as well as the knowledge they may have of their condition or treatments (ibid.: 171). In addition to the knowledge of care receivers, Barnes notes that carers and care workers also have knowledge which can benefit caregiving practice:

> *‘[C]ompetence in care giving requires drawing on the range of different types of knowledge that will contribute to ensuring good care that is appropriate to the particular personal, social and cultural context of the care receiver’*
>
> *(ibid.: 171)*

Recognition of the epistemological dimension in care is important because it shows that the practice of care is more than a ‘‘soft’ concept and practice’ (Barnes, 2012: 172). Furthermore, by drawing attention to the invisibility of care, related to its association with the home and family, ethics of care helps to make caring, and carers, more visible.

Importantly, ethics of care also has political and policy implications as it raises questions about the ways in which policy and practice should deal with dependency, and facilitate attentiveness to care needs (Barnes, 2011). For example, ethics of care requires the ‘ability and willingness to ‘see’ and ‘hear’ needs… and take responsibility for needs being met’ (Sevenhuijsen, 1998: 83). In order to avoid individual disadvantage, this implies collective responsibility for care (Barnes, 2012: 68). Whilst recognising that we all need care at some stage in our lives, Barnes (2012: 68) notes that all of us may not have the same experience of providing care; therefore, the concept of collective responsibility is necessary to ensure that those who *do* have direct experience of providing care are not disadvantaged as a result.

Ethics of care has been subject to critiques for being too abstract, and more suited to explanations of care at the micro-level (Barnes, 2011), however, it also provides criteria against which good care can be measured and evaluated, as noted in the discussion of Tronto’s conceptualisation of care earlier in this section. Notably, Sevenhuijsen (2004) developed ‘trace analysis’, which is a method for evaluating the normative frameworks of policy documents in relation to ethics of care. Trace analysis has particular relevance for the analysis of policies that are directly related to care, but it can also be applied to other policy areas (for example: poverty; environment; migration) (Sevenhuijsen, 2004: 13). Trace analysis is a useful tool because it highlights the underlying values, ‘moral concepts’, and competing discourses in policy documents, and reveals how these are otherwise hidden (Barnes 2011).

Despite care being essential in everyday lives and to human survival, it has been largely marginalised in policy (Barnes, 2012). Where care is recognised in policy, it tends to focus narrowly on care done by individuals, conceptualised in terms of ‘active citizenship’ or rights and obligations (Barnes, 2012). Ethics of care challenges these limited representations of care and reveals the implicit gendered values and assumptions which underpin them in policy; the ‘rational’, autonomous individual, motivated by self-interest and disconnected to others, is a myth (Barnes, 2012).

Policymaking is associated with abstract values, liberal justice, and moral reasoning (Barnes, 2012). Importantly, Barnes (2012: 171) draws on ethics of care to call for care in the policy process, proposing that policymakers need to care about people and issues; designing policies with care requires wider participation in the policy process, and the recognition and valuing of different perspectives, types of knowledge, and forms of expression.

The principles of trace analysis have been applied to personalisation policy (Lloyd, 2010; Rummery, 2011). Sevenhuijsen (1998) argues that a democratic society should provide the conditions which enable citizens to care for themselves and others, and to be cared for; care 'should be enshrined within the constitutional rights of citizens’ (191). It could be argued that personalisation policies reflect the concept of justice demanded by ethics of care in recognising the rights demanded by care users and providing the conditions for care needs to be met. Thus, personalisation could provide a way to reconcile the conflicting understandings of care offered by feminist analysis and the disabled people’s movement (Rummery, 2011: 149), which is discussed further below.

The persistence of the feminine association with care, outlined earlier in this chapter, is reflected in policy (Rummery, 2011). Whilst noting that addressing care, and the degree to which it is undervalued, is not the purpose of personalisation, Rummery (2011) proposes that, under certain conditions, personalisation could provide new opportunities to value care work. For example, if those who provide unpaid care are recompensed for their efforts or are able to take up paid work, or if the employment of paid care workers is protected, as a result of personalisation (ibid.: 146). Whilst warning of the potential risk of exploitation and abuse if personalisation schemes are not governed sufficiently, Rummery (2011: 148) suggests that personalisation could empower carers and those for whom they care because of the opportunity to exercise choice and control for both parties – thus avoiding ‘being trapped into unwanted caring relationships’. Enacted in this way, personalisation could help to create the conditions of increased choice for carers, and show that care work is valued by society and the state (Rummery, 2011).

The discussion above illustrates some of the moral and political aspects of care, and introduces ethics of care as an alternative way of conceptualising care. The moral dimension is evidenced by arguments that care is necessary to achieve social justice, and society benefits when everyone receives the care they need (Barnes, 2012). The political dimension is evident in feminist and disability movement perspectives. Ethics of care provides a useful way of understanding the complexity of care relationships; it recognises the moral and political dimensions and focuses on a more positive understanding of care, associated with attentiveness and interconnectedness.

My initial research proposal and subsequent understanding of the research topic, and choice of research questions, was informed by Tronto’s work and that of other feminist ethics of care writers cited in this chapter, including: Barnes; Fisher; Kittay; and Sevenhuijsen. In particular, I found that Rogers’ (2016) ‘care ethics model of disability’, which was discussed in section 2.2.3., resonated with the experiences of participants in this study. As set out earlier in this chapter, the ‘care ethics model of disability’ recognises the needs of people with learning disabilities (and those close to them) in relation to care and justice and was influenced by ethics of care theory (Rogers, 2016). Ethics of care literature therefore provided a critical lens through which I understood and interpreted participants’ narratives, discussed in the second part of the thesis (chapters five to seven).

2.6. Conclusion

This chapter set out to provide some of the context within which people with learning disabilities and their families have experienced changes to social care policy and service provision. As noted in chapter one, this thesis focuses on the experiences of people with learning disabilities aged 30 and over, as well as that of their families, and there are several factors which are particularly relevant in framing the experiences of this group. These issues include: extended transitions to adulthood for people with learning disabilities; the important role played by families in the lives of people with learning disabilities; increased life expectancy and ageing of people with learning disabilities and family carers; and experiences of various disability policy developments over the life course.

The four interrelated factors set out above provide the context within which participants experienced changes to social care policy and service provision. The first section provided an overview of the medical and social models, which have informed understandings of disability and policy development. The second section in this chapter looked at learning disability and the life course, highlighting issues related to transitions to adulthood, life trajectories, living arrangements, ageing and life expectancy. The third section discussed care and support provision for people with learning disabilities, and outlined the major policy developments which have determined daily lives and living arrangements. The final section in this chapter on disability and families, highlights contested issues in relation to care, and introduced ethics of care as a tool to understand the complex and messy lived reality of interdependent family lives.

The next chapter further contributes towards understanding the context of participants’ experiences of changes to social care policy and service provision, as it takes an in-depth look at policy development, with a particular focus on the emergence and implementation of personalisation policies in Scotland.

3. Literature Review II - Personalisation Policy Development & Implementation

3.1. Introduction

This chapter discusses the emergence of personalisation as the dominant narrative in social care policy, drawing on academic, policy and ‘grey’ literature to present current debates around personalisation. Policy can be broadly defined as the actions or intent of government (Howlett & Cashore 2014), and includes a range of instruments, including: legislation; strategies; and guidance. Various actors are involved in the policy-making process, including interest groups, charities and businesses, however governments have particular authority in relation to decision making (ibid.).

In order to contextualise the policy discussion throughout this chapter, the meanings of key terms are first set out in this introductory section. Thereafter, the chapter is structured in two parts; part one traces developments in social care policy, discusses the emergence of personalisation, and presents critiques to the dominant policy narrative. In part two, the discussion focuses on the emergence, implementation and progress of self-directed support in Scotland and how this has taken place at a time when the effects of austerity and wider welfare reform are being felt by disabled people and their families.

3.1.1. Terminology

One of the difficulties in discussing personalisation is that it is not always clear exactly what we are talking about – partly because the meaning of key terms has changed over time. The lack of clear definitions and ways in which terms – including personalisation, self-directed support (SDS), direct payments, personal budgets, and individual budgets – have been used interchangeably in the literature and in practice, even though they may be referring to different arrangements, has been noted by many writers (see, for example, Pearson et al, 2014; Beresford, 2014; Scottish Government, 2011). Each of these terms are outlined briefly below, and discussed in more depth throughout this chapter.

Personalisation

The ways in which meanings of key terms have changed over time is particularly evident in the use of 'personalisation'. Pearson et al (2014: 11) note that personalisation was previously used to describe 'people accessing a cash budget (personal budget or individual budget) to spend on their support and put together what help and services they wanted'. However, it is now used more generally 'to mean people having more choice and control and a more customised service, regardless of what service or form of support they receive, and however it is provided' (ibid.: 11).

More broadly, personalisation can be understood as an 'umbrella term' (Pearson et al, 2014; Scottish Government, 2011) to describe the shift from paternalistic services, which were designed and delivered by professionals and given to (or done to) service users, towards a system where people who require social care services can exercise choice and control over their support. Personalisation therefore represents a shift in power from professional 'experts' to individuals and families, whereby services are designed to suit the person who receives the service, rather than those who provide it (Pearson, 2015). The emergence and development of personalisation as a policy discourse is discussed in section 3.2.

Self-directed support

Self-directed support (SDS) is underpinned by the policy shift towards the personalisation of services, which recognises expectations that people should have choice and control over their support. Lloyd (2010: 189) distinguishes between self-directed support and personalisation by suggesting that, in practice, the former involves user control over deciding what their needs are and how these should be met, whilst the latter is concerned with ensuring services are tailored to individual need. However, in policy terms, personalisation involves both user control and the tailoring of individual services (ibid.).

Most relevant to this thesis, SDS is now commonly used to refer to social care in Scotland. This narrative is directly related to the Scottish Government’s aspiration to embed SDS as ‘Scotland’s mainstream approach to social care’ (Scottish Government 2018a: 1). This was set out in 2010, in the 10-year strategy named ‘SDS: A National Strategy for Scotland’ (Scottish Government, 2010), which informed The Social Care (Self-directed Support) (Scotland) Act 2013 that came into effect in 2014 (see section 3.3). The Scottish Government (2010: 7) describe self-directed support as '...the support individuals and families have after making an informed choice on how their individual budget is used to meet the outcomes they have agreed'. SDS should therefore enable people to have choice and control over their support arrangements, and hence, how they live their lives. Importantly, co-production is a key feature of the national strategy, which proposes that SDS demonstrates the Human Rights Principles of: equality; non-discrimination; participation; and inclusion (ibid.: 8). Co-production, and the Scottish approach to policymaking, is discussed in section 3.3.

In practice, this means that people are entitled to have a say in determining their own support arrangements, and that self-assessment should focus on meeting user outcomes rather than being driven by service provision (Pearson et al, 2014: 17). However, people may also choose *not* to take SDS and leave the local authority to make support arrangements on their behalf, since SDS should be 'available to everyone but imposed on no-one' (Scottish Government, 2010: 7). The development and implementation of SDS in Scotland is discussed in part 2 of this chapter.

Direct payments, personal budgets and individual budgets

Direct payments are cash payments made to individuals so as to enable them to purchase the support services they require – either from an organisation or by employing a personal assistant. Direct payments emerged from the activism of the disabled people's movement during the 1980s and 1990s (discussed in section 3.2), reflecting the philosophy of the independent living movement and driven by the desire to secure sufficient resources to enable disabled people to achieve independent living (Pearson et al, 2014).

Direct payments are sometimes conflated with personal budgets, however the underlying ideology differs (Pearson et al, 2014: 4; Slasberg and Beresford, 2015: 479). Direct payments emerged from the activism of disabled people themselves, influenced by the social model of disability (see chapter two) and underpinned by the drive for equality and the philosophy of independent living (Pearson et al, 2014). Whilst personal budgets are also associated with 'a cash alternative to directly provided services' (ibid.), the emergence of personal budgets is related to the personalisation of social care, which was influenced by the independent living movement, but largely driven by public bodies and third sector organisations (Pearson et al, 2014), as discussed in part 1 of this chapter.

Personal budgets are sometimes used interchangeably with individual budgets, but there are important differences. Personal budgets are funded by local authority community care funds, whilst individual budgets can involve joint assessment with other services (e.g. health, education) and include various funding streams (e.g. Access to work, ILF) (Scottish Government, 2010: 38), although this is rare in practice (Pearson et al, 2014: 12). Prior to implementation of the SDS Act, some Scottish local authorities used individual budgets to provide a small number of users with choice and flexibility; this meant that people knew the total budget available to them and could choose how they wished to organise their support (Scottish Government, 2010).

3.2. Part 1: Policy Development – from Direct Payments to Personalisation

The first part of this chapter traces the policy journey from disability activism in the 1970s to the current dominant narrative of personalisation. It begins with a chronological overview of key policy developments, and includes discussion of the independent living movement and the (relative) success of direct payments, as well as the emergence of personalisation. It then goes on to consider the association between personalisation and neo-liberalism – including the marketisation of care – and highlights contested issues in relation to choice and control.

3.2.1. The policy journey

The disabled people’s movement campaign for independent living has influenced social care policies over the past forty years, contributing towards the introduction of community care policies and direct payments, which have effectively paved the way for personalisation. The development of personalisation has been a long and gradual process, and there are legislative differences between Scotland and the rest of the UK. This section outlines the main factors which have contributed to policy development – with a particular focus on Scotland.

The discussion here is structured chronologically, although the emergence of policy was less linear in practice and the time periods inevitably overlap. The section begins in the 1970s and early 1980s, during which time institutions for disabled people reached their peak and the independent living movement began to emerge. It then moves on to the late 1980s and early 1990s, a period characterised by deinstitutionalisation policies, growth of the independent living movement, and implementation of the National Health Service and Community Care Act 1990. During the 1990s, there was a major victory for the independent living movement in the implementation of the Community Care (Direct Payments) Act 1996, which gave local authorities the power to provide direct payments. In the early 2000s, direct payment legislation was strengthened by placing a duty on local authorities to offer direct payments, while the mid-2000s saw a shift in political narratives and the emergence of personalisation.

Personalisation is highly contested, and is framed by different perspectives as ‘either the best thing since sliced bread or the end of the welfare state as we know it’ (Needham and Glasby, 2014: 5). Nonetheless, it is now the dominant narrative in social care. The discussion in this chapter highlights the ways in which ‘policies are developed on the basis of argumentation, ideology and emotion as well as formal evidence’ (ibid.: 24).

1970s - early 1980s

The segregation of disabled people in institutions peaked in the 1970s (Duffy, 2014). As discussed in chapter two, the historic segregation and institutionalisation of disabled people meant that people were physically excluded from participation in mainstream society, thereby denied civil, political and social rights, as well as full citizenship. However, ideas which would later result in the implementation of community care policies began to emerge during the 1970s and 1980s – largely as a result of concerns about the cost and quality of residential care (Glasby and Littlechild, 2016) and there was a gradual shift in resources from residential to community-based services (see chapter two for discussion regarding deinstitutionalisation and normalisation).

During this period, the dominant medical model of disability was being challenged through the emergence of the disabled people’s movement and the social model of disability (see chapter two). Crucially to subsequent policy development, it was also during this period that UK disability activists began campaigning for independent living.

The independent Living Movement

The drive for choice and control in social care services was originally instigated by a small group of disabled people in the United States, who were dissatisfied with the existing paternalistic social care services they received and, as such, campaigned for independent living (Campbell and Oliver, 1996). This meant that instead of receiving a directly provided service, they would receive a cash alternative that would enable them to arrange their own support.

The underlying philosophy of independent living is that disabled people should be able to live their lives equal to non-disabled people – with full access, participation and inclusion in mainstream society (Beresford, 2014). Independent living is not about a narrow definition of doing everything yourself, rather it is about people being able to make decisions and have the support they need to live their life the way they wish. Whilst there are various definitions of independent living, Morris provides the following useful (and much cited) four key values:

- *All human life is of value*
- *Everyone is capable of exercising choice*
- *Disabled people have the right to control their own lives*

- *Disabled people have the right to fully participate in society*

(Morris, 1993: 21)

The origins of the independent living movement can be traced to the campaigning and protests of disabled students in Berkeley, US, who sought to employ personal assistants and secure suitable accommodation to live 'independently dependent' whilst at University (Barnes and Mercer, 2006: 31). The campaign drew attention to issues of independent living for disabled people and expanded outwith the student population, leading to the first centre for independent living being established in Berkeley in 1972 (ibid.). The Centre for Independent Living (CIL) aimed to provide 'a non-residential, community-based, non-profit programme, controlled by users', and this inspired the growth of 'CIL-type organisations' in the US, reaching 300+ initiatives in the 1990s (ibid.: 32).

During the 1970s, the US protest movements attracted interest from disabled people outwith the US (Barnes and Mercer, 2006). There was growing dissatisfaction with traditional social care services amongst groups of disabled people in the UK who were living in residential homes (Barnes and Mercer, 2006; Pearson, 2012). Traditional services were controlled by providers (often charities), under-funded, and based on medical model conceptions of disability and associated assumptions regarding protection and dependency (ibid.).

Thus, in the UK, moves towards independent living began in Derbyshire in 1972, when disabled activists were involved in the development of the Grove Road housing development (Barnes and Mercer, 2006: 45-46). The Grove Road development provided some 'wheelchair-accessible' housing within a community whereby other housing would be let to 'non-disabled families willing to provide appropriate support to their disabled neighbours' (ibid.: 46).

During the 1970s and 1980s, other important developments in the UK were instigated by a group of disabled people living in a residential home in Hampshire. Residents of the Le Court Cheshire Home set up 'Project 81: Consumer Directed Housing and Care' in 1979, to draw attention to the 1981 UN International Year of Disabled People (Barnes and Mercer, 2006: 46). This project led to 'an innovative arrangement of 'indirect payments'', whereby the local authority made cash payments into a trust fund in lieu of residential care services, the funds from which were then used to enable the individual to purchase their own support and live in the community (ibid.).

Importantly, DeJong (1979, 1988, cited in Barnes and Mercer, 2006: 32) argued that only some impairment groups were represented within the independent living movement – observing that the movement was dominated by young, white, middle-class disabled people. The ways in which different user groups have been affected by policy change will be returned to later in this section.

Late 1980s – early 1990s

Policy and practice in relation to deinstitutionalisation, community care and independent living – which had begun to emerge during the 1970s and early 1980s – developed further during the late 1980s and early 1990s.

This period saw the implementation of the National Health Service and Community Care Act 1990, described by Lymbery and Postle (2015: 20) as '… a major change in policy for the care of adults/older people since the inception of the welfare state'. The Act was partly an attempt to address the complex and disjointed system at the time, but it was also instigated by concerns about costs and quality (ibid.). Factors which led to the introduction of the 1990 Act include: the level of spending on institutional care; beliefs that community care would be better and cheaper; and concerns about the messy and uncoordinated care system (ibid.).

The National Health Service and Community Care Act 1990 made local authorities responsible for assessment of need, and for ensuring delivery of services to meet need (Glasby, 2017). This period saw a shift away from local authorities being direct service providers, and towards being commissioners of social care services (Walker, 1993; Glasby, 2017). The 1990 Act encouraged local authorities to support the development of a mixed economy of welfare through supporting and commissioning private and voluntary services (Walker, 1993). However, there was a critical difference between implementation of the 1990 Act in England and Scotland. In England, the development of markets in health and social care was more acute, requiring commissioners to purchase 85 per cent of their services from private and/or independent sectors (Means and Smith, 1998). In Scotland, there remained a stronger reliance on public services and a more limited embrace of marketisation (ibid.).

Following the peak of institutions for disabled people in the 1970s, as noted above, the implementation of deinstitutionalisation policies in the late 1980s and early 1990s meant widespread closures of long stay hospitals and large institutions (Williams, 2013), as discussed in chapter two. Whilst the move towards community care and the closure of institutions was broadly seen as a positive development, it was far from ideal for the many people living with learning disabilities who remained segregated in separate services (Duffy, 2014). Duffy (2014) argues that the old institutions were just replaced by new ones, for example, group homes and day centres, which were controlled by professionals, and therefore denied disabled people real choice or opportunities for inclusion. Thus, while the underlying philosophy of community care was more positive, it remained strongly focused on medicalised conceptions of impairment and individual ‘deficit’.

At the same time, the independent living movement was gaining momentum, and during the 1980s and 1990s, local arrangements made it possible for a small number of disabled people to receive cash payments in lieu of care (Pearson et al, 2014). Direct payments were permitted under the Social Work Scotland Act 1968 in certain circumstances, though this was not well known (ibid.). However, they were illegal under the National Assistance Act 1948 (Glasby and Littlechild, 2016: 23) and there were only a small number of local examples where people were able to access direct payments at this time (Pearson et al, 2014).

1990s

A crucial factor in the subsequent development of personalisation policies was the implementation of the Community Care (Direct Payments) Act 1996. Activists' campaigns contributed towards the eventual implementation of the 1996 Act, following several years of political resistance (Glasby and Littlechild, 2016). The campaign for direct payments had initially been based on rights to independent living, however government opposition in the early 1990s led to campaigners adopting dual strategies of rights and cost cutting (Glasby and Littlechild, 2016). Whilst it was framed as a 'victory' for the campaigners and the independent living movement (Pearson, 2000; Glasby and Littlechild, 2016), critics have argued that the government's eventual decision to introduce the Act was, at least in part, influenced by the potential to reduce public spending (Glasby and Littlechild, 2016). When the health secretary announced the legislation in November 1994, the British Council of Disabled People (BCODP) were about to publish a report (see Zarb and Nadash, 1994), showing that direct payments '…were both cheaper than directly provided services and resulted in higher-quality services' (Glasby and Littlechild, 2016: 28). Inevitably, this would appeal to the Conservative government at the time, particularly as demand and costs for social care were rising (Needham and Glasby, 2014: 13). Ultimately, the foundation of rights *and* consumerism, on which the legislation was based – and described as a 'hybrid rationale' by Needham and Glasby (2014: 15) – was critical to the eventual implementation of direct payments, because it appealed to a broad range of political interests (ibid.: 15).

The Community Care (Direct Payments) Act 1996 gave local authorities the *power* to provide direct payments to eligible persons (Glasby and Littlechild, 2016: 29). These payments were intended to replace formal care by enabling people to employ workers themselves or to purchase care services from agencies (Rummery, 2011). Direct payments were not intended to replace unpaid informal care provided by friends or relatives and, initially, could not be used to pay family members (ibid.).

As noted previously, direct payments had been available prior to the 1996 Act, but this was not well known by service users or by professionals so availability and take up was very limited and largely subject to the discretion of individual local authorities (Pearson et al, 2014). Thus, the Act was highly significant because it clarified the legislative position with regard to direct payments for both local authorities and disabled people, and it was symbolically important in recognising rights to independent living.

While the 1996 Act was a major development, it did not make direct payments mandatory (Needham and Glasby, 2014: 13). The successful implementation of the Act was limited as some local authorities were reluctant to offer direct payments (Riddell et al, 2005), and take up remained low and subject to country-wide and regional variations (Pearson et al, 2014).

2000s

One of the ways in which the government attempted to address the limited take up of direct payments following the implementation of the 1996 Act was by passing further legislation to make direct payments mandatory (Priestley et al, 2010; Pearson, 2004). In Scotland, the Community Care and Health (Scotland) Act 2002 meant that the previous *power to offer* direct payments was replaced by a *duty to offer* direct payments with effect from June 2003 (Scottish Executive, 2003).

Despite the mandatory duty on local authorities to offer direct payments, take up remained 'slow, over-bureaucratic and limited by funding constraints' (Pearson et al, 2014: 5). This was particularly the case in Scotland, where local authorities were somewhat reluctant to provide direct payments (Pearson et al, 2014). Some of the factors which contributed towards local authorities' resistance to direct payments included: strong attachment to public services and rejection of care markets; social workers concerned about potential job losses withholding information about direct payments from potential users; and relatively little disability activism in Scotland (Pearson, 2004).

The (relative) success of direct payments

Although the uptake of direct payments was never more than marginal (Pearson et al, 2014), there is general acceptance in the literature that the introduction of direct payments was successful (Beresford, 2014). However, this was not the case across all user groups as it was mostly people with physical impairments who took up direct payments (Glasby and Littlechild, 2016); the situation was notably different for people with learning disabilities, discussed further below. The people who were able to access direct payments as a result of the 1996 Act tended to be those who were able to assess and communicate their own needs, and who shared the empowering beliefs of the Independent Living Movement that disabled people had the right to live equally (Slasberg and Beresford, 2015).

Nonetheless, for those people who *were* able to access direct payments, reported benefits included: improved life chances and health and wellbeing, and more control over their lives (Beresford, 2014: 18).

Furthermore, according to Slasberg and Beresford (2015), where direct payments were successful, three key (interrelated) factors were in place. First, support plans were based on an accurate assessment of needs; second, the allocated budget was sufficient to meet those needs; and third, users were able to use the budget flexibly (ibid.: 480-481). All three intersecting factors were evident in Slasberg et al's analysis of direct payment data, which found that those in receipt of direct payments received higher budgets (Slasberg and Beresford, 2015; Slasberg et al, 2012). The two main reasons for direct payment recipients having higher budgets than others were: assessment was individualised and person-centred, rather than resource led; and local authorities 'believed they were legally bound to meet all their needs' (Slasberg and Beresford, 2015: 480-481). Thus, although direct payments were simply an alternative mode of service provision and therefore not intended to be more generous than other forms of service, in practice, the combination of informed and proactive service users, as well as social workers' perceptions of the legislation, resulted in the disproportionate allocation of resources. Slasberg and Beresford (2015) support this argument by drawing on earlier data which found that spending on direct payment recipients was 80% higher than others (Slasberg et al, 2012: 1031). In this study, 13.7% of community-based support spending went to the 7.7% of service users who were on direct payments (ibid.), leading Slasberg and Beresford (2015) to conclude that the positive outcomes of this group may have been gained at the expense of others.

Notwithstanding the three key factors outlined above, how the direct payment was spent also contributes towards its effectiveness. Slasberg et al (2012) argue that better outcomes are associated with spending on Personal Assistants (PAs), and community and leisure activities, while suggesting that there is no evidence that direct payments used to purchase regulated services improve outcomes. Thus, better outcomes are related to person-centred assessments, sufficiency of funding and flexibility – since access to leisure requires more than ‘life and limb’ needs assessment (Slasberg et al 2014/15: 46-47).

Narratives about cost effectiveness have been strongly associated with the development of direct payments in policy and practice, yet this is highly contested (Glasby and Littlechild, 2016). In the BCODP’s influential report, Zarb and Nadash (1994) proposed that direct payments offered ‘better for less’, however several critics have questioned the evidence base for this claim (Glasby and Littlechild, 2016). While the discussion above suggests that direct payments may contribute towards better outcomes for individuals, there is little evidence to support the proposition that they are cheaper than other forms of service provision, with some suggestions that direct payments may cost more than traditional services (Beresford, 2014).

Importantly, the development and implementation of direct payments policy is strongly associated with the experiences of people with physical impairments. As noted earlier, the campaign for direct payments was activist-led; the dominance of ‘white men in wheelchairs’ (Oliver, 2004) within the disabled people’s movement has been noted by several writers[9]. Following the implementation of the 1996 Act, direct payments were ‘targeted’ at people with physical impairments (Needham and Glasby, 2014). Unsurprisingly then, it was mainly people with physical impairments who were the recipients of direct payments (Glasby and Littlechild, 2016).

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[9] See Campbell and Oliver (2013), who suggest that the movement is becoming more diverse and inclusive.

In contrast, the focus within learning disability policy and practice was inclusion and person-centred planning (Needham and Glasby, 2014). As discussed in chapter two, people with learning disabilities were experiencing a shift from services which were provided in ‘special’ settings to being in the community and public spaces. Rather than having a direct payment to employ a PA or purchase care services from other agencies, the focus within learning disability services was on empowering people with learning disabilities through individual budgets (Needham and Glasby, 2014). Individual budgets were flexible and people could use them to purchase anything that met assessed needs (Needham and Glasby, 2014).

During this period, developments within learning disability services contributed toward a policy shift from direct payments to personalisation and self-directed support (Glasby and Littlechild, 2016; Pearson et al, 2014). An important factor in the subsequent development of personalisation policies was the work of In Control with people with learning disabilities during the early 2000s (Pearson et al, 2014). In Control introduced personal budgets and developed a model of support which aimed to give people maximum choice and control over their budget and support (Hatton et al, 2008). The model of self-directed support introduced by In Control was underpinned by the assumption that:

> *…people who need support should still be in as much control of their lives as possible. If they are unable or unwilling to take control then a flexible set of supports is available to provide sufficient additional support.*
>
> *Duffy (2010: 257)*

From direct payments to personalisation

As the discussion above has shown, until the early 2000s, policy developments had generally been concerned with empowering disabled people through independent living and direct payments, though pilot projects with people with learning disabilities were beginning to introduce alternative models of support.

In the mid-2000s, however, new policy narratives of personalisation, co-production and partnerships began to emerge. Whilst the 'genesis' of personalisation is contested (Needham and Glasby, 2014: 11), the term itself, and its emergence as a policy issue, is attributed to Charles Leadbetter's 2004 report, 'Personalisation through participation: a new script for public services' (Needham and Glasby, 2014: 11). In this influential report, Leadbetter (2004) set out a new model for delivering public services in response to increased demand and constrained resources. Drawing on examples of public services, including social care and health, Leadbetter proposed a more active role for users, by:

> *…putting users at the heart of services, enabling them to become participants in the design and delivery, services will be more effective by mobilising millions of people as co-producers of the public goods they value.*
>
> *Leadbetter (2004: 19)*

Importantly, there are competing philosophies in the policy shift from direct payments to personalisation. Direct payments emerged from the activism of disabled people; they are associated with democracy, the philosophy of independent living, and commitment to a social model understanding of disability. In contrast, personalisation is associated with a managerial, consumerist agenda that has been instigated by government and professionals. Personalisation involves personal budgets, which are 'associated with the philosophy of 'normalisation'… integrating disabled people into society, rather than challenging its barriers and discrimination' (Pearson et al, 2014: 5). Importantly, direct payments were intended to provide a budget sufficient to enable independent living, while personal budgets are based on the allocation of available funding through the Resource Allocation System[10] (RAS) (ibid.: 5). Despite these fundamental differences, personalisation has adopted the language of the disabled people's movement, using terms such as 'empowerment' and 'user-led services' (Roulstone, 2014).

Since the mid-2000s, social care has become an area of political concern – partly due to demographic change, increased demand, and recognition that the existing system was not sustainable (Scottish Government, 2010). However, political concern has also arisen because of issues of social justice, as well as recognition that the existing system was not meeting the needs of disabled people and their families (Scottish Government, 2010). Together, these issues have motivated the review and reform of social care, most notably through 'Putting People First: Transforming Adult Social Care' in England in 2007, and 'Self-directed Support: A National Strategy for Scotland' in 2010. The reform of social care in Scotland is the focus of part 2 of this chapter.

3.2.2. Personalisation and the neo-liberal agenda

Personalisation is associated with the neo-liberal political agenda; it first emerged under a Conservative government and was further developed under New Labour (Ferguson and Lavalette, 2014; West, 2012) and subsequent Scottish National Party administrations. The ideas associated with personalisation suited both the Conservative agenda in relation to privatisation and developing markets, and New Labour's agenda in relation to the modernisation of public services (West, 2012). The 'central tenet' of neo-liberalism is greater individual responsibility and reduced role of the state (Ferguson, 2007: 394), and several

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[10] Originally developed by In Control, the RAS is a points-based model of allocating budgets, which was intended to increase transparency (In Control, 2015).

writers have argued that personalisation involves shifting responsibility for the provision of care from central to local government, and from the state to the private sector, third sector, and families (Rummery, 2011: 140). Importantly, personalisation is viewed as a sustainable long-term solution to the ‘problem’ of balancing limited resources with increasing demand for social care (Lloyd, 2010), and is supported by all the main political parties (Duffy, 2014). Within the context of austerity and public sector budget cuts (discussed in section 3.3), personalisation fits with government objectives of ‘capping’ demand (Rummery, 2011: 140) and reducing costs (Lloyd, 2010).

Marketisation of care

Whilst there may have been some ideological differences between Conservative and New Labour justification for personalisation (Ferguson and Lavalette, 2014), consumerism and marketisation are inextricably linked with neo-liberal policies. In relation to the personalisation of social care, this has resulted in the creation of care markets – although this has affected Scotland far less than the rest of the UK as Scottish Government policies have been less market-oriented (Ferguson and Lavalette, 2014). The vast change in social care provision as a result of the marketisation of care, associated with personalisation, is illustrated by Ferguson and Lavalette (2014: 18) who note that the majority of social care in England is provided by the private sector, in contrast with the 1980s, when 90% of social care was provided by local authorities. Notwithstanding the ‘massive transfer of social care provision to the private sector’ highlighted by Ferguson and Lavalette (2014: 3), Hood (2014: 55) notes that this shift is much more evident in services for older people than in services for people with learning disabilities – where the voluntary sector is the major provider.

Nonetheless, personalisation policies remain associated with the development of care markets, although several writers have highlighted incongruencies between neo-liberal consumerism and social care. For example, Ferguson (2007) argues that the marketisation of social care neglects structural factors, including poverty and inequality. Within a market discourse, people who use social care services are constructed as ‘rational’ consumers (Ferguson and Lavalette, 2014: 28), but free market principles rarely apply (Barnes, 1997 cited in Glasby and Littlechild, 2016). Social care decisions do not fit with free market principles where consumers have: information about the market; a range of alternatives to choose from; and the ability to switch easily between providers (ibid.).

There are also moral issues involved in the meeting of care needs which conflict with marketisation. For example, Ferguson and Lavalette raise questions about the motivation and purpose of social care provision, proposing that:

> *…care of vulnerable adults is now often in the hands of individuals and companies whose primary concern is not with the welfare of their clients and residents but rather with the generation of profit.*
>
> *(2014: 3)*

Importantly, feminist critiques emphasise moral issues in relation to collective responsibility and dependency, which conflict with the commodification of care that is associated with marketisation and consumerism. The operation of a retail style market for the provision of care services, and the associated emphasis on accountability, regulatory systems and governance, raises moral questions regarding collective responsibility 'to ensure justice, well-being and citizenship for those who are vulnerable to discrimination and marginalisation' (Barnes, 2011: 161). Drawing on Tronto, Barnes (2011: 161) acknowledges that individual care needs may well be able to be met in this way, but she expresses concern for the implications of this in understanding need and dependency sensitively. Thus, the commodification of care neglects important relational aspects (discussed in section 2.5) and contributes towards the devaluing of care (Barnes, 2012: 181).

The marketisation of care has been justified by narratives of increased choice and quality, but this has not materialised in practice (Ferguson and Lavalette, 2014). Marketisation alone does not address limited resources and demographic change (Lloyd, 2010), nor does it guarantee responsiveness to need or provide a solution to poor quality services (Barnes, 2011). The mismatch between neo-liberal consumerism and social care is evidenced by examples of instability, poor quality, and lack of continuity within the care sector (Ferguson and Lavalette 2014: 20). Ferguson and Lavalette (2014: 21) argue that commissioning policies pay ‘lip-service’ to quality; price is the key determinant in commissioning practices, which has contributed towards a ‘race to the bottom’ within the third sector and little evidence of any increase in the quality of care (ibid.: 30).

Personalisation also impacts upon the employment market for care workers. Noting the dominance of private sector care providers in England, Ferguson and Lavalette argue that workers are frustrated because they do not get enough time to do their job properly, and highlight workforce issues including: the deterioration of workers’ conditions; low pay; and high levels of staff turnover (2014: 21-22). Low payment rates and unregulated employment conditions result in the ‘potential for exploitation and abuse of vulnerable workers’ (Rummery, 2011: 146), and contribute towards the undervaluing of care work, as well as reinforcing the classed and gendered division of labour (Rummery, 2011: 147).

Individualism

The individualist solutions to the ‘problem’ of care offered by personalisation have been criticised for being in conflict with the collectivism of the disability movement (Barnes 2011: 154). Ferguson (2007: 401) argues that the most successful advances for disabled people have emerged from collective experiences and self-organisation, citing examples including: advocacy; the social model, and Centres for Inclusive Living. However, the individualised approach to the procurement and provision of care services associated with personalisation effectively undermines collective provision, reducing opportunities for self-organisation (Barnes, 2011; Roulstone and Morgan, 2009) and resistance (Ferguson, 2012). Roulstone and Morgan (2009) utilise the concept of ‘enforced individualism’ to describe the situation where individualised care arrangements and day centre closures result in increased isolation and dependency on family carers, as disabled people are forced to spend more time at home with occasional ‘visits to town centres with key workers’ (Roulstone and Morgan, 2009: 342). They contrast this with the concept of ‘enforced collectivities’, associated with the ‘warehousing’ of disabled people, which was challenged by the disabled people’s movement (Roulstone and Morgan, 2009).

Choice and control

Personalisation is associated with the powerful discourse of ‘choice and control’. Whilst there are many positive associations, the concept of choice and control is itself highly contested.

Opportunities

One of the main strengths of the personalisation agenda is the potential to increase choice and control for social care service users and for those who provide care (Rummery, 2011). Personalisation may release people who need social care support from being tied to inflexible state services (Rummery, 2011), offering instead the ‘promise of ensuring person-centred responses to diverse needs’ (Barnes, 2011: 162), and providing opportunities for more flexible arrangements.

Furthermore, it has been suggested that the increase in choice and control for people in receipt of care services signifies a ‘radical shift in the relationship between citizens and government’ (Barnes, 2011: 154). An important aspect of personalisation is the political recognition of the rights and capacities of disabled people to control their own care, rather than this being determined by professionals; Lloyd (2010: 189) notes that ‘a key characteristic of the personalisation agenda in social care specifically is that an individual’s interpretation of her/his needs and the way in which these should be met must be at the heart of any intervention’.

As well as a shift in the relationship with the state, the potential to 'outsource' aspects of care provision from within the family or household may also contribute towards empowerment in personal relationships; ‘decoupling relationships from care: allowing intimate relationships to be characterised by being spouses or parents or children…, rather than carers’ (Rummery, 2011: 148). Personalisation may offer the potential to reduce care obligations and avoid being ‘trapped into unwanted caring relationships’ for people who require care and for those who provide it (Rummery, 2011: 148).

There is much evidence to suggest that wellbeing, outcomes, independence and citizenship are improved when disabled people have choice over their care and support arrangements (Rabiee and Glendinning, 2010). Drawing on the discourse of independent living, which proposes that having control over support may enable disabled people to exercise choice in other areas of life (Morris, 2006, cited in Rabiee and Glendinning, 2010), Rabiee and Glendinning reported a range of benefits associated with choice, including: health; independence; identities; lifestyles; and relationships. However, Rabiee and Glendinning’s study also noted that choice is only meaningful if people have access to the information they need to exercise choice, and if there are options available to meet personal preferences. In practice, participants in Rabiee and Glendinning’s study often felt they had no real choice.

Choice is contested

The powerful discourse of choice and control associated with personalisation makes it very difficult to challenge, as Ferguson notes: ‘who could be against empowerment or against choice in health and social care services?’ (2007: 388). As highlighted in section 2.4, in relation to the closure of day centres, powerful narratives serve to undermine alternative views (Needham, 2014). For example, people who argue against personalisation are portrayed as ‘lacking in confidence or exhibiting a form of false consciousness’ (Ferguson, 2012: 62). However, choice is not necessarily a pre-requisite of good care; Mol (2008) argues that good care is the outcome of collaborative and continuing relationships, and has little to do with choice or consumerism.

Relatedly, Barnes (2011: 165) warns about the potential risks of relying on ‘those who are able to exert ‘privileged irresponsibility’ to commit to ensure public funding of high-quality welfare provision' under neo-liberalism. Individual solutions may also mean that the state can effectively discharge the ‘moral and physical responsibilities’ (Rummery, 2011: 149) for care of citizens, as responsibility for the quality of care is devolved to recipients (Barnes, 2012). The idea of 'privileged irresponsibility' is illustrated by Tronto, who argues that the powerful can ‘ignore the needs of others for care' as well as 'the importance of receiving care to enhance people’s own capacity to live their lives as they wish’ (Barnes, 2011: 158).

Furthermore, personalisation assumes care recipients to be independent, autonomous and reflexive individuals who are able and willing to determine their own care needs (Barnes, 2011; Ferguson, 2007). In an analysis of policy documents, Barnes (2011: 157-158) argues that ‘the image of the independent choice maker ... embodies masculinised ‘virtues’’ and raises questions regarding the extent to which such views 'reflect the lives and circumstances of social care service users and those who care for them’. Ferguson traces these assumptions to the origins of personalisation in Leadbetter’s 2004 paper (discussed in section 3.2), arguing that Leadbetter neglected structural inequalities and the ‘reality of service users’ (Ferguson, 2007: 395). From a social work practice perspective, Ferguson argues that the recipients of personalisation policies have little choice and social capital available to them, and have ‘more modest ambitions’ than Leadbetter’s imagined citizen.

Arguably, the concept of ‘choice’ is problematic as it implies that everyone is equally able to make choices and therefore neglects the existence of wider inequalities. In relation to health care, Rabiee and Glendinning (2010) found that some respondents were experts in their own conditions and therefore wanted to make the decisions about their care; others felt professionals were the experts and were best placed to make decisions on their behalf; while some respondents needed others to make decisions for them as they were too ill to do it themselves. Citing Dowse (2009), Rabiee and Glendinning (2010: 828) note that ‘…making complex decisions can be cognitively demanding’. For some people, impairment may affect ability to understand, make decisions and take control. Additionally, interdependency in relationships means choices have implications for others (ibid.: 829). Choices made in relation to care and support are particularly complex as they may require consideration of the impact upon others with whom we have relationships (e.g. family, friends, workers).

Disabled people are a diverse group, with some valuing choice and self-determination more than others (Rabiee and Glendinning, 2010: 343). In Rabiee and Glendenning’s study, participants highlighted the importance of continuity in their support – particularly in relation to staff. In a study of the personalisation of social care services for older people in England, Lloyd (2010:

193) argues that policy takes a ‘highly instrumental view of social care, portraying services as a means of restoring people to their functions as active citizens’, which was not necessarily realistic or desired. Lloyd’s study highlighted that choice and control were affected by various factors – such as budget allocation, staff availability and individual capacity – which were problematic for some participants (Lloyd, 2010: 194). Whilst personalisation offers the potential to tailor services to meet the diverse needs of individuals, it rests upon normative assumptions of independent individuals. Diverse people, needs, and social and cultural contexts are not reflected in policy which assumes 'that people want to live independently’ (Barnes, 2011: 157).

Importantly, simply having a budget does not guarantee choice and control (Ferguson, 2012). In their longitudinal study, Rabiee and Glendinning (2010) found that choices were constrained by a range of factors, including: eligibility criteria; accessibility and affordability of alternatives; and understandings and expectations of professionals. Highlighting resourcing issues, Ferguson (2012: 63) notes that choice is dependent on both the extent of the budget and the local availability of services and support. The impact of austerity and public sector cuts is discussed in section 3.3, however it is relevant to note here that local authority budget cuts affect public services (e.g. libraries, community groups, leisure centres) which have been increasingly seen as alternatives to day centres (Ferguson, 2012).

The discussion above highlights contested issues in relation to personalisation, which suggests the need for further research to establish the impact and effectiveness of personalisation (Beresford, 2014; Duffy, 2014).

3.2.3. Policy Development – concluding comments

The first part of this chapter traced developments in social care policy and considered critiques to the dominant narrative of personalisation. In part 2, the discussion moves on to look at policy development and implementation in Scotland.

3.3. Part 2: Personalisation in Scotland

The shift in political narratives around public services, which emerged from the mid-2000s, is evident in the development of personalisation policies in social care. In Scotland, the most notable development is the development and implementation of self-directed support (SDS). Part 2 of this chapter begins by outlining the Scottish approach to policy before moving on to discuss the national strategy, and subsequent legislation, for SDS. The discussion then moves on to look at the implementation of SDS, and the impact of austerity on progress to date.

3.3.1. The Scottish approach

The distinctive approach to policy making, and the delivery of public services, in Scotland is often referred to as the 'Scottish approach' (Cairney et al, 2016). Although the concept of a 'Scottish policy style' had been the subject of academic studies since the late 1990s (Cairney et al, 2016: 337), the Scottish approach is generally associated with the reform of public services, notably the report of the Christie Commission (Christie, 2011) and the Government's response (Scottish Government, 2011b). Importantly, the Scottish Government promotes a distinctive Scottish approach, based on the 'four pillars' identified by Christie, involving:

- *a decisive shift towards prevention*
- *greater integration of public services at a local level driven by better partnership, collaboration and effective local delivery*
- *greater investment in the people who deliver services through enhanced workforce development and effective leadership*
- *a sharp focus on improving performance, through greater transparency, innovation and use of digital technology*

(Scottish Government, 2011: 1)

The Scottish approach is associated with a bottom-up, collaborative style, in which policies are designed through consultation and negotiation, and delivered in partnership with a range of other actors (Cairney et al, 2016; Cook, 2017; Cairney, 2017). The range of actors include: local authorities; health boards; private sector; voluntary organisations; academics; interest groups; and the public (Cairney et al 2016). This approach is possible because of Scotland's relatively small scale; partly because collaborative policy requires connections between key individuals and organisations, and partly because the limited capacity of the civil service in Scotland means it relies on information and support from other actors (ibid.: 340).

A key concept associated with the Scottish approach is co-production, which is seen as 'a means to empower individuals and communities' (Cook, 2017: 10). The concept of co-production is strongly evident in all aspects of SDS policy, discussed later in this section. Co-production is promoted by government in terms of '…sharing of power between professionals and people using services, their families, or citizens in general, in order to deliver improved outcomes' (Coutts, 2019: 4). The features of co-production include:

- *Recognising people as assets*
- *Including all perspectives and skills*
- *Supporting people to meaningfully share and participate*
- *Public services becoming change agents that facilitate people's inclusion*
- *Everyone benefiting from working together*
- *Developing networks of mutual support*

(Coutts, 2019: 4)

Furthermore, a focus on outcomes and distinct governance style are integral to the Scottish approach (Cook, 2017; Cairney et al, 2016). The Scottish Government sets out broad national priorities in the National Performance Framework (NPF) with the expectation that public bodies will work together to achieve its aims (Cairney et al, 2016). The national outcomes in the NPF determine national spending and activities (Scottish Government, 2018d), and Community Planning Partnerships produce local plans which contribute towards the achievement of the broad national aims (Cairney et al, 2016). Importantly, Cairney et al (2016: 346) note that 'there is an inescapable trade-off between a desire to harmonise national policies and to encourage local discretion', highlighting that local policymaking may result in the emergence of local policies and a 'postcode lottery' (ibid.).

However, the idea of a distinctively Scottish approach to policy and public services is contested by several writers (Mitchell, 2015; Cairney et al, 2016;

Cairney, 2017). For example, Mitchell (2015) argues that the concept of a particular policy style implies a homogenous approach and neglects diversity in policy styles in Scotland. Furthermore, Cairney et al (2016) highlights the multiple levels within which policymaking operates while noting that some important factors are determined by the UK government, and suggests that the Scottish Government often deals with policy ‘problems’ in similar ways to other governments. Notwithstanding the distinctiveness of the Scottish approach, Cairney et al (2016: 341) caution that ‘we should not assume or overestimate its effect’.

3.3.2. SDS – the national strategy

As part of the Scottish Government reform of health and social care policy, ‘Self-directed Support: A National Strategy for Scotland’ was launched in 2010 (Scottish Government, 2010). The ten-year strategy, which aimed to 'deliver better outcomes for individuals and communities' set out to increase the uptake of self-directed support, making it the mainstream option for the delivery of social care (Scottish Government, 2010: 2). The reform of health and social care policy was a response to demographic change and the economic climate, and recognition that existing policy and provision would be unable to meet future needs (Scottish Government, 2010).

Importantly, the national strategy sought to fundamentally change the structure and culture of social care in Scotland, driving ‘a cultural shift around the delivery of support that views people as equal citizens with rights and responsibilities' (ibid.: 12). In order to achieve this, the strategy promised transparent planning processes, 'improved information and advice', and 'focused assessment and review' (ibid.: 2).

A key feature of self-directed support is the emphasis on co-production in both policy and practice, in keeping with the ‘Scottish Approach’, discussed earlier in this section. The national strategy was developed in consultation with service users and support organisations, and contains a commitment that the principle of co-production should be delivered at local and national levels by stating that self-directed support should be 'designed and delivered in equal partnership between people and professionals' (ibid.: 7). In practice, this means that people are entitled to have a say in determining their own support arrangements as self-assessment should focus on meeting user outcomes and not be driven by service provision (Pearson et al, 2014: 17). The National SDS implementation group, made up of stakeholder representatives, works with the Scottish Government and COSLA to support delivery of the national strategy (Scottish Government, 2010: 58).

Crucially, the national strategy had set out the government’s intention to introduce legislation to support the delivery of self-directed support (ibid.: 61). The Social Care (Self-directed Support) (Scotland) Bill was introduced to the Scottish Parliament in March 2012, and received Royal Assent in January 2013 (Scottish Parliament, 2013). Consequently, the Social Care (Self-directed Support) (Scotland) Act 2013 came into effect from April 2014.

Social Care (Self-directed Support) (Scotland) Act 2013

Like the national strategy, the Act was co-produced by the Scottish Government and a range of stakeholders, in consultation with the public (Scottish Government, 2014). The Act introduced several new legal duties for local authorities, with effect from April 2014, including:

- *Duty to have regard to the general principles of* ***collaboration, informed choice*** *and* ***involvement*** *as part of the assessment and the provision of support*

- *Duty to take reasonable steps to facilitate the person's* ***dignity and participation*** *in the life of the community*

- *Duty to* ***offer four options*** *to the supported person*

- *Duty to explain the nature and effect of the 4 options and to "signpost" to other sources of* ***information and additional support***

(Scottish Government, 2014a: 9-11)

As noted earlier in this chapter, direct payments had been available in Scotland since the late 1990s, but uptake had been minimal. One of the reasons for the limited uptake of the pre-existing scheme of direct payments was that some people were reluctant to manage the financial arrangements for their support (Scottish Government, 2010). The national strategy therefore proposed a range of options to enable people to exercise choice over their support, and the subsequent Act required local authorities to offer eligible people the following four options for receiving support:

Option 1: Direct payment

Person receives their budget from the local authority and organises their own support.

Option 2: "Directing the available support"

Person chooses how their budget is spent, but the local authority, or another organisation, arranges it on their behalf. Local authorities have

> discretion over the ways in which this option is delivered, though it should differ from options 1 and 3.
>
> **Option 3: "Services arranged for the person by the authority"**
>
> Person chooses to allow the local authority to organise their support.
>
> **Option 4: A mix of options 1,2 and 3**
>
> Person chooses a combination of the above options.
>
> (Scottish Government, 2014a: 10-11)

Consistent with the ‘Scottish Approach’ to policy and governance, discussed earlier in this section, SDS implementation and processes are delegated by the Scottish Government to individual local authorities. Also, in keeping with the ‘Scottish Approach’, local authority guidance on the implementation of the Act was developed by the Scottish Government, in conjunction with COSLA and other stakeholders (Scottish Government, 2014a). Notably, the statutory guidance document states that local authorities ‘… must follow both **the letter and the spirit** of the guidance’ and ‘must not depart from the guidance without good reason’ (ibid.: 4).

Values and principles

The national strategy and the Act are underpinned by commitments to human rights and independent living. This is explicitly set out in the statutory guidance document, which opens with a ‘Statement of Intent’, proclaiming:

> *…Self-directed support, alongside many other policies, is intended to support, promote and protect the human rights and independent living of care and support users in Scotland. It aims to ensure that care and support is delivered in a way that supports choice and control over one's own life and which respects the person's right to participate in society.*
>
> *(Scottish Government, 2014a: 4)*

The statutory guidance sets out government and stakeholder expectations that local authorities will consider the following values in local delivery and implementation: respect; fairness; independence; freedom; and safety (Scottish Government, 2014a: 15). Additionally, there are four national *statutory* principles that 'apply to the initial assessment of need and to the provision of choice in order to meet those needs' (ibid.: 15):

1. Participation and Dignity

Fundamental to the achievement of independent living, this places a legislative requirement on local authorities to respect the rights of disabled people and carers to dignity, and to participate in the community.

2. Involvement

This principle recognises that disabled people know about their own lives and support needs and should, therefore, be involved in determining support.

3. Informed choice

Essential to enable involvement in the SDS process, appropriate assistance should be provided to ensure people can actively participate and make informed choices.

4. Collaboration

> Recognising that both the disabled person and professionals are involved in the SDS process as ‘equal’ partners, this principle notes the potential value of working together.

The policy guidance includes an additional three good practice principles in relation to responsibility, risk enablement and innovation, and also outlines the relationship between SDS and human rights, but the four principles outlined above are the key principles of the Act. This means that these are not simply recommendations or best practice, but statutory principles which place a legal duty on local authorities.

In keeping with the ‘Scottish approach’, and commitment to co-production and collaboration in the policy process outlined earlier, national organisations demonstrated their commitment by producing a ‘Statement of values and principles’ for care and support in Scotland (Scottish Government, 2014b). Symbolically, the statement was signed by individual representatives of the national organisations.

3.3.3. SDS Implementation

Whilst there has been progress in the implementation of SDS (Audit Scotland, 2017), the radical transformation in social care promised by the legislation has yet to be seen (Pearson et al, 2018). As discussed below, there are a number of reasons for this.

Progress in implementation

It is difficult to accurately ascertain the extent to which SDS has been implemented in social care throughout Scotland (Scottish Government, 2019a; Audit Scotland, 2017). This is related to inconsistent or unreliable social care data at the national level, and local variation in SDS implementation practices and processes (Scottish Government, 2018a, 2019a; Audit Scotland, 2017). In their 2017 progress review, Audit Scotland noted the need for more reliable data – particularly in relation to measuring uptake of the different options chosen (Audit Scotland, 2017). In response to Audit Scotland’s report, the Scottish Government acknowledged the difficulties in determining ‘the extent to which self-directed support has been fully embedded in practice across the country’, and commissioned research which would ‘contribute to improved understanding of the impact and effectiveness of self-directed support at a national level’ (Scottish Government, 2019a: 3).

The published report from the Scottish Government study acknowledges unresolved challenges in undertaking a full evaluation of SDS implementation and notes that ‘measures of uptake of the different options in a local authority is not a suitable proxy for genuine implementation of self-directed support and fidelity to its principles’ (Scottish Government, 2019b: 27). Further highlighting the complexity in determining the national picture in relation to implementation, Self Directed Support Scotland (2018) note that national data reporting is based on whether people had ‘choice’, yet the meaning of ‘choice’ is not clear.

Although the most recent published national data on SDS shows an implementation rate of 70% in 2016-17 (Scottish Government, 2018a), this is accompanied by several caveats in relation to data collection and calculation methods which advise caution over the reliability of this figure. In reporting the SDS implementation rate, the Scottish Government note that:

> *‘The key criterion for inclusion [in the calculation] is that the client was given a choice – an individual should only be included [in this data] if they have undergone an assessment during which the available SDS options were explained.*
>
> *Scottish Government (2018a: 4)*

Notwithstanding the difficulties noted above in relation to data collection, it would seem that SDS has yet to become the ‘mainstream approach’ to social care envisioned by the national strategy in 2010. Recent evidence suggests that, in practice, ‘little has changed in the type of services people are receiving’ as the majority of people are still receiving traditional services under option 3 (Pearson et al, 2018: 663). Large variations in implementation rates between local authorities and between different user groups (Audit Scotland, 2017) further illustrate that SDS is not yet the ‘mainstream approach’ to social care; for example, the implementation rate for Glasgow is reportedly less than 40% (Scottish Government, 2018a).

The limited progress to date has been attributed to a combination of related but external factors, most notably: the integration of health and social care; constrained public sector budgets; and social care workforce shortages (Scottish Government, 2019a; Audit Scotland, 2017). Prior to the implementation of the Act in 2014, a review of barriers and facilitators to self-directed support found that factors affecting uptake included: availability of information; clarity over the legal position (of direct payments); perceptions of risk; and perceptions of cost effectiveness (Scottish Government, 2011c). The legislation and regulatory guidance attempted to address some of these issues, however the lack of research evidence on the impact and effectiveness of self-directed support for users and their families, or best practice in implementation, may also have impacted upon progress.

Are more people experiencing choice and control and improved outcomes?

Within the context of the limited progress in the extent of implementation noted above, there have been some small studies which have attempted to ascertain the impact on the lives of people who *have* experienced SDS. For example, a pilot study of SDS users carried out by Self Directed Support Scotland in 2016 reported that, although there was little understanding and awareness of SDS and the different options, most respondents felt they had choice and control over their support (SDSS, 2016). However, this was a small, quantitative study which was not intended to produce statistically significant data.

In the same year, Learning Disability Alliance Scotland carried out a national survey of people with learning disabilities, half of whom had gone through the SDS process and half of whom had not (LDAS, 2016a). The survey results suggested that there had been some progress in relation to people feeling they had control over their care as those who had gone through the SDS process were more likely to report that their views were included in the care plan, and that they had enough information to make choices. However, the survey responses to questions about outcomes showed little difference between the two groups.

Prior to the national roll-out of SDS, the Scottish Government (2011a) funded three local authorities as test sites from 2009 to 2011. While test site participants generally reported experiencing increased choice and control, it was not clear whether this was a direct result of having SDS, or if it was related to the additional funding and support provided in the test sites (ibid.).

Findings from Scottish Government funded ‘Independent Support’ projects suggest that information, creativity and flexibility are necessary in order to achieve outcomes (Evaluation Support Scotland, 2015a). Similarly, a pilot project undertaken by Glasgow Disability Alliance (GDA) reported that a focus on person-centred support and user-defined outcomes, as well as sufficient resources, were key factors in achieving the vision associated with SDS (Witcher, 2014).

With the exception of small pilot studies, as in the case above, most of the limited research on SDS to date is from the perspective of professionals as opposed to the individuals and carers who use services (Manthorpe et al, 2015). Addressing this gap is of critical importance because there are strong indications that disabled people are not experiencing improved outcomes in the current economic climate (Pearson and Ridley, 2017), there are concerns about adequate resourcing (West, 2012) and there is a potential disconnect between policy discourse and user experience (ibid.: 646). Furthermore, research 'about' disabled people has been strongly contested by the Disabled People's Movement (see chapter four), and the lack of attention to users' perspectives conflicts with the overarching aspiration of personalisation and its aim to shift power from professionals to service users.

Nonetheless, evidence from the test sites and pilot projects suggests there are lessons to be learned in relation to SDS and improved outcomes. The findings from these projects show that the key to improved outcomes is not choice and control per se; rather, it is the ethos of independent living which underpins SDS policy and is, subsequently, reflected in its values and principles. A focus on person-centred assessments and user-defined outcomes, as well as adequate funding, were identified as vital factors in achieving the aims of SDS (Witcher, 2014). However, support alone is not enough to remove the barriers faced by disabled people in society – such as negative attitudes, inaccessible transport, inequality in education and employment (Witcher, 2014) – and achieve the aspirations set out in the National Strategy.

Resourcing

The discussion above highlights the importance of funding in successful implementation. This is supported by Roulstone and Morgan (2009: 343) who argue that planning and resources are crucial to transforming social care in order to meet the goals of 'genuine personalisation'. Longstanding issues in relation to the funding of social care are highlighted by West (2012), who notes that there were concerns about the sufficiency of resources for implementing personalisation policies in England pre-austerity. More broadly in relation to public services, Ferguson and Lavalette (2014: 22) argue that the goal of 'doing more for less' pre-exists austerity.

Personalisation policies have a longstanding association with cost savings (Pearson and Ridley, 2017). As discussed in section 3.2, the potential cost savings proposed by BCODP influenced the eventual acceptance of direct payments legislation in the 1990s (ibid.). Within the context of SDS implementation in Scotland, and notwithstanding the evidence outlined above which shows the importance of sufficient resourcing, policymakers' concerns about the cost effectiveness of SDS are illustrated in the recent Scottish Government Implementation study (Scottish Government, 2019a). Acknowledging the challenges in resourcing personalisation policies in England, Slasberg et al (2014/15: 50) propose that policymakers need to recognise the existence of unmet need and, in doing so, make a commitment to closing the current funding gap over time.

The personalisation agenda has emerged at a time when the rights of disabled people are being undermined due to austerity measures, which have targeted welfare benefits and resulted in substantial reductions in local authority social care budgets (Pearson and Ridley, 2017). Instead of extending autonomy for service users, the implementation of SDS in the current economic climate has resulted in the allocation of individual budgets sufficient to meet only basic needs – ‘critical’ rather than the ‘aspirational’ needs – associated with the policy aims, and the reframing of eligibility criteria which denies social care to some groups (ibid.).

Whilst IRISS (2012) caution against conflating SDS and austerity, the policy context inevitably affects local authority implementation and therefore user experiences. In some local authorities in Scotland, SDS has been used as a means of achieving cost savings (Pearson and Ridley, 2017). Importantly in relation to this thesis, there is a body of evidence that Glasgow City Council adopted this approach in learning disability services (Main, 2014: 34; LDAS, 2016a: 2; SCSWIS 2011: 9). As one of the three test sites, Glasgow City Council approved the roll out of SDS in learning disability services in 2010, announcing that SDS would result in £10m of savings during 2012/13 (Main, 2014). Presenting SDS as the fair way to allocate scarce resources, one of the ways in which cost savings have been achieved is through the closure of day centres for people with learning disabilities (Main, 2014).

As discussed in chapter two, resources previously directed towards collective provision have been redirected to individual budgets (Hall, 2011). The combination of personalisation policies and austerity has led to the contentious closure of day services for people with learning disabilities as segregated, specialist provision has been replaced by individual care packages (Power and Bartlett, 2015). Whilst this policy shift presents opportunities for alternative places of care to emerge, the loss of collective spaces risks increased isolation for people with learning disabilities (Power, 2014). The shift in resources from collective provision to individual budgets, and the lack of alternative provision, has resulted in fewer options for people with learning disabilities. For many people with learning disabilities in Glasgow, the implementation of SDS has been experienced as offering them ‘less choice, less money and less say’ (Main, 2014: 34).

Austerity

The implementation of SDS in Scotland is taking place at the same time as public spending cuts and welfare reform associated with austerity. In April 2014, when the SDS Act came into effect, local authorities in Scotland were also dealing with substantial budget cuts (Pearson and Ridley, 2017). As noted above, both the Scottish Government and Audit Scotland acknowledge that constrained public sector budgets have contributed towards SDS implementation taking longer than expected (Scottish Government, 2019a; Audit Scotland, 2017).

Public spending cuts have been presented as an essential government response to the challenging global economic climate (Levitas, 2012); however, this is highly contested. Clarke and Newman (2012: 303) propose that the UK government has reacted to the global economic crisis with cuts 'deeper and harder than most EU countries', and have presented this as a righteous and necessary response to the problem of 'Britain's broken society' (ibid.: 310). Describing these actions as an ‘assault on welfare’, Ferguson and Lavalette (2014: 5) argue that the global financial crisis made it possible for the UK government to make structural changes which would have been met with resistance at any other time. Thus, the global financial crisis has undergone an ideological transformation through political discourse, being reframed as a crisis of the welfare state, blamed on the Eurozone, the recklessness of previous governments, and welfare dependency (Clarke and Newman, 2012). The reframing of the problem of, and solution to, the global financial crisis has enabled the cost of the financial crisis to be shifted on to ‘the shoulders of the working class’ (Ferguson and Lavalette, 2014: 5).

The 'age of austerity' has resulted in radical cuts to the UK welfare state, with the greatest impact felt by the most disadvantaged groups in society (Ginsburg et al, 2012). Disabled people are particularly vulnerable to cuts because this group is disproportionately reliant on health, social care, housing and transport services, and are more likely to live in poverty or be on benefits because of low rates of employment and high costs of living with impairment (Demos, 2010; EHRC, 2010). Spending cuts have a cumulative effect on the lives of disabled people, with the potential loss of benefits resulting in additional demand for social care services at a time when local authority care budgets have been cut, eligibility criteria has been increased, and charges for care services have also increased (The Hardest Hit, 2012; Morris, 2011).

There is some evidence to suggest that cuts to local authority budgets have resulted in individual social care budgets being set at a level which just meets basic needs – particularly for people who need personal care in their own homes (Pile, 2014). Pile argues that service cuts and closures, and 'management pressure to trim care packages', are being carried out under the guise of personalisation (Pile, 2014: 55). Furthermore, the effects of reduced social care budgets are being exacerbated due to cuts in community services – such as libraries and leisure centres (Pearson et al, 2018; Ferguson, 2012). Whilst both the national strategy and the SDS Act are underpinned by commitments to human rights and independent living, there is evidence to suggest that this has been compromised by the timing of SDS implementation and the impact of austerity (Pearson and Ridley, 2017).

3.3.4. Personalisation in Scotland – concluding comments

The second part of this chapter focused on the development and implementation of SDS in Scotland. Notwithstanding the challenges in ascertaining the extent of implementation and the perspectives of service users and carers, there is little evidence to suggest that people are experiencing more choice and control or improved outcomes.

3.4. Conclusion

This chapter set out to trace the emergence of personalisation as the dominant narrative in social care policy, and to consider the implementation and progress of self-directed support in Scotland. The first part of this chapter highlighted key developments – from disability activism in the 1970s, to the development of direct payments and the highly contested concept of personalisation. The second part of this chapter focused on the emergence, implementation and progress of self-directed support in Scotland and how this has taken place at a time when the effects of austerity and wider welfare reform are being felt by disabled people and their families.

4. Methodology

4.1. Introduction

This chapter explains my approach to carrying out the research, beginning with a discussion of the emergence of the research topic. It goes on to discuss theories which have influenced my approach to this topic and to the research questions, including debates about feminist research methods and 'emancipatory' disability research. There are political, practical and ethical challenges in researching families and relationships, and in carrying out research with people with learning disabilities. These challenges combine in this study, which involves people with learning disabilities and their families. My understanding, approach and reflections on these challenges in relation to this study are set out here, before moving on to discuss the research design and practicalities of 'doing' this research. Some of the many methodological challenges I encountered along the way are discussed, together with critical reflections on the process and limitations of the study. The chapter then concludes with a summary of the main methodological issues in this study.

4.2. The Emergence of the Research Topic

This study set out to explore the experiences of people with learning disabilities and their families at a time of considerable change to social care policy and service provision. As outlined in chapter one, this was not the intention when I began the PhD process; the topic emerged from my initial engagement with relevant literature and informal discussions with disabled people, family carers and care workers.

My original plan had been to explore the experiences of older parent carers and their disabled adult children. I was interested in understanding how ageing, caring and social support intersect, as well as documenting the challenges faced by parents and their children as they both grow older. The initial research proposal had been highly influenced by my personal and professional experiences, and (relatedly), my academic and political interest in this area. My motivation to understand more about families' experiences of disability was rooted in my family's own 'biographical disruption' (Bury, 1982) as my (now 21 year old) daughter had been diagnosed with cerebral palsy, aged 20 months. Prior to embarking on the PhD, I had just completed an undergraduate degree in Sociology. My dissertation had explored the experiences of older mothers in West Dunbartonshire who were caring for their disabled adult sons and daughters, and I had undertaken a summer placement within the learning disabilities team in a local authority social work department.

In 2012, when I applied to the ESRC for 1+3 PhD funding, I was motivated to research the experiences of older parent carers and their disabled adult children because I had glimpsed some of the everyday challenges experienced by this group whilst working as a support worker, volunteering with the 'Best Buddies' programme[11] and with a carers organisation, and through my undergraduate dissertation research. As a worker, and as a volunteer, I formed relationships with a small number of people who had learning disabilities and, in some cases, with the family members who cared for them. Even when I had little contact with families, I was acutely aware of issues related to ageing, caring and social support as folk would often share stories about their families and home lives. No doubt the ways in which I interacted with the individuals and families I encountered in my roles as a worker, and as a volunteer, were strongly influenced by my academic understanding of disability and care[12], as well as by the insight I had gained as mum to a disabled daughter.

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[11] 'Best Buddies' is an international organisation which works with people with learning disabilities, see: https://www.bestbuddies.org/. Enable Glasgow runs a local initiative to encourage friendships between people they support and students at the University of Glasgow.

[12] As a working-class woman who left school aged 16 to take up a full-time job, I had never encountered feminism or the social model of disability until I came to University in my 30s.

I began my PhD studies in earnest in January 2014 (after a ‘false start’ in September 2013) and very quickly realised that the most important issue for parent carers and their disabled adult children at the time was changes to social care policy and service provision. In Glasgow, the restructuring of learning disability services, alongside the implementation of the Social Care (Self-directed Support) (Scotland) Act 2013, were highly contentious and emotive issues, and there was an active, high profile group of carers campaigning against day centre closures – it was this which provided the context for family relationships. Having realised that these changes were such major issues for people with learning disabilities and their families in Glasgow at the time, I revised my research proposal in June 2014 to reflect this. My revised research proposal set out to explore the experiences of people with learning disabilities and their families within a shifting policy environment, focusing on people with learning disabilities who were aged 30 and over, and living in Glasgow.

4.3. Theoretical Approach

This study set out to explore the experiences of people with learning disabilities and their families at a time of considerable change to social care policy and service provision. The research was concerned with understanding how policy change played out within family lives, and the main research questions were:

- In what ways have changes to social care policy affected the day-to-day lives of people with learning disabilities and their families?
- How does the dominant policy discourse of ‘Personalisation’ reflect the needs and wishes of people with learning disabilities and their families?

- In practice, does self-directed support policy increase choice and control for people with learning disabilities and their families?

The research questions set out above necessitate enquiry into potentially sensitive, emotive and intimate areas of individuals and family lives. Capturing participants' own descriptions of personal experiences – and the ways in which they understood, interpreted and attributed meaning to these experiences – was fundamental to this qualitative study.

Qualitative research includes a range of different methods and is associated with various approaches (Ormston et al, 2013). Qualitative research methods are associated with interpretivist epistemology and beliefs that knowledge about the social world is always subjective (Snape and Spencer, 2003). Interpretivism holds that conclusive knowledge of the social world is not possible because the social world is not 'governed by regularities that hold law-like properties' (Ormston et al, 2013: 24). Because individuals understand and interpret experience in different ways (Snape and Spencer, 2003), social researchers need to attempt to '…explore and understand the social world through the participants' and their own perspectives…' (Ormston et al, 2013: 24).

Qualitative research is associated with constructionist ontology, which considers the social world to be socially constructed, produced through interactions and continually changing (Snape and Spencer, 2003). Whilst qualitative research is generally associated with a 'bottom up' inductive approach to knowledge, Ormston et al (2013: 25) propose that this is a 'misleading simplification' because researchers are also influenced by our existing assumptions and knowledge – affecting the questions we ask, the data we collect, and the analytical categories we adopt. I share the views of Ormston et al (2013: 23) that '…there is no completely 'neutral' or 'objective' knowledge…' as the research process, and the relationship between researcher and participant(s), is interactive and affects the data collected and the analysis undertaken. Acknowledging the subjectivity of social research does not mean that the data or analysis is not rigorous or robust, but it provides an opportunity for researchers 'to be reflexive about their role and the influence of their beliefs and behaviours on the research process' (Ormston et al, 2013: 24).

Importantly for this study, Spencer et al (2003: 34) suggest three main ways in which qualitative research can contribute to policy research and evaluation. First, qualitative research can enable policy researchers and policymakers to understand complexity and explore issues in depth. Second, qualitative research has an 'exploratory and generative role' in policy, allowing researchers to explore issues where little is already known. Third, qualitative research can provide researchers and policy-makers with insight into the social worlds of participants so as to 'see through the eyes of the people you are studying' (Spencer et al, 2003: 34).

For the purposes of this study, qualitative research methods were chosen to enable the collection of rich narratives about personal lives (Spencer et al, 2003), from the perspectives of the people themselves whose lives were affected by changes to social care policy and service provision. My approach to the methods and design of this study were influenced by a range of theories and perspectives, including: feminist research methods; ethics of care theory; and 'emancipatory' disability research methods. I did not draw exclusively from any one of these perspectives; instead, I took a much more pragmatic approach, selecting aspects from each which I felt were appropriate and practical to the objectives of the study. I was keen to ensure that issues of inclusion and accessibility were prioritised in designing the study, but I was also mindful of practical considerations and the limitations of the available resources (e.g. time, money, skills). In this regard, I share the views of Ormston et al (2013: 22), that '…quality in research practice has more to do with choosing the right research tools for the task rather than with methods that are confined to specific traditions'.

4.4. Feminist Research Methods

Whilst the concept of a specifically feminist methodology is contested, there are some key features of feminist research which distinguish this from other approaches to social research, including a focus on feminist theory and commitment to addressing issues of subordination and injustice (Ramazanoglu and Holland, 2002). Importantly for this study, feminist research methods recognise that the researcher's subjective position influences the research process (Oakley, 1981). I share Ramazanoglu and Holland's belief that 'all researchers... carry intellectual, emotional and political baggage with them' (2002: 148) and acknowledge that this study is influenced by my personal and political feminist position in various ways. This includes, but is not limited to: the choice of research topic and questions; the ways in which I engaged with participants and collected data; and the ways in which I have analysed the data and presented the findings of this study.

A central feature of feminist research is the acknowledgement of power within the research process (Maynard, 1994). Mauthner and Doucet (1998: 139) propose 'this power differential between researcher and researched is likely to be particularly pronounced when doing research both *on* and *in* the private, rather than the public sphere'. It is ultimately the researcher who makes the decisions which shape the research and I was acutely aware of my responsibility (as a caring and ethical researcher) to mitigate power differentials, particularly as the project would explore potentially private and emotive issues for participants. Feminist research recognises that participants are experts in the research project (Ramazanoglu and Holland, 2002); in order to mitigate the impact of power differentials, I was keen to use methods which would emphasise reciprocity and rapport in the research relationship (Maynard, 1994).

4.5. ‘Emancipatory’ Disability Research

Within disability studies, there has been much debate about ‘doing’ disability research – which is often focused on questions about how, what, why and by whom. Most notably, Mike Oliver (1992) proposed an ‘emancipatory research paradigm’ based on three fundamental principles: reciprocity; gain; and empowerment. Strongly influenced by disability politics and the social model, this was a challenge to conventional ways of conceptualising and understanding disability at that time (Barnes, 2003). Oliver’s influential paper highlighted the political nature of the research process, illustrating issues of power and control in the resources and processes of knowledge production (Oliver, 1992).

In recent years, there has been a shift towards participative and user-led disability research – partly due to challenge from the disability movement and changes in research funding (Barnes, 2003) – but the idea of a truly emancipatory research paradigm remains contested. Barnes (2003: 7) suggests that one of the main problems with the model is accountability as it would be impossible for researchers to be accountable to all disabled people – given that the population is so vast and diverse. Barnes (2003: 12) proposes that ‘the rationale of the emancipatory disability research paradigm is the production of research that has some meaningful practical outcome for disabled people’, yet this is problematic; Oliver (1997) himself notes that it is researchers themselves who are the main beneficiaries of social research. Furthermore, emancipation and empowerment are active concepts, aspects of which lie outwith the control of the researcher, as Oliver notes:

> *The question of doing emancipatory research is a false one, rather the issue is the role of research in the process of emancipation. Inevitably this means that research can only be judged emancipatory after the event; one*

> *cannot 'do' emancipatory research (nor write methodology cookbooks on how to do it), one can only engage as a researcher with those seeking to emancipate themselves.*
>
> *Oliver (1997: 25)*

Whilst the principle of emancipatory disability research has been highly influential, the discussion above has illustrated some of the difficulties in doing research which could be considered truly emancipatory. It could be argued that this is particularly the case for PhD research, given that the ultimate goal is to attain a qualification attributable to the individual researcher, and that the PhD student is likely to have little power to influence any potential outcomes.

My approach to this study has been influenced by the debates outlined above – as well as critical social research more broadly. Critical social research is associated with challenges to traditional approaches by oppressed groups, where the focus is 'emancipatory goals, and … openly partisan and politically committed research' (Barnes and Mercer, 1997: 4). The methodology for this study has therefore been informed by a critical understanding of power and control in the research process, and commitment to a broadly social model understanding of disability. Though I do not claim that this research is emancipatory, the study generates new knowledge that I hope will contribute towards policy and practice. As noted by Oliver (1997), I acknowledge that I stand to gain more from this process than my participants, and I was extremely uneasy with this. Whilst there may have been benefits to some participants as a result of taking part in this study (e.g. I received an email from one family which said how much they had enjoyed speaking with me – see Appendix A), the transient nature of the research relationship means I have no way of knowing. Many of the participants in this study felt that they were not being listened to, so taking part in a research interview and feeling that they have been heard could be perceived as empowering. Nonetheless, I have (indirectly) benefitted materially as a result of undertaking this study because it contributed to my securing a permanent post as a social researcher within health and social care analysis at the Scottish Government in 2017. In some ways, this has helped to lessen my unease about who benefits from this research because my job means I interact with policymakers in relevant areas (such as social care, carers, adult support and protection) on a regular basis and I take every opportunity to contribute insight gained from the data and related literature.

4.6. Participatory Research with People with Learning Disabilities

As shown above, there are serious challenges to ‘doing’ emancipatory disability research; participatory research methods address some of the challenges. Some writers suggest that participatory research can be empowering for people with learning disabilities (Walmsley and Johnson, 2003). There are important advantages to adopting participatory methods in studies involving people with learning disabilities. For example, they may have experience of services and therefore know what questions to ask of others and how to frame questions appropriately, and they may get more honest answers from participants (Walmsley and Johnson, 2003). However, participation does not necessarily mean equal participation in the research process. The extent of participation can vary from acting in an advisory capacity to undertaking the role of co-researcher; studies involving people with learning disabilities as co-researchers have tended to be limited to specific types – often autobiographies and service evaluations (Walmsley and Johnson, 2003).

The relationship between impairment and participation in research is highly contested in the literature about doing research with people with learning disabilities. Highlighting the social model’s neglect of impairment, Stalker (1998: 15) proposes that ‘it is important to acknowledge that very little is known about the potential implications of intellectual impairment for involvement in the research process’, suggesting that data analysis may be particularly challenging. Walmsley and Johnson (2003) argue that we cannot expect everyone to take on a fully participatory role as co-researcher because the role of researcher requires particular skills (e.g. understanding, listening, interest in others) that not everyone will have. However, other writers challenge this view with examples of studies where people with learning disabilities have been fully involved at all stages of the research process (e.g. Williams, 1999).

Even the most emancipatory studies involving people with learning disabilities are usually driven by ‘others’ - researchers (often allies) who 'name what is going on as 'research'; it is she who identifies theorizing' (Walmsley and Johnson, 2003: 162). I can relate to Walmsley and Johnson, who note that many researchers striving to produce inclusive research 'feel uneasy about the extent to which their research is truly inclusive and how we can responsibly exercise the power we have' (162). Like Walmsley and Johnson, I welcome the shift which has seen self-advocates becoming more willing to challenge power in the research process and, as such, I view this as an opportunity to reflect on my own practice.

My approach to this study was influenced by these debates, though, in practice, the research design was largely determined by practical considerations – most notably recruitment challenges (discussed in section 4.9). The research questions and methods have been determined by me, underpinned by my belief that participants are the experts in their own lives and we can (and should) learn from listening to this expertise. As noted in chapter one, the topic emerged from my initial engagement with relevant literature and informal discussions with disabled people, family carers and care workers. I undertook training in easy read materials through SCLD, who subsequently advised on and approved relevant documents. Furthermore, I adapted my initial approach as a result of feedback from people with learning disabilities; some people did not want their families involved in any discussion about their care and support, whilst others requested a focus group, rather than an interview (see section 4.9).

Perhaps naively, I had not anticipated these issues in designing the study, and it was somewhat in conflict with my research questions which were concerned with the impact on disabled people and their families. However, I recognised and respected this feedback, and felt this was an important methodological consideration in view of the long history of exclusion and silencing of this group; not only in research, but also in society more generally. So, although I have not adopted explicitly participative research methods due to practical constraints, the research design was adapted in response to feedback from people with learning disabilities. I wanted the research to be inclusive and tried to be attentive to the needs and wishes of potential participants so as not to exclude certain groups or silence particular perspectives; therefore, in some cases, I interviewed individuals rather than family groups.

Ultimately however, it has been me who made all the decisions about this study (including deciding what to ask for advice/input on), and I do not describe this study as participative; research participants (disabled people and family carers) were involved only within the confines of that role. Notwithstanding the ideal of participatory research, Walmsley and Johnson (2003) note that we would know little about the lives and experiences of people with learning disabilities without the involvement of allies in undertaking such research. Despite its shortfalls, I hope that this study sheds some light on how people with learning disabilities and their families have experienced the policy shift towards personalisation.

4.7. Researching Families and Relationships

In this study, the recognition and inclusion of multiple perspectives was important because of the underpinning theoretical frameworks and conceptualisations of care and inter-dependency (see chapter two), and my (related) observations that changes to policy and service provision affected people with learning disabilities and family carers. As discussed in chapter two, care has often been treated as though it were simply a matter of the performance of tasks, and research has tended to focus on either the perspectives of those who receive care or those who provide care. The focus on the practical dimensions of care and positioning of ‘carers’ and ‘cared for’ as two distinct groups has resulted in the neglect of the emotional and relational dimensions involved. This study was informed by feminist perspectives which have challenged ideas about knowledge and highlighted the political in private issues, and my approach was influenced by feminist research methods which recognise different ways of knowing and the situated perspectives of participants and researchers.

4.7.1. Linked lives and multiple perspectives

Within families and relationships research, growing recognition that ‘interviewing one person in a relationship may result in telling half the story’ has meant that research methods which include multiple participants who are connected to each other are becoming increasingly common (Jamieson, 2011: 125). The importance of telling both sides of the story has been highlighted by research with married couples (Song, 1998), as well as parents and children (Jamieson, 2011). Song (1998) suggests that sociologists have not extended the practice to researching other family relationships. This study contributes towards addressing this knowledge gap, in relation to people with learning disabilities and their families, by showing how policy change plays out within everyday family lives.

4.7.2. Advantages of multiple perspectives

Some of the reasons for the inclusion of multiple perspectives in families and relationships research include the possibility of attaining a ‘richer and more complete story’ (Song, 1998: 115) and to ensure different voices are ‘heard alongside’ others (Harden et al, 2010: 441). Importantly, the accounts of participants are valid and valuable in their own right; multiple perspectives research is not about privileging one perspective over the other (Song, 1998). However, one of the advantages of including multiple perspectives in research is the ability to privilege voices which often go unheard (Song, 1998). This was important in this study because adults with learning disabilities and their families are seldom represented in the literature. We know a bit about families with disabled children, but there is little recognition of (inter)dependency and family relationships as people grow older[13]. Privileging often unheard voices requires recognition and reflection about the complex ways in which some relationships might be affected by structural factors. For example, parent-child relationships are structured by gender and generational power differences, whilst sibling relationships might be more equal (Song, 1998: 106). In this study, participants were related in various ways[14]; the association of structural factors with particular types of relationships and the intersection with impairment adds further complexity to the data.

4.7.3. Challenges in multiple perspectives research

There are particular ethical challenges in relation to confidentiality and avoidance of harm that need to be considered in research with multiple connected participants (discussed in section 4.8), as well as challenges in recruitment and fieldwork (Lewis, 2009; Walmsley, 1996). Individual family members can act as ‘gatekeepers’: influencing access to others and the

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[13] Bigby (2012) is a notable exception.

[14] This was deliberately not defined at the outset to reflect the complexity and fluidity of families (see section 2.3).

mediation of information (Lewis, 2009); selecting family members who will present them in a positive way (Song, 1998); or excluding those who may tell contradictory stories (Ribbens McCarthy et al, 2003).

Additional challenges in relation to gatekeepers include communication and negotiations around consent. Lewis (2009: 406) observed that parents can believe that 'they are the responsible decision-makers' for their children; creating tension for researchers who view children as agentic individuals, and is in conflict with ethical practices which require each party to provide consent (ethical issues and informed consent are discussed in section 4.8). This is further complicated in this study because it does not involve children per se[15], but it does involve parents and their adult sons and daughters who have learning disabilities, where parents are often involved in 'lifelong parenting' (Seltzer et al, 2011), and the nature of impairment likely means their sons and daughters require support to make decisions. The challenge for researchers is to ensure that all participants receive relevant information, and to be satisfied that each and all potential participants not only understand and agree to participation, but are also not being pressurised or coerced by others (Lewis, 2009).

The importance of pre-interview communication and negotiations in achieving informed consent is discussed in section 4.8. Communication with multiple participants brings additional challenges and potential for misunderstanding (Lewis, 2009), so it is important that participant information is appropriate and relevant to the needs and understandings of all potential participants. In this study, I tried to address some of the communication needs which people with learning disabilities may experience by providing easy read information and consent sheets (see Appendices B and D), though I recognise that this only addresses some of the difficulties for some people, and so I took an individual

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[15] I note here that we all remain our parents' 'children', regardless of age!

approach to communication, which often involved family members or support workers.

Sociological research often involves individual interviews, but there are benefits to interviewing family members together (Harden et al, 2010). For example, family members can provide prompts and reminders, or question and contradict each other (ibid.). Additionally, research interviews are like a public performance; participants present themselves in ways that make them look ‘good’ or credible to the interviewer (Song, 1998; Harden et al, 2010). This may be particularly the case for group interviews, as participants are required to perform to fellow participants, as well as the interviewer.

There are further challenges at the analysis stage in multiple perspective research with families. Ribbens McCarthy (2003: 20) notes that vast amounts of data may be produced, therefore analytic strategies can be complex. The volume of data means more information, revealing gaps and silences which may raise further questions, and the possibility of greater understanding (Ribbens McCarthy, 2003). Research which involves multiple participants from families is inevitably ‘messy’, but this allows the researcher to get closer to ‘reality’ (Jamieson, 2011).

Multiple perspective data analysis is messy and complex, particularly if there are different types of data, and this can be ‘overwhelming’ (Harden et al, 2010: 450). For example, individual and group interviews produce different data because of the interaction between participants in group interviews and the possibility of these interviews taking different directions (Harden et al, 2010). In research with children and parents, Harden et al note that researchers should take care to give participants’ accounts equal emphasis and suggests that there may be a temptation to attend more to parents’ data because it may be denser and more detailed than children’s accounts. In this study, both group interviews and individual interviews were carried out, so the analysis was complicated because of different types of data. Additionally, participants with learning disabilities generally provided much shorter responses than family carers and I was keen to make sure these voices were not drowned out by carers' lengthier or more articulate narratives in the analysis.

4.8. Ethics

In any research project, there are important ethical considerations in order to maintain professional standards and avoid harm to both researcher and research participants (Bryman, 2008). In this project, there were very particular ethical challenges inherent in the research questions which were related to three main features of the study: it involved multiple related participants; it explored potentially sensitive issues; and it involved a group perceived as 'vulnerable'. I will briefly explain here why there were particular ethical challenges in relation to these three features, and I will return to them throughout the subsequent discussion in this section on ethics.

First, in seeking to understand the experiences of people with learning disabilities and their families, the study involved multiple related participants. This raises particular challenges in relation to informed consent, confidentiality and avoidance of harm. As noted in section 4.7, some family members can act as 'gatekeepers' in multiple perspectives research, affecting communication and negotiations around participation and consent. Furthermore, related participants may disclose information which is either not known by other family members, or which they may not wish to disclose or discuss.

Second, understanding how policy change played out within family lives required exploring private, potentially sensitive and emotive issues that may be distressing for participants to discuss or hear, necessitating the need for extremely sensitive handling.

Third, the study involved people with learning disabilities who may be perceived as a ‘vulnerable’ group. I share Aldridge’s view that ‘vulnerability’ is a highly contestable concept, but philosophical or conceptual debates are not the main concern of the researcher (Aldridge, 2014); rather ‘what is important is that research participants themselves are not put at further risk of harm or their vulnerability is not exacerbated by research processes’ (Aldridge, 2014: 114). Nonetheless, the potential ethical challenges in relation to carrying out research involving people with learning disabilities required very careful attention in order to satisfy the requirements of the University ethics process.

4.8.1. Informed consent

Ethical principles in relation to informed consent require that participants are given sufficient information about the research project in order that they understand the consequences of their participation, and can therefore make an informed decision about whether they wish to take part in the study. As noted above, there were very particular ethical challenges inherent in the research questions in this study; this meant that I had to think carefully about what informed consent meant, and how it might be achieved in practice.

Like Lewis (2009) and others (such as Walmsley and Johnson, 2003), I recognise ‘consent as a continual dialogue, rather than a discrete event, which begins from the very first point of contact and throughout all further arrangements’ (Lewis, 2009: 406). Understanding consent as a continual process was particularly appropriate because the study involved multiple related participants and a group perceived as ‘vulnerable’. This meant that achieving informed consent was more than simply obtaining a signature on a form at the outset.

In relation to research involving multiple related participants, Harden et al (2010) highlight the importance of addressing issues of participation and consent appropriately, reinforcing that everyone's views are important and recognising that children may be influenced by parents, in order to ensure family members may each reach a decision individually. Unlike Harden et al’s participants, the participants in this study were adults, and I do not wish to reinforce the idea that people with learning disabilities are ‘eternal children’ (Priestley, 2003), however the issues illustrated by Harden et al are also relevant in this study. Understanding consent as a continual process is an important factor in undertaking research with people with learning disabilities because they may have limited insight about what is involved at the outset and come to understand more about this as the research progresses (Walmsley and Johnson, 2003).

It is the responsibility of the researcher to ensure that participants’ consent is informed by understanding; the continual negotiation of consent requiring that I be attentive to the needs of participants throughout the process. In practice, I achieved this by active listening and appropriate communication, and by paying attention to participants’ demeanour and non-verbal signs. This was in addition to obtaining written consent (see Appendices B, C, D and E for participant information and consent form in standard and easy read formats) or recorded verbal consent at the outset, as required by the University ethics process.

Further consideration is given to issues of informed consent for research involving people with learning disabilities because of uncertainties regarding capacity. Iacono (2006) argues that decisions about capacity to consent to participation must be made on an individual basis, considering both the individual and the nature of the study. However, it is important to note that there are limitations to informed consent, particularly when undertaking research with people with learning disabilities:

> *...it is one thing to consent to the face to face aspects of the research… and it is quite another to consent to the hidden or behind-the-scenes aspects of research i.e. the researcher going away with your answers, analysing them, coming to conclusions about you and your situation (which you may not even understand, much less agree with) and then informing other people what they have discovered about you and people like you. Obviously the more significant the learning disability, the less insight people are going to have, or be able to develop, about the hidden aspects of research.*
>
> *(McCarthy, 1998: 143, cited in Walmsley and Johnson, 2003: 158).*

While Walmsley and Johnson (2003) critique the idea of 'behind-the-scenes aspects of research', instead arguing that researchers should foster open and inclusive research processes, they agree with McCarthy that the ability to fully understand consent is affected by intellectual capacity, so may not be possible for some people with learning disabilities (Walmsley and Johnson, 2003: 158-159).

Whilst some people with learning disabilities may have difficulty in understanding what is involved in participating in a research project, many are capable of understanding and making their own decisions if they are provided with appropriate and accessible information. Iacono and Murray (2003) propose that informed consent can be effectively achieved by involving family members, support workers or advocates, together with the provision of information in plain language and in pictures. In practice, consent from participants with learning disabilities was obtained through a process of supported decision-making (Bach and Rock, 1996); consent was discussed at the outset and was subject to continuous negotiation. Bach and Rock's supported decision-making model is based on presumed competence and allows significant others to help evaluate risks. Highlighting that we do not ask people who do not have learning disabilities why they made particular decisions, Bach and Rock argue that everyone makes decisions within a social context, asking the opinions and advice of others, and that this is the process by which people become self-determining. Participants were therefore supported (by family members, support workers and me, as appropriate) to understand what was involved in participation and to reach their own decision, in conversation with others. In addition to using the easy read information which I produced for this study (see Appendices B,C,D & E), I drew on my experience of supporting people with learning disabilities to communicate appropriately.

4.8.2. Confidentiality and the avoidance of harm

Ethical principles in relation to confidentiality and the avoidance of harm require researchers to consider any potential risks to participants, and take action to mitigate these risks, before commencing any project (Gray, 2004). Additionally, researchers are required to treat personal information in accordance with the legislative requirements of General Data Protection Regulation (GDPR) (Information Commissioners' Office, 2018).

In this study, there were particular ethical considerations in relation to confidentiality and avoidance of harm because it involved research with multiple connected participants and the exploration of potentially sensitive issues. The importance of trust in families and relationships research is discussed by Gabb (2010), who notes that participants in multiple perspectives research are often not only revealing information about themselves to outsiders, but also to each other. Harden et al (2010) discuss the difficulties researchers may experience in group interviews with connected people, noting that tensions between parties may require careful management in order to mitigate distress or embarrassment (447).

In a family group interview, it can be more difficult for researchers to control certain risks (e.g. upset, embarrassment, etc.) and these interactions require skilful management, which social researchers are not trained for (Harden et al, 2010). Furthermore, the subjects of families and relationships research could be considered emotive or sensitive topics, which may be distressing for participants to discuss or hear. However, Gabb (2010) is critical of the conjoining of harm and distress in ethics, emphasising the normalcy of emotions in family experience. Drawing on Daly (2007, cited in 2010: 471), Gabb argues that we need to bear in mind that 'emotions are a normal part of talking about family experience'; therefore, we cannot expect participant narratives to consist only of positive experiences.

Ethics frameworks in social science have been influenced by ethical regulations in biomedical research; however, the potential risks involved in social research are not equitable to those involved in clinical studies (Gabb, 2010). Gabb argues that 'there is a significant difference between the risk of causing distress and the risk of causing harm'; whilst social research interviews may have personal impact on the researcher and/or participant in terms of emotional distress, the process does not put participants 'at risk' (ibid.: 466). Instead of avoiding the discussion of sensitive issues in order to protect participants from the potential harm of distress at recalling emotive experiences or events, Gabb proposes that what matters most is how we respond to these emotions, suggesting that these can be managed by non-judgemental, empathetic listening in order to mitigate harm to participants.

In designing the research, I carefully considered the potential risks to participants in relation to confidentiality and the avoidance of harm, and took care to mitigate these potentialities. Given the topic of the study, interviews inevitably included discussion of ‘family practices’ (Morgan, 1996) and relationships, which may be considered sensitive or emotive. I anticipated that there may be conflict and disagreement within families (e.g. concerns about safety, perceptions of risk). Furthermore, because disabled people are at greater risk of abuse than non-disabled people (Hughes et al, 2012), I anticipated the possibility that such discussion may reveal issues of abuse, neglect or other safeguarding concerns.

The discussion of sensitive or emotive issues was managed appropriately through active listening and careful acknowledgement of participant responses. During interviews, I was attentive to the general demeanour of each participant and careful to remain mindful of non-verbal signals which may indicate distress, reluctance or discomfort. Such indications were managed sensitively; for example, by providing reassurance of confidentiality if appropriate (see below for details of when this may not be possible) or by offering a gentle reminder that participation is entirely voluntary and they do not need to answer any questions which made them uncomfortable.

Whilst I had anticipated that it was unlikely that issues of abuse, neglect or other safeguarding concerns would become apparent during the interviews, in order to satisfy the requirements of the University ethics committee, I had planned how I would deal with this situation. My plan was largely informed by my previous training and experience of adult and child protection (from working as a support worker with adults with learning disabilities, as well as 20+ years as a Girlguiding leader) and was agreed with my PhD supervisor. The plan involved my responding to any relevant concerns by reminding the participant that I have an ethical obligation to pass on information in order for them to receive the appropriate support; this information would then be confidentially escalated to my supervisors or PGR convenor as soon as possible, and actioned in accordance with their recommendations. It was extremely fortunate that I had this plan in place, as there were two interviews where participants may have been at risk of potential harm, which were handled in accordance with the procedure agreed in advance.

4.8.3. Reflections on ethics

Ethical considerations are important to maintain professional standards and avoid harm to both researcher and research participants (Bryman, 2008). The discussion of the ethical challenges in this study highlights some important issues, most notably in relation to research which involves people with learning disabilities. Ethical regulations are helpful because they make researchers think through research strategies carefully and anticipate potential issues in advance, however this carries the risk of giving an 'artificial sense of ethical security' since it is never possible to anticipate every eventuality given the 'tensions, fluidity and uncertainties' which characterise everyday lives (Gabb, 2010: 467).

Protection from harm is a central tenet of ethical research, however increasingly conservative and protectionist ethics have the potential to exclude some people with learning disabilities from participating in research (Iacono, 2006). Furthermore, Gabb (2010) argues that increased ethical regulations conflict with the trusting, caring relationships which underpin feminist research. Describing ethics committees as 'combative', Gabb (2010: 466) argues that the process has been 'designed to protect innocent research subjects from the 'barbarian researcher' who is always trying to take advantage in some way'.

Drawing on the example of ethical procedures regarding consent, Gabb (2010) agrees that consent forms are important in order to ensure people know what is involved in participation, but suggests that, in practice, research participants do not pay much attention to them. Thus, rather than facilitating informed consent, Gabb proposes that the insistence on consent forms by ethics committees has become part of a standardised checklist, serving instead as an audit trail in order to protect institutions against challenge or litigation (2010: 467).

My experience of ethics approval in this study confirms Gabb’s proposition. As noted earlier, I understand consent to be a process of continual negotiation, but having a signed consent form is the default option in the University ethics application process. Furthermore, this assumes participants are able to read, write and understand a consent form. The ability to fully understand consent is affected by intellectual capacity and it may not be possible for some people with learning disabilities (Walmsley and Johnson, 2003). Thus, the ethical requirement for individual informed consent effectively excludes particular groups from participation in research (ibid.: 158-159). The risk of excluding particular groups from research demands consideration because of the risk of losing knowledge and understanding about a group which has historically experienced exclusion (Iacono, 2006; Booth, 1996).

Feminist care ethics provide an alternative way of thinking about ethical issues in research. Families and relationships research in the UK has largely been undertaken from a feminist standpoint and is influenced by feminist care ethics, in addition to standard ethical regulation (Gabb, 2010). This type of research emphasises researcher integrity, trust and care within the research relationship and is characterised by: attention to the vulnerability of certain groups; respect for the private and sensitive nature of research data and the intrusion into private lives; and the importance of reflexivity (ibid.). Adopting a feminist care ethics approach means the research relationship is conceptualised as an '...agreement [that] remains based on trust and respect which stretches far beyond legal obligations and formalized risk assessments’ (Gabb, 2010: 467-468).

It seems to me that there is a strong critique of ethical requirements in relation to consent when undertaking research with participants who have learning disabilities, which may also apply to other impairment groups. Researchers are required to make ongoing judgements about whether participation is willing and informed, regardless of an initial signature on a consent form, therefore perhaps a less rigid conception of evidence of consent is required. For example, at the beginning of our interview, Michelle, a woman in her 30s who has learning disabilities, wrote her name on the easy read consent form after I explained it to her. However, during the course of our interview, Michelle drew a beautiful, colourful picture (Appendix F) which seemed to me much more powerful evidence that Michelle was happy in the interview setting than her signature on the consent form.

4.9. Research Design

4.9.1. Recruitment

Social research is inevitably ‘messy’ (Law, 2004) and I did not expect the recruitment of participants for this study to be linear or straightforward. I was aware of the inherent (and compound) challenges in doing research involving people with learning disabilities, multiple related participants, and emotive or sensitive subjects (as discussed throughout this chapter). I did not, however, anticipate quite how challenging, complicated, and protracted the recruitment process would turn out to be. On reflection, there were many reasons why participant recruitment turned out to be extremely challenging, broadly related to: the characteristics of the population I aimed to recruit; and the existence of conflict and tension within and between the local learning disability ‘community’[16] at the time. To some extent, I had expected challenges in

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[16] I use ‘community’ in the broadest sense here, to refer to people with learning disabilities and family carers, and the range of individuals and organisations involved in the provision of, and negotiations over, social care services (or lack thereof) in Glasgow. This includes, but is not

relation to the former, and prepared for this in the research strategy, in so far as I could anticipate. However, I did not appreciate the extent of the latter, and these challenges proved particularly difficult, if not impossible, to overcome.

The plan

I anticipated that I would be able to recruit participants through local organisations that work with people with learning disabilities. From working within the sector, I knew that there were user groups within service provider organisations, as well as local Disabled People's Organisations (DPOs), and expected that it would be possible for me to gain access to these existing groups. I hoped to be able to go along to their meetings to speak directly with potential participants in order to explain the project, answer any questions and invite people to take part. Recognising that there has been a tendency in research to involve parents and carers or professionals, as if they can speak for people with learning disabilities, rather than the people themselves (Walmsley and Johnson, 2003), my priority was to 'target' people with learning disabilities via DPOs in the first instance and, if they were happy to take part, they would then approach their families and invite them to speak to me too. This was both a political and strategic decision, recognising that people are experts in their own lives.

I was also concerned about possible issues which could arise in recruiting via service provider organisations with whom potential participants had ongoing relationships with, and envisioned that the relationships between DPOs and members would be more equal. For example, I was concerned that service providers may cherry-pick ‘suitable’ participants or attempt to promote a particular position. This is because the organisations themselves were involved in policy implementation in their contractual relationships with the local

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limited to: social work; local authority officials; service providers; and Disabled People’s Organisations.

authority and in delivering services to disabled people, and therefore had a vested interest in the research topic. Recognising that unequal power relationships exist between service users and service providers, I was also keen to avoid potential participants feeling obliged or compelled to participate in the research if they were approached directly or indirectly via service provider organisations.

The reality

Initially, I contacted key individuals in three large DPOs to provide some information about the study and request assistance with recruitment. Although none of the three were able to assist with recruitment directly, one agreed to communicate my call for participants via their newsletter and social media. I do not know if they did so, as I did not receive any contact from people who had seen these communications, nor did I see them myself, and this did not result in the recruitment of any participants. However, despite being unable to assist themselves, all three DPOs suggested other individuals or organisations for me to contact.

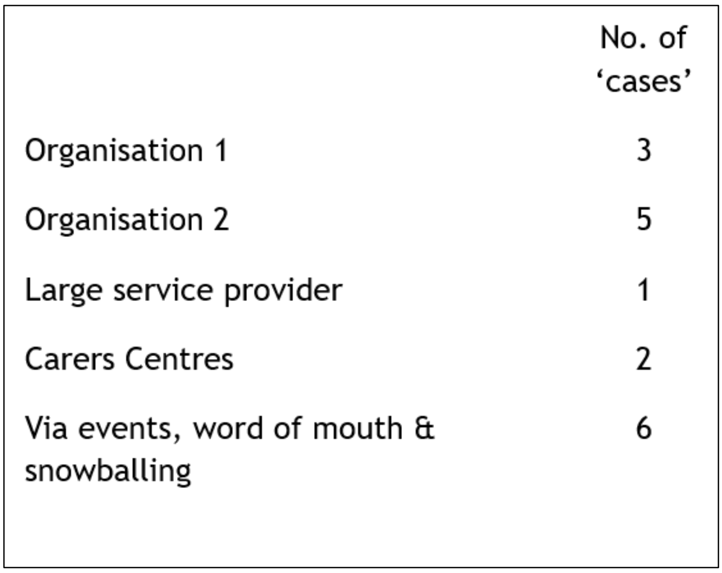
Several of the organisations which the DPOs had suggested did not respond to my emails or phone calls. However, two individuals and one group who had been actively involved in campaigns against day centre closures in Glasgow provided interesting contextual information and indirectly resulted in the recruitment of 2 families. As a result of these introductions, I had several fruitful meetings with various people who had been (personally or professionally) involved in, or affected by, day centre closures and changes to social care services in Glasgow. Although these individuals did not meet the criteria and therefore are not participants in the study, the discussions provided rich information about the history of day centre provision in the city and recent developments in the sector. This was invaluable in developing my understanding of social care provision in the local context and historical development of services, and provided me with some insight into the contested issues which later emerged in participants' narratives.

At this early stage in the recruitment process, I also had informal discussions with personal contacts who worked within learning disability services. These conversations were invaluable in refining the research design and developing my knowledge and understanding of recent changes to service provision in Glasgow, and provided valuable background information within which I could frame interview and focus group questions and interpret participants’ experiences. These initial discussions were also valuable at this stage because they provided me with reassurance that the research topic was relevant and that there were issues deserving of investigation.

As my initial plan to recruit potential participants had been largely unsuccessful, I revisited my research strategy, and gradually extended my approach to other organisations. In the end, over a six-month period, I approached 65 organisations operating within Glasgow, including: learning disability service providers; carers’ organisations; advocacy groups; impairment specific groups; and community and social groups of disabled people. This change in approach presented challenges, which are discussed in the next section.

Despite my attempts to access potential participants via relevant organisations, in the end, a substantial proportion of participants were recruited through speaking informally to people at events, word of mouth, and 'snowballing' (see figure 2 – below). A summary of interview participants and relationships is contained in appendix G. I have not provided an overview of individual families in in the interests of anonymity.

Figure 2 – Recruitment Summary



	No. of 'cases'
Organisation 1	3
Organisation 2	5
Large service provider	1
Carers Centres	2
Via events, word of mouth & snowballing	6

Challenges in recruitment

Families and relationships research can be difficult because family and domestic life is perceived as private and sensitive (see section 4.7). This makes recruitment challenging as people may be reluctant to speak about 'private' family matters or be concerned about confidentiality; for example, one woman expressed interest in participating but was reluctant to broach the subject with her 'very private' elderly parents.

There are also challenges in relation to the recruitment of multiple related participants (see section 4.7). Rather than a relatively straightforward two-way interaction between participant and researcher, recruiting family groups is inevitably more complex and time consuming, and refusal issues are more common (Ribbens McCarthy et al, 2003). Each family group requires negotiations with several individuals, so there are multiple interactions between participant(s) and researcher(s), as well as between family members themselves. Whilst communication and negotiations with multiple family members are time consuming, attentiveness to each individual is necessary to ensure their participation is willing and informed. In this study, these known issues also intersect with barriers to participation related to: impairment effects (Thomas, 1999); health; ageing; and caring. For example, two families expressed interest but were later unable to take part, due to illness and personal circumstances.

Gatekeepers

In multiple perspectives research, family members may act as gatekeepers (discussed in section 4.7). A particular challenge in this study has been gaining access to people with learning disabilities as family members and organisations have acted as gatekeepers. I note some of the issues in relation to organisational gatekeepers in my reflections on recruitment below, and focus here on family members.

For example, one potential participant told me that their mum would not allow me to speak to their sibling (who has learning disabilities) alone, although they would be happy to meet with me as a group[17]. Several families agreed to take part in the study, but advised me that the family members who had learning disabilities would not be able to answer questions or take part in the research. This is illustrated by the following data extracts:

1. *From fieldnotes:*

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[17] Unfortunately, this family were subsequently unable to participate due to illness and work commitments.

> *In the pre-interview phone call, Sheila said that Gillian would be unlikely to answer questions as she was 'bordering on profound impairment' and had an IQ of 40.*
>
> *2. Interview – Elizabeth:*
>
> *K: …could I arrange to speak to Catherine?*
>
> *E: She doesn't have enough speech and language dear, she couldn't tell you…*
>
> *3. Interview – Deborah:*
>
> *K: Would it be ok to speak to Michael too?*
>
> *D: Not really Karen, because he lacks capacity.*

There are particular issues in relation to informed consent for research involving people with learning disabilities because of uncertainties regarding capacity (see section 4.8). The examples provided above simply illustrate the role of family members as gatekeepers in this study; as a (feminist) researcher, it is neither my place nor intention to comment on the capacity of these individuals, or perceptions of capacity, nor to deny the reality of impairment effects (Thomas, 1999). They do however highlight the intersection of the accessibility of research processes and the role of relationships and key individuals in supporting, enabling (or disabling) participation[18].

Reflections on recruitment

In spite of my having carefully thought through my research strategy in advance, in practice, the organisations had more control over the recruitment process than I did. As noted earlier, I had hoped to speak directly with potential participants at meetings/groups, but organisations generally wanted letters and flyers to pass on instead. Although I did not feel this was the best way to engage potential participants, I had little choice (see Appendix H - Excerpt from Fieldnotes). Organisations may have been selective in passing on information about the study, and I was concerned about paternalism and the extent to which service providers make decisions for people with learning disabilities (e.g. speaking to family carers, assumptions regarding risk or ability). Furthermore, when organisations have control over research communication, the researcher is unable to monitor how and what message is conveyed to potential participants. For example, I was really pleased when a local carers' organisation agreed to help recruitment by posting information on social media for me, however their post was not how I would have communicated the message (see Appendix I) and I was not surprised when it did not generate any response.

Furthermore, my initial plan to recruit via speaking at group meetings would have avoided the necessity for potential participants to be able to read or write, and the organisations' preference for distributing flyers or using social media inevitably excludes particular groups. Although I also provided information in

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[18] I experienced a lovely moment when one participant (who has learning disabilities) exceeded their family member's expectations, as the following extract from my fieldnotes shows:

> *Irene looked surprised and delighted to see Theresa sign her own name on her (easy read) consent form, after I explained it to her, saying 'we always just sign everything for her!'*

easy read format, I understand this to be only one option from a range of communication methods which can be provided in order to make the research process more accessible. Participants in this study had varying degrees of impairment (e.g. some could make phone calls, read and write independently, while others could do some or none of these tasks without support). Whilst I would argue that social research always requires flexibility and attentiveness to the needs of participants, this is even more important when carrying out research with people with learning disabilities as the nature of impairment necessitates individual, tailored and attentive communication.

In my extensive interactions with organisations and in my analysis of the interview data, it became clear that there were several factors outwith my control which could affect the willingness or ability of organisations to assist with participant recruitment. Firstly, organisations did not have the time or resources to actively assist with recruitment; even when they were very interested in the study, often the most they could realistically do was display a poster or flyer in their premises. Secondly, I was aware of ‘research burden’ as these organisations (and their members) are often asked by students and researchers to assist in their research. Thirdly, changes to local social care service provision have contributed towards a climate of conflict and competition, and the topic of this study may have been viewed with suspicion.

The research topic itself was also a challenge to recruitment, in relation to the willingness of potential participants to speak about it. I was aware that changes to social care had been a fairly high-profile issue in Glasgow and I personally knew families who had been affected by it. On reflection, I underestimated just how sensitive and emotive the situation had been, and continues to be, and I did not foresee the impact this would have on the willingness of families to participate in research. As discussed in chapters five and six, many participants spoke about feelings of anger, disbelief and disappointment over the way in which changes to social care services had been handled by the local authority, and there have been protest campaigns, heated exchanges and divisions within and between families, DPOs and service providers. Some service providers and DPOs were perceived by participants as profiteering, rather than representing the interests of members or service users. Some families were perceived as 'selling out', putting financial gain or self-interest first, and others were perceived as exploiting disabled family members.

As noted earlier, the recruitment of participants for research concerning families may be difficult because family and domestic life is perceived as private and sensitive. People may be reluctant to speak about ‘private’ family matters or be concerned about confidentiality, and these concerns may have been exacerbated due to the nature of this research topic. Recent policy change had affected families differently, but a lack of transparency in the process and (related) lack of trust in social work and service providers may also have affected willingness to participate. For example, one local community activist tried to arrange for me to meet with a group of carers but after much negotiation, the carers declined to speak with me because they were '...feart it would get back to social work'.

Although there was willingness to support recruitment from some service provider organisations, there were several problems with this. Gatekeepers effectively operate at multiple levels within organisations, and successful recruitment methods require buy-in and commitment at various levels. For example, in the organisations who said they would forward information to relevant services/managers, my dealings were with people who held senior positions within the organisations who seemed interested in the research and were keen to assist. Assuming that the information was passed down the line to individual service managers, I do not know what interactions took place thereafter; whether service managers were equally interested and willing to assist or whether (and how) information was passed on to potential participants. Whilst senior management within an organisation may buy-in to a research project, it is unlikely that they are in regular direct contact or have existing close relationships with potential participants – so recruitment is dependent on the commitment and involvement of unknown others. The staff members at the bottom of the institutional hierarchy (the support workers) are those who are most likely to have established relationships with 'service users', and are perhaps the most powerful of gatekeepers in practice, since people with learning disabilities may require support to understand what they are being asked to participate in.

A major breakthrough came when two relatively small organisations[19] expressed interest in the study. On reflection, the key factor to the success of recruitment in both organisations was the involvement of a member of staff who had an interest in academic research, who had an existing relationship with potential participants, and who actively assisted in the recruitment process.

Issues relating to power and control in the lives of people with learning disabilities were apparent in many of the discussions I had with various professionals during the recruitment stage. Whilst the vast majority of professionals I spoke to were encouraging, some were dismissive of the research topic. Several social care workers told me I should be speaking to staff and went to great lengths to give their take on the situation in Glasgow; one social worker told me it would be more valuable to do research ‘about’ young adults with learning disabilities (rather than aged 30+); and one academic told me that they had already done a very similar study several years previously. Whilst I recognise the valuable knowledge, experience and insight which these professionals undoubtedly have, these discussions illustrate who is considered (and considers themselves to be) 'experts' in the lives of people with learning disabilities, which ironically conflicts with the ethos of personalisation.

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[19] I have witheld the names of the organisations to maintain participant anonymity.

Why should people participate?

It would be remiss to discuss challenges in recruitment without asking the question 'why *should* people participate?' As with all social research, there are issues about who benefits and I am very much aware that I stand to gain more from this process than my participants. I am also aware that participants may have their own agendas, and I suspect that some families hoped their participation would further the campaign against the closure of day centres. I am mindful that participation requires people to give up their valuable time and that they are unlikely to see any direct benefit. For example, I went along to a carers' group, with the hope of meeting families and recruiting participants; however, it so happened that there were another 3 researchers there that day, giving a presentation about a research project the group had previously been involved in. Given that the aim of the group was to provide social support for older parents of people with learning disabilities, I felt that it was potentially unethical and exploitative for me to 'hi-jack' the agenda, and I wondered how the carers felt about their lives being considered such an interesting 'subject' of research by outsider academics.

However, there may be some opportunities for reciprocity in the research process. Together with one of the organisations who helped with the recruitment, I was pleased to be able to organise a group visit and campus tour of the University for 9 people. There were some logistical difficulties in the planning of the event (mainly due to identifying and securing accessible rooms and toilet facilities) but everyone seemed to enjoy the visit (reported highlights were lunch, the Museum and the Chapel) and lots of photos were taken by group members who are in a photography group.

As noted in section 4.4, I also received feedback to suggest that some participants might appreciate the opportunity to talk about their lives and be listened to, so while participants may not benefit directly from any research outcomes, I hope that there is some impact nonetheless.

4.9.2. Data collection

In designing this study, I was keen to ensure data collection methods were flexible and attentive to individual needs.

The plan

I hoped to carry out informal, loosely structured face-to-face interviews with family groups and with individual family members. My focus was on ensuring the interviews were as inclusive and accessible as possible for each individual participant, and I expected to use some visual methods (e.g. drawings, prompt cards) to help address some of the communication barriers within the research process.

The research aims and underpinning theoretical approach meant it was vitally important to include the perspectives of people with learning disabilities and family members in this study. Recognising that family relationships are complex and experienced differently by different parties within the same relationship, I was keen to ensure that the perspectives of both groups were heard.

I chose to use interviews in order to facilitate in-depth discussion and gain insight into the ways in which participants themselves understood and interpreted their experiences, and designed a topic guide (Appendix J) to be used flexibly in the interviews. I expected that initial interviews would be carried out in a group, consisting of the person with learning disabilities and their family member(s), and that I would be able to carry out subsequent interviews with individual group members. I felt that an initial group interview would help with transparency and relationship building; providing a supportive and reassuring environment to address any concerns which participants may have regarding the research process or meeting an unknown researcher.

In order to address the possibility that individual responses may be limited or constrained in group interviews (Harden et al, 2010: 444), I envisaged that the subsequent one-to-one interviews would facilitate in-depth and confidential discussion of potentially sensitive issues. At the same time, I planned to discuss, and/or write, and/or draw, what a 'typical' week of activities looked like, along with participants with learning disabilities. I anticipated that there may be several short interviews with the person with learning disabilities and one longer interview with each family member. I was conscious that individual interviews, group interviews and visual methods would produce different types of data, and these different techniques (and the contexts within which they are produced) could also affect the data. Throughout all of this, my priority was to be responsive and flexible to individual needs and wishes.

Combining individual and group interviews in families and relationships research provides opportunities for group interaction, discussions and shared narratives, as well as individual perspectives and sensitive issues. Gabb (2009: 33) endorses the mixing of qualitative methods because of the potential to show the ‘emotional messiness, uncertainties and fluidity that constitute relational experience’. However, although these methods produce rich data and complex understandings, this does not mean we are, or can, capture the complex ‘reality of lived lives’ (ibid.: 33).

I also hoped that this flexible, mixed methods approach would help to address some of the barriers within the research process. Aldridge (2014) discusses the application of multi-method designs in undertaking research with ‘vulnerable’ groups, emphasising the importance of flexible and sensitive methods, and the ability to adapt conventional methods appropriately. Although the term ‘vulnerable’ groups is problematic (see section 4.8), I recognised that some participants may require assistance and felt that initial group interviews would provide a supportive and reassuring environment for families, and help to establish how the research process can be made accessible for participants. There is a small body of research which uses augmentative and alternative communication (AAC) tools – such as ‘Talking Mats’ (for example, see Brewster, 2004) – but I did not have either the skills or resources to adopt these methods. I acknowledge that the research design would not be completely accessible to everyone[20]; however, I hoped that a flexible approach would help to address some of the barriers within the research process, as well as increasing engagement and making the process more participatory.

The reality

Despite my carefully considered plan, in practice, data collection was inevitably affected – to some extent – by others. Just as organisations had affected the recruitment process, they also affected the data collection. One of the organisations who helped me to recruit participants told me that some of their members would like to speak as a group, rather than in individual or family interviews. Although I did not feel that this was the most appropriate method to answer the particular research questions in this study, and it had not been my intention to undertake focus groups, I was committed to making the research as inclusive and accessible as possible. I therefore took these comments on board, amended the research design to include focus groups, and obtained ethical approval for the change.

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[20] Research questions (and discussion about everyday topics) can involve complex concepts which can be difficult to unpack. For example, an ostensibly simple question about whether a participant enjoyed shopping did not generate a clear response, but further probing revealed that she liked shopping for certain things (including pencils, notebooks and soft toys) but strongly disliked going to the supermarket to buy food!

Importantly, participants also determined what was possible in practice. My original plan to undertake initial group interviews followed by individual one-to-one interviews was conceived with the best of intentions, but on reflection, this did not take into account participants' busy and stressful lives. Implicit in my design was an assumption that people would be happy (or at least not object!) to my taking up their precious time, asking questions about their private lives, with little incentive for them. In practice, there was only one occasion when I visited a family more than once[21]; in every other case, there was only one interview carried out.

Reflecting on these issues, I wonder if there may have been a conflict between the needs and wishes of participants with learning disabilities and family carers. Almost without exception, the family carers I met spoke about feeling under pressure, and several were clearly stressed and exhausted; under these circumstances, it would have been completely unethical (and uncaring) of me to add to their busy lives by requesting another meeting. Furthermore, I generally felt that the research questions had been sufficiently explored with family carers in these single interviews, so there was no need to revisit. However, for those participants with learning disabilities, the extent of participation and level of input was much more variable, and I could not be sure we had fully explored the research questions. In some of these cases, the research could have benefitted from further interviews, but (as noted earlier), I did not have direct access to this group and their participation was usually determined by (organisational or family) gatekeepers whose time was limited. This is an extremely complex issue. Whilst the participation of people with learning

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[21] Patience and attentiveness are vital research skills. I visited Gillian and Sheila on two occasions because Gillian was 'not in the mood' (Sheila) when we first met. See (below) extract from fieldnotes of the 1st visit:

> *When I arrived, Gillian was asleep in another room. Sheila said Gillian had recently started new medication and was very sleepy and she had arrived home in a bad mood, but this was not unusual as Gillian was "quite often distressed and upset these days". For much of the interview, Gillian was curled up in Sheila's lap and spoke very little.*

disabilities could be determined by others to a large extent, I do not wish to deny individual agency; ultimately people could, and did, decide whether or not to answer the questions asked[22].

As much as possible, I tried to ensure the interviews were informal and conversational (e.g. sharing details of my own life when it felt appropriate), whilst remaining mindful that 'in reality, although a good in-depth interview might look like a conversation, it will not feel like one for the researcher or participant – both are working hard' (Yeo et al, 2013: 178).

Notwithstanding the limitations of doing interviews with multiple related participants, as outlined above, in practice participants' interactions with each other were a source of valuable insight into family lives and private practices. For example, family members prompted[23], probed and provided reminders to each other, in a process of shared meaning making. There were numerous examples of 'banter', teasing and joking between participants, and recognition that family members had different, equally valuable perspectives[24]. This was not limited to verbal data; physical interactions demonstrated distress and emotional labour, as well as affection and practical support.

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[22] During Joyce's interview, I started to notice that she was losing interest, and I was thinking about what to say to give her the option to stop the interview, when she suddenly stood up and said: 'It was nice meeting you. Will I send Raymond in now?', providing a great example of exercising agency!

[23] There were also some examples of this in interviews where support workers were present. For example, the support worker helped Scott to remember activities which he had forgotten.

[24] Extract from Pauline and Richard's interview:

> *Richard [to me]: Tell me when I can come in, when Pauline's gave her views, and then I'll give you mine.*

4.9.3. Analysis

There are particular challenges at the analysis stage in multiple perspective research with families. Ribbens McCarthy et al (2003: 20) note that vast amounts of data may be produced, so analytic strategies can be complex. The volume of data means more information, revealing gaps and silences which may raise further questions, and the possibility of greater understanding (Ribbens McCarthy et al, 2003.). Harden et al (2010) acknowledge that the messy and complex process of analysing multiple perspective data is exacerbated when it also involves different types of data. Mixed methods and 'mess' is discussed by Gabb (2009), who argues that researchers should not attempt to 'tidy' data too much when analysing information about personal relationships, since these are inevitably messy, and that this does not mean reduced 'analytical rigour' (19). In this study, both group interviews and individual interviews were carried out, producing different types of data, so the data (and analysis) was particularly messy and complicated. I share Ormston et al's (2013: 23) view that rigour is attained through 'well-designed and well-conducted' research.

All interviews were audio-recorded and transcribed verbatim. This was an extremely time-consuming process; some of the interviews were very long (in one case, 3 hours), many involved multiple participants, and some participants had speech impairments. I transcribed the vast majority of interviews myself, but eventually (following discussion with my supervisor) decided to use £400 of my Research Training and Support grant to pay for a professional transcription service to help speed up the process.

I undertook a thematic analysis of the transcripts, coding the data in order to organise the results and present the findings (Boyatzis, 1998), and I used NVivo as a data management tool. Thematic analysis is often used to analyse qualitative data (Bryman, 2008). Although it is not a distinct technique, thematic analysis broadly involves the analyst identifying categories, or themes, throughout the data which relate to the focus of the research (Bryman, 2008). Coding qualitative data is an extended process which involves a range of stages, including: transcribing; reading and reflection; exploration; connections; reviewing and refining (Bazeley and Jackson, 2013).

In my initial reading and re-reading of the transcripts, some overarching themes began to emerge from the data. However, the emergence of themes is not a passive process; it requires the analyst to move from familiarity, to engagement, and immersion in the data through repeated reading and reflection. In my repeated readings of the paper transcripts, I noted brief observations in the margins. These were generally aspects which I perceived as important, interesting or unusual, and these observations provided the initial key themes and subsequent subthemes. At this stage, I used NVivo to manage the large volume of data, creating 'nodes' for the key themes and subthemes (appendix K). The initial coding of the data in NVivo helped to break down the vast amount of data in the transcripts into more manageable categories as the transcripts were sorted and clustered within these 'nodes'.

However, the coding framework in appendix K implies a sanitised version of the messy reality of analysing large volumes of qualitative data. Spencer et al (2013) use the concept of 'analytic hierarchy' to provide a useful explanation of how coding happens at various 'levels' of data. This is not a linear process and the researcher is constantly moving back and forth between the various levels (Spencer et al, 2013). Thus, the themes and subthemes evolved over time as I immersed myself in the data and I continued to analyse the data within each of the themes and subthemes, looking for connections, similarities and differences within the data extracts, using mind maps (appendix L).

Coding is an interpretive process (Spencer et al, 2013), and the interpretation of the data here is entirely mine; notwithstanding the ontological and epistemological underpinnings set out earlier in this chapter. I acknowledge that the researcher affects the analysis, and there is a risk that we hear our own perspective (Harden et al, 2010: 446), so I was particularly careful to ensure my analysis was ‘heavily grounded in and supported by the data’ (Ormston et al, 2013: 22).

Fieldnotes were not coded or included in the formal data analysis, however they provided rich context in relation to the recruitment process and my immediate reflections on the interviews, and I referred to them throughout the analysis and writing up process. Referring to fieldnotes enabled me to check my understanding and interpretation of the (formally coded) data and, where appropriate, I have included selected excerpts as footnotes in the thesis to provide context for the reader.

4.10. Conclusion

This chapter set out my approach to carrying out the research, beginning with a discussion of the emergence of the research topic. As outlined previously, the research topic, questions and design emerged from my engagement with relevant literature and informal discussions with disabled people, family carers and care workers.

My approach to the methods and design of this study were influenced by a range of theories and perspectives – including debates about feminist research methods and ‘emancipatory’ disability research – though I ultimately took a pragmatic approach. I was aware of the inherent challenges in doing research involving people with learning disabilities, multiple related participants, and emotive or sensitive subjects. I did not, however, anticipate quite how challenging, complicated, or protracted the process would turn out to be! There were many reasons why this was an extremely challenging project; some of these challenges proved particularly difficult, if not impossible, to overcome. I have discussed at length in this chapter how the process did not always go to plan and how, in practice, the project was affected by others; participants and organisations were active in the process, and they determined what was possible. Most importantly, I tried to make the research as inclusive and accessible as possible without compromising on analytical rigour.

This chapter concludes the first part of the thesis, which set out to contextualise the study with an overview of relevant literature and policy, and relatedly, my approach to carrying out the research. The next section of the thesis presents the data in three themed chapters. The first of the data chapters focuses on participants' experience of SDS assessment and implementation, and the second data chapter presents participants' experiences of support services. The third data chapter continues the discussion to show how the private sphere of home, family and relationships was inextricably related to changes to policy and service provision for participants in this study.

5. The Personalisation Process: An Impersonal Experience

5.1. Introduction

This study set out to explore the experiences of people with learning disabilities and their families at a time of considerable change to social care policy and service provision. This chapter draws on data from interviews with people with learning disabilities and their families to show how participants experienced the shift to personalisation – focusing on the assessment process and local implementation of self-directed support.

The interview data in this chapter comes mainly from the perspectives of family members, rather than the participants who had learning disabilities themselves. The difficulties in ensuring the voices of people with learning disabilities are heard in research, and my reflections on how this affected the research process and data analysis, were outlined in chapter four. In this chapter, which focuses on the assessment process and policy implementation, the voices of participants with learning disabilities were overshadowed by those of family carers because it was predominantly family members who spoke about this part of the process. Whilst the participants who had learning disabilities generally understood that they should have choices, and that support workers were not to make decisions for them, they did not appear to know much about the SDS assessment process. The interview data shows that it was often family members who dealt with professionals on behalf of people with learning disabilities, although decision making may be a process of negotiation within families.

This chapter presents participants' experience of the personalisation process, and reveals a vast gap between policy and practice, particularly in relation to the values and principles which underpin SDS policy (see chapter three). It begins by discussing carers' experiences of the SDS assessment process, and shows how initial high hopes turned into disappointment for families. The discussion then moves on to consider the context and timing of SDS implementation for people with learning disabilities in Glasgow, drawing attention to the impact of austerity and longstanding resourcing issues within social work. The chapter concludes by examining the unequal power relationships and hierarchies which were evident in participants' experience of assessments, and proposes that the ethos of SDS has not been embedded throughout the policymaking process.

5.2. SDS Assessment – Carers' Experiences

This section discusses carers' experiences of the SDS assessment process and reveals little evidence of the policy values and principles outlined in chapter three. The discussion begins by presenting participants' experiences of the SDS assessment process as time consuming and stressful, and then moves on to show how the reality contrasted with people's initial expectations, leaving families feeling disappointed and let down by policymakers, professionals and services. The section closes with a discussion of the particular circumstances for this group of carers, most of whom have been supporting their family members for decades, highlighting the social relational context within which SDS policy implementation took place.

5.2.1. Assessments were time consuming and stressful

Fifteen family carers were interviewed in this study, and twelve of them had experienced SDS assessment at the time of meeting. In contrast with the positive policy values and principles set out in the guidance (see chapter three), and the initial high expectations families had for SDS, only one carer had found the assessment process to be a positive experience. Richard (90s) was extremely satisfied with the support arrangements for his daughter Pauline (40s) and felt they had been listened to and involved in the process. However, their situation was a notable exception amongst the data; all of the other carers in this study who had experienced SDS assessment described it as a negative experience. Rather than feeling listened to and involved, carers experienced the assessment process as time consuming and stressful, and in some cases, it had caused distress and family disruption.

Perceptions of the assessment process were inevitably intertwined with outcomes, and negative experiences of assessment were related to conflict over budgets and service provision. However, it was not simply unsatisfactory outcomes which made the assessment process difficult for families; SDS assessments themselves were time consuming and stressful. In the analysis of the data, three interrelated factors contributed to participants' experiencing the SDS assessment as time consuming and stressful: increased workload for carers; lack of knowledge and information; and distress and disruption.

Increased workload for carers

The eleven participants who had negative experiences of the SDS assessment process provided extensive narratives of this period. This had often involved months of work for both families and social workers, some of which remained unresolved when we met. Participants recounted the numerous letters, forms, emails, and phone calls which had gone back and forward between families and social work during the assessment period. Two mothers in particular were keen to show me the large files of paperwork which they had accumulated during this time. This was very powerful and tangible evidence of the workload involved for carers, who are already often time poor, stressed and exhausted by their caring work (Carers UK, 2018).

There was also additional work involved for carers in learning about SDS, such as: attending meetings; asking questions; and gathering information. In addition to their direct dealings with social workers and service providers, families sought advice and support from other organisations (including advocacy services and Learning Disability Alliance Scotland), contacted political representatives, and spoke to other family carers. Additionally, four carers had undertaken extensive online research in an effort to understand SDS policy. This group were particularly frustrated and angry about their experience of implementation because they observed a massive gap between policy and practice but felt powerless to challenge the local authority (issues of power and the difficulties in challenging decisions are discussed in section 5.4).

Knowledge and information

Despite high profile campaigns by the Scottish Government and third sector organisations, participants had very limited knowledge about the four options for delivering SDS, and the related policy ethos. In the three years leading up to SDS implementation, the Scottish Government invested £30m in a range of activities intended to support the transformation of social care (Scottish Government, 2018a: 22), which included awareness raising and communications (ibid.: 4), and there were a raft of information leaflets and websites, including easy read formats, which were publicly available. Nonetheless, accessing and understanding the vast quantity of available information requires both time and particular types of knowledge (e.g. IT skills); resources which were in short supply for participants.

In addition to not knowing about the four options for delivery of SDS, the policy values and principles were not fully understood and many participants did not see the point of the policy. Participants were aware that one of the things SDS could be used for was to employ a personal assistant (PA); however, none of the participants in this study wanted to employ one, so this was not seen as an advantage to them. As discussed in chapters two and three, there has been longstanding reluctance to take direct payments in Scotland (Pearson, 2004), and managing a budget and employing a PA can be particularly difficult and stressful for people with learning disabilities (Hamilton et al, 2017), so it was not surprising that participants were not interested in employing a PA. Additionally, taking a direct payment to employ a PA was seen as a risk by several carers; they relied on social care services to support their family members and give them a break from caring, as Sandra explained:

> *When you went to these meetings it was always, “oh get yourself a PA”, until somebody said, “what do you do when they’re rubbish? What do you do when they never turn up? What do you do when they’re always off sick?”... meanwhile you’re paying them and you wouldnae have any services…*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Distress and Disruption

In addition to the time consuming and practical work involved in preparing for and undergoing assessments, the SDS process also had an emotional impact for families. All participants spoke of the stress, distress or family disruption experienced whilst going through the assessment process. For example, Sheila explained:

> *…I found it very stressful …the social workers were trying to cut you back and ignore what you were saying…*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

This group spoke of being worn down by the SDS assessment process; the meetings, the letters, the phone calls, as well as the logistical difficulties of being able to fully engage in the process whilst caring for their disabled daughters, sons, sisters and brothers. The all-encompassing nature of caring, which was heightened by the workload involved in SDS assessment, was illustrated by Sylvia:

> *…it's getting very difficult, it really is. And this doesn't help… I can't tell you how much o' my life I spend looking at this [SDS paperwork], or trying tae write letters or convince people… And you're trying to look after [Andrew] and [Andrew has] behavioural problems… You think "God, I don't need it"… I mean caring for someone with autism, it isn't only stressful, it's emotionally dead draining… trying to anticipate what's gonna happen. Trying to thwart what's gonna happen… Trying tae put up with how they don't understand things. And some, I don't know, they're dead aggressive is all I can say…*
>
> *(Sylvia, 60s, mum to Andrew, 30s)*

The additional workload for carers was exacerbated by misinformation, confusion and delays. Systems and procedural issues in relation to SDS implementation are discussed later in this chapter, and the impact of these failings was felt by carers. The vast majority of participants felt that the local authority had tried to rush through SDS implementation for people with learning disabilities, before appropriate systems and processes were in place.

Failings in relation to systems and processes added to the workloads of carers and social workers, resulting in confusion and delays which caused distress and disruption in the lives of individuals and families. As an example of this, for Maureen and Dan (60s), regular holidays were a vital coping mechanism and they relied on respite[25] services several times a year so they could have a break from caring for their son Derek (40s), but arrangements were hampered by delays in the SDS assessment process. Previously they had been able to book the respite service a year in advance, but SDS implementation meant the family were left waiting for budget approval until two months before their holiday, causing additional unnecessary stress and uncertainty.

Half of this group spoke of the amount of time and energy they had invested in the SDS assessment process, but without a return which justified the additional workload. In all but one case, the SDS process effectively had a negative return because participants felt disempowered, distrustful and dissatisfied. For Sandra (60s), this meant she had "*…lost trust and confidence in the people and system meant to support us*". Consequently, participants' experiences of SDS assessment had been detrimental to fostering the positive, trusting relationships between families and professionals, which were fundamental to collaborative partnerships.

Following on from this discussion of participants' experiencing SDS assessment as time consuming and stressful, the next section shows how this contrasted with people's initial expectations. The divergence between expectations and reality left families feeling disappointed and let down by policymakers, professionals and services.

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[25] I use the term 'respite' throughout the thesis because this was the term used by participants. I acknowledge that the term is highly contentious, associated with narratives of care which frame disabled people as 'burdens'. Recent policy literature generally uses the broader term 'short breaks' rather than 'respite'.

5.2.2. Expectation and disappointment

Prior to experiencing the assessment process, participants generally had high hopes for SDS. As outlined previously, SDS policy was underpinned by progressive and positive values including: respect; independence; fairness; safety; and freedom. SDS was promoted as enabling disabled people to exercise choice and control over their own lives because of the promise of personalised, flexible and creative solutions to support needs. In Glasgow, one of the ways in which SDS was initially communicated to participants was through meetings, which people who attended day centres and carers were invited to attend. Eight carers recalled attending these meetings, in which local authority officials promoted the transformative potential of SDS to families by telling success stories from pilot studies where disabled people had used their SDS budget to buy football season tickets, gym memberships, televisions, and holidays:

> *…it was, like "oh yeah, you'll have a budget and if you want to buy a caravan, you can buy a caravan, and if you want a television… and you can go on holidays…" and by God, that soon changed!*
>
> *(Irene, 50s, sister to Theresa, 50s)*

Promoted by examples of creative solutions and positive outcomes, SDS sounded transformative and families welcomed the opportunity to have more say in support provision. Disabled people and their families were to be empowered by the policy shift away from professional control towards individual, personalised support, but this had not transpired in practice. This was disappointing for carers, who felt angry and let down by the local authority because the policy they were promised was not delivered. Overwhelmingly, participants had come to feel that SDS had been imposed upon them, thus negating the potential for empowerment and in conflict with ‘choice and control’. Participants’ experience of SDS had not lived up to expectations; instead it reinforced carers’ lack of power and control and contributed to feelings of anger and distrust towards policymakers, professionals and service providers. This was not conducive to the policy principles of collaboration and involvement, which required disabled people, carers and professionals to work together as ‘equal partners’ (partnerships and power in relation to SDS assessments are discussed in section 5.4).

This section highlighted how participants’ experiences of SDS assessment contrasted with their initial expectations and left families feeling disappointed and let down by policymakers, professionals and services. The next section moves on to show the social relational context within which SDS policy implementation took place, highlighting how the particular circumstances of this group of carers, most of whom had been supporting their family members for decades, interacted with their experience of the assessment process.

5.2.3 The social relational context of SDS assessment

This study was concerned with the experiences of people with learning disabilities who were aged 30 and over, and their families. There were particular characteristics and experiences common to this group which had affected their ability and propensity to participate in the SDS assessment process, however the social and relational context within which people experience policy is invisible within an ostensibly objective and systematic process. In the analysis of the interview data, three main interrelated areas emerged in relation to the context of participants’ experiences of SDS assessment: previous experience of policy and service provision; fear and vulnerability; and health and ageing. This section will discuss each of these areas to illustrate how the particular characteristics and experiences shared by this group provided the context within which they experienced the SDS assessment process.

Previous experiences of policy and service provision

Participants had decades of experience negotiating with professionals about family care and support needs, and the legacy of previous conflict and failure was a longstanding and deeply held lack of trust. This meant that carers entered into the SDS assessment process feeling suspicious, or at least wary, about the potential outcome. For example, Deborah felt her family had been ‘fobbed off’ and let down by social work, health, and education professionals during her son’s childhood and throughout his transition to adulthood. She recounted incidents when information had not been disclosed or had been deliberately withheld from her, and when her son had been excluded from participating in leisure or educational opportunities due to a lack of support. Deborah’s son was in his 30s at the time we spoke, but the memory of this extremely difficult period in the family’s lives, when she was also caring for an elderly parent, remained painful for Deborah. She felt guilty about not being able to get the support her son had needed, and was hurt and angry because she had felt unsupported by professionals at a time when she most needed it.

In addition to having personal experiences which had caused a lack of trust in professionals, families were also influenced by the experiences of others, and these framed interactions with the SDS assessment process. Several carers spoke about recent high-profile incidents where people with learning disabilities had been subject to serious, and sometimes fatal, failings in social care, (discussed further in chapter six). Understandably, issues of harm and risk associated with failings in social care are a source of fear and worry for carers, and previous negative experiences are detrimental to developing trust in professionals. Achieving the statutory policy principle of collaboration (see chapter three) requires families and professionals to work together as equal partners; it is an active process, which requires time and trust. Power (2014) notes the importance of trust-building between families and professionals in implementing changes to support for people with learning disabilities; yet participants entered into the SDS assessment process with little trust in professionals or the social care system, and there was no evidence in the data to suggest that SDS implementation acknowledged or addressed this.

Support for carers

Personalisation is not simply about the (disabled) person with (assessed) care needs; SDS policy is also closely related to carers' policy. Under the Social Care (Self-directed Support) (Scotland) Act 2013, local authorities retained their existing duty to provide carer's assessments to eligible people[26] who requested them, and introduced a new legal power in relation to the provision of support to carers. Despite recognition of the role of carers, the legal duty to provide a carer's assessment, and the new legal power to provide support to carers following a carer's assessment, the experience of participants in this study suggests this was just policy rhetoric, rather than practice. Few participants in this study had had a carer's assessment and most did not see any value in it, feeling it was just a paper exercise, as Janet noted:

> *…it's nothing you know, naebody adheres tae it.*
>
> *(Janet, 50s, mum to Michelle, 30s)*

The data suggested that carers' screening assessments were being undertaken as part of the SDS assessment process, however it was not clear that this was the consistent approach. One participant was advised to have a carer's assessment as part of the SDS assessment process, but there was general confusion about what screening and assessments entailed, and about the roles of social workers

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[26] Unpaid carers are eligible for a carer's assessment 'where the carer provides or intends to provide a substantial amount of care on a regular basis' (p8) in statutory guidance. See: http://www.gov.scot/Resource/0044/00446933.pdf

and carers’ centres. One mother believed social workers were actively discouraging carers from having assessments:

> *I demanded a carer's assessment. I was told [by social worker] “No, no, we don't… you really don't get anywhere with a carer's assessment”. At the end up, I demanded it and I said it was my right… Don't get me wrong – it doesnae get you anywhere… [carers] cannae be bothered with the hassle… going through all the assessment.*
>
> *(Deborah, 50s, mum to Michael, 30s)*

Whilst most participants felt that the carer’s assessment was just a pointless exercise, Deborah and Susan reported that their respective family members had each received additional budget as a result of their individual circumstances being noted and formally acknowledged in the SDS assessment:

> *The only reason I get respite in Michael's budget is because of my carer's assessment.*
>
> *(Deborah, 50s, mum to Michael, 30s)*
>
> *I've got a lot of health issues of my own, so the social worker we had at the time… he did write a good assessment based on that, so we were given transport [budget for taxis to take Lorna to and from services]…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

The two examples above were in keeping with the statutory guidance and suggested a more holistic approach to assessment as they recognised that Deborah and Michael, and Susan and Lorna’s lives were inextricably inter-linked. However, this was not always the case. For example, in Maureen and Dan’s case, there was a clear gap between their assessed needs and the support provided for their son Derek. The carer’s assessment for Maureen and Dan stated that they needed 56 days’ respite per year but the SDS budget approved for Derek only allowed for 28 days’ respite provision. When they queried this in a phone call, they were told it was ‘not negotiable’.

Fear and vulnerability

Overwhelmingly, families believed that SDS implementation was motivated by cost cutting. This perception was not surprising as the local authority had been vociferous about the need to reduce costs in relation to social care, as well as other local authority services, due to budget cuts (Main, 2014). The impact of austerity on the implementation of SDS is discussed in section 5.2, but the relevant point here is that the negative association between SDS and cost cutting resulted in feelings of fear and vulnerability for carers. Participants described feelings of vulnerability and of being under pressure throughout the SDS assessment process, which was not conducive to developing the strong and equal collaborative relationships required to deliver the policy objectives.

Initiating the SDS assessment process was viewed as a risk because carers fully expected the outcome to be a reduction in the provision of support services for their family member, as Sheila explained:

> *…it’s a risk because of what would happen if you don’t get support. If I didn't get the support, I couldn't do it [care for Gillian]… I found it [SDS assessment] very stressful…*

(Sheila, 70s, mum to Gillian, 30s)

This was a serious concern because any reduction in services meant more ‘work’ for carers, many of whom were already struggling. SDS was, therefore, not seen as an opportunity to improve and empower lives; it was understood by participants as an opportunity to shift responsibility for support from the local authority onto carers.

The fear of what might happen as a result of the SDS assessment outcome was evidence of carers’ vulnerability; participants were dependent on the support received from the local authority and the possibility of losing this essential resource brought this to the fore. The statutory principle of collaboration required families and professionals to work together as ‘equal partners’, but the data showed this was not a relationship of equals.

In many cases, expectations about SDS assessment outcomes were borne out; support services were reduced and families were dealing with this in various ways (discussed in chapter six and seven). Yet even in the small number of families whose services were not directly reduced, SDS assessment and implementation had caused stress and worry, and carers felt vulnerable. Every carer in this study recounted stories of other families they knew who had experienced drastic cuts or complete withdrawal of services, fuelling fears of what might happen to their family in the future. This was particularly concerning to this group of ageing carers (the youngest were in their 50s), caring for family members in their 30s, 40s and 50s, because the intersection of health, ageing and caring made them inherently vulnerable and dependent on social care support. Rather than the SDS assessment process being equal and collaborative, it was disempowering for participants because it heightened feelings of fear and vulnerability.

Health and ageing

Relatedly, most (n=12/15) of the family carers reported having long term health conditions which could impact upon their ability and capacity to engage with the assessment process, or which could be impacted upon by the stressful, time consuming assessment process. The prevalence of health problems in this group is unsurprising given the age of participants, half of whom were post-retirement age, and will be discussed in relation to daily lives in chapter seven. However, health and ageing was pertinent to the SDS assessment because it affected carers' ability to provide support and because the associated stress and worry could exacerbate carers' health conditions.

The majority of participants felt that physical caring labour had become more difficult – either because of their own declining health or ability or because of their family member's support needs increasing with age – as Sheila explained:

> *…I'm getting to the stage in life where I'm looking for more support with my daughter and [local authority officials] …are happily withdrawing it without any conscience…*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Sheila's quote above demonstrates the vulnerability and powerlessness of ageing carers, related to the intersection of health, ageing and caring. Similarly, for one couple, caring for their son had become much more physically and emotionally demanding because his support needs had increased at the same time as they were becoming less physically able due to ageing. Dan and Maureen were already struggling to cope, and the additional work and worry involved in the SDS assessment process was experienced as an additional burden.

Furthermore, two thirds of carers (n=10/15) reported that they were, or had previously been, dual carers; reflecting the age range and life stage of participants, most of whom were, or had been, caring for an elderly parent, or an elderly or disabled spouse, in addition to caring for a family member with learning disabilities. Whilst SDS policy had the potential to enable more personalised support for carers, taking into account individual circumstances including carer health, ageing and other caring responsibilities, this was not the experience of participants. Instead, the SDS assessment and implementation process had meant more work, more stress, and less support. As Susan commented:

> *…we just think it's been an absolute mess. It's created more pressure for us, certainly for me.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

This section has discussed carers' experience of the SDS assessment process and provides evidence of the gap between policy and practice which has left carers disappointed and disempowered. In contrast to SDS policy discourse, participants did not experience the assessment process as collaborative or empowering. Instead, participants' narratives spoke of vulnerability and powerlessness; not being listened to, anger, frustration and tears. Participants' accounts of the assessment process revealed the importance of understanding the context of policy implementation and recognising the particular needs of family carers.

Thus, the discussion in this section supports the proposition by ethics of care theorists that policy is underpinned by a false conceptualisation of the autonomous, self-interested, and disconnected individual (Barnes, 2012), discussed in chapter two. Furthermore, participants' experiences of the SDS assessment process demonstrated the absence of ethics of care principles and values proposed by Tronto (1993), as discussed in chapter two, in practice. Attentiveness to the needs of carers was absent in the assessment process which resulted in more work, distress, and disruption, and the absence of responsibility for meeting needs was illustrated by participants' narratives of disappointment and feeling let down. The absence of competence was evidenced by participants not receiving the knowledge and information they needed to participate fully in the assessment process, and the neglect of the social- relational context within which participants experienced the assessment suggested a lack of responsiveness within the system.

To examine where the breakdown between policy and practice happens, the next section looks at the context of SDS implementation, before moving on to examine partnerships and power.

5.3. Context of Implementation – Austerity

This section considers how the context of SDS implementation in learning disability services in Glasgow affected participants' experiences of policy change. Beginning with a discussion of the timing of implementation and the association of SDS with cuts and closures, the discussion then goes on to look at system and procedural issues, the Resource Allocation System (RAS) and the client contribution. Following on from the discussion of carers' experiences of SDS assessment earlier in this chapter, this section finds that the additional labour for families in navigating the assessment process and negotiating budgets could have been alleviated to some extent if the system had been less complex and more transparent.

5.3.1. Cuts and closures

The timing of implementation of SDS in Glasgow made the assessment process particularly challenging for participants. As outlined in chapter one, Glasgow City Council took the decision to ‘phase the closure of day centres in line with the roll out of Personalisation’ in 2012[27]. This was part of an ongoing programme of reform in learning disability day services, which pre-empted the statutory national implementation of SDS and reduced the number of day centres for people with learning disabilities from eight to two between 2011 and 2015 (see timeline in chapter one). As outlined in chapter one, the local authority viewed personalisation as a way in which they could make budget cuts, and participants were well aware of this, as Mhairi explained:

> *…it was a cost saving exercise by the council, bottom line, and the damage that they've created is despicable…*
>
> *(Mhairi, 50s, sister to Theresa, 50s)*

For six families in this study, the negative impact of the additional workload involved in the SDS assessment process was exacerbated because they were also dealing with the practical and emotional impact of day centre closures at the same time. The reorganisation of day services in Glasgow are discussed in detail in chapter one, and contested issues around spaces and places of care for people with learning disabilities are outlined in chapter three, but is also pertinent here because of the association between SDS implementation and cuts and closures. Participants reported that the widespread closure of day centres was a major

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[27] http://www.glasgow.gov.uk/CouncillorsandCommittees/viewSelectedDocument.asp?c=P62AFQ81812UDNZL

upheaval for many families, causing changes to family routines and relationships, and was extremely distressing for many disabled people who could not understand why they were no longer going to ‘their centre’ or seeing their friends (explored further in chapters six and seven).

The perspectives of those participants who had learning disabilities on the closure of day centres are discussed in chapter six. At the same time as undertaking the additional workload involved with the SDS assessment process (discussed in section 5.2), most families had also seen their caring and emotional labour increase and were experiencing additional stress in dealing with their loved one’s confusion and distress. The emotional labour of carers in managing this confusing and distressing change was illustrated by Sheila, whose daughter Gillian had attended a day centre for twenty years until it closed:

> *It was all a routine and then, all of a sudden...gone… and try as you will, how do you explain?... first of all… [Gillian thought] people were going because they didn't like her…just disappearing in ones and twos... then when her turn came... she couldn't get it,... where was everybody?… why was she going to these things on her own? …she's been all over the place for the last year, and it's been really very difficult…*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Furthermore, the extent of the conflict over the closure of day centres had resulted in extremely acrimonious relationships between families, service providers, disability organisations and Glasgow City Council. This was a huge barrier to achieving the statutory SDS policy principle of collaboration, because the closure of the day centres and conflict with organisations had left many families feeling distrustful, disappointed and disempowered. Collaboration requires families and professionals to work together as equal partners and the local authority's decision to go ahead with the widespread closure of day centres – despite carers' high-profile campaigns against closures – was clear evidence that families and professionals were not equal partners; ultimately, power was held by professionals.

Eight of the carers interviewed had been involved in campaigning against the closures, though some more actively than others. This group had personal, direct experience of attending meetings with senior representatives from Glasgow City Council and reported feeling patronised and not listened to. The disregard and defeat of carers' campaigns against day centre closures had left families in no doubt about the power of the local authority to make decisions about their lives and those of their family members. For these families, the principles and values of the SDS Act were entirely absent in the actions of the local authority with regard to the reorganisation of day services. This left a legacy of distrust of the local authority, professionals and service providers, which was entirely incompatible with fulfilling the values and principles of the SDS Act.

As discussed in chapter one, within the context of national budget cuts, Glasgow City Council publicly stated that SDS would result in savings of £10m from its social care budget of £89m during 2012/13 (Main, 2014). SDS was presented as the fair way to allocate scarce resources during a time of public sector cuts. As a result of the local authority being vociferous on the need to cut spending – together with the high profile, highly contested, closure of day centres – participants firmly associated the implementation of SDS with budget cuts. This created a climate which was not conducive to trust and collaboration, as families entered into the assessment process with trepidation and reluctance. Sheila explained:

> *…you know they just want to cut you…*

> *(Sheila, 70s, mum to Gillian, 30s)*

SDS implementation was therefore inevitably intertwined with cuts for this group. This association was detrimental to the development of collaborative relationships, which were critical to the success of personalisation, and potentially left long lasting impact for successful partnership working. The importance of relationships is discussed in chapter seven. In relation to the timing of implementation, participants experienced SDS assessment as a battleground; families in need on one side and the local authority in a position of power on the other:

> *Everything's a fight. Everything's an argument with the council. Getting what you're entitled to… that's more stress. It's the council that causes the stress…*
>
> *(Janet, 50s, mum to Michelle, 30s)*

Collaboration required trust and common goals, but families and social workers were effectively pitched against each other in the struggle for limited resources, as Sheila explained:

> *…I'd like to think I was prepared for it all, I worked on it, you know, and then they throw in a trick question …and you think 'argh! I should've realised what she was trying to say…' I just answer as honestly as I can.*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

The timing of SDS implementation in Learning Disability Services in Glasgow undoubtedly created a negative association between SDS policy and cuts and closures, diminishing the transformative potential of personalisation policy. Participants perceived SDS implementation to be motivated solely by cost cutting and this was irreconcilable with the policy values and principles. As a result of this, even those participants without direct experience viewed SDS policy negatively. For example, Alistair attended a third sector service 4.5 days per week and was very happy with this arrangement. At the time we met, he had not yet gone through the SDS assessment process and he was not looking forward to it because he was expecting a reduction in services as a result. Instead of SDS being empowering for Alistair, the quote below illustrates the absence of choice and control he was anticipating:

> *…Glasgow City Council pay my funding, but they're saying next April I could go intae Self-directed Support, and you might no' get the same budget tae go every day.*
>
> *(Alistair, 50s)*

In addition to the negative impact of the association of SDS with austerity, the fear of cuts and closures as a result of the timing of implementation was also detrimental to fulfilling the policy values and principles. Budget cuts impacted directly on individuals and families, but they also had wider indirect impact. All participants in this study had either experienced budget cuts themselves, or knew other families who had. One of the main areas in which families had experienced the impact of budget cuts was respite provision. Service provision is discussed in chapter six, however cuts to respite services are relevant here because this was an example of dependency and vulnerability, worry and fear, and a further negative association with SDS policy implementation for carers. As an example, two families had not had their budget reduced and were able to continue with existing respite arrangements post-SDS assessment. However, this was still a source of worry for them; Sheila and Elizabeth both expressed concern about the sustainability of respite services and reported the closure of some services. They believed that many people were no longer using respite services because of insufficient budgets and were concerned there would be further closures; although Sheila still had sufficient budget for Gillian's respite service, she was worried about the future, and how she would cope if services closed:

> *…that's always been my worry, cause it's a big thing to me, because I'm on my own… if not enough people use the respite [service], or use their funds for respite, they're going to close it aren't they? They're not going to keep something going that's not paying… that really worries me…*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Welfare reform

The climate of worry and fear in relation to SDS implementation, budget cuts and centre closures, was exacerbated because of simultaneous welfare reform measures as a result of austerity policies. Whilst the participants who had learning disabilities said little about the SDS assessment process, several issues were raised in relation to welfare reform and included concern about potential benefit cuts. None of the participants who had learning disabilities in this study were in paid employment, so they were dependent on the income received from state benefits. Potential cuts to benefits were therefore a source of worry which had led to one potential participant withdrawing from the study; on the morning we were due to meet, I received a phone call to say they had become very distressed at the thought of meeting with me in case I was 'going to cut his money' (key worker). This interaction reveals the power of professionals in the lives of people with learning disabilities and the ways in which disabled people have been rendered vulnerable by austerity policies, and illustrates a further barrier to achieving the values and principles of SDS policy.

The particular difficulties for people with learning disabilities in understanding policy change is illustrated by the exchange below, which took place during my interview with Pauline (40s) and her dad Richard (90s). Pauline had attended a day centre for over 20 years until it closed, and she associated cuts to day centres with cuts to benefits:

> *P: I'd like tae ask Karen a decent question.*
>
> *K: What's that Pauline?*
>
> *P: You know that… the thing coming up about the benefits?*
>
> *K: What thing about the benefits?*
>
> *P: Some o' them are getting cut. They're closing down the centres as well. They're closing down the centres too.*
>
> *(Pauline, 40s)*

The implementation of SDS at the same time as austerity and wider welfare reform resulted in increased worry and fear, emphasising vulnerability and dependency. Several participants were concerned about changes to ESA and the transfer of DLA to PIP, and three were concerned about 'proving' impairment or being called for assessments. Narratives about benefit assessments in the media were evident in some cases, so even if people did not end up with benefit cuts themselves, the *climate* of cuts had a negative effect. For example, Pauline's dad Richard explained how he had found the experience of applying for ESA for Pauline particularly stressful:

> *…all these things that I had tae write down, and at first I thought: "I wonder if they'll believe all the things that's wrong with this girl?"…I was reading that much about wheelchair-bound people getting told tae appear and see if they were fit… she's just a name on their sheet… but they took my word for it… They just replied and said she'll never be called for an interview for work.*
>
> *(Richard, 90s, dad to Pauline, 40s)*

5.3.2. People and processes

In addition to the timing of implementation and conflation with cuts and closures, inadequate systems in relation to people and processes were also detrimental to the SDS assessment process and policy implementation.

People

Good working relationships between families and professionals were implicit in the SDS policy principle of collaboration[28]. However, the timing of SDS implementation was not conducive to good working relationships for participants; one of the main barriers was the absence of pre-existing relationships with social workers. Longstanding resourcing issues within social work, together with the decimation of social care funding as a result of austerity, meant participants did not have existing relationships with social workers, as Sheila explained:

> *I did have a regular social worker but they withdrew them quite a long time ago… social worker would be phoning me up the night before to see*

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[28] In relation to the principle of collaboration, statutory guidance states: 'the professional and the supported person should work together' (Scottish Government, 2014a: 17).

> *what's been happening the last year… so she could go to the review!... And then that was withdrawn...*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

In all cases except one, SDS assessment was carried out by social workers not known to the families and this was a barrier to collaboration for several reasons: lack of trust and feelings of vulnerability; assessors were not experts in this field; insufficient time was allocated to complete assessments; and social workers did not have all the information required. Each of these issues will be discussed in the following section.

Lack of trust and feelings of vulnerability

The nature of the assessment required people to reveal intimate details about private family lives and having a trusting relationship with the 'assessor' could help to support this, as Sandra explained:

> *It's obviously trust involved isn't it? That you're telling, your child's problems, their needs… they're taking it in, they're writing it down as they see it.*
>
> *(Sandra, 60s, mum to Sharon 30s)*

Families were made vulnerable by the requirement to disclose personal and intimate information to an unknown (potentially powerful) individual coming into their home for the first time. Admitting to social workers, and perhaps also to themselves, how difficult things could be placed families in a vulnerable position, as Sandra explained:

> *…they're not that nice, happy, bright person all the time… They can be violent… sometimes people are kind of ashamed to admit that.*
>
> *(Sandra, 60s, mum to Sharon 30s)*

The vulnerability of families and the power of social workers was further illustrated by Janet, who spoke of the risks of revealing the truth about the pressure of caring:

> *…you're tae tick a box*[29]*…[in relation to the impact of caring] but you're feart tae [say too much]… because what would that mean? **They come and take your wean away?***
>
> *(Janet, 50s, mum to Michelle, 30s)*

Whilst participants were mainly positive about individual social workers, one family had a particularly negative experience and this had made the SDS assessment process even more stressful. Sheila felt that her parenting was being criticised by a social worker who did not understand the difficulties in her caring

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[29] The tick box options were:

1. I am able and willing to continue my current caring role

2. My caring responsibilities have some impact on my daily life

3. I have some difficulties carrying out my day to day life

4. My carer role has a substantial impact on my lifestyle

5. My caring role has a critical impact on my lifestyle including a significant impact on my health and wellbeing

6. I am no longer fit or able to continue in my caring role as a carer even with support

role. Sheila did not allow Gillian in the kitchen whilst she was cooking because Gillian was inclined to touch hot pans and sharp knives; Sheila considered this to be caring for Gillian, but the social worker's assessment disagreed:

> *I've had social workers say "you're not looking after her"… she [social worker] said to me… "and you're always in the same room as Gillian?" I said, "No, I'm not necessarily in the same room… but if Gillian's in the house, I'm in the house"… "well, you're not giving her full-time care then"... Well, I think I'm looking after her because I don't have her in the kitchen!… it's in her interests not to be in the kitchen, you know, but that's the rules…*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Both Sheila and Janet's narratives of the assessment process demonstrate their genuine fear and defensiveness in response to administrative power and bureaucracy. The importance of intimate knowledge and trusting relationships was rendered invisible by being implicit in policy narratives relating to collaboration and partnerships. Having existing trusting relationships with social workers may have helped mitigate the risk felt by families in revealing intimate details about their private lives. However, social work structures and resourcing were not set up to maintain the type of long-term relationships with families which could have enabled knowledge and trust to develop.

Assessors were not experts in this field

Participants reported that social workers had been 'drafted in' from other teams in order to get through assessments as quickly as possible, as a result of both the restructuring of learning disability services and anticipated savings in the local authority's social care budget.

This was a barrier to collaboration because social workers did not know the families, or understand their complex lives or histories, and may not have had experience in learning disabilities. As noted previously, only one family knew the social worker who carried out the SDS assessment with them; for the others, this was a barrier to understanding the complex realities of family lives and impairment. Additionally, participants reported that social workers were under pressure to complete assessments quickly, which meant that they did not have sufficient time to fully engage with SDS values and principles and implement these in their practice. Nonetheless, individual social workers were often described positively; families understood they were under pressure from management and were sympathetic towards them.

The process of ‘drafting in’ social workers from other areas meant social workers did not appear to have sufficient understanding of impairment effects (Thomas, 1999) in relation to learning disability, which was detrimental to fulfilling SDS values and principles. For example, expecting people with learning disabilities to participate in meaningful ways in a normative assessment process neglected that the nature of impairment could affect ability to answer questions. Janet noted that Michelle would agree with whatever question or suggestion was put to her, and Sandra explained:

> *…you can’t ask … questions because by the time it’s all gone in and processed, then they have to come up with an answer, it just freaks them out. They just tell you anything.*
>
> *(Sandra, 60s, mum to Sharon 30s)*

Insufficient time was allocated to complete assessments

In some cases, the SDS assessment took the form of a short meeting with an unknown social worker. In one case, a social worker completed the form herself in order to save time, as Sheila explained:

> *..."oh, I don't use the form… I just ask questions and I'll fill in the form"… I said "I want to see the form before you send it in" ... so then I discovered she'd answered the questions that I should be answering! She'd just ticked the boxes where she thought! So, I thought, "no, that's not going in", so she wasn't pleased… I did that amendment and she said "I haven't time for any more amendments, so you'll just have to put up with it".*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

In another example, the social worker took extra time and worked closely with the family but was berated by management as a result:

> *…I know she gets her knuckles rapped for not getting through them quick enough, so there's pressure on the social workers.*
>
> *(Sandra, 60s, mum to Sharon 30s)*

The failure to invest sufficient resources into the processes of SDS implementation suggested that the values underpinning SDS policy had not been embedded. Collaboration takes time, yet participants' narratives showed that practitioners were overstretched and under pressure to complete assessments as quickly as possible.

Despite the limited time allocated to undertake assessments, there was one notable example of collaboration in the data. Maureen and Dan had anticipated difficulties in the assessment process and took a proactive approach to the assessment in order to mitigate this:

> *D: We told him [social worker] what was going on the form… he just kinda accepted that… it's all about covering yourself… how long did it take us tae write, to fill it in?*
>
> *M: Three months. It must be three months. We went over it and over it and over it… there's things… that you don't think to put down, but you've got to put every single thing down.*
>
> *D: I would say ours was probably one o' the best documented…*
>
> *M: …and I typed it all out.*
>
> *(Maureen and Dan, 60s, parents to Derek, 40s)*

Following the initial assessment, the family and social worker continued to work collaboratively; the initial budget figure was not sufficient to meet Derek's support needs and the social worker challenged this and negotiated an adjustment prior to advising Maureen and Dan of the budget. Although the revised budget still meant a reduction in Derek's supported hours, Maureen and Dan felt they had been listened to and 'the guy had done his best for us' (Dan).

This example suggested that some people were better placed to challenge systems; Maureen and Dan felt that their previous professional experiences helped them to negotiate the assessment process. However, not everyone is equally able to challenge in this way and be listened to. There was a risk that those with the greatest existing resources benefitted most from collaboration with professionals.

Social workers did not have all the information required

Participants strongly believed SDS was implemented before the appropriate systems and processes were in place, and this resulted in miscommunication and misinformation. Participants observed a lack of responsibility and accountability; social workers were under pressure from management but they did not have all the information required to do their job properly, as Irene explained:

> *…she wasn't specialising in this – she was drafted in to get as many people put through this as quickly as possible... even when we were going back to her with things, she was kinda like "oh, don't come back to me, I'm just the messenger"…*
>
> *(Irene, 50s, sister to Theresa, 50s)*

For most families in this study, knowledge about SDS was largely limited to rhetoric about choice and control; participants were provided with little information about the actual SDS process, the four delivery options, service provision, or financial matters. However, SDS policy required much more than superficial discourse around choice and control; in order to fulfil the policy values and principles, the ethos of SDS needed to be instilled throughout the system.

Processes

As discussed in chapter three, co-production is key to SDS. However, rather than SDS assessments and care plans being co-produced and empowering for disabled people and carers, participants largely found their interactions with social workers and assessors to be a negative experience and there was little evidence of choice and control. Having the right people and structures in place prior to SDS implementation would have helped greatly. Participants believed that SDS was rushed in without appropriate support, causing long lasting damage to their engagement with SDS policy and with the local authority.

In addition to the problems related to staffing outlined above, there were also failings related to procedural issues. All of the families who had experienced SDS assessment at the time of the interviews recalled incidents of misinformation or miscommunication. These were often attributed to social workers having insufficient knowledge of SDS and learning disabilities. In most cases, participants felt they had not received the information they needed from social workers as part of the assessment process, and many felt that this was because the social workers themselves did not have a sufficient grasp of the key SDS processes. Failing to ensure systems were in place, and that social workers were fully informed, was a failure of the statutory principles of involvement and informed choice; disabled people and families could not fully participate in assessments or make informed choices without this.

SDS assessments were a complex and often time-consuming process for participants, and this was exacerbated because forms and processes changed throughout. Several participants reported having numerous versions of the self-evaluation questionnaire (SEQ) which formed the basis for the assessment. This was particularly confusing for participants who were in contact with other families, and two participants suggested inconsistencies in local implementation contributed towards confusion.

In addition to misinformation and confusion because systems were not in place at the outset, there were failures relating to the accessibility of information. As noted previously, the participants with learning disabilities had little to say about the SDS assessment process and it was the carers who were most involved. In order to ensure the statutory principles were met in relation to people with learning disabilities, the accessibility of information should have been a key priority. For example, one mother noted that time constraints meant that the assessment did not focus on her daughter and that there was no attempt made to address the communication barriers which prevented her participation. Janet explained that the social worker had directed questions to her, rather than Michelle:

> *…so, she's asking me the questions, no' Michelle! And I said, "**this isnae for me. This is for Michelle's choice and her control and what she wants**" … I didnae even think tae say, "Michelle can dae Makaton, can you dae Makaton? …bring somebody oot that can dae Makaton".*
>
> *(Janet, 50s, mum to Michelle, 30s)*

The quote above illustrates a failure of the statutory principles of involvement and informed choice. Michelle was prevented from being involved or having an informed choice because no attempt was made to provide information in an accessible way or to facilitate Michelle's participation. The quote illustrates that Janet too had very limited involvement in the process; the onus was on Janet to raise the issue of accessibility, rather than the social worker actively anticipating and addressing potential barriers. Furthermore, Janet was unable to instigate a conversation about Michelle's accessibility requirements, perhaps because she is not used to having control in negotiating support. Janet believed that the social worker was too busy to ensure that Michelle's communication needs were met, but it also did not even occur to her to raise this. Social workers needed to be able to create the conditions for people to understand what might be possible before they could begin to truly exercise choice and control.

5.3.3. Resource Allocation System (RAS)

The SDS assessment process involves social workers and families agreeing responses to a series of multiple-choice questions about the disabled person's support needs in various aspects of daily life (e.g. overnight, personal care, safety, work/volunteering, etc.). In Glasgow, the responses are then allocated points and scored using the RAS, with the resultant score translated into a monetary budget. Families were very confused about how budgets were calculated; lack of transparency was a further barrier to fulfilling the statutory principles of Involvement and Informed choice:

> *…[social worker and her manager] … they don't know how these things are worked out. Some bugger must know but I think they [social workers] don't know… It's tweaked and it's twisted and it's added and it's taken away from. And I don't think anybody knows how to do it… I mean [social worker]'s boss didn't, she'd never seen that thing with all the scoring… So, they don't see that… I presume the RAS group must see it… somebody must see it…*
>
> *(Sandra, 60s, mum to Sharon 30s)*

In practice, it was extremely difficult to fit complex and varying needs into a series of tick boxes. The messiness and complexity in quantifying individual needs was particularly evident in the narratives of Elizabeth, Sandra and Sheila. These mothers spoke of the difficulty in quantifying social and emotional support needs – which can fluctuate for varying and sometimes unexpected reasons.

Noting that it was easier to quantify physical and practical support like '… needing your carrots cut up', Elizabeth suggested that the effects of not attending to social and emotional needs were equally as serious as not attending to physical needs. The unpredictability and difficulties in measuring social and emotional support needs were illustrated in a number of detailed examples set out in the carer interviews, for example:

> *…say she had her period, she goes to the toilet, the towel's all blood, she freaks out… If she felt sick… she just sits up and spews all over the bedcovers… and she gets really frightened… she has bowel problems and she kind of holds on… it gives her a headache and it gives her a sore stomach… if you don't attend to these kinds of things, what you're gonna get is mental health problems cause she self harms… bashes her head…*
>
> *(Sandra, 60s, mum to Sharon 30s)*

Participants tried to mitigate the risk of such incidents, dealt with the repercussions when such incidents happened, and then managed their family members' distress and anxiety afterwards. These are all factors that relate to impairment, and two participants suggested that the RAS criteria was written purely for people with physical impairments. Not recognising that social and emotional support needs were just as important as 'needing your carrots cut up' (Elizabeth) revealed and reinforced normative assumptions about capacity, rationality and self-regulation.

Complex lives and conditions

In order to calculate a budget, the RAS attributes numeric values based on responses to multiple-choice questions in the self-evaluation questionnaire (SEQ). However, participants' narratives show the impossibility of accurately reflecting complex daily lives within pre-determined criteria, suggesting that the RAS is not fit for purpose. For example, in the SEQ, Sharon was assessed as not needing overnight support; the quote below shows the reality of night-time in the household, where Sandra is effectively always on duty:

> *…hear her getting in and out of bed… you sleep but… if you hear her going to the toilet… I sat and listened to her for about two hours muttering to herself… And when the social workers came… "she's not up one or two times a night" … but I cannae guarantee she'll no' be… She might no' get to sleep for four hours, 'til you sort out what's worrying her. And how will you know what's worrying her, cause she cannae tell you!*
>
> *(Sandra, 60s, mum to Sharon 30s)*

Furthermore, questions about individual needs neglected the hostile environment which created support needs. Experiences of assault and abuse in public places were highly prevalent in the narratives of participants (discussed further in chapters six and seven). Whilst individuals may not require physical support when out and about within the community, the prevalence of hate crime against people with learning disabilities created social and emotional support needs for some people. For example, Andrew was assessed as being able to travel independently, however assault and abuse in the street and on public transport were regular occurrences for him, as Sylvia explained:

> *…[school] boys knocking him off the pavement, stealing his bag… We've had a ticket collector saying, "oh see him, he never has a ticket coming on this train…", demeaning him… He's been assaulted, he's had his phone stolen… hats stolen, bags stolen. It's a jungle…*
>
> *(Sylvia, 60s, mum to Andrew, 30s)*

As a result of these experiences, together with the nature of impairment meaning Andrew was unable to cope with change (for example, change to bus route, train cancellations), travelling independently was a source of great anxiety for him. The complexity of Andrew’s situation was therefore not reflected in the simple SEQ descriptor 'able to travel independently'.

Irrelevant questions

Multiple choice questions were often too simplistic to capture the complexity of participants’ social and emotional support needs. This was frustrating for carers, who felt many of the questions being asked in the SDS assessment were not relevant to their particular circumstances – exacerbating feelings of not being listened to. Some participants believed the assessment criteria was more relevant to people with physical impairments, and people with learning disabilities were being forced into tick boxes which did not really apply. Questions concerning employment and volunteering in the SEQ were particularly problematic as they were underpinned by assumptions that everyone could and should undertake these activities, but this was not a realistic option for most participants.

Participants reported that responses to questions about employment included: being in Eastenders; working in a shop; driving trains. These were not necessarily realistic expectations for individual participants, and impairment effects (Thomas, 1999) were not sufficiently recognised in such questions. There was no option for people to respond with “I am unable to undertake employment or volunteering”; the closest response was “I do not wish to”, which was not necessarily an accurate assessment. The problem of unrealistic expectations and assessments were illustrated by Susan:

> *…social worker said to her, "would you like a job?" And she would, she'd like to be on the till… it would be like, "Oh are you liking those? I like those biscuits as well… do you like…? Have you ever tried…?" …it would go on like this! She cannae count, she cannae read… it's unrealistic, but it was down on her thing as she wanted a job.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Manipulating complex lives into a system of tick boxes and multiple-choice questions was not conducive to individualised assessments or support. Truly individualised, personalised support required accurate and honest assessments, recognising the knowledge and expertise of disabled people, carers, and social workers. Whilst this was reflected in policy rhetoric, the conditions of implementation were a barrier to the realisation of personalised support.

Issues around transparency in the assessment process

One of the main issues people had with the RAS was that they did not understand how budgets were calculated, and they felt the system was complex and confusing. Several participants disagreed with the budget they were given and described time-consuming negotiations with social workers, formal and informal complaints, and seeking advice from other families or organisations, including: advocacy services; Learning Disability Alliance Scotland (LDAS); and carers' groups. However, challenging social work carried risks; participants were dependent on services and worried about what would happen if budgets or services were withdrawn. Everyone had either personally experienced – or, more often, knew others who had experienced – having budgets withdrawn or reduced, or overpayments reclaimed. Negotiating budgets was a further source of labour (physical, emotional and intellectual), stress, and worry for families.

Participants were also concerned about ‘deflator’ questions in the SEQ and felt that these were unjust. These questions were concerned with the 'resources' available to the individual and could reduce the budget considerably. For example, if the person being assessed for support lived with family, the budget was reduced by 40%. Of the 17 cases in this study, 9 lived together in the family home, and could therefore receive only 60% of the budget. This was important, both practically and symbolically, as it implied that family support was obligatory and without value – contributing towards the devaluing of care.

Decision making

Participants were aware that the system used for allocating budgets in Glasgow was a computerised, formula driven model. Families therefore strongly believed that budgets were based on resource availability rather than individual needs, as Sandra explained:

> *…I think they just go through it knocking down scores where they can… because they know that’ll be less money*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Participants also believed that the ultimate decisions regarding their respective budgets were not being made by individual social workers. They understood that the social workers who undertook the SDS assessment had little control over the final budget, which may have contributed towards the generally positive views of practitioners. Families believed that budget decisions were being made at a higher level, by management, and were extremely critical about this, as Janet observed:

> *…everybody was put under pressure, social workers, wi' the bosses, "do this, do that" … the money men… saying "if we spend that on that, well we need to cut back on that" … it's these people that are making the decisions…*
>
> *(Janet, 50s, mum to Michelle, 30s)*

Making budgetary decisions on a strictly points based system undermined social workers' professional expertise and neglected the statutory principles of involvement and collaboration.

5.3.4. Client contribution

The client contribution[30] was a particularly contentious issue in the interviews. Unanimously, families felt angry and resentful about this, and particularly about the way it had been introduced. Because families had to start paying the client contribution once they moved onto SDS, people associated the charge with SDS policy, rather than government austerity policies and local authority budget cuts:

> *…nobody told us when they give you this individual budget,* ***you are charged for having that budget****… Nobody mentioned it… we would've picked up on that if it had been mentioned*
>
> *(Maureen, 60s, mum to Derek, 40s)*

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[30] The 'client contribution' is also sometimes called the 'client charge' or the 'care tax'. Participants used all three terms in the interviews and this is reflected in direct quotes. Outwith direct quotes, I have used 'client contribution' throughout the thesis for consistency.

Prior to SDS implementation, people with learning disabilities in Glasgow did not pay anything towards social care services, so the introduction of a charge was viewed as unfair and directly linked to SDS. Families were understandably angry about having to pay for services which they had often received for twenty or thirty years previously without charge. Importantly, participants did not receive sufficient notification of the introduction of the client contribution and this added to the confusion and resentment, as Susan explained:

> *It didn't exist before. When Lorna was at the centre, no money changed hands at all. And when the council, social work, first talked about personalisation we went through everything… I was at loads o' meetings… never did they mention a client charge. Nobody ever told us about the client charge until you got personalisation and then you got a letter to say you were to pay a client charge…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

For one family, the client contribution had been a major source of conflict, which resulted in them no longer receiving any social care services. At the time of assessment, the family were told by social workers they would have to pay a ‘small contribution’, but were later unexpectedly billed for £60 per week. Irene explained the situation:

> *…a small contribution - you're maybe talking about a fiver a week or something like that... but £60 a week was far off a small contribution! So had there been something in place – or the right people coming out for starters… giving you a true costing, that would’ve been different... but from going from nothing, to a small contribution, to £60 a week!*

> *(Irene, 50s, sister to Theresa, 50s)*

Furthermore, poor communication and misinformation meant that participants were unclear how much the charge was[31], how it was calculated, what it was for, and whether the money went to the local authority or to service providers. Several participants reported that they knew people who were refusing, or were unable, to pay the client contribution. The impact of the client contribution on household income is discussed in chapter seven, however it is noted here that none of the people with learning disabilities in this study were in paid employment, therefore the client contribution was either being paid from state benefits, or by carers, many of whom were retired or not in employment due to caring.

There was confusion about offsetting disability related expenditure in order to reduce the amount of the client contribution[32], and a minority of participants had received advice from LDAS and advocacy services about eligible expenses, though most knew nothing about this. Sylvia had sought advice from LDAS and was one of two participants who had successfully managed to have disability related expenditure offset in the client contribution calculation:

> *…if you needed tae spend your money on something then you could try and get exemption or reduction of the client contribution… they must have these vitamins, or shoes… doesn't walk properly so they all get worn down in one bit…*

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[31] Participants quoted sums from £25 - £75 per week.

[32] Glasgow City Council Social Care Charging Policy states that: 'Consideration will be given to representations to take into account other specific costs of living e.g. in relation to disability related expenditure' (12.2). See: http://www.glasgow.gov.uk/CHttpHandler.ashx?id=5470

> *(Sylvia, 60s, mum to Andrew, 30s)*

Disability related expenditure is discussed in relation to household budgets in chapter seven. Importantly, some social workers seemed to know about disability related expenditure in relation to budget calculations, but others did not. This caused confusion and suspicion:

> *I asked the woman who came out to us, the social worker who came out, and she said no, but then again, she wasn't specialising in this…*
>
> *(Irene, 50s, sister to Theresa, 50s)*

> *…you're getting told "Oh, we don't know anything about disability-related expenditure" and I can assure you they dae!*
>
> *(Deborah, 50s, mum to Michael, 30s)*

Whilst in some local authorities budgets can be paid net (i.e. the client contribution is deducted at source), this is not the case in Glasgow where budgets are only paid gross[33]. Where families were unable to pay the client contribution from household income, they did not receive the budget or the social care support they were assessed as needing, meaning needs could go unmet.

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[33] The statutory guidance states that direct payments (SDS option 1) can be paid net or gross, but there is no specific guidance in relation to options 2 or 3 (see 8.6 in https://www2.gov.scot/Resource/0044/00446933.pdf).

Two families in this study no longer received any services, despite being assessed as having eligible needs and having budget approval. Theresa and Michelle both attended day centres full-time prior to SDS implementation, but did not receive any services at the time of the interviews because their families could not, or would not, pay the client contribution. There was no choice and control for Theresa and Michelle; the possibilities over which they could make decisions were restricted by powerful others:

> *…I went, "oh wait a wee minute, I have tae refuse this budget". She went, "how?" I said, "look I could be rotten and take that budget", I says, "and take Michelle tae the food bank… how can Michelle afford that?"*
>
> *(Janet, 50s, mum to Michelle, 30s)*

In the example from Theresa's family, her sister tried to negotiate alternative arrangements, including explicitly asking social work if the client contribution could be deducted at source. This would have reduced the number of hours Theresa could go to the day service, but ensure the family did not have to pay any additional monies from the household budget. They were told this was not possible; in order to get any services, they would have to pay the client contribution. This was a powerful example of choice and control being undermined by an administrative issue; for Theresa and her family, 'deducting [the client contribution] at source would have resolved so much' (Irene).

As a result of not paying the client contribution and not taking up the approved budget, both Michelle and Theresa were no longer in contact with social work. This constituted a risk, potentially compromising the local authority's ability to meet their duty of care, as Janet explained:

> *…there's a lot more vulnerable people that has dropped off the radar... people with elderly carers… They [social work] don't know if my daughter's at risk… they've never come back and I never went back to them…*
>
> *(Janet, 50s, mum to Michelle, 30s)*

This section set out the context of SDS implementation in learning disability services in Glasgow. The timing of implementation coincided with the restructure of learning disability services and reductions in local authority budgets, resulting in SDS policy being conflated with cuts and closures. Additionally, the lack of appropriate systems and processes prior to implementation created further difficulties for participants and contributed towards negative experiences. The additional labour for families in navigating the assessment process and negotiating budgets could have been alleviated to some extent by less complex and more transparent systems and process. Nonetheless, participants were dependent on services and the local authority has the power to provide or withdraw resources. The next section moves on to consider partnerships and power.

5.4. Power of Professionals – An (Un)equal Partnership

Policy guidance emphasises the importance of collaboration and equal partnerships (Scottish Government, 2014a); however, this neglects fundamental inequalities of power. Conflict between families and social workers has been discussed in the preceding sections of this chapter. This section first looks at SDS implementation as a disempowering experience for participants, who felt SDS had been inflicted upon them. Next, the role of hierarchies and constraints on practitioners are examined, before considering the difficulties for families in challenging power.

5.4.1. A disempowering experience

As noted previously in this chapter, prior to implementation, SDS was promoted as enabling personalised, flexible and creative solutions to support needs. However, all but one carer in this study was fairly satisfied with previous support arrangements and simply wanted good, reliable services for their family members who had learning disabilities. Whilst this suggested that carers had low expectations and aspirations in relation to learning disability service provision, it also illustrated the lack of power families had in relation to policy, as the following quote demonstrates:

> *…we came out of the personalisation process quite well. The fact that we didn't want the personalisation process in the first place is another issue. We really didn't want anything to do with it. She was happy where she was.*
>
> *(Susan 50s, sister to Lorna, 50s)*

Rather than SDS policy empowering people, the quote above demonstrates the absence of choice and control felt by this family; for Susan, the implementation of SDS against her will was disempowering. It was ironic that the implementation of a policy promising choice and control was experienced by participants as being inflicted upon them against their will. This group did not drive SDS policy – they were effectively told by policymakers and ‘experts’ what was best for them.

Participants were further disempowered because they felt they had been let down in local policy implementation by individuals and organisations whom they had previously trusted and respected. Whilst participants were somewhat critical of Westminster and Scottish Governments in relation to austerity, they were strongly critical of Glasgow City Council and local third sector organisations. Reflecting the local political history, several participants were vociferous about the (then Labour) local council forgetting their socialist roots, stating that they would never again vote Labour[34].

Some participants had tried to seek support from MPs or MSPs, but this was not a successful strategy because local implementation of SDS meant there was little they could do; Glasgow City Council was responsible for implementation decisions and participants felt the local authority was not on their side.

Participants were powerless to challenge the local authority themselves, their elected representatives were unable to act on their behalf, and third-party organisations had a conflict of interests in SDS policy. Janet noted that:

> *…big charities never came oot and spoke up for people wi' learning disabilities and their carers… these charities have jumped on the bandwagon a' learning disabilities. They're a' making money oot the weans…*
>
> *(Janet, 50s, mum to Michelle, 30s)*

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[34] The 2017 local election saw the traditionally Labour council replaced by a minority SNP-led administration: https://www.bbc.co.uk/news/uk-scotland-glasgow-west-39959319

Inherent power inequalities were exacerbated because the local authority was beyond challenge. These were not the conditions of collaborative, equal partnerships. Without support and systems in place to challenge decisions, power remained firmly with professionals – not disabled people and carers.

5.4.2. Hierarchies and constraints on practitioners

Participants were all familiar with the terms ‘choice and control’ in relation to SDS, however only one person believed their family had choice and control over their lives and support. All others were extremely critical of the rhetoric of choice and control because they had not seen this in practice. Participants therefore strongly believed that money was at the heart of policy decisions, not values and principles. In reality, participants had very little choice over their lives; instead daily lives and routines were largely dictated by powerful others.

Local implementation determines available choices

Understandings of the terms ‘choice and control’ are contested (see section 3.2). In policy discourse, choice and control are fundamental to all aspects of support (Scottish Government, 2014a). However, as social care policy is implemented locally, it was the local authority that determined the framework for choice and control. For example, Janet and Deborah had undertaken extensive online research in an effort to understand SDS policy and they perceived a massive gap between policy rhetoric and personal experience:

> *…SDS legislation is not being followed in Glasgow… It's Glasgow City Council's policy that they're going on, not SDS legislation.*
>
> *(Deborah, 50s, mum to Michael, 30s)*

> *…Scottish Government [need to] hammer doon on the policy… "we said SDS, is four choices. You ain't gieing them they four choices" …*
>
> *(Janet, 50s, mum to Michelle, 30s)*

In practice, local authority discretion resulted in direct and indirect limits on choice and control. Examples of restricting choice and control included: not giving people the option of having the budget paid gross or net of the client contribution, and determining the availability of services through direct provision or commissioning, which is discussed further below.

The local authority's refusal to deduct the client contribution from the budget at source, despite policy guidance explicitly stating that people may take the budget gross or net of the client contribution, restricted choice. The insistence on paying budgets gross meant families had to find monies for the client contribution from the household income. This resulted in two families in this study 'choosing' not to take their budget, and therefore no longer receiving any social care services.

Furthermore, the local authority determined what services were available for people to choose from. The restructuring of learning disability services and widespread closure of council day centres in the city (discussed in Chapter six) meant that many people were unable to choose their desired option of a day centre. For example, when Michelle's day centre closed, she wanted to move to another centre with her friend, but she was unable to exercise this choice because the new centre was only taking people who used wheelchairs.

Additionally, the local authority determined the availability of services provided by other organisations directly through their commissioning policies, indirectly through encouraging or discouraging people to choose particular providers, and by controlling the availability of information, as Sandra explained:

> *What they'll say is, if you go to another provider, that's your choice and if it doesn't work out or something terrible happens don't bother coming to us complaining… I've heard of people who maybe have a budget and they've got so many hours and they've looked at the budget and thought, "oh I could get more hours than that if I went cheaper", and they've been told they couldn't… if you are a new person and you're arranging support, they should actually give you the list of approved providers. They never give the list to anybody.*
>
> *(Sandra, 60s, mum to Sharon 30s)*

Whilst SDS policy was underpinned by independent living values, participants experienced implementation as restricting choices, increasing isolation, and reducing opportunities for independent living. An important contributory factor was the lack of joined up policy approaches, including the provision of community resources and support for carers. Several participants were concerned about reduced opportunities for college courses, linked to separate funding streams for social care and education support, as well as constrained further education funding.

Service provision is discussed further in Chapter six, however it is also relevant here because these examples illustrate that choice and control are not unrestricted, uncontested concepts. For many participants in this study, individual choice and control was an illusion, because the possibilities for choice and control were determined by the powerful organisations and structures within which individuals operated.

The lack of community facilities, specialist provision, and support to access mainstream activities can contribute towards the marginalisation and isolation of people with learning disabilities. Two mothers suggested that isolation could be particularly damaging for some people who have autism because they will stay at home, unable to cope with the outside world, when appropriate interventions could avoid this, as Elizabeth explained:

> *…not getting access to any social facilities… become really almost recluse. Because in autism, that's an easy thing to do, you know? They just go to their room and they have their telly and they have their computers and they don't want to interact… they get isolated as they stop meeting other people. It almost self-perpetuates itself.*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

Reduced opportunities for independent living are further evidenced by an increase in guardianships in the GCC area[35]. Several families in this study reported that they had arranged guardianship as a direct result of SDS implementation, and this can be interpreted as a loss of choice and control for the person with learning disabilities. However, one mother had refused to apply for guardianship because she strongly believed that her daughter should be able to make her own decisions:

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[35] http://www.ldascotland.org/guardianship/

> *…why go doon that road [applying for guardianship] when Michelle can say aye and no?*
>
> *(Janet, 50s, mum to Michelle, 30s)*

SDS values and principles not embedded throughout the process

Participants believed social workers were being constrained by management. Despite the policy narrative of collaboration and equal partnerships, practitioners were disempowered by institutional structures. For example, one family were unusual in that they had an existing strong and long-standing relationship with their social worker, and they worked together over a considerable amount of time to agree the assessment. However, the social worker subsequently came back and told the family that some of the responses they had agreed together were being changed:

> *…We agreed on everything... if that's her opinion and then she goes away and "we've downgraded it" and [social worker] has to come back cause she works for them… saying, "oh it was a misunderstanding". And you think, "no… it's the bloody system". And she knows that as well. But she's in an awkward position… it's not the social workers – it's this hierarchy! She's done a good job, she's done her best ... It's no' her problem.*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

The example above demonstrates that the power of management as ultimate decision makers can undermine attempts at co-production. Although the values of social work[36] correspond with the ethos of SDS, the professional expertise of social workers was undermined by implementation. Collaboration was impossible within unequal relationships; there were tensions and conflict because social workers were being constrained by resource decisions.

Ultimately, it was felt across the study that decisions were being made at a higher level, by people completely removed from the recipients of policy, and where the impact of those decisions was felt less acutely. Participants believed decisions were made simply on the basis of cost savings and were understandably angry about this.

The closure of the day centres had contributed towards participants' views of decision makers as detached and uncaring. During the consultation period, local authority representatives had not come across positively in public meetings, as the following (typical) examples show:

> *... [senior local authority official] was an arrogant swine. He says: "I'm not here to be badgered" ... We're just trying tae get answers!*
>
> *(Dan, 60s, dad to Derek, 40s)*

> *...I said: "Do you know, there's no inspiration or aspiration in these services." He [senior local authority official] said: "We don't do that. We just do need".*

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[36] Social work values and principles (including commitment to human rights, social justice and professional integrity) are outlined in the BASW code of ethics: https://www.basw.co.uk/about-basw/code-ethics

(Elizabeth, 60s, mum to Catherine, 30s)

There were many similar narratives in the interviews, suggesting that the values and principles of SDS had not been embedded throughout the system and were not being felt by those using the system. In order to achieve the transformation in social care promised by SDS, values and principles cannot simply be the responsibility of practitioners; the ethos of the Act requires it to be understood and enacted by policymakers at all levels.

Rather than an opportunity to empower, SDS had been experienced by those interviewed as the exercise of power by policymakers, practitioners and ‘experts’. Policy rhetoric concerning collaboration and involvement assumes equal partnerships and equal power relations, but this was not the case in this study. Whilst some families were more able to challenge authority than others, power was ultimately felt to lie with those who controlled resources.

5.4.3. Difficult to challenge

Several participants were acutely aware of the gap between SDS policy and practice, but it was extremely difficult for them to challenge the local authority. As discussed earlier in this chapter, carers felt powerless to challenge social workers, though some were more able than others; for example, Maureen and Dan drew on their professional skills and experience in negotiating the assessment process. However, there were additional practical and emotional factors affecting participants’ ability to challenge decisions. Challenging the local authority was a risky strategy, because families were dependent on services and three families suggested there could be negative consequences for individuals who challenged decisions. Perceptions of processes of intimidation at play were illustrated by Deborah:

> *…you kinda become a target then… Any kinda vocal carer in Glasgow that kinda challenges Glasgow City Council… you start tae get targeted and you start tae get scrutinised.*
>
> *(Deborah, 50s, mum to Michael, 30s)*

A further factor affecting the ability of carers to challenge the local authority was the lack of politicisation of carers. Many participants felt any previous solidarity had broken down and families had become self-interested. This was attributed to the closure of day centres, as well as the impact of health and ageing. The closure of day centres meant that carers had fewer opportunities to meet with other families, and there was also a legacy of acrimonious relationships related to the campaign against the closures (discussed in chapter six). Processes of depoliticisation were evident in several narratives, for example, Mhairi believed that:

> *…folk are very much browbeaten… looking out for their own families as much as they can... that's why you've got folk thinking: "I'm alright Jack"... they've no' got time to meet up with other folk... "how are you, what's happening in your family?... could we band together and put forward a case for this, that, or the other?"*
>
> *(Mhairi, 50s, sister to Theresa, 50s)*

This section discussed the difficulties of collaborative policy within the context of inherent inequalities of power. In conflict with SDS policy values and principles, participants experienced the SDS process as disempowering, reinforcing the power of professionals over their lives. Local implementation and accountability were major issues, as participants felt let down and unsupported, yet were unable to challenge decisions.

5.5. Conclusion

This chapter set out to show how participants experienced the shift to personalisation, focusing on the assessment process and SDS implementation, and provides evidence of a vast gap between policy and practice. Beginning with carers' experiences of the SDS assessment process, the discussion showed how initial high hopes turned into disappointment for families.

Analysis of participants' experiences of SDS assessment highlights the absence of care, as conceptualised by Tronto (1993) in the implementation of social care policy. As discussed in chapter two, Tronto (1993) proposed four phases of care (caring about; caring for; care giving; and care receiving) and associated moral values (attentiveness; responsibility; competence; and responsiveness), arguing that good care requires all four phases to work together. Participants' experiences of the SDS assessment process demonstrated the absence of all four phases of care, illustrating a lack of care, for and about, the intended recipients of social care policy.

Discussion of the context and timing of SDS implementation for people with learning disabilities in Glasgow drew attention to the impact of austerity and long-standing resourcing issues within social work. The chapter concludes by examining the unequal power relationships and hierarchies which were evident in participants' experience of assessments. The data presented in this chapter suggests that clear systems and processes could have helped to address some of the barriers to achieving the policy values and principles, and proposes that the ethos of SDS has not been embedded throughout the policymaking process.

The next chapter further develops this discussion by focusing on participants' experiences of social care services and support. Chapter six begins by looking at the closure of day centres and the impact this has had on the lives of participants before moving on to look at participants' experiences of (ostensibly) more personalised support, following the closure of day centres.

6. 'Personalised' Care and Support

6.1. Introduction

This thesis set out to understand the day-to-day lived experiences of people with learning disabilities and their families at a time of major change to social care policy and service provision. The previous chapter drew on interview data to begin to show how participants experienced the shift to personalisation, focusing on self-directed support (SDS) assessment and implementation. This chapter further develops the discussion by showing how participants experienced support services.

One of the main issues affecting learning disability service provision in Glasgow at the time of this study was the widespread closure of local authority day centres. Thus, the first section of this chapter looks at the closure of day centres (see section 2.4) and the impact this has had on the lives of participants. The second section of this chapter then moves on to look at participants' experiences of (ostensibly) more personalised services, following the closure of day centres.

6.2. Part 1: Exploring the Impact of Day Centre Closures

This study focused on the experiences of people with learning disabilities and their families in Glasgow. Whilst social care policy is set at the national level, policy implementation is devolved to local authorities, so the experiences of people in different areas may differ as a result of local decision-making in relation to service provision and budget allocation. An important change throughout Scotland has been the introduction of the Social Care (Self-directed Support) (Scotland) Act 2013, putting a duty on all local authorities to offer SDS to eligible people with effect from April 2014, the development of which is discussed at length in chapter three. Prior to the 2013 Act, Glasgow City Council was involved in the pilot of SDS (Scottish Government, 2011a) and was one of the first local authorities in Scotland to roll-out the policy (Smith, 2014). This meant that some participants had longer experience of SDS than people in other authorities elsewhere in the country.

In addition to changes as a result of wider welfare reform, there has been significant change in local service provision, coinciding with the introduction of SDS. In Glasgow, it has been argued by some commentators that SDS was seen as a means to reduce social care spending at a time when local authority budgets were facing substantial cuts as a result of austerity measures (Ferguson and Lavalette, 2014; Smith, 2014). Furthermore, it has been suggested that the widespread closure of day centres for people with learning disabilities was one of the ways in which Glasgow City Council attempted to make the cost savings required as a result of the reduction in their social care budget (Main, 2014). As outlined in chapter two, day centres are a highly contested issue; on the one hand, they are critiqued for their role in the segregation of disabled people from ‘mainstream’ society, whilst on the other hand, they are highly valued by many people with learning disabilities and their families who have strongly resisted closures.

Notwithstanding these contested understandings, for participants in this study, the programme of widespread closures in Glasgow resulted in significant change in the day-to-day lives of the people who attended the centres and their families - many of whom have been faced with making alternative arrangements, often with limited funds. As commentators such as Main (2014: 38) have argued, this group has experienced the move to SDS in terms of offering them ‘less choice, less money and less say’.

The first section of this chapter on ‘personalised’ service provision begins by looking at participants’ experiences of the day centre closure consultation process. It presents evidence of their lack of choice and control, contrary to the policy narrative. Participants were clear that many people wanted to go to day centres and were being denied the opportunity to do so, under the guise of choice and control. In contrast to critiques of day centres and the marginalisation of people with learning disabilities, participants' narratives strongly highlighted positive aspects of attending a day centre, including feelings of belonging and inclusion. Following the discussion of participants' lack of choice and control in relation to the closure of day centres, the chapter moves on to consider day centres as places of care and inclusion for people with learning disabilities and their families.

Part two of this chapter explores participants' experiences of services following the closure of day centres and the implementation of SDS. Instead of the more 'personalised' support envisioned by the Act (discussed in chapter three), participants' narratives revealed no evidence of a power shift from professionals and service providers to individuals and families.

6.2.1. Experiences of 'choice and control' in day centre closures

Personalisation policy is associated with the concepts of choice and control, yet the widespread closure of day centres for people with learning disabilities undoubtedly resulted in reduced opportunities for choice and control for the vast majority of participants. As discussed in the previous chapter, the context and timing of implementation resulted in SDS being conflated with cuts and closures for participants.

Of the eighteen people with learning disabilities involved in this study[37], eight had attended day centres prior to SDS implementation. Following SDS implementation and the restructure of learning disability services, only one participant attended a day centre. However, the reduction in the number of those attending day centres was not evidence of increased individual choice and control. Instead, participants emphasised what they perceived as a lack of choice and control, as Deborah explained:

> *…[SDS] was a smokescreen for the day centre closures. There is very much learning disabled people who want tae attend a day centre. Noo, they people should be able tae make that choice… they've been told: "No, you can't, because you're not in a wheelchair. You can't go because your centre's shutting down" …*
>
> *(Deborah, 50s, mum to Michael, 30s)*

Six people who had attended day centres immediately prior to the restructure strongly wished to continue with this arrangement, but had been denied the opportunity. SDS had therefore effectively afforded only one participant choice and control and the opportunity to explore alternative support arrangements, but this was not the case for the vast majority of this group.

6.2.2. The consultation process

Participants' experiences of the local authority consultation concerning the closure of day centres highlighted further evidence of their lack of choice and

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[37] 13 people with learning disabilities took part in the interviews. A further 5 people with learning disabilities were not included in the interviews (2F & 3M) as their family members advised that they would be unable to take part due to capacity.

control, contrary to the policy narrative. Overwhelmingly, participants felt that GCC had already made the decision to close day centres prior to entering into the consultation. This group strongly believed that the concerns and opinions voiced by those who attended the centres and their families, in numerous meetings and communications during the consultation period, were not listened to by the local authority, as Irene and Mhairi explained:

> *I: …you were going to they meetings and it was a done deal… you didnae have a hope in hell…*
>
> *M: They dressed it up as if they were really giving consideration to what people really wanted. They weren't… they had made up their minds…*
>
> *I: They said there was a consultation but nobody to this day knows where the consultation was at the initial stages... we don't know anything about that.*
>
> *M: …it was a Professor somebody, he was saying: "this is wrong, you cannae be doing this" but the council just went right ahead and did it... They didn't take the advice of anybody, **they had made their minds up and that's what they were going to do**.*
>
> *(Irene and Mhairi, 50s, sisters to Theresa, 50s)*

The disempowering effect of holding a consultation in which participants did not feel listened to was particularly powerfully illustrated by Irene, who recalled attending a meeting where the local authority had invited speakers from other service provider organisations:

> *…at this point, we're still fighting to try and save [centre] and they're bringing on other providers… **so they're kinda telling us, we have no say,** you're no' saving them, and this is your options here…*
>
> *(Irene, 50s, sister to Theresa, 50s)*

The narratives of participants in this study suggest that only those perspectives which were conducive to achieving the local authority priority of cost reduction were heard. It was felt that the voices of those who wanted to retain the day centres – and those who arguably had most to lose by the closures – were disregarded, which was in conflict with the policy principles of co-production and collaboration outlined in chapter three. Participants strongly believed that people with learning disabilities should be involved in decisions about service provision, however there was little evidence that the voices of those who attended day centres had been listened to by the local authority. Several participants recalled incidents during the consultation when they had felt ignored, patronised, or disrespected by local authority representatives, as Sheila explained:

> *…they just weren't interested… didn't even say sorry… I can remember meeting some of them… just sitting staring into space, wasn't even listening to what was being said on the floor… it's just a job or something and you can detach yourself from the reality of it…*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Despite 'involvement' being a national statutory principle of SDS, only the perspectives of the minority of stakeholders who supported the council's proposal of closure were utilised.

Additionally, there was evidence of the intersection of power and structural inequalities, including class and gender, in participants' narratives of the consultation process. The campaign to save the day centres largely involved working-class women, whilst the decision makers were largely middle-class men. Mhairi and Irene reflected on the perceived assumptions held about them:

> *M: …I'll never forget… we were leaving one of the meetings and he [GCC official] said: "I'd like to congratulate you on the way you've conducted yourselves" … because we all didnae go bananas in the meeting…*
>
> *I: He thought it was gonie be a rabble…*
>
> *(Mhairi and Irene, 50s, sisters to Theresa, 50s)*

Furthermore, families were deeply hurt and angry about the comparison of day centres to long stay institutions. This was partly because of contested understandings of 'institution'; some families disputed that day centres were institutions, whilst others agreed they were, but rejected negative connotations of the term. Those who rejected negative connotations proposed instead that institutions were a routine part of daily life, as explained by Mhairi:

> *…when you go to work, you're institutionalised, you know, you're going in from 9 'til 5. I think it suited them to use the word "institutionalised" in a real NEGATIVE context, rather than, you're going in, meeting up with folk that you know, and you're chatting… this is your routine…*
>
> *(Mhairi, 50s, sister to Theresa, 50s)*

An important reason for anger about the comparison of day centres to long stay institutions was because families, particularly parents, were furious about the implicit suggestion that parents wanted their sons and daughters ‘locked away’. For families, this misconception confirmed to them that the local authority had no real understanding of day centre life.

Several participants knew people who had been ‘patients’ in Lennox Castle[38], and one participant, Scott, had lived in Lennox Castle for many years. This suggests that participants were well qualified to observe differences or similarities between day centres and long stay institutions. Pauline (40s) and her dad Richard (90s) spoke about people they knew from the day centre that had lived in Lennox Castle. Richard strongly agreed with the closure of long stay institutions, describing Lennox Castle as ‘a dumping ground’, and felt there had been considerable progress in the treatment of disabled people during Pauline’s lifetime; though he disagreed with the closure of the day centres. However, the expert knowledge and lived experience of disabled people and their families was dismissed and disputed by powerful ‘expert’ professionals and decision makers.

Ultimately, the campaign to save the day centres, and the subsequent defeat, had taken a toll on those participants who had been actively involved, furthering feelings of disempowerment, as Susan explained:

> *…it all came to nothing in the end and I really feel quite scarred… it took a lot out of me. We used to go to these meetings and I was in tears in the*

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[38] Lennox Castle Hospital was a large institution in Dunbartonshire, which was built to house approximately 1200 people with learning disabilities in 1936. It was eventually closed in 2002. See: http://www.lennoxcastlestories.co.uk/

> *City Chambers one day and I thought: “I can't keep doing this” … It was tearing me apart, hearing all these stories… the hardships and the problems…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

6.2.3. The emotional impact

The ages of the eight participants who attended day centres prior to the closures ranged from early 30s to mid-50s. They had all attended special schools, and all except the youngest participant had gone straight into the day centre system on leaving school. The average duration of day centre attendance was 27 years, and participants went to their centres five days per week, so they had firmly established routines and relationships centred round the day centre.

> *There was people that Lorna had known for thirty years at the centre, 'cause it was the same people that went. …she'd grown up, you know, wi' the other service users. …I've seen some o' them come in straight from school – like kids – and they're in their forties now.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Day centre closures were experienced as a major disruption to daily routines and relationships. They were greatly missed by participants, and the closures had resulted in feelings of loss, hurt, distress and confusion for those who had attended the centres themselves, and also their family members. For the seven participants who had attended day centres until they closed, the emotional impact of the closures was exacerbated because of the difficulties in understanding this momentous change. This was powerfully explained by two family carers:

> *…it’s just so difficult to explain to her… she doesn’t understand yet. She used to say: “I want to go back to [centre]” … “no, can’t do that”, “PLEASE MUM? I WANT TO GO BACK!” … “Can’t do that dear” … she’s been broken-hearted.*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

> *…trying to cope with Lorna leaving her centre and going to new services was very stressful... tears every day. Terrible times, trying to cope with it. She didn't want to go. She really didn't want to leave her centre. She said: “I'm not leaving my centre.” Oh, it was terrible! You had to literally take her fingers off the bus… she just didn't want to leave and she still wants to go back…*
>
> *(Susan 50s, sister to Lorna, 50s)*

For many of the participants who had attended day centres, the nature of impairment affected their ability to articulate emotions verbally during the interviews. Whilst family carers provided extensive narratives of the emotional impact of the closures, those participants with learning disabilities, who were most directly affected by the closures, provided only short responses to questions. This is illustrated in the quotes below, which were extracts from separate interviews with two friends, Joyce and Raymond, who had both attended day centres for over 30 years:

> *J: A lot of folk like going to their centres and it’s hard for a lot of people to leave.*

> *K: Was it hard for you at the time?*
>
> *J: It was hard for me at the time, aye. It was hard for Raymond as well. Raymond was upset when he left that day and so was I.*
>
> *(Joyce, 50s, attended day centres for over 30 years)*

> *K: So, tell me about what you like to do…*
>
> *R: I miss the centre.*
>
> *K: Yeah, what is it you miss about it?*
>
> *R: The centre.*
>
> *(Raymond, 50s, attended day centres for over 30 years)*

There are particular considerations in carrying out research with people with learning disabilities, which are discussed at length in chapter four. In this study, one of the challenges was giving sufficient weight to the voices of participants with learning disabilities when the voices of family carers were much more evident in the data. Despite the brief verbal responses, the emotional impact of the closures was apparent in the demeanour and expressions of participants, and it was clear to me that the feelings of sadness and loss ran deep. During one interview, I was aware that one of the participants, Theresa, was visibly sad and tearful whilst her sisters spoke about her day centre. Issues in relation to researching sensitive topics are also discussed in chapter four. In this case, whilst I was keen to hear what Theresa thought and felt about the day centre, in addition to her sisters' perspectives, I was reluctant to pursue this line of questioning because I did not want to cause her further distress. The following interaction took place when Theresa left the room to go into the kitchen:

K: I was just conscious about asking there… I didn't know about asking Theresa about her centre… She looked really sad when we were talking about it.

I: Ask her about it if you want to.

K: I don't want to upset her though.

I: No, it'll no'. She really liked [centre], she really enjoyed it… but [the day centre] was closing anyway… she had to move on.

… [Theresa returns to the room] …

K: …Theresa, how did you feel about [the day centre] closing?

T: Gutted.

K: Were you gutted?

T: Gutted, aye.

K: What did you like about going to [centre]?

T: Well… I've got friends as well.

K: Yeah…

T: Tam Hennigan and all that.

K: So, do you no' see them anymore?

T: Nope.

(Sisters Theresa and Irene, 50s)

Like Joyce and Raymond (above), and Gillian, Lorna, Michelle, and Pauline, it was clear from their sad, and sometimes tearful, physical response in the interviews that the emotional impact of the closure of the centres was felt deeply. The loss of friendships and relationships was particularly notable in participants' narratives and is discussed in part 2 of this chapter, and in chapter seven. The neglect of their perspectives in the consultation process evidently served to silence, disempower and exclude people with learning disabilities. Importantly, there was one example of blatant disregard and silencing of disabled people's emotions from Janet, whose daughter Michelle attended a day centre with her friend Duncan:

> *"I want my day centre, I want tae die in my centre", that's what he [Duncan] always used tae say. And* ***he was told no' tae say it again****.*
>
> *(Janet 50s, mum to Michelle, 30s)*

As discussed in the previous section on the consultation process, it was strongly felt that the voices of those who wanted to retain the day centres were disregarded in favour of those perspectives which were conducive to achieving the local authority priority of cost reduction. These data suggest that the difficulties experienced by people with learning disabilities in verbally articulating emotions may make it easier for them to be discounted and disregarded by those making decisions about policy implementation and service provision.

6.2.4. Day centres as places of care and inclusion

In contrast with professional and political narratives about day centres contributing towards the segregation and exclusion of disabled people (as outlined in chapter two), for participants, one of the most important and overlooked functions of day centres was that of being a place of inclusion. This was particularly important because participants experienced few opportunities for inclusion elsewhere, as Elizabeth explained:

> *…to say that people can all be in the community, it's all very well, but the community has not got anything for them. There's not enough services yet in the community. And they actually do need a building of some sort to go to, even if it's to meet or to have lunch or do something…*
>
> *(Elizabeth, 60s mum to Catherine, 30s)*

In restructuring learning disability service provision to only provide day centres for people with the most complex or profound needs, people with learning disabilities have been segregated by the perceived extent of impairment and, as such, further isolated from their own communities. Thus, it was felt that the closure of day centres simply served to further discriminate and exclude people from places where they previously experienced inclusion and relationships.

The gap between perceptions of day centres by those outwith and within the day centre community was illustrated by one family. Janet had initially not wanted her daughter to go to a day centre and was keen for Michelle to be included in mainstream activities and to attend college. However, after spending two years on various courses and feeling isolated and excluded, the family agreed to a trial at a day centre, which Michelle loved from the first day:

> *Council say we're feart of change, I'm no' feart of change, don't stand there and criticise me as a parent and a carer cos my daughter never went to a day centre, until the day she did go, she wisnae isolated after that…she never went 'til she was about 20 odd, and she went and she came back skipping in the gate, "I met this yin, and I met that yin, and look at this"… I couldn't get over it... the biggest mistake I've made. I isolated her.*
>
> *(Janet, 50s, mum to Michelle, 30s)*

The quote above illustrates differing perceptions of day centres and inclusion; Michelle felt excluded at college and included at the day centre. Participants' experiences of attending college are discussed in part two of this chapter.

Belonging and community

> *For thirty-two years she was there five days a week. From twenty, she went, to fifty-two.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Like Lorna, several participants had attended day centres for their entire adult lives. The closure of the centres resulted in a loss of familiar routines and relationships which had structured participants' lives. Although families generally acknowledged that day centres were 'not perfect' (Irene), those participants who had attended the centres themselves reported that they had been happy there.

Only those people assessed as having the most complex needs were able to access local authority day centre provision following the restructure. One participant in this study, Derek, had moved to a different day centre following the closure of his previous centre. The importance of the day centre in Derek's life, and his distress during the period of the re-structure, was explained by his parents, Maureen and Dan:

> *M: He was so distressed about the whole thing… "Am I gonnae get my centre?" … see if he's got a migraine, he can't go, he's really upset. His centre's his life.*
>
> *D: If it's a long weekend… he's just: "When am I going back? Is it Monday yet?"*
>
> *M: …he doesn't have a life. Do you know what I mean? He can only go out if we take him out. But he's happy as long as he's going to his centre.*
>
> *D: …he's happy because he's got a life in the centre. If that stopped, he would be unhappy.*
>
> *(Maureen and Dan, 60s, parents to Derek, 40s)*

Furthermore, the day centre was vital in supporting Dan and Maureen to be able to continue caring for Derek at home:

> *D: See, if he didn't go to that centre, I don't know what we'd do.*

> *M: We couldn't cope. …Over and above caring, you're worrying about that [closures]. And Derek's got very complex health needs…*
>
> *(Maureen and Dan, 60s, parents to Derek, 40s)*

Family members strongly felt the day centres were part of the local community as well as a community within themselves, where disabled people and their families and support staff experienced belonging.

Places of care

Within the context of hostile and risky environments for people with learning disabilities (see chapter seven), having a place where people feel safe has arguably never been more important. Family members acknowledged that day centres were not perfect; however, there was accountability and resolutions when things went wrong. For example, Michelle had been bullied at the day centre but this was resolved once it was brought to the attention of the staff:

> *…there's always staff aboot… I'm no' saying they were aw the best… but they were good. You were guaranteed if anything happened that there's gonnae be a comeback on it…*
>
> *(Janet, 50s, mum to Michelle, 30s)*

Having confidence in staff was very important to carers. Fostering trusting relationships was highly valued, but this requires time and consistency in staffing.

It was clear from participants' narratives that, in many cases, day centres were more than safe places; they were caring places, where attentive relationships existed. Individuals and families knew workers, and workers understood likes and dislikes as well as support needs. Janet gave the example of workers knowing when people needed encouragement to do things, so they would prompt them to take off their coat or go to the toilet. Additionally, Susan valued the relationship between day centre staff and the whole family, which meant when she phoned the centre, she knew exactly who she was speaking to and they knew exactly who she was.

Care was also important in relation to health needs. For Lorna's family, it was particularly important that staff understood her specific medical needs, and they felt confident that staff were able to care for her when she became ill, as sometimes happened.

Health and therapeutic needs

Day centres also provided valued health and therapeutic benefits. Participants recounted close involvement with health professionals, including physiotherapists, occupational therapists and learning disability nurses, who were either based in the centre or visited regularly. Many participants had long-term health conditions and access to these services was viewed as an important factor in maintaining or managing health and wellbeing. The benefits of health professionals working within the day centre included building effective relationships and providing individual therapy; for example, Derek was being encouraged to maintain strength in his legs through exercise and activities.

Additionally, health professionals provided programme input and supported day centre staff to offer therapeutic activities. For example, Michelle was encouraged by staff to be physically active through activities she enjoyed, like using the trampoline, in the day centre. The close relationship with health professionals helped to monitor and manage existing health conditions, as well as promoting a preventative approach to health and wellbeing. Janet believed that day centre staff were attentive to individual health needs and '...*watched oot for other things'*, and Susan felt confident that Lorna's health condition was being monitored and any potential concerns addressed.

Activities

Participants recounted a wide range of activities undertaken at day centres over the years. Activities which people had enjoyed included: exercise and dance classes, music and drama, arts and crafts, sports and games, gardening, computers, and nail painting. Several family members reported that day centre staff were attentive to the needs and interests of individuals, and skilled in thinking up ideas and making suggestions for activities. For example, Pauline and Lorna both enjoyed work experience within the day centre – assisting on reception, in the office, in the cafe and in the hairdressers. The opportunity to develop skills was a valuable benefit for many participants, and creative, attentive staff were highly valued:

> *There's a guy in [centre] an' I don't know how he did this, he actually taught Derek the alphabet… on the keyboard. I mean, I've tried in the past. He can't read and all the rest of it, but he now knows the alphabet from the keyboard and Jack taught him this. He's a great guy.*
>
> *(Dan, 60s, dad to Derek, 40s)*

In recent years, activities within the day centres had reduced and there were more opportunities to take part in activities within the community. For some people, this was a positive change which enabled them to gain work experience and develop skills, including independent travel. For Michelle, the day centre provided a base from which she could pursue other interests and she enjoyed work experience in a cafe, where she learned to make and serve tea and sandwiches:

> *…she wisnae really in the day centre, she was oot… She was signing in… then leaving... they were dain' sports… healthy eating, keep fit, things like that. They were going oot and dain' that ootside the building…*
>
> *(Janet, 50s, mum to Michelle, 30s)*

However, the shift to community inclusion was less positive for other participants:

> *…the council cut it back so you had to go out and use the things in the community… and that became more of a problem, cos at one point, Gillian refused to get back on the bus…*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Whilst participants enjoyed a range of activities at day centres, it was clear that relationships were the most important factor:

> *K: …and what was the best thing about the centre?*
>
> *P: I just liked meeting up with my friends and stuff like that. And if you had any problems you spoke to them.*
>
> *(Pauline, 40s, attended day centre for 25 years until closure)*

Friendships

The importance of friendships and the impact of friendships lost was a powerful narrative for many participants, as Elizabeth explained:

> *…they're asking about: "Oh, where's so-and-so today?" and "Is he coming?" or "Is she coming?" and it's all part of it… when you shut down day centres, you take away all these friendships from people.*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

For example, Pauline had attended a day centre for 25 years, since leaving her special school. She had lots of friends at the centre, many of whom she had known since childhood, and she particularly missed one friend who had supported her when her mum died. Pauline was visibly emotional when speaking about her friend, and her dad Richard acknowledged 'she feels it deeply'. Interestingly, when Pauline spoke about not seeing her friends anymore, Richard interjected '*you see them in [supermarket] constantly*'. However, brief chance meetings in the supermarket were far removed from the familiarity and intimacy which comes from seeing the same people every day and spending prolonged periods of time together. Richard's almost flippant disregard for Pauline's friendships in this respect appeared in stark contrast with his previous acknowledgement of Pauline's feelings, which suggested that he may have been trying to alleviate Pauline's feelings of loss by reassuring her that her friends had not completely disappeared. The complexity of researching families and relationships, and particularly family group interviews, are discussed in chapter four. The extract below provides an emotive example of Pauline’s relationship with her friend, how close they were and how deeply she feels this loss, as well as Richard’s love and care for his daughter and her emotions:

> *R: …Pauline took it badly and so did I, but I says: “Pauline, your mother would've told you that life is for living.”*
>
> *P: … I've went tae phone [friend], she must've knew right away because she started crying as well.*
>
> …
>
> *R: …from the age of six or seven, they went through all the handicapped [sic] centres and schools, and they were friends up until, what, two or three years ago at the most? But, suddenly, the girl's disappeared off the face of the earth. And she was so friendly. And it comes over her now and again, what's happened to her. “Why has she not contacted me?” I say: “Oh, Pauline, there's umpteen things might've happened.” …Pauline still thinks about her. She's got the feelings that… they're sometimes too deep wi' Pauline. Which you would say, well, it's better that than not caring at all. But she looks after me well, don't you?*
>
> *(Richard, 90s, and Pauline, 40s)*

The extract above demonstrates the importance of relationships and the emotional impact of friendships lost. The closure of day centres neglects the value of relationships. When families raised the issue of day centres as a source of social lives in meetings with the local authority, it was suggested that they could organise this themselves, as Irene explained:

> *…the kinda socialisation aspect… these guys really need… it's like, they're going to their work and they're meeting the same folk, and they NEED that social aspect… "where are they gonie go, when all these places are closed?" He [GCC official) said: "get a room, you can hire out a room somewhere"*
>
> *(Irene, 50s, sister to Theresa, 50s)*

The suggestion that people’s needs in relation to social lives and friendships could be met simply by hiring a room demonstrated that local authority officials had no real understanding of the complex reality of people’s lives and the role of day centres. For participants, day centres were much more than a physical place which could simply be substituted for a hired room; day centres were the people and relationships that went on within the building. In addition to failing to recognise the value of relationships for wellbeing, and the importance of place in facilitating and maintaining relationships for people with learning disabilities, the assumption that family carers could organise social opportunities themselves neglects the logistical difficulties in self-organising for disabled people and family carers. Because it was mainly older adults who attended day centres, this responsibility largely fell to elderly parent carers, as Mhairi explained:

> *“…get a room somewhere and people will all be able to meet up” …no’ even giving any consideration to the fact that a number of the carers are in their 70s and 80s… they wouldn't be able to do it… the centres were a lifeline for folk, many of whom were single carers as well, given the age of them.*
>
> *(Mhairi, 50s, sister to Theresa, 50s)*

Staff relationships

In addition to peer relationships, participants had also often known day centre staff members for many years, and several of the people who had attended day centres considered staff members to be friends.

These relationships defied conventional boundaries of friendship because of the absence of reciprocity; it is unlikely that the staff members would describe their 'clients' or 'service users' as friends. Nonetheless, it was clear that there were personal, attentive and caring relationships between participants and staff, which were valued by those who attended the centres and their families. For example, having a relationship with the staff at Lorna's day centre was highly valued by her family:

> *…when you have a key worker they get to know you as a family very well… You build quite a personalised relationship… they know how you are. They just know the family. And we don't have that at all now… we knew about their life and their families. I don't know anything about the people that deal with her now, not a thing. There's nothing personalised about the relationships. And she [Lorna] doesn't know either.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

In addition to the loss of friendships between peers discussed in the previous section, several participants felt the loss of staff relationships deeply. Affection towards staff, and feelings of sadness as a result of the loss of these relationships were powerfully illustrated by Theresa and her sister Irene. Following the closure of the day centre, the family had organised a get together in the function room of a local pub to celebrate Theresa's birthday, and Theresa and her friends from the day centre were delighted to see her former key worker, Jill:

> *I: …we invited her [Jill] and she came as well, so they were all really pleased to see her*
>
> *T: Mind ma face*
>
> *I: Aw Theresa... aye, the tears were running doon your face when she walked in*
>
> *K: ...cos you were that happy to see her?*
>
> *T: Aye the tears were running doon ma face*
>
> *I: Cos I hadn't told Theresa that Jill was gonie come cos we weren't sure if she was gonie make it or not... if it hadn't shut Jill would still have been working there... Theresa had a great relationship with Jill.*
>
> *(Theresa, 50s, and her sister Irene, 50s)*

All of the participants who had experience of day centres recalled individual members of staff with whom they had special relationships. Day centre staff were often viewed as confidantes by those participants who attended the centres, and family members felt it was important that they had a trusted person outside the family whom they could speak to:

> *…she loved her driver and escort, she really did. She saved all the best stories for them. And sometimes… if there was something with her that we didn't know about, the escort could tell us… 'Cause she knew, she had*

> *conversations with her that we didn't have. She was a bit of a confidante to her as well. She loved her.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

For Susan and Lorna, Lorna's relationship with her bus escort was particularly highly valued because Lorna often forgot to tell her sisters things that had happened during the day and the escort could help ensure they received relevant information.

6.2.5. Exploring the Impact of Day Centre Closures – concluding comments

Part one of this chapter discussed the closure of day centres, which was part of the local implementation of SDS in Glasgow, and the impact this has had on the lives of participants. The data revealed little evidence of the independent living values (set out in chapter three), as well as the statutory principles of participation and dignity, involvement, informed choice and collaboration underpinning SDS, in relation to the closure of day centres for people with learning disabilities in Glasgow.

Day centre closures had a substantial detrimental impact in the lives of many participants. In relation to Tronto's conceptualisation of care (see chapter two), analysis of participants' experiences illustrated the absence of care in the closure of day centres. Analysis of the impact of day centre closures revealed little evidence of ethics of care. Notably, the local authority's apparent disregard for the opinions and perspectives of the people who attended day centres and their families suggested a lack of caring about and caring for (Tronto, 1993) the needs of this group. Furthermore, in contrast with the negative perceptions of day centres put forward by the local authority, participants had largely experienced day centres as places of care and inclusion. Analysis of participants' narratives revealed evidence of all four phases of care proposed by Tronto (1993); for participants in this study, day centres could be caring places.

In part two of this chapter, the discussion moves on to look at participants' experiences of services following the closure of day centres and the implementation of SDS. Instead of the more 'personalised' support envisioned by the Act (discussed in chapter three), participants' narratives revealed no evidence that power had shifted from professionals and service providers to individuals and families.

6.3. Part 2: From Day Centre Closures to Support in the Community

The shift from local authority social care services towards support in the community had resulted in an increase in learning disability service providers. Whilst this suggested more choice for people who used services, in accordance with SDS values and principles, this was not the experience for participants in this study. Instead, the result of increased numbers of learning disability service providers was more work for carers in managing services and mitigating risks. Although participants were involved in various activities, many felt there was not enough provision for disabled people and spoke of cuts to local social clubs and activities in recent years. Rather than increased choice and inclusion in the community, participants had experienced a reduction in opportunities, and this had led to increased isolation and segregation for some people.

Part two of this chapter on 'Personalised' support begins with a discussion of the activities participants were involved in, and the spaces in which these activities took place, following the shift from largely local authority-provided specialist services to more ‘mainstream’ and community-based services. There were a small number of examples of good quality, co-ordinated service provision in the data, but, more commonly, participants experienced poor quality services which were characterised by ‘filling the time’, service failures, and additional work for carers. The discussion moves on to consider the factors that distinguish the good examples from the bad, drawing on Rogers’ (2016) conceptualisation of ‘care-full’ and ‘care-less’ spaces, outlined in chapter two.

There was a broad spectrum of support arrangements for participants, ranging from two people who did not receive any formal services (although they were eligible and had approved budgets) to one participant who received twenty-four hour support. Some participants had formal support with personal care and household tasks, though this was mainly those who did not live with family members. Those who lived with family members usually had some formal support to participate in social and leisure activities, though the extent of this varied, with personal care and household tasks mainly performed by family carers. For participants living in supported accommodation, there was less evidence of activities outwith the home and little one-to-one time with staff members. The discussion in this section relates to support for participation in social, education and leisure activities, rather than personal care and household tasks, although the two categories sometimes intersect.

6.3.1. Range of activities

Collectively, participants took part in a wide range of activities. However, the quantity, quality and suitability of activities were not evenly distributed. Many participants attended groups and activities organised by support providers, which took place in the organisation's own premises, or in hired rooms in community centres. Activities in these settings included: snooker; table tennis; arts and crafts; jigsaws; and bingo. In most cases, the activities would take place in one room and were limited to 'things you can do at a table' (Susan, 50s, sister to Lorna, 50s). Those who attended these groups usually did so on one or two days each week, and several participants attended two or more of these groups.

Satisfaction with these groups and activities varied, and it was clear that some organisations were providing more person-centred services than others. For example, Paul was passionate about music and was supported by staff to use his knowledge and skills to take on the role of 'pop quiz master'. Similarly, Scott's interest in 'doing paperwork' was harnessed by participating in the group newsletter, supported by staff.

However, there were strong critiques of 'one size fits all' types of activities offered by some services, which appeared to be just about filling the time, rather than attending to individual interests. An example of this approach was given by Susan:

> *There's a lot o' colouring in and a lot o' jigsaws. In fact, she was even taking her own colouring in things in… they didn't have good pens. And I wasn't really impressed with colouring in… Lorna loves computers and drama… she did a photography course at college. So, she could be doing these kinda things…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Several families reported that services had low expectations and aspirations. Rather than a focus on individual outcomes, these families believed that services were solely designed to '...keep them out of harm's way. The goal is don't let it end up in a tragedy...' (Susan). Poor quality activities – related to low expectations and aspirations – caused additional work for one family. Susan felt that Lorna was bored because she was not being stretched or stimulated by the available activities, and this caused her to behave in ways that were challenging for the service provider and for the family. Lorna's family were also particularly annoyed to find out that one of the 'activities' was listening to a novel being read aloud by staff:

> *…after lunch some people need personal care so there's a lot going on, so they would have a story… It could be Catherine Cookson or Maeve Binchy… who's interested in reading a part of a book? Lorna would rather have a football book or read the TV guide or something… I says: "Could you not have a sing-along? Karaoke or something that they could join in?" …*
>
> *(Susan, 50s, sister to Lorna, 50s)*

The quote above reveals how activities were designed around the needs of the service provider; one worker read a story aloud to occupy a group of people whilst other workers attended to personal care needs. The quote also illustrates the absence of person-centred service provision; Lorna was not remotely interested in this activity – it was done *to* her, not *with* her.

6.3.2. Spaces and places of support

Participation in 'mainstream' public spaces included: local authority gyms; libraries; shops; ten-pin bowling; and eating out. Some participants were only accompanied by a support worker, whilst others were in groups with other disabled people and support workers.

Community centres

In many ways, community centres replaced day centres for people with learning disabilities in Glasgow. The majority of participants spoke about community centres as being places they, or people they knew, spent time in, supported by service providers. These activities took place during the day on weekdays, like day centres. The kind of activities (discussed above) which people took part in whilst in the community centres were activities which had also gone on in day centres. However, community centres also differed from day centres in several respects, as discussed below.

Activities were generally limited to one room in the community centres, whilst other groups or activities went on elsewhere in the same building. In contrast, day centres had been largely purpose built and self-contained, so a range of different activities were available in different rooms, which people could move between as they wished. From the experiences of participants in this study, it would appear that people had less autonomy in their day-to-day lives in community centres than in day centres:

> *…she'd more autonomy in the centre because it was a big building and she could wander about. She knew her way… That's what she can't get used to with her new services – she doesn't have the autonomy to go right round the building 'cause she's in a room. She's always in a room now, whereas the centre, they had the run o' the place…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Being physically in the same building as other community groups does not mean people experience inclusion in the community; being restricted to one room with other people with learning disabilities and support workers simply meant that people were segregated within a public place. Furthermore, the ‘community’ in community centre was not even the same geographical community in which people lived; for example, Gillian travelled twelve miles by taxi from her home to a community centre in another part of the city.

Several participants felt that there was a very limited range of poor-quality activities on offer in community centres. This was attributed to low staff numbers and skills, as well as the facilities. Furthermore, because community centres also served other groups within the community, many activities closed during school holidays because the halls were being used for children’s clubs. Whilst families were not satisfied with these arrangements, a lack of alternative options meant they had become resigned to them. For example, Sheila was deeply dissatisfied with the community centre activities Gillian attended, but felt that the only alternative was staying at home:

> *…the support worker will come back and say: “I don’t think she really enjoyed that. The only thing she wanted to do was colouring in and they’d run out of colouring in books” …there’s no alternative, there isn’t anything else to do. So, I kinda think, well she’s better going out and mixing… she’s dependent enough on me.*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Another mum, Janet, was also critical of the poor-quality activities in community centres; she strongly believed that the lack of physical and mental stimulation was detrimental to people’s health and wellbeing. Although Janet’s daughter Michelle was content with the activities on offer, Janet disagreed:

> *…[Michelle] will say aye tae anything. She’ll say: “aye I like dain’ that” … but it’s no’ good for you, going tae sit in that community centre fae ten o’clock in the morning right up tae three o’clock…*
>
> *(Janet, 50s, mum to Michelle, 30s)*

Community centres had become the main replacement for day centres, but without the same level of resources, skills, experience and facilities. In contrast with the policy narrative of choice and control, and focus on individual outcomes, participants’ narratives suggested that those attending community centres did so because of a lack of alternative options and were simply being kept occupied, without any real attempt to meet individual needs or outcomes.

Public places and spaces

Personalisation is part of a broader policy shift from segregated, specialist service provision towards inclusion in the ‘mainstream’ of society, discussed in chapter two. However, there were particular challenges in relation to participation in mainstream activities, and families had mixed experiences of local groups. For example, for Sandra, an important advantage of her daughter Sharon participating in ‘mainstream’ activities was that she became a familiar and accepted person in her local community, and a recent experience provided evidence of this for her:

> *…on the bus with Sharon and this woman said: “Hello Sharon”. And she said: “I know her from [leisure centre]” … things like that, that she’s no’ a scary person… nobody’s frightened of her cause they see her about.*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

The example above demonstrates the importance of people being visible in public places within the area in which they live; however, the previous discussion about community centres showed this was not always the case. Glasgow is a large urban environment and Elizabeth felt this could be a barrier to the inclusion of people with learning disabilities:

> *…a bit of a hit and miss when you've got a big community. A smaller community is much easier*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

Additionally, inclusion in mainstream environments required the acknowledgement of the embodied experiences of impairment; recognising her daughter's individual support needs, Janet felt that:

> *…[the] world is too fast for her. It's too fast for anybody wi' learning disabilities.*
>
> *(Janet, 50s, mum to Michelle, 30s)*

Similarly, Lorna's sister Susan noted that the impact of a chronic health condition intersected with learning disability:

> *…she's really not fit to be going out in the winter time and walking the streets. It's not good for her to be out, going to bus stops, waiting for the bus, getting two buses to go to the bowling…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

One of the barriers to participation was a lack of community resources; none of the people with learning disabilities who participated in this study were in paid employment, only two were volunteering, and two were attending college. The majority of participants felt that there were not enough opportunities for disabled people in relation to education, leisure, employment and volunteering. The existence of community resources was implicit in SDS policy, but the gap between rhetoric and reality was illustrated by Elizabeth:

> *I think it's about actually providing* ***better resources in the community****… it's all very well to say: "Nobody needs a building" but would you have liked to spend, what, a whole day wandering round shopping centres because it's pouring with rain? …There needs to be better resources available. Not necessarily that they're in there the whole time, but there's places to go and things to do…*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

Importantly, the community was seen as a hostile environment for people with learning disabilities. Several participants had direct experience of harassment and abuse in public places; as such, participants believed that they were not wanted in the community and this was a major barrier to their inclusion. Elizabeth explained:

> *…the community doesn't really want them either… people are very intolerant [of difference] … they're bullied and intimidated…*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

The context of fear and vulnerability within which people with learning disabilities and their families exist is discussed in chapter seven, in relation to the emotional context of family care. Chapter seven shows how experiences of verbal and physical abuse impacted upon participants with learning disabilities and those who cared for, and with, them. However, this is also relevant to the discussion here because the policy shift from segregated, specialist service provision towards inclusion in the 'mainstream' does not address the hostile environment which excludes people with learning disabilities.

College

Most participants felt that opportunities to undertake college courses had reduced due to budget cuts, and three participants believed that college places were only available to people with learning disabilities if they were under the age of 25. Only two participants in this study were attending college (both in their early 30s), but a further four had previously undertaken college courses. In addition to fewer places being available (related to further education budget cuts), there were additional barriers due to restrictions on funding to support people in college. For example, whilst the SDS budget could be used for support to get to and from college, it could not be used for support required during the college day.

Colleges were generally viewed positively in terms of skills development, however participation was limited to specific classes (e.g. life skills, cooking, computing) which were often repeated. Furthermore, there was no evidence of inclusion in wider college life; people were segregated and excluded within the college environment in relation to the limited range of ‘special’ courses as well as socially, within the canteen and common areas. One participant, Grant, visited several colleges because of his job, and observed that inclusion was an illusion:

> *…I'd spoke tae one o' the lecturers an' she was saying tae me that it was total integration. I went: “Well, they're no' integrating in here… aw the special needs people are sitting on their own. They're no' mixing wi' normal students.” That was the thing that surprised me, 'cause she was saying tae me: “Oh, it's fantastic. They're integrating wi' aw the other people, the other students.” But, tae me, they weren't… they were aw sitting in their ain wee groups, which is understandable 'cause they're used tae each other an' aw that. There's very few people would approach them and integrate wi' them, you know what I mean? Tae me, it wisnae proper inclusion.*
>
> *(Grant, 50s, brother to Alistair, 50s)*

Specialist groups and activities

In contrast with the policy drive towards ‘mainstream’ provision, there was strong support for specialist groups and activities amongst participants. A minority of participants were involved in a range of interest groups, including: music; drama; dance; arts; and horse riding. There were a range of reported benefits as a result of attending these groups, and participants derived pleasure from different aspects. Some of the benefits of specialist groups was the pleasure and enjoyment derived from the activity, as well as the social aspect of spending time and developing relationships with people outwith the family, as Elizabeth noted:

> *Some of these young people are absolutely fantastic artists. Others are not, but they really enjoy being in the place and with people… it's what each individual gets from it. I mean, Catherine gets the intensity of the painting and being able to use different mediums and work. Other people get the company of people…*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

As well as the social aspects and enjoyment, there were also important benefits in relation to personal development, though this could take a long time. For example, Sharon attended a dance group for five years before she begun to participate; their patience was also paying off in the drama group as Sharon had begun to speak out. Sandra was pleased when another parent commented:

> *"My goodness, what a difference in that girl. She's actually speaking out in the drama class."*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Having a place where people could spend time with peers was viewed as particularly important because of the reduced opportunities for friendships and relationships following the day centre closures, outlined in part one of this chapter.

Specialist groups provided opportunities for inclusion and participation, whilst attending to individual abilities; Sandra particularly valued the slow pace and attentiveness to the needs of each individual offered by the music group Sharon attended:

> *…If you want Sharon to hit something when you tell her you're onto plums! Or even play the same thing twice… you are asking more than is humanly possible! But, you know, there was all sorts of people there. And everybody contributed what they could contribute, and then we had a wee song and it was recorded so it was good participation…*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

The above quote provides evidence of inclusion and participation, which was highly valued by families. Specialist groups recognised that everyone was different and provided a space where different abilities were valued. However, there was one example where a specialist group had not been so inclusive; Janet recalled taking Michelle to a disability drama group where they were told not to come back:

> *…I've never felt under pressure in a' my life wi' somebody wi' learning disabilities trying tae get them tae dae something. She's saying: "that's no how you dae that… you cannae come back" … Tears were running doon ma face … I cannae believe what I put myself through …*
>
> *(Janet, 50s, mum to Michelle, 30s)*

The above example was a very distressing experience for both Janet and Michelle, however this was an isolated example; overall, specialist groups were highly valued by participants for providing a place of inclusion and participation.

Cuts to social groups and activities

As well as cuts to college places, participants felt that opportunities in relation to community groups and social clubs had diminished as a result of local authority budget cuts. This had affected social opportunities, and participants recounted a music group, drama group and film group which had closed due to the withdrawal of funding. In one example, an evening social club had been run by volunteers with financial support from the local authority to cover the cost of the hall and transport. However, the local authority stopped providing a minibus and driver due to budget cuts and the club closed. Several participants felt there was little for them to do in the evenings; there was some awareness of evening social clubs and groups, but it was difficult for people to get there unless transport was provided. However, two participants attended an evening social club run by volunteers, for which transport was provided, though it was not clear how the transport was funded.

‘Care-full' and ‘Care-less’ spaces

There were a small number of examples of good quality, co-ordinated service provision in the data, but, more commonly, participants experienced poor quality services. As noted in chapter two, Rogers (2016) highlights the existence of ‘care-less’ spaces within ostensibly caring settings and within relationships for people with learning disabilities and their families. This section draws on Rogers’ (2016) discussion of ‘care-full’ and ‘care-less’ spaces for people with learning disabilities to categorise participants’ experiences of support services.

‘Care-full' spaces

‘Care-full’ spaces are the settings and relationships where care and caring work are carried out *with* care (Rogers, 2016). There were three examples of good quality, co-ordinated service provision in the data, which are categorised here as ‘care-full’ spaces (Rogers, 2016). Two of these examples predate SDS and were managed by parents who had professional skills and experience which equipped them to act as ‘care managers’. In addition to a range of quality activities, ‘care-full’ spaces involved good relationships and communication between workers and families, and attentiveness to individual need.

One example of ‘care-full’ and personalised service provision was provided by Sandra, who coordinated her daughter Sharon’s support. This was not a result of SDS implementation though, as Sandra had always managed Sharon’s services, thereby suggesting that there was already potential for flexible, individualised services prior to SDS implementation. In fact, the implementation of SDS had made Sandra’s ‘job’ of managing Sharon’s care much more difficult because of delays and bureaucracy. Nonetheless, Sandra’s professional experience offered her a strong starting point to use a budget to ensure Sharon’s needs were met but this was not the case for the vast majority of participants. Sandra explained that the nature of Sharon’s impairment meant that routine was extremely important so they had scheduled a regular programme of activities *“…tae fill her week in a meaningful way”*. Being with other people was also important to Sharon, so Sandra and the service provider scheduled opportunities for her to meet others. For example, on Mondays, Sharon went to an activity with her support worker in the morning, then they met up with two other disabled people and their support workers to have lunch, before going on to another activity in the afternoon.

Similarly, on Tuesdays, Sharon and two other disabled people went to the local leisure centre separately, each with their own support worker, to do different activities before meeting up for lunch. Over lunch, the friends and their support workers would agree what to do in the afternoon. Typical Tuesday afternoon activities included: cinema; mini golf; or using the computers in the library. Sandra was aware this arrangement was unusual and felt it would not be possible with other service provider organisations, but the support workers in this particular small organisation had been empowered to work in this flexible and personalised way.

In the only clear example of good quality, well co-ordinated services which could be attributed to SDS implementation and day centre closures, Pauline received one-to-one support provided by a small group of regular support workers employed by a local third sector service provider organisation, six days per week. As a result of the implementation of SDS, and the closure of the day centre Pauline had attended for many years, her support was reviewed, resulting in an additional sixteen hours per week. Pauline and her dad Richard had developed strong relationships with the small team, of staff and the arrangements were clearly benefitting Richard, as well as Pauline:

> *Without [service provider organisation] we'd be completely shattered. Couldn't cope, you know, all day, no time tae myself or anything like that.*
>
> *(Richard, 90s, dad to Pauline, 40s)*

The quote above shows how vital the support was for both Pauline and Richard. However, it was not clear whether it was the new model of support put in place after the day centre closed that benefitted Pauline and Richard – preventing them from being “completely shattered” – or whether it was the additional support hours they had been awarded.

Both Sharon and Pauline’s experiences provide examples of ‘care-full’ personalised service provision; good relationships and communication between workers and families, attentiveness to individual needs, and a range of quality activities. However, even within ‘care-full’ services, difficulties occurred; change was inevitable and needed to be carefully managed, as Elizabeth explained:

> *…they've got some new clients and therefore new staff as well and Catherine's been having days where it's been really hard because it's different … then it ended up [crisps] thrown at staff … self-harm started… these things can just trigger… and you don't know where you are.*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

The quote above shows the complexity involved in maintaining ‘care-full’ spaces within often unpredictable circumstances. The following section discusses participants’ experiences of services which could be described as ‘care-less’ (Rogers, 2016).

'Care-less' spaces

‘Care-less’ spaces are the settings and relationships which are associated with care, but where a lack of care and caring exist in practice. In contrast with the small number of examples of good quality, well co-ordinated services outlined above, there were many more examples of poor-quality support. Participants often spoke about people ‘filling the time’; going to cafes and fast food restaurants was a very common activity. There were also examples of service failures – either as a result of bad practice or poor coordination – which impacted upon people with learning disabilities and their families. Additionally, complicated service arrangements created additional work and disrupted the lives of family carers.

‘Filling the time’

There was a prominent theme of people just passing time, rather than being involved in any meaningful activity, and there was little evidence of attention to individual outcomes. As others have noted (see Roulstone and Morgan, 2009; Ferguson, 2012), spending time in shopping centres and coffee shops has replaced going to a day centre for many disabled people; this was clearly evident in the data. For example, Susan described the typical activities Lorna was involved in:

> *…they go to [museum] for a coffee and then they go to McDonalds for lunch… take the bus out to [another town] and they go to charity shops… eight of them all go together for lunch… it's all go for a coffee, go for lunch… I like going out for lunch but I wouldn't want to do it every day, you know? To McDonald's, to Burger King… I wouldn't want to go to these places anyway. It's all cheap places 'cause they don't have a lot o' money… it's like, take the bus to [another town] 'cause that'll take up time…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

In addition to identifying a lack of quality activities, family carers expressed concern about the lack of engagement from some support workers. Whilst some workers were highly regarded by participants, experiences of (and perceptions about) the lack of engagement from some support workers emerged strongly in the data, particularly in relation to mobile phone usage, as Maureen noted:

> *…we've seen the people that are out with [care workers]. I've seen them myself on the bus, sitting on their mobile phones, ignoring the person they're looking after. On a number of occasions I've seen that.*
>
> *(Maureen, 60s, mum to Derek, 40s)*

This highlights the low value which is placed on support for people with learning disabilities, as well as the importance of adequate resourcing and skilled, professional staff. In contrast with the policy narrative of person-centred services, which focused on individual outcomes, participants felt services were very much resource-led, as noted by Susan:

> *…what is it they call it? Person-centred? It is not! It's not the least bit person-centred… It's about getting her into a group. There's no personal outcomes… nobody's ever suggested an outcome… they don't stretch her at all.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Service failures

In addition to the examples of poor-quality activities and engagement outlined above, some participants had experienced serious service failures. These included examples of bad practice, as well as poor communication and coordination. For example, Richard recounted unsafe and unprofessional practice involving two members of staff who no longer worked with Pauline:

> *…she [worker 1] says to Pauline: "We'll go to [community centre] … I can leave you there an' go up to my mother's…" And she's telling me this! I says: "You're supposed to be with her the whole day!" … They have tae ask Pauline where they're going… [worker 2] was in her thirties and should've known better, she said: "I've got a programme written out of what we'll do all summer."*
>
> *(Richard, 90s, dad to Pauline, 40s)*

Furthermore, participants also described instances where, as a result of poor coordination and communication, service failures had put individuals at risk of harm. For example, Sheila recounted several instances where support workers were uninformed about Gillian's routine or medical condition. On one particular occasion, the seriousness of the situation meant Sheila reluctantly complained to the service provider, however constant staff changes meant she was unable to name the support worker:

> *…she said: "she looked a bit tired this afternoon so I just got her a wee doughnut" …she's got [food intolerance] … I said: "well actually that wasn't alright"… she was very apologetic… anybody that fills the gap... but she should've been versed in what she can and cannot eat… so when I was speaking to her boss about something else, I said: "oh by the way, I don't want a fuss made, I'm just pointing out that someone arrived the other day and thought it was suitable to give Gillian a doughnut"… and then he said: "oh who was it?" and I said: "to tell you the truth, I can't remember her name", and I couldn't. So, he supplied a name and I said: "… I still don't know, I see so many folk, but just, it would be nice if they came better prepared" …*
>
> *(Sheila 70s, mum to Gillian, 30s)*

Another serious service failure occurred when Lorna had become ill whilst at a group organised by the service provider. Staff left a message on her home answering machine, but did not attempt to contact the family's mobile phones:

> *…if I'd got that message right away and got down there, I don't think it would've escalated the way it did. And I think if it'd happened in the [day] centre, her key worker or link worker would've said: "Come and sit with me and I'll look after you" …somebody would've given her a cuddle and*

> *they'd have looked after her. If they didn't get us in the house they'd have phoned us on our mobiles… they'd have got a hold of us and we'd have gone straight there and she'd have gone from a cuddle wi' them to a cuddle with us and I just think it wouldn't have become the issue it became… she was shaking like a leaf… She could barely walk. We couldn't get her out the car. She was covered in vomit… I was quite shell-shocked the next day… it was like a child, it escalated very, very quickly.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

These examples demonstrate the seriousness of service failures for individuals and carers. Poor coordination and communication within services, and between services and families, made people with learning disabilities vulnerable and caused additional work, worry and disruption for carers.

Workload for carers

Complicated support arrangements meant the carers in this study effectively became care managers, a role most did not want. Support needed to be managed and coordinated, and people with learning disabilities often require help to do this, or need someone else to do it for them. It was clear that this support was not being provided by services, which meant considerable additional work for family carers. This was particularly the case when people were being supported by more than one service provider, as Gillian was:

> *[We use] … three different organisations… which I hadn't really expected when they said: "oh she'll be supported". I had visions of the same person having her all week.*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Dealing with multiple organisations and workers meant extra work for families and this was made more difficult because the structure of services was not conducive to developing relationships between services and home. For Lorna's family, dealing with three service providers resulted in extra work for her sisters; they greatly missed having a named key worker who knew the family and felt this had resulted in services becoming less person-centred:

> *She doesn't have a key worker, you don't have any personal contact… mostly, I deal with [service provider] by email, and it's really just a case of: 'She won't be coming in tomorrow'… I'll just get an email back saying: 'Right, okay.' So, I don't bother explaining: 'She's going into hospital' or whatever.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Poor communication and coordination within services and between services and families was also a cause of additional work and stress for families, as Sheila explained:

> *…the support mechanism is not really working and you're saying: "where are you taking her today?" "That's not what she does on a such and such" …"is the taxi ordered?" …and then it doesn't turn up of course... it wouldn't be so bad… if I didn't have to double check everything they're doing… I feel I can't go on, it gets to me now… "what variation have you been told for what she's doing today?" ...after a year! They still don't know what she's doing!*
>
> *(Sheila 70s, mum to Gillian, 30s)*

The quote above demonstrates the additional stress placed on Sheila as a result of poor communication and coordination in services. The following quote is typical of several examples in the data where family carers picked up service shortfalls:

> *…the support worker's here at 10 [am]… no taxi arrived… phoned the office: "oh yeah we'll get a taxi organised"... phoned back: "no, no, taxi's all organised"… didn't come… she was going for an activity at 11 and this was at ten to 11! We got the key worker… I said: "look there's no point in you even phoning the taxi now because they're not going to make it. I'll put them in the car and take them" … I'd spent an hour trying to organise, trying to get some response from them, and I thought: "I'm not paid to do this, you are!"*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

In addition to the extra work for carers in managing services, there was also emotional labour involved in managing the consequences of shortfalls in service provision for loved ones. As demonstrated above, in addition to spending time phoning services, Sheila ended up driving Gillian and the support worker to the activity herself. In another example of managing the consequences of shortfalls in service provision, Susan had additional work in managing Lorna's emotions, triggered by poor quality activities:

> *…if she's not stretched and happy during the day, she's not gonnae come home happy… and if she comes in upset, I've got tae spend time trying to talk her round to go back the next day. That's a problem... when they're just hanging about… she usually has a fight wi' somebody…*

> *(Susan, 50s, sister to Lorna, 50s)*

Complicated, unreliable and unpredictable arrangements also made it difficult for carers to balance caring responsibilities with other activities:

> *...every day she goes out at a different time, comes back at a different time... whereas at the centre, it was always about half past three she came home, five days a week. So, we knew what we were dealing with.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

What are the factors that distinguish 'Care-full' and 'Care-less' spaces?

The discussion above highlighted a small number of examples in the data where services were clearly carried out with care – described as ‘care-full’ spaces (Rogers, 2016). Importantly, it also highlighted many examples where there was a notable lack of care, described as ‘care-less’ spaces (Rogers, 2016). The factors which distinguished the good examples from the bad were broadly related to trust and resources.

Trust

Families generally lacked trust in provider organisations and support workers. In relation to provider organisations, trust was influenced by previous experience, fear and suspicion, and compounded by lack of relationships as a result of dealing with multiple organisations. Issues of trust in support workers were also affected by relationships, perception of power, as well as skills, turnover, pay and responsibility.

Organisations

Generally, there was a lack of trust in service provider organisations. This was partly related to the closure of day centres because many people felt let down by organisations which they had previously trusted. Rather than representing members' interests, participants felt that some organisations had become just service providers. In many cases, these organisations were seen as complicit with the local authority over day centre closures because of local funding arrangements; their survival was dependent on local authority funding. Provider organisations competing for limited resources was not conducive to the collaborative policy ethos and several participants were suspicious about the allocation of contracts by the local authority.

There were also concerns about the regulation of services, and one participant noted that activities in community centres were not inspected in the same way as day centres. In order to have trust in an organisation, families need to be satisfied that they are appropriately monitored for safety.

Participants' lack of trust in service providers was often related to previous bad experiences, regardless of how long since incidents had occurred. Having multiple service providers further impacted on trust because it inhibited relationship development.

Staff

Relationships with individual workers were important to fostering trust. For Richard, staff were not just workers; they were seen as trusted friends. Richard spoke highly of the team of people who supported Pauline, demonstrating the importance of the relationship with the whole family:

> *…I like tae get tae know the girls and they get tae know me an' they're now friends… I tell them that once you enter the door they can do as they please – have tea, sit, talk. As long as they take Pauline tae where she wants tae go and bring her back safe… the girls that walk in the door for her now, they're all welcome… two o' them, in particular… they'll sit and chat for half an hour… You don't get to know them unless they're sitting talking to you.*
>
> *(Richard, 90s, dad to Pauline, 40s)*

Where there were good relationships with staff, there was evidence of choice and control; good staff supported people and helped them to develop skills, rather than just doing things for them; for example, Joyce and Raymond were helped to dust and hoover, supporting them to develop skills and look after their (supported) flat. However, there was also evidence of workers exercising power and determining individuals' choice and control; in many cases, schedules were structured by individual workers or service provider organisations. Several participants gave examples of having to leave clubs and activities before they were ready, suggesting that the transfer of power from professionals to individuals had not yet happened. For example, Scott used to go to a popular country and western night for people with learning disabilities at a local pub with his two housemates and support workers, but this had stopped because shift patterns meant they were no sooner there than they had to leave. Situations like this impacted on opportunities for friendships because people had limited time with their peers.

The high turnover of social care staff was a further issue impacting upon experiences of service provision. Participants' narratives suggested that high staff turnover could be particularly detrimental to people with learning disabilities and autism because change can exacerbate impairment effects (Thomas, 1999).

Families felt that care work was skilled work, which they valued highly, yet there were many examples of staff not being sufficiently trained or skilled. Care work has become increasingly regulated and professionalised, and workers in Scotland must be registered with the Scottish Social Services Council (SSSC), which requires holding or working towards relevant qualifications. Despite this, however, there was substantial variance in staff skills. For example, Lorna attended a service which purportedly supported people with learning disabilities, though it had previously only supported people with sensory impairments:

> *…I don't know what their training is, but they just don't seem to have a handle. They're not very professional, as far as I'm concerned… Now it's opened up to people like Lorna, they don't seem to know how to occupy them… I think they were more used to people maybe wheelchair-based and more manageable in certain ways, and now they've got people like Lorna and a lot of other people – there's rivalries… you get an awful lot of tension and drama because these are all adults… they're all at different levels and they all want their voices heard and they all want to win…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

The above quote highlights the changing nature of care work; workers need to be sufficiently skilled to deliver person-centred services. However, at the same time as increased professionalisation, budget cuts may mean increased reliance on voluntary services, which could potentially devalue care work. For one family, risks associated with their son’s complex needs meant they were very concerned about the quality of care and having skilled, professional staff, and they believed pay and responsibility were incongruent.

> *M: There's danger. There's danger all the time.*
>
> *D: You need qualified people.*
>
> *M: And you need people that know him.*
>
> *D: People that you've got confidence in.*
>
> *M: …An' I didn't have confidence. I wasn't confident that he would be looked after there [third sector service] …an' I didn't want tae employ a carer tae come intae the house.*
>
> *K: That's what I was wondering, if that would've been an option, to employ a personal assistant yourself?*
>
> *D: He just doesnae want to be in the house here. One carer cannot take him anywhere. Too dangerous – just walk out the door and fall. And what do they do? I bet they wouldn't come back… 'Cause these people are not paid a lot o' money … I wouldn't want tae take that responsibility for £7.50 an hour.*
>
> *(Dan and Maureen, 60s, parents to Derek, 40s)*

Resources

Resources were clearly a key issue in distinguishing 'care-full' and 'care-less' support (Rogers, 2016). In addition to the perceived lack of suitable services, as highlighted earlier in this chapter, SDS budgets and transport were also important factors.

SDS budgets

People needed a sufficient budget in order to get suitable services, but the majority of participants had a budget which only covered basic social care needs. There was a clear tension between the principles underpinning SDS (discussed in chapter three) and what could realistically be achieved within very constrained budgets. For example, Elizabeth described the local authority's approach to budgets as: *'…just making sure they're clean and tidy and parents get a bit of a break…'*.

The impact of basic need budgets was particularly notable in this study where participants lived in supported accommodation. This small group of participants reported minimal one-to-one time and few activities outside the home. They were also generally aware that resources were very limited, and that their options were determined by both money and staff availability, as the extract below from an interview with Scott illustrates:

> *K: So, when you have your one-to-one time on a Tuesday, what kinda things do you like to do?*
>
> *S: Sometimes go to Wetherspoons… no' all the time… cos that costs a fortune... we're trying to keep away from things like that now cos it costs a lot of money… we used to do a lot...*
>
> *(Scott, 40s)*

One of the ways in which services had attempted to stretch limited funds was by pooling budgets, however this meant limited choice for individuals. For example, sharing a support worker with two other people meant everyone had to do the same thing at the same time, and this ruled out certain activities where people required individual support, like swimming. This was more common for participants who lived in supported accommodation than for those who lived with family carers; as noted above, this group were particularly aware that money and staff time were limited, as Joyce noted:

> *…and the staff have got everybody… they just canny see one person, they've got a lot of people to see here…*
>
> *(Joyce, 50s)*

Narratives of individual outcomes were not apparent in the interviews; rather, this small group of participants who lived in shared, supported accommodation were accustomed to compromising, as Scott and Joyce's respective comments above show. For example, Scott liked ten-pin bowling, but rarely got to go because it was too expensive and because: *"…June [one of Scott's housemates] can't do it cos she can't see"*.

There were also costs incurred in participating in activities which fell outwith the SDS budget, for example, entry fees or membership subscriptions. This additional expenditure had to be met from household budgets and is discussed in chapter seven.

Transport

Participation was dependent on access to transport. Budgets for transport were a particular area of concern and confusion for many participants, and it seemed that this was an area which had been particularly susceptible to cuts.

Few families had SDS budgets for taxis, but even those who did have them encountered difficulties. For example, Lorna had funding for taxis to and from services, but not for an escort. This meant that she was using taxis unaccompanied and with unknown drivers, which was a source of worry for her family. This was exacerbated because she had been taken to the wrong place on more than one occasion:

> *S: We've had a few incidents with taxi drivers. I think that exposes her. I think she's very vulnerable. And, okay, nothing terrible has happened, but we've had two incidents where taxi drivers tried to take her somewhere else and said: "This is where you live".*
>
> *L: I didn't get out then.*
>
> *S: No, I know you didn't. You told him… I think it exposes them to more risk, but the council didn't want to know that. They said unless you can prove the risk… well, you can't prove a risk until something bad happens!*
>
> *(Lorna and Susan, 50s)*

In some cases, transport cuts have resulted in additional work for families. As detailed earlier, despite Gillian's taxi budget and the availability of a support worker, taxis would very often come late or not at all. This upset routines and caused distress for Gillian and additional work for Sheila. Similarly, Sandra and her husband frequently drove their daughter and her support worker to activities because although Sharon had a budget for public transport, it was not practical within her schedule of activities.

Bureaucratic barriers in relation to transport also prevented Michael from participating in activities. Although Michael has a Motability car, he was unable to get out and about because, in addition to being able to find support staff who could drive his car, his family could not afford the insurance excess required:

> *...[service] providers won't take responsibility for any accidents, with the excess you've tae pay. So, it gets left tae us... If the car's in an accident or whatever, you've got tae pay the excess. When you're on benefits… you havenae got that money tae pay an excess...*
>
> *(Deborah, 50s, mum to Michael, 30s)*

The quote above illustrates the financial context within which budget cuts take place; disabled people in receipt of the mobility component of Disability Living Allowance were expected to use this for transport costs, however this was a fixed amount, unrelated to actual transport costs[39]:

> *… doesnae get you a lot for taxis if you're heavily reliant on them. You could erase it in a few journeys.*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Whilst reductions in transport budgets for taxis might be expected to increase use of public transport, and therefore inclusion in 'mainstream' society, this was

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[39] There are two 'bands' for the mobility component of DLA. The lower rate (for people who require 'guidance or supervision outdoors') is £23.20 per week, and the higher rate (for people who have 'any other, more severe, walking difficulty') is £61.20 per week. See: https://www.gov.uk/dla-disability-living-allowance-benefit/DLA-rates [accessed 05/05/2019].

not the case for this group. Instead, cuts had contributed towards the exclusion and isolation of people with learning disabilities and increased workload for carers. Participants were restricted from participating in activities outside the home because of impairment effects (Thomas, 1999) and barriers to public transport, including physical inaccessibility and the prevalence of abuse and assault of people with learning disabilities.

6.3.3. From Day Centre Closures to Support in the Community - concluding comments

Part two of this chapter on ‘Personalised’ service provision highlighted the activities participants were involved in, and the places in which these activities took place, following the shift from largely local authority-provided specialist services to more ‘mainstream’ and community-based services. The subsequent discussion of ‘care-full’ spaces (Rogers, 2016) provided examples of good quality, co-ordinated service provision, though these were isolated examples in the data. More commonly, participants had experienced poor-quality services and ‘care-less’ spaces (ibid.), characterised by ‘filling the time’, service failures, and additional work for carers. Part two concluded by considering the factors which distinguish between ‘care-full’ and ‘care-less’ support.

Furthermore, in relation to Tronto’s conceptualisation of care (see chapter two), analysis of participants’ experiences of ‘personalised’ service provision revealed little evidence of ethics of care. Fewer opportunities, poor quality services and activities, and additional work for carers in managing services and mitigating risks demonstrated the absence of caring about, caring for, care giving, and care receiving (Tronto, 1993).

6.4. Conclusion

The first part of this chapter looked at the closure of day centres and the impact this had on the lives of participants, before moving on to look at participants' experiences of (ostensibly) more personalised care and support, following the closure of day centres, in the second part of the chapter.

The discussion in part one showed how participants were disempowered by the consultation process in relation to day centre closures. People wanted to be able to choose to go to day centres but were denied the opportunity, under the guise of choice and control. The data suggests that difficulties experienced by people with learning disabilities in articulating emotions and opinions may make it easier for their perspectives to be disregarded by powerful actors. In relation to Tronto's conceptualisation of care (see chapter two), analysis of participants' experiences of attending day centres revealed evidence of all four phases of care; caring about, caring for, care giving, and care receiving (Tronto, 1993). Paradoxically, analysis of the impact of day centre closures showed the absence of ethics of care principles. Furthermore, within a context of widespread discrimination and exclusion of people with learning disabilities in mainstream society, the closure of day centres served to further discriminate and exclude people from places where they previously experienced inclusion and relationships.

Part two of this chapter illustrated that activities offered by service providers were often simply about filling the time, rather than attending to individual interests and outcomes, in contrast with policy rhetoric. Participants' narratives demonstrated how people with learning disabilities experienced exclusion and segregation within public places, like colleges and community centres, and inclusion within specialist 'segregated' services. Furthermore, flexible personalised support needs to be managed and coordinated, and people with learning disabilities may require help to do this, or someone to do it for them;

the absence of this support caused additional workload for families. Finally, having multiple service provider organisations and support workers inhibited relationship development, and relationships were fundamental to families having trust in services. Ultimately, participants' experiences of 'personalised' service provision demonstrated the absence of caring about, caring for, care giving, and care receiving (Tronto, 1993) in the implementation of social care policy.

The next chapter shifts the focus from services and support in the public sphere to the private sphere, and shows how policy change played out within homes, families and relationships.

7. Personalisation and the Private Sphere

7.1. Introduction

This thesis set out to understand the impact of policy change for people with learning disabilities and their families. The previous two chapters drew on data from interviews with people with learning disabilities and their families to examine how participants experienced the shift to SDS; chapter five focused on experiences of SDS assessment and implementation, and chapter six focused on experiences of support services. This chapter continues the discussion of the interview data to show how private sphere experiences were related to changes to policy and service provision.

The private sphere of home, family and relationships was inextricably linked with changes to social care policy and service provision. This chapter begins with an overview of family lives and routines; showing how daily schedules, competing demands on time, and household finances were linked with policy change. It then moves on to consider policy change within the emotional context of family care; showing how care was framed in language and experiences of love and affection, conflict and compromise, and independence and dependence. The chapter further considers the importance of friendships and support networks, how these were related to policy and service provision, and the particular challenges participants experienced in having and maintaining these relationships. Finally, the chapter discusses health and wellbeing, particularly in relation to ageing and the life course, and experiences of 'challenging behaviour'; issues which were strongly linked with social care policy and service provision.

7.2. Family Lives and Routines

In chapter six, participants' daily lives and routines in relation to support services were discussed. This chapter begins with a brief summary of participants' daily lives within the private sphere of home, family and relationships. In many cases the two are inextricably linked, particularly for those participants who live in the family home. This section shows how policy change played out in family lives and routines.

7.2.1. Weekly schedules and activities

As discussed in chapter six, participants with learning disabilities took part in a range of activities, often organised or supported by care workers. A small number of this group had very busy weekly schedules of activities, which had largely been identified and planned by well-informed and well-connected mothers, and they were supported by care workers to allow them to attend and participate. In order to have a busy weekly schedule of activities, these families supplemented the services being provided or purchased with their social care budget by buying in additional services from their own funds. This group were the family carers who were most knowledgeable about social work and social care; they had held professional positions in related sectors prior to retirement, and remained involved with related organisations. In many ways, these families already had choice and control over support arrangements; knowledgeable mothers were effectively acting as 'care managers' (see chapter six) prior to the formal introduction of SDS. For them, rather than increasing choice and control, policy implementation had resulted in lower budgets, fewer services to choose from, and more paperwork and bureaucracy. However, this small group of participants who had busy weekly schedules of activities were the exceptions in the data.

The vast majority of participants had only a small number of regular activities outside the home. This was particularly the case for those living in supported accommodation, who received social care services for housing support and personal care. It appeared that reduced support budgets may not have been sufficient to meet social and leisure outcomes. This is in conflict with the social model of disability and principles of independent living which underpin the Scottish Government’s approach to social care (discussed in chapters two and three) and a breach of the statutory principle of ‘Participation’ in the SDS Act 2013 (discussed further in chapter eight).

7.2.2. Competing demands on carers

For those participants who lived with family members, weekly schedules involved a small number of hours doing things outside the home with support workers; the majority of the time was spent with family, mainly at home. Almost always, the small amount of time spent with support workers took place during the daytime and on weekdays, and evenings and weekends were almost exclusively spent with family members. For example, Irene felt that Theresa did not get out as often as either of them would have liked because Irene did not have the time or energy, as a full-time worker and dual carer:

> *…she's no oot that much through the week… to be honest, at the weekend, when I've done a week's work, I cannae be arsed going oot at the weekends… so there are a lot of times when we're no oot that much…*
>
> *(Irene, 50s, sister to Theresa, 50s)*

The amount of time spent at home and/or with family resulted in considerable work for carers. In addition to a vast range of practical tasks (including: personal care; driving; cooking; shopping), carers spoke about considerable emotion and administrative work. Emotion work included managing their family member’s fear, confusion and distress; administrative work included dealing with services and organising activities.

Household tasks intersected with emotion and administrative work, and the compound effect was additional labour for participants that resulted in carers being always ‘on duty’. For example, while out shopping, Sandra had to pay careful attention to Sharon, while Sheila had to watch Gillian carefully when she was cooking. Not only were these parents undertaking cooking and shopping for their adult children, they had the additional, concurrent labour of watching over them, anticipating risk and mitigating harm:

> *…if she goes into a shop and she sees something she likes she just grabs it. “I want this, I want this, I want this”. And she would put it in her bag and walk out the shop.*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

> *…she was coming in and going round the cooker and trying to lift the pot lids… if she was to wander in and I had left a knife lying… I kind of make a game of it… when she comes in… "What did I tell you! Shooo!" and she laughs and giggles and off she goes.*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

For family carers, their daily lives and routines were entirely determined by the schedules of their family members. Susan explained how her schedule was constrained by Lorna’s complicated social care arrangements:

> *…Tuesday she's out half nine and she's back about ten past two, so it's quite a short day. Friday, she finishes at three… [goes out at] quarter to ten on a Thursday and she's usually home by three o'clock… the taxi's not meant to come 'til three o'clock, but sometimes it comes at ten to, so we have to be back…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Furthermore, these times could be unpredictable as care workers frequently brought people home earlier than expected. Despite the difficulties family carers experienced in managing their own lives within the time constraints of service provision, carers were resigned to this happening and made sure they were home early, suggesting they had low expectations of services:

> *…I got back about 2, not having had any lunch, having stopped at the supermarket… putting the stuff in the fridge and… "oh sounds like Gillian" … half an hour early… that doesn't let me organise my life... I've kinda got used to that now… I come back earlier, but to begin with, I was thinking: "well she's due back at quarter past 3" and I was coming back at the back of 3…*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

7.2.3. Household finances

Changes to social care policy and service provision also affected household finances. Families incurred additional expense as a result of paying for activities, purchasing additional hours of support, and the introduction of the client contribution. Furthermore, impairment-related expenditure could be a considerable additional financial burden for families – particularly those who were reliant on state benefits.

Cost of activities

Many of the participants' weekly schedules involved activities which incurred a cost in the way of entry fees or membership subscriptions. As discussed in chapter six, activities included: swimming; gym; ten-pin bowling; cinema; and specialist groups and clubs for disabled people. Whilst the SDS budget could pay for a worker to support someone to attend activities, and perhaps transport to take them there, it did not cover the costs of the activities, which inevitably impacted upon household finances. Even when activities were subsidised (for example, council leisure facilities and discounted cinema tickets), these were still a considerable additional cost to the household. Going to cafes, pubs and fast food restaurants was very much a regular 'activity' for participants (discussed in chapter six), and the additional cost of buying food and drinks outside the home also had to be met from limited household budgets. Sandra explained how this all added up over the week:

> *…what isn't covered is the cost a' things… going to the mini golf it's £8 … £20 subscription for the [activity] and £3 a week. And for [activity] it's something like £50 for eight or ten weeks. She has to pay that herself… pays to get into the swimming… pays for the gym. If they go somewhere in the afternoon it's money… I maybe give the girls £5 to just go and get a cup a' tea somewhere in the morning, after the [activity] … her night out … £20.*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Purchasing additional support

The shift to personalisation and cuts to care budgets had clearly impacted household budgets when families needed to buy-in additional private hours. Several families provided examples of when they had purchased additional support services from their own funds – either on an ad-hoc or regular basis. Susan recalled one occasion when she had paid for someone to sit with Lorna so she could go to the theatre. However, as she explained, this was a significant additional cost:

> *…£15 an hour for this woman to come and sit with her. To come and watch the television. So, the two of them just sat and she had her dinner. It cost £60. It would've been cheaper to actually take her… Things like that are difficult…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

For Sheila, it was vitally important for her own wellbeing that she was able to attend a fitness class once a week. However, the class took place in the evening when Gillian was at home, so Sheila paid privately for a support worker to take Gillian out for two hours. Interestingly, Sheila framed this as her 'choice', rather than essential support. Being economically independent enabled Sheila to exercise this 'choice'; by contrast, many families in this study had limited means and little choice.

These examples reflect the importance of getting a break from caring, which the Scottish Government acknowledged in the publication of the Carers Act (Scotland) 2016[40]. However, this vital support was often only available to those

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[40] Launching the Act in 2018, Public Health Minister Aileen Campbell said: "It is vital that all carers receive the support they need to look after their own health and wellbeing, and have a

who were able to pay for it privately, meaning carers had to balance their need for a break with the impact on household finances. Despite the policy rhetoric set out in the legislation for SDS, participants' narratives showed that a break from caring was still seen as a luxury rather than a necessity.

Some participants were aware of the existence of short break funds which they could apply to for additional services that supplement the SDS package. Sharon had been able to get a subsidised place on an outdoor activity holiday which she had enjoyed, and which had enabled her parents to have a break from caring. However, accessing these resources was reliant on families knowing about them, being able to apply, and having some private resources to supplement them. For many of the families who took part in this study, accessing additional support was impossible because they had limited disposable income. For example, Janet did not apply because the fund would only cover part of the holiday cost and she could not afford the rest:

> *I never put in for it because I've never got enough. Say you want tae go away for a weekend, you're like that: 'well that's gonnae cost me a fortune'… you might only get £200… by the time you get your train, your hotel… the rest has to come oot your ain money.*
>
> *(Janet, 50s, mum to Michelle, 30s)*

Client contribution

As discussed in chapter five, the highly contested 'client contribution' was introduced at the same time as SDS within learning disability services in

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life alongside caring. That is what the Carers Act will deliver" (See: https://beta.gov.scot/news/landmark-new-rights-for-unpaid-carers/).

Glasgow. The implementation of the client contribution directly affected household finances because families were required to pay towards the cost of social care services, which had previously been provided without charge. Two families in this study were unable or unwilling to pay this, and were therefore without services at the time of the interviews. For Janet, a lone parent who was unable to work due to caring for her daughter and entirely dependent on state benefits, paying the client contribution meant she would have to '*…take Michelle tae the food bank*'. Although this was a minority within the sample, there appeared to be many families in similar situations; almost without exception, family carers told me in the interviews about other families they knew who had been unable to pay the client contribution.

As well as addressing the practical impact of a reduction in disposable income – as a result of increased monthly household outgoings created by the client contribution – there was also a symbolic impact. Families in this study had been receiving social care services for a long time and remembered a time when people got 'paid' for going to day centres and training centres, rather than paying to go. Several participants recalled their family members coming home with small, regular cash payments in a 'pay packet', which were framed as wages. For these families, their situation had changed from being 'paid' to attend services, to having to pay to receive services. Under the guise of 'choice and control', the sums being paid by families towards the cost of services (the 'client contribution') were substantially more than the nominal sums people had previously received to attend services.

Impairment-related expenditure

Impairment-related expenditure was a particular issue which affected household budgets for participants. This additional spending included the cost of special diets and the frequent replacement of clothing, shoes and bedding. As Sandra explained:

> *…you get to the stage where you think: 'I'm no washing any more shitty knickers, I've had enough!'… she's a picker… So, you go and there's a big hole… or it's burst up the side. Or the lace is hanging away from the thing. We just constantly buy new knickers and socks. her trousers, they're picked at the crotch. And socks, Sharon does not have a pair a' socks that are no picked. And they're picked tae buggery… great big… holes on them!*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Disability Living Allowance (and its replacement, Personal Independence Payment) was set up as a non-means tested social security benefit to cover additional costs of impairment (see Machin, 2017). It differs from SDS support in that it is paid through the social security system[41] rather than local authority funding. However, income from DLA was taken into account in assessing how much client contribution families were required to pay. A small number of participants had allowable expenses included in the assessment, thus reducing the amount of client contribution they were required to pay, but the lack of clarity and awareness about allowable expenses meant few families had this taken into account (see chapter five). Derek's only income was DLA and income support; from this he paid £100 per month for the client contribution. This made no sense to his parents, who noted that:

> *…you get this [income support entitlement] letter saying: 'This is what we say you need to live on' …but they're gonnae come and take a' that money off him…*

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[41] Disability Living Allowance (DLA) and Personal Independence Payment (PIP) are amongst the ill health and disability benefits devolved to the Scottish Parliament by the Scotland Act 2016. (See: https://beta.gov.scot/policies/social-security/).

> *(Maureen, 60s, mum to Derek, 40s)*

It was therefore implicit that families would contribute towards the client contribution and the additional costs of impairment:

> *…somebody like Derek… he needs a lot of trousers, he needs a lot of bedding… all these things have to be replaced frequently…* ***who's gonnae pay for it if he's not got any money****?*
>
> *(Maureen, 60s, mum to Derek, 40s)*

There were also some additional impairment-related costs reported by participants that fell outwith the scope of DLA. For Sharon, manifestations of distress often resulted in considerable additional financial costs to the family. As this example shows, the family had to frequently replace costly items – such as an iPod:

> *…when she gets angry, she smashes things... we take out the insurance and every time you go back… you think: 'God, they're gonnae just ban us!'… she'll just break it again… see since she's got it [iPod] back, she's such a happy girl…*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

It could be argued that an iPod was a luxury item; but for Sharon and her family, it was seen as an essential expense. Sharon loved her iPod and became highly distressed and aggressive when she did not have it, leaving her parents to deal with the practical and emotional consequences. Regularly replacing the iPod therefore became essential to the family’s wellbeing – whatever the financial cost.

As noted previously, several of the families were low-income households, dependent on state benefits. This was the result of long-term disadvantage in employment related to disability; either having learning disabilities or caring for someone with learning disabilities. For these families, impairment-related expenditure was particularly difficult.

This section has begun to show how the public and private spheres were inextricably linked for participants. Changes to social care policy and service provision greatly impacted upon family lives and routines, through determining weekly schedules and activities, competing demands on carers, and household finances. The additional care labour for families was produced by changes to policy and services, but adopted as an ‘ordinary’ part of family life, demonstrating Morgan’s (1996) conceptualisation of ‘family practices’, discussed in chapter two.

7.3. Emotional Context of Family Care

The discussion of the relationship between the public and private spheres in the previous section is developed further here by focusing on the emotional context of family care. This section considers participants’ experiences of policy and service provision within the context of love and affection, conflict and compromise, and dependency and interdependency.

7.3.1. Love and affection

Feelings of love and affection were both implicit and explicit in the interviews. One of the advantages of doing family group interviews was that these emotions were visible in the interviews and through the interactions between family members (discussed in chapter four). These were often characterised by warmth, gentleness, affection and humour – despite sometimes very challenging family circumstances. For example, during the interview with Gillian and Sheila, Gillian was cuddling in to her mum and repeatedly asking for her sister, while Sheila tried to soothe and reassure Gillian in her speech and touch. In other family group interviews, mutual affection was displayed through ‘banter’, good natured teasing and humour; for example, Lorna teased Susan about football.

Context of fear and vulnerability

However, these sentiments were situated within the context of fear of the future. There was an awareness of vulnerability and a lack of trust in services (discussed in chapters five and six), contributing towards concerns and protection over the longer term. As Deborah explained:

> *…the fear, Karen, that I'm gonnae end up as one of these elderly carers… not resting in my grave, that my son's gonnae be thrown intae some institute place… what's gonnae happen tae my son when I'm not here?*
>
> *(Deborah 50s, mum to Michael 30s)*

Fear of the future was a particular worry for older parent carers, and is discussed later in this chapter in relation to ageing and caring. However, this was not limited to concerns about what might happen in the future; fear for the safety and wellbeing of loved ones was a constant presence in the minds of family carers. This was evident both in terms of individual vulnerability and the hostile environment for people with learning disabilities.

Furthermore, these experiences were longstanding; family carers had experienced fear and vulnerability in relation to the safety and wellbeing of their loved ones for many decades. For many of the parent carers, fear and vulnerability were situated in broader narratives around the birth of their child, despite this being many years ago. Although these sentiments existed prior to the implementation of personalisation policies, they are relevant here because they provide the context within which families interpret and experience policy change. The emotional impact of coming to terms with being a parent of a disabled child was powerfully illustrated by Richard:

> *When Pauline was born, Annabelle [Pauline's mother] wouldn't accept there was anything wrong with her, and they didn't tell her. So, when I went tae visit the morning after the birth, all the other women were nursing their babies… [Annabelle] said: "Why am I the only one that's not holding the child?" An' I had tae break the news to her. She wouldn't believe me…*
>
> *(Richard, 90s, dad to Pauline, 40s)*

In addition to longstanding feelings of fear and vulnerability, there were also more recent contributory factors; for some participants, social media exacerbated their fears. This was not an issue for the older carers, who were less likely to be active on social media. However, carers who used Facebook and Twitter were acutely aware of recent high-profile incidents of service failures in relation to people with learning disabilities in England. This knowledge contributed towards carers' beliefs about the 'care-less' (Rogers, 2016) social care system, fears about the power of professionals, and an awareness of the relative powerlessness of carers. This was illustrated by Janet, who had been actively following #JusticeforLB[42] and the case of Mark and Stephen Neary[43]:

> *…and that is the worst thing that could happen, if they locked her up… a lot of carers are scared of that, in case that happens to their weans.*
>
> *(Janet, 50s, mum to Michelle, 30s)*

Additionally, personal experiences of a hostile environment contributed towards feelings of fear and vulnerability. As noted in chapter six, several of the participants who had learning disabilities had direct experience of harassment and abuse in public places. The narratives of family carers in this study revealed the deep impact such incidents had had on the wider family, and how family members felt fiercely protective. Bill (80s) recounted how hurt and angry he felt when he discovered that his son Alistair (50s) was being singled out and verbally abused by teenagers on the bus:

> *…I would've went on that bus and, believe you me, they would never have been at school for a while anyway, once I'd… I'd have stuck up for him…* ***You feel angry and sore… why should we get it an' naebody else?***
>
> *(Bill, 80s, dad to Alistair, 50s)*

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[42] #JusticeforLB is a campaign for justice following the tragic and preventable death of 18 year old Connor Sparrowhawk in an assessment and treatment unit in 2013. (See: http://justiceforlb.org/).

[43] Stephen Neary, aged 20, was detained in a care home 150 miles from home for 12 months, against his will and that of his family. A court hearing later found Stephen was unlawfully deprived of his liberty and awarded the family financial compensation. (See: https://markneary1dotcom1.wordpress.com/).

Demonstrations of love and care

Protection and over-protection may be understood as a response to feelings of fear and vulnerability; Richard (90s) felt that his wife had been '…*ultra-possessive of Pauline, wouldn't let her do anything*…' However, protection may also be understood as a way of demonstrating love and care. Within the difficult context of carers' experiences of SDS assessment and changes to services (discussed in chapters 5 and 6), Deborah tried to protect Michael from the worry and distress she was experiencing:

> *He disnae understand… he has seen me crying… there's times when you just… you've got tae get yourself up… brush yourself back doon. And there's times that you're just… destroyed… you don't see any way oot. And you've just got tae take a deep breath and say: "No. I need tae…"*
>
> *(Deborah, 50s, mum to Michael, 30s)*

Demonstrations of love and affection and family care were complex, tangled with obligation and understandings of responsibility as well as what was considered appropriate for families to do for their members. This was underpinned by strong beliefs that family care was the best form of care, and was further complicated by the existence of family care hierarchies. Families in this study took many forms, however it was mainly mothers who undertook the role of primary carer, with fathers or siblings stepping in to the role only when mothers were no longer able. Lynch et al (2009) proposed that men only care when there are no women available, however this study suggests that care hierarchies are more complex than Lynch et al suggest. In three of the families who took part in this study, the primary carer was a father over the age of 80. In all three cases, Dad had taken on the role of primary carer following the death of his wife, and was being supported by other family members or care workers.

This was the case for Theresa and her dad Walter (80s), who strongly believed it was his duty and responsibility to care for her after her mum died. However, Theresa wanted to live with her sister Irene and her family – and Irene believed Theresa would be happier with her – but their dad would not even consider it:

> *…it's company for him in the hoose… he would still see that as a real failing… I think that's maybe a kinda generational thing as well…*
>
> *(Irene, 50s, sister to Theresa, 50s)*

Several families were, or had been, involved with disability organisations or providing informal support to other families (support networks are discussed later in this chapter). This can also be understood as a way of demonstrating love and care for disabled family members, and empathy for others, as Susan explained:

> *I think it makes you a better person, being a carer. It does, you know, because you're more caring towards other people as well… you're not as selfish as you might've been…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

However, an alternative explanation for participants' active involvement with disability organisations and supporting other families is necessity; individuals' response to a lack of collective provision and a hostile 'mainstream' environment.

Love and affection, and the emotional aspects of care relationships, dominated narratives of informal, unpaid care, but were notably absent from negotiations over formal care. The lack of attention paid to emotions and feelings in discussion with social workers and service providers was illustrated by Deborah:

> *…and they turn round and say: “He'll be okay. He'll get used tae it.” …for a social worker tae turn round and say that… When we know our sons and daughters and* ***the love and care that they've had in our home****, just tae be put away somewhere…*
>
> *(Deborah 50s, mum to Michael 30s)*

Successful co-production of policy and practice in social care (see chapter three) requires families and professionals to work together, and this demands trust and respect. Understanding the context of fear and vulnerability within which family care relationships exist and intersect with social care policy would help professionals work with families to co-produce services and meet needs.

7.3.2. Conflict and compromise

The emotional context within which families experienced social care policy and services was often a site of conflict and compromise. Conflict and compromise are ordinary and integral parts of family lives. For these families, who were already living with the challenges of ageing and caring, changes to social care policy and service provision caused unnecessary additional conflict and compromise. Reduced social care budgets and services, and additional work and worry in negotiating provision, resulted in conflict between families and professionals (discussed in chapters 5). Notably, changes to daily routines and relationships, as a result of the closure of day centres, were extremely confusing and distressing for many people (see chapter six), resulting in conflict within families as carers were left to mitigate the impact of these changes.

As well as conflict between families and those outwith the household, changes to social care policy and service provision resulted in conflict and compromise within families. Reduced budgets and services demanded that compromise by made as families had to find ways to manage with much more limited hours of support. Sometimes compromise meant buying additional support hours privately; more often, compromise meant family carers providing additional support themselves. The associated conflict and tensions which arose within families can be attributed directly and indirectly to changes to social care policy and service provision.

Conflict and compromise directly related to service provision

Family lives were inextricably linked with service provision, and the suitability of services affected the atmosphere in the home. The quality and quantity of social care support affected individuals' mood and relationships between family members. In chapter five, it was noted that dealing with services caused additional work for family carers, resulting in many carers feeling stressed and exhausted. In chapter six, it was noted that the closure of day centres had caused considerable distress and confusion for participants with learning disabilities. These issues, which arise outwith the household and family, play out within homes and families, and caused additional emotion work for family carers – as noted by Susan:

> *Lorna doesn't know or care about people in the Council. It's my fault…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Not having any formal service provision, following the closure of the day centres, often resulted in conflict and compromise for Janet and Michelle. Mother and daughter were together all day, every day, trying to fill the time with little money:

> *…you get bad days… she gets fed up wi' me and I get fed up wi' her… always taking packed lunches wi' you because you cannae afford to eat oot a' the time… It's terrible, just stoating aboot… It does get depressing.*
>
> *(Janet, 50s, mum to Michelle, 30s)*

For one family, changes to service provision had resulted in serious conflict between its members, and this had been extremely distressing for all of them. The closure of Theresa's day centre and the introduction of the client contribution led to her 'retiring' from services because her dad refused to pay for her to attend a new centre. Theresa and her sisters strongly disagreed with their dad, but in the end, he had the final decision:

> *T: …my dad stopped it.*
>
> *I: It was costing £60 per week and my dad objected strongly…*
>
> *M: …that caused a massive family disruption…*
>
> *I: Yeah, a massive argument didn't it hen [to Theresa]? First argument ever with my dad who is [in his 80s] … we were just all coming at it from different angles. It was not good! And then Theresa decided…*

> *T: …to retire… Enough's enough!*
>
> *M: She was very much in the middle of it, realising everything that was going on…*
>
> *I: We felt very strongly that Theresa should go because it was important for her to be amongst her friends in this new centre, but the financial aspect of it for my dad was just too much... he was Theresa's main carer as well, so there was only so much of a fight we could put up.*
>
> *M: **It nearly destroyed the family, it really did**.*
>
> *(Theresa, Irene, Mhairi, 50s)*

The interview extract above provides a powerful example of how 'public' policy plays out in the private sphere of home, families and relationships. Theresa was 'in the middle of' the conflict between her dad and sisters, but she was powerless over the outcome. This highlights the complex negotiations, individual perspectives, competing interests, and power dynamics which affect experiences of policy.

Conflict and compromise indirectly related to service provision

In addition to the conflict and compromise, directly related to service provision discussed above, household experiences of conflict and compromise were also indirectly affected by policy and service provision. This was broadly related to carers having to balance multiple demands on their time, other people and negative attitudes.

Carers balancing multiple demands

The vast majority of carers were balancing caring with other demands on their time, including work, family, and managing their own health. For example, visiting Maureen’s mum in a nursing home, spending time with their other children and grandchildren, as well as caring for Derek, was a source of conflict and compromise for Maureen and Dan:

> *…I cannae do it [visit mum] every week. I maybe go once a month… she doesn't know really and it's just too much. And you try going out on that motorway on a Saturday an’ you're stuck there for ages… an' I've got Derek tae look after, you know? I've got a daughter and grandchildren and other family things, you know?*
>
> *(Maureen, 60s, mum to Derek, 40s)*

Changes to policy and service provision had resulted in fewer hours of social care support for Derek, and more hours of family care provided by Maureen and Dan. The couple also reflected on the long-term compromise in their lives due to caring responsibilities. For example, Maureen’s career opportunities were limited as she had only been able to work locally and part-time to fit around the day centre hours. Whilst Dan had always worked full-time, he had retired early to help care for Derek as it was becoming impossible for Maureen to care for him on her own because Derek’s support needs had increased and his support hours had decreased. Maureen and Dan would have liked to retire abroad but felt this was not feasible because of Derek’s support needs. Long-term and continuous compromise related to service provision is illustrated by Maureen:

> *You can't plan, you've no freedom. You're ruled by when the bus comes… I remember years and years ago, I used to work in [employer] an' I used tae have tae sit in the road, in the cold, waiting on the bus coming…* ***our life’s just been controlled by what Derek's doing****.*

(Maureen, 60s, mum to Derek, 40s)

These were not isolated examples. The vast majority of family carers spoke of long-term compromise – in work, home and relationships – as a result of caring. Whilst this was not the direct result of recent policy change, understanding the long-term effects of caring provides the context within which families experience the implementation of personalisation policies. For example, Susan had returned to the family home when her mum died to care for Lorna and their elderly dad. Although Susan had lived abroad at the time, and had a successful career, she felt that her family expected her to come home and take over from her mum.

Balancing their own needs with caring for family members was a continuous source of conflict and compromise for family carers. Scottish Government (2018e) policy recognises that having a break from caring can be vitally important to carers' health and wellbeing, and to enabling them to continue to provide care. As noted in chapter five, one of the main areas in which families had experienced the impact of budget cuts was respite provision; even when participants did manage to access services, respite could be a source of compromise and conflict. For example, Susan depended on Lorna going to respite so she could have a short break from caring. Susan did not like to go too far from home in case Lorna became ill whilst at respite, so she was still 'on call', even when she was having a break. Nonetheless, respite enabled Susan to do things she could not usually do easily, like theatre trips and overnight stays, and she valued this time. However, the sisters' needs were not necessarily compatible, which often resulted in conflict and compromise within the household:

> *…within about a day of being there, she phones and says: “Can I come home?” But that's usually because somebody's said: “You can't have this” or “You can't do something”. She doesn't like the word ‘no’.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Issues of ‘challenging behaviour’ are discussed further in section 7.5 in relation to health and wellbeing; however, it is important to note here that this was a major source of conflict and compromise for many families. This could be triggered or exacerbated by changes to policy and service provision. For example, Gillian was very distressed about the closure of the day centre and changes to her routine, and Sheila found it difficult to cope at times:

> *…things can be a bit fraught, certainly the behaviours been much worse, but then she's got other reasons for bad behaviour as well, so… it’s difficult to know what's going on.*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Other people and negative attitudes

Dealing with people outwith the immediate household was a further source of conflict and compromise within the household. Lack of support and understanding, and feeling judged as a parent, affected relationships and caused tension within families. For example, in order to avoid Gillian becoming distressed, Sheila allowed her to choose what to watch on TV. However, other family members thought Sheila was spoiling Gillian, which caused conflict:

> *…you do the best that you can… they tell you what you're doing wrong and shout at you!*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Sheila recalled one particularly stressful episode when they were visiting a family member, and Gillian had become very distressed late at night:

> *… "get her to shut up!"… "I can't get her to shut up! Do you think I want her to be standing screaming, wakening all your neighbours at 11 o'clock at night?"… "That's terrible… so embarrassed"… I thought: "Well I'm very sorry, but that's life!".*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

Dealing with other people's lack of understanding and negative attitudes also resulted in conflict and compromise when a friend went on holiday with Elizabeth and Catherine:

> *…about day three she said: "I'm having to make a lot of compromises here. Can we do something different today?" and I said: "No, no. This is autism. We have a plan, we're sticking to it."*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

Elizabeth had also experienced judgement from other people when she made the decision to enable Catherine to move out of the family home. Whilst Elizabeth believed this had been the best decision for both her and Catherine, she was made aware of the judgements of others:

> *I had one mother say to me not so long ago that she thought I was just the most terrible person when I let Catherine go into her own flat… that I was just giving up on my child…*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

The individual sources of compromise and conflict outlined above, which were directly and indirectly related to policy change, intersected with family lives and thereby compounded their effects. The data suggests that many of the issues which caused compromise and conflict – within and outwith families – could be mitigated by good services and support.

7.3.3. Independence and dependence

Issues of dependency are highly contested within disability studies and ethics of care literature, as discussed in chapter two. Participants’ lives were largely characterised by interdependency and the data highlighted the complexity within which families experience policy. Ethics of care reveals the false dichotomy of independence and dependency (Sevenhuijsen, 1998); participants were neither one nor the other. The messy reality of participants’ lives was therefore more complicated, with degrees of independence and dependency existing within interdependent relationships.

The vast majority of participants were dependent on social care services and several carers were acutely aware of this. For example, independence and autonomy were far removed from day-to-day reality for Susan and her family:

> *Our whole life is dependent on services – social services and NHS – and we can't go anywhere where we can't get that. You know? We're not free to move about. We don't have freedom of movement. Nobody who's a carer does.*
>
> *(Susan, 50s, sister to Lorna, 50s)*

Participants' narratives showed that carers often sought to ensure their family member could have some degree of independence. Family group interviews were particularly useful here because they revealed the dynamics between participants (see chapter four). For example, Richard (90s, dad to Pauline) was keen to make sure I heard Pauline's perspective before I heard his, and noted that: '*What we do together is just part of her life on a daily basis*'. The value placed by carers on having some degree of independence, both for themselves and their loved ones, is evidenced by Elizabeth:

> *…it would've been really easy when my husband died for me to just coorie up with Catherine in the house… just give my life to this child and that's it, and I have no life or do anything… it wouldn't have been good for Catherine and it wouldn't have been good for me.*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

Gillian, who had become less able to do things for herself as a result of ageing and learning disability, demonstrated to her family that it was important to her to do some things for herself, like opening the front door and letting herself in. Her mum, Sheila, had helped Gillian to develop this skill many years previously and worked together with one support worker to make sure Gillian had opportunities to exercise this ability:

> *…when I was working… I managed to teach her how to open the door… she's retained that, which is really good, so, Janice just drops her off and watches while she opens the door and lets herself in… it's nice just to try and encourage her to be as independent as she can be, as long as she's safe… it's getting the happy medium.*
>
> *(Sheila, 70s, mum to Gillian, 30s)*

However, carers were realistic about what independence meant. Realistic conceptions of independence recognised 'impairment effects' (Thomas, 1999) and accepted the existence of vulnerability. For example, although Andrew often went out alone and travelled by train, impairment effects (Thomas, 1999) and disabling barriers determined the extent of his ability to travel independently. Therefore, his parents acted to facilitate and mitigate this. Independence is complicated; as well as the unpredictable environment (e.g. train cancellations, hostile reactions), Andrew often found it difficult to make good judgements about risk. As Sylvia explained, Andrew could perceive risk where it did not exist and not perceive risk where it did exist:

> *…he'll walk up [quiet lane] at night… when specifically told not to… he doesn't see… risk there. But if he's walking along the road and there's some boys he freaks out. Cannae cope with youth 'cause he expects trouble…*

> *(Sylvia, 60s, mum to Andrew, 30s)*

The data suggests that co-ordinated, collaborative support was essential to achieve some degree of independence for participants with learning disabilities. The extract above from Sheila shows how this had been made possible for Gillian. Working with families, services could also support carers to have some degree of independence, as shown by Richard:

> *…what the girls have done… funny thing tae say, but* ***they help me as much as Pauline****…*
>
> *(Richard, 90s, dad to Pauline, 30s)*

Services have a role to play in supporting independence for carers and people who require support. The data suggests that good services did not create dependency, yet long term lack of support, paternalistic and non-existent services did. For example, not having suitable services meant Michelle spent all her time with her mum, so was entirely dependent on her family. Her mum, Janet, wanted a part-time job, but was unable to work and had few outside interests because she provided full-time care for Michelle.

As shown above, the concept of independence is complex; families and services may have different ideas about independence. It has been argued that the increase in guardianship for people with learning disabilities since the introduction of SDS (discussed in chapter five) has effectively reduced independence for disabled people (LDAS, 2016b). However, this reflects a simplistic understanding of independence, rather than the more nuanced experiences evidenced here. The interaction of independence, risk and protection was illustrated by Andrew's family, who had guardianship for him. For them, risk did not only come from unknown strangers in quiet lanes; Sylvia felt she also had to protect Andrew from a system that did not understand his needs:

> *…nobody could ask, nobody can do things tae your child or ask them questions or assume they knew what they were doing if you are guardian of a young person with, and deemed to be, have incapacity…*
>
> *(Sylvia, 60s, mum to Andrew, 30s)*

In order to achieve co-ordinated, collaborative support, families and services needed to work together, but there were considerable barriers to achieving this. Chapters five and six noted the importance of families being well-informed and proactive in dealing with professionals; yet in the vast majority of cases, this had not been possible. Michael and his mum Deborah had experienced a long-term lack of support and had a very difficult relationship with social workers, which contributed towards both of them having little independence and feeling unsupported:

> *…I had no idea that I could get help… I was very naive to, you know, like social care and things like that… when you have a disabled son, you're not handed a book… I didnae know what I was entitled to. I didnae know… I could get support off social work. I was just left tae it so I just got on with it…*
>
> *(Deborah, 50s, mum to Michael, 30s)*

The discussion above demonstrates the complexity of dependence and independence. Whilst family carers valued independence, they were realistic about what this meant for their families, recognising impairment effects (Thomas, 1999) and vulnerability.

This section further demonstrates the inextricable links between the public and private spheres for participants. Changes to social care policy and service provision, located in the public sphere, were experienced within the emotional context of family care; themes of love and affection, conflict and compromise, and dependency and interdependency were notable in the interview data. As discussed in chapter two, ‘family practices’ (Morgan, 1996) are affected by relationships with others (Smart, 2007); this was evident in participants’ narratives of balancing caring responsibilities and multiple demands, as well as long-term compromise in work, home and relationships.

In relation to Tronto’s conceptualisation of care (see chapter two), analysis of the emotional context of family care provided evidence of all four phases of care and associated values proposed by Tronto (1993), in contrast to the absence of ethics of care within the social care system, discussed in chapters five and six. ‘Caring about’ (Tronto, 1993), was evident in carers’ attentiveness to the needs of their family members and in the interactions between them. ‘Caring for’ (Tronto, 1993), was demonstrated by carers in taking responsibility for ensuring the needs of family members, and others, were met. ‘Care giving’ and ‘care receiving’ (Tronto, 1993) were evident in the performance of practical caring tasks and emotional care labour.

7.4. Friendships and Support Networks

This chapter continues the discussion of the interview data to show how private sphere experiences were related to the implementation of personalisation policies. Following on from the previous section, which looked at the emotional context of family care, this section moves on to look at friendships and support networks. Whilst friendships and support networks are largely sited within the private sphere, this data shows these were intrinsically linked to social care policy and service provision.

7.4.1. Friendships

Having friends and relationships was important to participants and allowed them to feel included in their communities. The discussion in chapter six showed the prevalence and the impact of the loss of friendships and relationships resulting from day centre closures; relationships with peers and day centre staff had been highly important, often leading to a blurring of identities between friend and worker. The importance of seeing friends, and this blurring of boundaries, was highlighted by Sandra:

> *…she loves Wednesdays 'cos she goes to college and she knows some a' the people. Then they become her friends… they don't have friends the way you and I would. But tae them it's a friend 'cos they see them every week. And the people who take them…*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Similarly, Maureen and Dan noted the importance of everyone in the day centre for Derek. Without the social contact in the day centre, Derek would spend all his time with his parents. Having social contact was therefore vitally important to him, and '…he enjoys the repartee he has with the staff' (Dan, 60s, dad to Derek, 40s).

For people with learning disabilities in this study, building and maintaining friendships and relationships required support from others. Within the context of the closure of day centres and reduced service provision, there were far fewer opportunities to establish and maintain friendships and relationships outwith the family. The loss of collective spaces combined with impairment effects (Thomas, 1999), which meant that people needed support to participate in social activities, increased the need for services or family to create and facilitate friendship opportunities. This resulted in additional work for some carers, but it also assumes families are able and inclined to organise. The vast majority of carers in this study were unable to create these opportunities due to old age, poor health, limited time and money.

There were only two examples in the data where friendships were self-organised by people with learning disabilities; Alistair visited his girlfriend most weekends and Joyce sometimes met a friend for lunch. Being able to organise and maintain relationships without support from others was related to impairment effects (Thomas, 1999). Alistair and Joyce were amongst the most 'able' participants; for example, they could travel independently, communicate verbally, and understood how to use money – and they used all of these skills to organise and socialise with their friends. Whilst impairment had limited effect on Alistair and Joyce's ability to maintain these relationships, their friends' impairment effects (Thomas, 1999) affected the frequency and opportunity to socialise. Alistair explained that his girlfriend had developed dementia and moved into a nursing home, which meant he did not see her as often, while Joyce explained how her friend's health affected their being able to meet up:

> *I've got a friend that I used to go to the centre with. Sometimes I meet her, sometimes we go out for lunch, other times I go out myself. It depends… she goes to the hospital, she takes fits, she's got epilepsy, so she's got to watch.*
>
> *(Joyce, 50s)*

The quote above also demonstrates the importance of services in providing opportunities for people to meet and develop friendships and relationships. Whilst Alistair and Joyce were able to maintain these relationships independently, forming these relationships in the first place had been affected by policy and service provision as Joyce had first met her friend, and Alistair his girlfriend, at services for people with learning disabilities.

For the vast majority of participants, there were few opportunities for socialising with people outwith the family. When there were opportunities to socialise with others, at clubs and groups for example, these were determined by others and time limited. For example, Janet took Michelle to a weekly social group, attended by many of her friends from the day centre they previously attended, however Janet felt this was not enough:

> *…she's limited wi' her pals… it's only a couple a' hours and then they need tae go.*
>
> *(Janet, 50s, mum to Michelle, 30s)*

The result of limited opportunities for socialising was that the majority of participants spent most of their time with family or support workers. For Paul, being dependent on others to create opportunities for socialising meant he felt lonely and isolated. Paul lived with his sister, who worked full-time, and had only a small number of weekly support hours, which meant he spent most of his time at home alone. Paul enjoyed listening to music and horse racing, and desperately wanted people to share these interests with:

> *…I don't want tae stay lonely all my life. I don't like it. I hate being lonely, and I just want somebody that can sit doon and say tae me: 'right, what do you want tae dae Paul', and I'll say: 'well I want tae put the gee-gees on the day'…*
>
> *(Paul, 40s)*

The discussion above shows the importance of having friendships and relationships, and some of the barriers to having friendships and relationships for people with learning disabilities. Whilst personal relationships reside in the private sphere of home and family, the data shows how these were affected by policy and service provision in the public sphere. Changes to policy and service provision resulted in people with learning disabilities becoming more isolated and dependent on family carers to facilitate their social lives. However, this was not inevitable; good services could support friendships and relationships, and mitigate the risks of people becoming isolated, by being attentive to individual needs and creating opportunities for people to socialise. In a rare example of this in the data, Sandra explained how Sharon's support provider actively created opportunities for Sharon to meet with her friends, which was vitally important to Sharon's wellbeing:

> *…it's always a one-to-one for Sharon, but when she goes out on a Monday, she knows people in her dance class… she does dancing in the morning, art*

> *in the afternoon. Another wee girl does the reverse… as they're both crossing over, they meet for lunch…*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

7.4.2. Support networks

In addition to the lack of opportunities for friendships for people with learning disabilities, the data also provided evidence of an absence of support networks for family carers. The availability of support networks was largely related to ageing; the parent carers in this study experienced less family support over time due to bereavement (most notably the loss of a partner), and the ageing and ill health of partners and siblings. Five of the families who took part in this study included a widowed parent caring for their disabled son or daughter. Previously, parent carers had partners, children, siblings and parents who had provided support, but this was no longer the case. In many cases, adult sons and daughters moved out of the family home and had careers and children of their own, limiting their availability to support their parents and disabled siblings; though, in a few cases, siblings had become the main caregivers for their disabled brothers and sisters.

In contrast with the majority of families who lacked informal support networks, Theresa's family had lots of support from their large, extended family. Whilst Theresa's sisters, Irene and Mhairi appreciated the support provided by the wider family, in the interview they reflected that this had largely absolved the state of responsibility for supporting Theresa:

> *M: …when they ask: "what's your support network?" …ours isn't bad actually.*

> *I: In a way that's good, and in a way it's bad as well I suppose.*
>
> *M: In what way?*
>
> *I: Well, that we're just doing it ourselves, we're no' having to rely on anybody else… for giving us places for Theresa… and money… it's making it easier, is basically what I'm saying, for Glasgow City Council…*
>
> *(Irene and Mhairi, 50s, sisters to Theresa)*

With the exception of Irene and Mhairi above, carers appeared to have few friends, which contributed to the lack of support networks. Without exception, this was the case for all the parent carers, and was directly related to lack of time as a result of long-term caring. Parents did not have many friends because they had never had the time to develop and maintain friendships; caring responsibilities, combined with work and families, were all-consuming, as Sandra explained:

> *You just kind of get your head down and get on, and you tend to kind of neglect your life. You neglect having friends, you neglect going out…*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Sandra's quote above illustrates how parents' needs were neglected at the expense of their child's needs. There were numerous sentiments like this in the interviews with parent carers. Over many decades, they had had to prioritise the needs of their sons and daughters over their own because of insufficient or unsuitable service provision. This was exacerbated because long-term exclusion limited opportunities to meet other families and to be part of the community:

> *…you're not at the school gate. Your child's not part o' the community and neither are you… that's where a lot a' things start, isn't it? People make friends and kids get together… you don't have that at all, cause you're no there…*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

Furthermore, three participants observed that there were additional barriers to maintaining friendships as an older parent carer. These participants felt that their lives were very much different to their peers, who were enjoying retirement and leisure, and this meant they had little in common. The reduction in social care services (particularly building based services like day centres), which had previously provided spaces for meeting other families, meant fewer opportunities to meet other families. The policy shift from building based collective services towards individual support in public spaces meant limited opportunities for socialising and developing relationships and support networks for people with learning disabilities and family carers, as Maureen noted:

> *We don't really meet a lot o' other families… the [carers'] meetings are held in the day centre… but people that aren't going to the day centre, how do you tell them?*
>
> *(Maureen, 60s, mum to Derek, 40s)*

Whilst carers' groups or organisations could provide opportunities for carers to meet other families, very few participants were involved in such groups, and there were varied levels of awareness of local groups. One mother was keen to attend a monthly meet-up for carers of people with learning disabilities but had been unable to do so because she could not take her daughter and she could not leave her daughter at home alone. However, the general lack of engagement with carers' groups may also have been related to conflict over the campaign to save the day centres (discussed in chapter five), which had resulted in the breakdown of solidarity amongst local groups.

There were some informal opportunities for developing support networks, which could have emerged with the support of services. Six families were, or had been, involved in the running of disability groups or by providing informal support to others. These were important because they provided collective spaces and activities for people with learning disabilities and their families. Grant explained how this had contributed towards their family feeling part of their local community:

> *…We thought: "Oh, naebody else is like that up here". But it was amazing when my ma started the club… it was amazing the amount o' folk wi' disabilities that lived in [area]…*
>
> *(Grant, 50s, brother to Alistair, 50s)*

For some participants, particularly those who lived in supported accommodation, it was paid workers who provided their support network – showing that services could facilitate this function. However, for family carers, there was generally a lack of trust in services and feelings that family care was the best care. Despite the lack of informal support networks and fear of the future, there was little evidence of contingency planning; families either assumed other family members or social care services would step in if anything happened to them, or they just could not bring themselves to think about it. The absence of support networks meant carers were largely isolated and this was detrimental to health and wellbeing.

Furthermore, the absence of support networks was also detrimental to SDS policy implementation. Information and support are key to the implementation of SDS and the lack of informal support networks, as well as distrust in services, were barriers to people accessing the information they needed to make informed decisions. Knowing others in similar situations could help carers be better informed about services, unlike Theresa's parents:

> *…they didnae know that respite existed… They knew that folk would maybe go away somewhere, but they didnae know about building based respite… I think there's probably a lot of carers out there who still don't know that these things exist…*
>
> *(Irene, 50s, sister to Theresa, 50s)*

This section further demonstrates the links between public policy and the private sphere of home, families and relationships. Social care policy and services could facilitate friendships and support networks for people with learning disabilities by providing opportunities for people to meet. Instead, the loss of collective and inclusive community spaces meant fewer opportunities to develop and maintain friendships and support networks.

7.5. Health and Wellbeing

Following the discussion above which looked at friendships and support networks, this section moves on to consider health and wellbeing – including the challenges of ageing and caring, and ageing with learning disabilities. Health and wellbeing are largely sited within the private sphere; however, participants' experiences were intrinsically linked to social care policy and service provision.

7.5.1. Complex lives of carers of people with learning disabilities

Ageing and the life course provide important context to the experiences of this group. The ages of family carers in this study ranged from 50s to 90s, and this impacted upon their caring status. Some had become sole carers due to bereavement, while – in addition to being long-term carers for their disabled adult children – some had also become dual carers due to ageing and ill health of partners, parents or siblings. For example, Elizabeth had lost her husband and become sole carer for their daughter, and Deborah had become a carer for her disabled husband in addition to caring for her son.

Parents spoke about caring for their adult sons and daughters with learning disabilities as an extension to the ‘normal’ parenting role; most parents also had other adult children who had long since left the family home and many of them had children and relationships of their own. Parents were also acutely aware that long-term caring responsibilities had determined their choices, or lack thereof, throughout their lives – notably in relation to work, home and leisure. Whilst all parents might reasonably expect to make compromises in these areas while raising children, those in this study had been making compromises for at least 30 years and expected this to continue indefinitely, and the associated lack of autonomy impacted upon health and wellbeing.

The idea of continuous or extended parenting and need for support for families in this situation was illustrated by Sandra:

> *…it’s your child but… somebody must help you somewhere along the line. If you’re ill… people help you. This is just a long-term help, isn’t it? And the help’s for all of you, no’ just your kids…*

> *(Sandra, 60s, mum to Sharon, 30s)*

The relentlessness of long-term caring with limited outside support was also articulated by participants caring for siblings. As Susan, who cared for her sister, observed:

> *…Lorna's [in her fifties] and we'll still be doing this when she's [in her seventies].*
>
> *(Susan, 50s, sister to Lorna, 50s)*

In addition to the expectation that participants' caring roles would continue indefinitely, for some families the caring role was all-encompassing because of the extent of impairment and limited outside support. Several family carers therefore felt it would be unsafe to leave their relative at home alone:

> *…I just wouldn't take the risk. What if somebody came to the door? What if the fire alarm went off? It's too worrying. You know, you don't know what could happen. You know, I can't take the risk o' something happening on my watch because how would you live with yourself? You don't go out and leave a toddler in the house, do you, kinda thing? I can't take the responsibility…*
>
> *(Susan, 50s, sister to Lorna, 50s)*

For two families, some parts of the parenting role which they previously carried out themselves had since been devolved to support workers. This suggested that these roles could be successfully accommodated elsewhere, given the right support. For example, Richard had stopped going to watch Pauline's drama shows and Elizabeth had stopped going swimming with Catherine, arranging instead for support workers to carry out these tasks. However, these examples were unusual in the study, and were instigated as a result of Richard and Elizabeth being no longer able to do this themselves due to their own health and ageing.

Family obligations were also a major motivating factor for participants who were caring for siblings with learning disabilities. Four female participants in their 50s had taken over from their elderly or deceased parents by caring for their disabled siblings, and were negotiating this with other commitments. Negotiating change to family roles and responsibilities was complex, and a source of additional emotional work for these women.

The importance of having a break from caring – in order to support carers' health and wellbeing and thus enabling them to continue caring – is recognised in the Carers (Scotland) Act 2016. Participants' narratives showed that arrangements to enable carers to have a break from caring need to be flexible to respond to unforeseen circumstances and impairment-related conditions. For Maureen and Dan, this was vital to their health and wellbeing and they planned breaks well in advance so they could go away on holiday when Derek went to respite. Having holidays to look forward to was crucially important for Maureen and Dan as this kept them going when things were difficult. However, strictly limited provision and inflexibility exacerbated their stress during a particularly difficult time:

> *…it was really stressful… we were really up against it an' I phoned and said: "Look, can we have even a weekend?" You know, a break… And she went, she says: "I'll need to speak to my boss." …an' she came back an' she said: "I've spoken to [her] and she says, no, give up your week later on in the year and you can have it now."*
>
> *(Maureen, 60s, mum to Derek, 40s)*

Care labour was complex and demanding for the vast majority of family carers in this study. Support needs were diverse and varied – related to ageing, impairment, health conditions and formal support provision – with needs changing on a day-to-day basis over the long term. Policy implementation needs to take account of individual circumstances and complex lives, yet only one family had received additional support which reflected the complex circumstances of being an ageing parent carer. Richard, sole carer for his daughter Pauline, was happy with Pauline's support arrangements and felt they accommodated both his and Pauline's needs. Pauline's support hours had been substantially increased and she had a team of regular support workers. However, this was an isolated example in the data as participants had generally had their support hours reduced, suggesting that the additional support needs arising from having an ageing parent carer were not being recognised in assessments.

7.5.2. Ageing and caring

Narratives of participants in this study showed the intersection of health and ageing of family carers and people with learning disabilities. As carers aged and experienced declining health, they became less able to provide support and had fewer family members to draw on for support due to ageing and bereavement, as discussed in section 7.4. At the same time, their disabled family member was also ageing and, in many cases, experiencing declining health and requiring additional support.

As mentioned earlier, fear of the future was a major source of stress and worry for carers – particularly older parent carers. The older participants were very aware that they were getting older and were not as fit or healthy as they had once been and were concerned about what would happen to their disabled sons and daughters when they died. Several had experienced the death of a partner, which may have contributed towards their awareness of their own mortality, and some had themselves experienced serious illness. Since losing her husband, Elizabeth had experienced serious illness, and both of these experiences contributed towards fears about her daughter Catherine’s future:

> *I worry all the time… I worry about what will happen when I die… I've said to some people: “You wouldn't really understand how much time I've had to spend since [husband] died worrying about my own death rather than thinking about how can we get on with our lives.”*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

Although this group were very conscious of their own mortality, there was little evidence of future planning. For example, Sandra and her family had not made future plans, nor did they have contingency plans in place in case of emergencies. With hindsight though, she felt they had ‘*made a mistake*’ by continuing to support Sharon in the family home for so long because, at some point in the future, they would not be able to do so:

> *…if you have no family, who’s gonie look after them? So really, it’s better that they’re settled… while you’re still here to keep an eye on things.*
>
> *(Sandra, 60s, mum to Sharon, 30s)*

7.5.3. Ageing and learning disability

People with learning disabilities have substantially lower life expectancy than those who do not (Scottish Government, 2013). As outlined in chapter two, life expectancy for people with learning disabilities has increased over the lifetime of participants in this study, however serious health inequalities remain. Furthermore, people with learning disabilities can experience the effects of ageing at a younger age than their nondisabled peers; for example, people with Down's Syndrome are at risk of congenital heart conditions and early onset dementia (Bigby, 2012). The effects of ageing at a relatively young age were evident in the experiences of participants in this study. For example, Gillian had developed dementia in her 30s, which caused her increasing frustration and confusion, while decades of seizures and surgery had affected Derek's mobility.

Many of the people with learning disabilities in this study had multiple and complex health conditions which required medical intervention, and families had ongoing dealings with health services and medical professionals – often attending several different hospital clinics. Reported conditions included: epilepsy; heart conditions; asthma; diabetes; sensory impairments; coeliac disease; obsessive compulsive disorder; post-traumatic stress; and anxiety. Complex health conditions and complex needs demand careful support planning, good communication with families, and highly skilled workers. However, as the discussion in chapters five and six showed, this was not the case.

One of the difficulties that is inherent to age-related deterioration of health for people with learning disabilities is that older parent carers are also experiencing the deterioration of their own health, so parents become less able while adult children need more support. Although this is well known within services, and acknowledged in the literature about ageing with learning disabilities, it is absent from policy. Developing this existing knowledge, participants in this study also spoke about other changes related to ageing and the life course which had detrimental impact on the health and wellbeing of their family members with learning disabilities; for example, siblings leaving the family home. Every family in the study had experienced household change which caused practical and emotional difficulties. The death of one or both parents was the biggest factor affecting changes to living arrangements. For example, three participants had moved into supported accommodation following the death of their parents.

Household changes related to the life course of family members affected routines and living arrangements. Additionally, participants had to deal with changes to routine as a result of changes to policy and service provision, which caused confusion and distress – particularly for people with autism. This, in turn, impacted upon the health and wellbeing of disabled people and family carers. Furthermore, settling in to new services, getting to know new staff, and staff getting to know individuals and families, takes time and effort in building relationships and understanding. Whilst difficulties seemed inevitable when dealing with this amount of change, these could be reduced by services and families working together. For example, Derek’s move to a new day centre was a source of considerable change, but the transition had been helped by using a diary to support communication between home and services; with day centre staff writing in Derek’s diary every day about where he had been, what he had for lunch, and so on. This reassured his parents but also helped the family’s relationship; Derek’s impairment meant he did not know or could not tell his parents much about his day, but Maureen and Dan could draw on the information in the diary to chat to Derek. The small act of writing in a diary improved communication and helped build relationships between the family and workers, and between family members. Blurring the boundaries between services and home, staff were effectively supporting Derek and his family’s home life, whilst supporting Derek at the day centre.

For participants who had previously attended day centres – but were no longer able to as a result of the local implementation of personalisation policies and widespread closure of day centres – carers unanimously felt that they were less active and more isolated. Additionally, carers also felt this was detrimental to the health and wellbeing of their family members. The detrimental effects of loneliness and isolation on health and wellbeing are well-documented (Scottish Government, 2018b). When combined with the existing health inequalities experienced by people with learning disabilities, this is a cause for concern. Three mothers particularly noted that the nature of impairment meant that it was easy for people with autism to become isolated; these mums were all working to try and mitigate and manage the impact of isolation for their sons and daughters, who have autism. They strongly believed that services had an important role to play in supporting people with autism to avoid isolation, but that this was largely not being met.

Diet and exercise were also prominent themes in the narratives of family members. In some cases this was because of a medical diagnosis which required particular dietary needs (e.g. diabetes, coeliac disease, food intolerance), and in others this was related to reduced physical activity, weight gain and/or declining mobility. Regardless of the cause, maintaining healthy weight and activity had become more difficult because changes to service provision had resulted in fewer opportunities for people to be physically active.

7.5.4. ‘Challenging behaviour’[44]

For four families in this study, dealing with episodes of difficult behaviours were a major part of family life and affected health and wellbeing. Whilst

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[44] ‘Challenging behaviour’ is highly contested as a concept and as a term. I understand ‘challenging behaviour’ to be a manifestation of distress, often related to unmet need (see: https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018), but I understand that such behaviours were experienced by carers as extremely

‘challenging behaviour’ affected a relatively small proportion of participants, the impact was severe – causing exhaustion and stress, as well as seriously affecting health and wellbeing. For the people who were displaying ‘challenging behaviour’, this was a manifestation of powerful emotions (including: fear, distress, confusion and frustration) in response to difficult situations. ‘Challenging behaviour’ was associated with impairment effects (Thomas, 1999) related to autism.

As discussed above, for some people with learning disability, age-related health degeneration occurs earlier; and in three of the four families dealing with ‘challenging behaviour’, this had got worse over time. Carers understood this to be related to health and ageing, as well as changes to routine and services. Whilst changes to health and ageing were somewhat inevitable, changes to routine and services were not, and could potentially have been mitigated with appropriate support. Importantly, increases in incidents of ‘challenging behaviour’ were experienced within the context of family carers getting older, having less support, and being less able to cope. As discussed previously, carers had less family support at a time when they felt they needed it more than ever; where previously their children were younger and there were partners, siblings and grandparents to help.

The difficulties of caring for someone displaying ‘challenging behaviour’ were exacerbated by worries about, and experiences of, negative views of others. Carers felt that other people were less understanding about displays of ‘challenging behaviour’ in adults than they were about similar displays in children. Barriers to inclusion, including negative attitudes and behaviours, are discussed in chapter six. For these participants, other people’s lack of understanding meant challenging public situations were made more difficult.

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challenging, and this is the language participants used to understand and describe their experiences.

Caring for someone who could display ‘challenging behaviours’ was understood as being a particular barrier to having informal support networks. In addition to the barriers to support networks for carers previously discussed in this chapter, Sheila noted that her family and friends did not understand the extent of Gillian’s behaviour. This was related to superficial understandings of support needs, particularly where there were no visible markers of difference.

In addition to the effects of negative attitudes and behaviours, carers had to micromanage situations to pre-empt and mitigate potential risks – thereby affecting what they could do as a family. Going for days out and holidays, being in strange environments, and being amongst other people could mean unpredictable events which triggered ‘challenging behaviour’ episodes, as Elizabeth explained:

> *…people don't realise the depth of her disability because they see this quite well-behaved young woman who is coping in an environment which we have made sure is perfectly safe… if there's one sudden step out of it, there's quite a real… if suddenly a small child comes towards her drawing or whatever… she really could knock over that child and really hurt them. We've had two incidences… recently… I just could see it happening and I ran, threw myself over…*
>
> *(Elizabeth, 60s, mum to Catherine, 30s)*

By discussing the challenges of ageing and caring, ageing with learning disabilities, and ‘challenging behaviour’, this section further demonstrated the links between public policy and the private sphere of home, families and relationships. Although largely sited within the private sphere, participants’ experiences of health and wellbeing were intrinsically linked to social care policy and service provision.

7.6. Conclusion

This thesis set out to understand the impact of policy change for people with learning disabilities and their families. This chapter continues the discussion of the interview data in the preceding two chapters by highlighting the ways in which private sphere experiences were related to changes to policy and service provision.

Participants' narratives illustrated how the private sphere of home and family was inextricably linked with changes to social care policy and service provision. Beginning with an overview of family lives and routines, the first section showed how daily schedules, competing demands on time, and household finances were linked with policy change. Social care policy and service provision greatly impacted upon family lives and routines, through determining weekly schedules and activities, competing demands on carers, and household finances. The additional care labour for families was produced by changes to policy and services, but adopted as an 'ordinary' part of family life, demonstrating Morgan's (1996) conceptualisation of 'family practices', discussed in chapter two.

The chapter moved on to consider policy change within the emotional context of family care; showing how family care was framed in language and experiences of love and affection, conflict and compromise, and independence and dependence. This section further demonstrated the inextricable links between the public and private spheres for participants, who experienced social care policy and service provision within the emotional context of family care. As discussed in chapter two, ‘family practices’ (Morgan, 1996) are affected by relationships with others (Smart, 2007); this was evident in participants’ narratives of balancing caring responsibilities and multiple demands, as well as long-term compromise in work, home and relationships. Furthermore, in contrast to the absence of ethics of care within the social care system, discussed in chapters five and six, the emotional context of family care provided evidence of all four phases of care and associated values proposed by Tronto (1993). For example, carers were attentive to the needs of family members, and took responsibility for ensuring these needs were met, directly and indirectly.

Thereafter, the links between the private and public spheres were further demonstrated by looking at friendships and support networks. Friendships and support networks were largely absent for participants, with the analysis of the interview data revealing some of the ways in which policy and service provision contributed towards these barriers – thereby preventing participants from having and maintaining these relationships. In the final section of this chapter, the links between public policy and the private sphere of home, families and relationships are further developed by looking at health and wellbeing. In discussing the challenges of ageing and caring, ageing with learning disabilities, and ‘challenging behaviour’, this section showed that participants’ experiences of health and wellbeing were inextricably linked to social care policy and service provision. Taken together, all four sections in this chapter highlight the multiple ways in which private sphere experiences were related to changes to policy and service provision.

This is the last of three chapters presenting interview data, and the end of the second part of the thesis. The next chapter returns to the key research questions, sets out the main findings of the study, and proposes potential ways forward.

8. Discussion and Conclusion

8.1. Introduction

This study set out to explore the experiences of people with learning disabilities and their families within a shifting policy environment, focusing on people with learning disabilities who were aged 30 and over, living in Glasgow. The first part of the thesis (chapters one to four) explained the context of this study, with an overview of relevant literature and policy as well as my approach to carrying out the research. The second section of the thesis (chapters five to seven) presented the interview data in relation to participants' experiences in three main areas: SDS assessment and implementation; care and support services; and the private sphere of home, family and relationships.

In the third and final section of the thesis, this chapter draws the discussions in the previous two sections together to address each of the three research questions set out in chapter one. It goes on to outline the main findings of the study, and what this means for policy and practice. Thereafter, the discussion moves on to explain the originality of this research and its important contribution to knowledge, before outlining some limitations and suggesting areas for further research. The chapter concludes with some brief reflections on the research process and the role of my lived experience in shaping the study, and an overview of the key findings and potential ways forward.

8.2. Research Questions

The discussion here returns to the three main research questions, which were set out in chapter one, and considers each of these in turn. This study was concerned with understanding how policy change played out in family lives, focusing on the experiences of people with learning disabilities aged 30 and over, and their families, living in Glasgow. The main research questions were:

1. In what ways have changes to social care policy affected the day-to-day lives of people with learning disabilities and their families?
2. How does the dominant policy discourse of 'Personalisation' reflect the needs and wishes of people with learning disabilities and their families?
3. In practice, does self-directed support policy increase choice and control for people with learning disabilities and their families?

Taken together, the findings in relation to these three questions reveal a vast gap in policy and practice, as discussed below. The originality of this study, and its valuable contribution to knowledge, is outlined later in this chapter, but it is important to note here that these are important findings within the current policy context. As the ten-year strategy for SDS (Scottish Government, 2010: 2) approaches its end, the Scottish Government and COSLA are currently developing a programme to reform adult social care in Scotland (Scottish Government, 2018a: 21; Scottish Government, 2018b: 69).

8.2.1. In what ways have changes to social care policy affected the day-to-day lives of people with learning disabilities and their families?

It is clear from the data that changes to social care policy had resulted in major changes in day-to-day lives and routines. Overwhelmingly, the alterations to daily lives and relationships that had resulted from changes to social care policy and public spending cuts were perceived negatively by participants. As noted throughout this thesis, changes to social care services and public spending cuts were intrinsically related; SDS was conflated with cuts and closures for this group, as discussed in chapter five.

Participants were very aware that Glasgow City Council viewed personalisation as a way of achieving budget cuts. As outlined in chapter one, the restructure of learning disability services in the city, including day centre closures, was justified as being part of the roll-out of SDS. For participants, this narrative strongly contributed towards framing SDS as ultimately being about cuts and closures, rather than choice and control for people who require social care services. This supports Needham's (2014: 94) analysis, discussed in chapter two, as day centre closures were framed as a 'positive consequence' of personalisation by the local authority. As noted throughout this thesis, the appropriateness of day centres as places of care and support for people with learning disabilities is highly contentious. Nonetheless, it is clear from the data that widespread closures have resulted in major disruption in the lives of many participants, and this is reflected in the discussion below.

For presentation purposes, the discussion here considers the impact of changes to social care policy for people with learning disabilities and their families separately, however, this is a false distinction; in practice, the lives of participants were intrinsically linked. For participants with learning disabilities themselves, policy change has resulted in: increased isolation and exclusion; the loss of collective spaces; change to long-established routines; and limited and/or poor-quality activities. The discussion below expands on each of these interrelated issues, before moving on to consider the impact on the lives of family carers.

Many of the participants who had learning disabilities experienced increased isolation and exclusion because of changes to social care policy and service provision. As discussed in chapter six, most were receiving less support from formal services, which was related to individual budget cuts. For participants living in supported accommodation, budget cuts meant fewer opportunities for activities outwith the home and little one-to-one time with staff. Overall, people were spending more time at home and with their families, and there were fewer opportunities to attend social groups or clubs due to funding cuts.

The closure of day centres meant the loss of collective spaces, as discussed in chapter six. As set out in chapter two, support networks are vital in the lives of people with learning disabilities (Hall, 2011), but day centre closures resulted in the loss of longstanding relationships and had caused substantial emotional distress. Furthermore, the loss of collective spaces meant fewer opportunities to make and maintain relationships.

Ultimately, the closure of day centres meant the loss of long-established routines for those who attended the centres and their families. In most cases, going to the day centre had been their daily routine for decades. As discussed in chapters six and seven, the loss of the familiar routine, combined with the effects of impairment, resulted in considerable emotional distress and confusion for many participants.

Additionally, the closure of day centres – combined with a lack of suitable alternative support provision – resulted in participants' experiencing limited and poor-quality activities, as noted in chapter six. Participants reported few opportunities to be physically active and several 'activities' appeared to be simply time-filling. In many ways, community centres had replaced day centres, however activities in these venues were often limited to one room and several participants felt that there was a very limited range of poor-quality activities on offer.

For family carers, participants' narratives strongly suggested that policy change had resulted in additional work and stress, discussed in chapters five and seven. Fewer support hours meant family members were doing more unpaid care, as well as managing and co-ordinating formal care arrangements, which could involve several different service providers. The implementation of SDS and budget cuts also caused additional household expenditure, including the client charge and costs of activities. Importantly, changes to social care policy created additional emotional work for carers in managing conflict, distress and uncertainty.

Thus, for many participants, changes to social care policy had resulted in more time spent at home and with family members, and less in their community, doing the things they wanted to do, like spending time with friends and having fun. Throughout the discussion above there are two overarching and related themes of relationships and wellbeing. Within the context of the longstanding exclusion and marginalisation of this group, as well as the challenges related to the intersection of ageing and caring, supporting relationships and wellbeing should be central to social care policy and practice.

8.2.2. How does the dominant policy discourse of 'Personalisation' reflect the needs and wishes of people with learning disabilities and their families?

Generally, the policy discourse of personalisation, in terms of the SDS values and principles noted in chapter three, reflected the needs and wishes of participants. However, in addition to these shared principles, generally valued collective provision of services. Thus, the association between personalisation and individualism, discussed in chapter four, was not congruent with the needs and wishes of this group. Crucially however, this study found a vast gap between the needs and wishes of participants and personalisation *as implemented.* As discussed later in this chapter, this study found little evidence of the values and principles underpinning SDS in practice.

As noted throughout this thesis, the context within which people experience policy is important, and there are particular factors which frame the experiences of this group. Previous experience and expectations of social care services intersected with impairment, health, ageing, and reduced support networks. Participants' need for formal support was often increasing, and Glasgow's socialist political history was evident in carers' narratives of public service provision. Thus, although participants were broadly in agreement with SDS values and principles, these contextual factors contributed towards this group not wanting radical change in existing support arrangements.

There were several fundamental aspects of the policy discourse of personalisation that resonated with participants' views. As noted above, the four statutory principles of SDS (Collaboration; Involvement; Informed choice; and Participation and Dignity) resonated with participants, however they had seen little evidence of these in practice. For example, participants agreed that disabled people should be able to make choices about their lives and their support, and most were initially positive about the opportunity presented by personalisation. However, as discussed in chapter five, participants did not receive the support they needed to exercise choice.

Relatedly, as discussed in chapters two and three, SDS is underpinned by a commitment to independent living, which reflected the needs and wishes of participants, though it is noted that achieving independence required support from others. However, one of the barriers to independent living, which was not addressed by SDS, was the hostile 'mainstream' environment, noted throughout this thesis. Furthermore, the longstanding association between independent living and direct payments, discussed in chapter three, was not relevant to this group who did not want to manage direct payments.

Another aspect of personalisation discourse which reflected the needs and wishes of participants, but had not transpired in practice was collaboration and co-production. Co-production in policy and practice is a key feature of SDS, and of the Scottish approach to policymaking, discussed in chapter three. Furthermore, personalisation is associated with a shift in power from professionals to people who use services, discussed in chapter two. Despite this, it was clear from the data that power largely remained with professionals and it was extremely difficult for families to challenge, as noted in chapter five. This may be related to austerity and local implementation; as discussed in chapter three, there are local variations in SDS implementation, and constrained public sector budgets have contributed towards implementation taking longer than expected (Scottish Government, 2019; Audit Scotland, 2017). However, the lack of collaboration and co-production experienced by participants may also be related to fundamental issues with co-production, discussed later in this chapter. For example, What Works Scotland (2019: 4) notes that partnership and collaborative working is ‘patchy’ in Scotland, despite ‘shared and widespread’ supportive narratives.

Importantly, one area of personalisation discourse which did not reflect the needs and wishes of participants in this study was the association with individualism, discussed in chapter three. As noted throughout this thesis, personalisation is associated with a shift from the provision of collective services to individual support in the community (Power, 2014). However, as discussed in chapter seven, collective spaces, including day centres and specialist groups, were highly valued, and many participants wanted to have this option. Furthermore, SDS does not address the barriers to inclusion in public places for disabled people (Witcher, 2014) and there were few good quality alternative services available to participants, as discussed in chapter six. Additionally, personalisation is associated with neo-liberal politics and the rolling back of the state, discussed in chapter three, and family carers in this study generally held strong views about public service provision, noted in chapter five.

Nonetheless, the policy discourse of personalisation generally reflected the needs and wishes of participants in this study, although their experience of SDS implementation did not. It is clear from the data that the promised transformation of social care has not yet materialised and there was little evidence of the values and principles of SDS being embedded in practice.

8.2.3. In practice, does self-directed support policy increase choice and control for people with learning disabilities and their families?

For participants in this study, the implementation of SDS had not resulted in more choice and control. Whilst participants were familiar with the term ‘choice and control’ in relation to SDS, there was little evidence of this in practice. As discussed in chapter five, the widespread closure of day centres, despite strong resistance from individuals and families, was evidence of the absence of choice and control, contrary to policy narratives. Within this context, SDS implementation effectively reinforced this groups’ lack of power, as discussed in chapter five. Furthermore, as evidenced by Pearson and Ridley (2017) and noted throughout this thesis, the implementation of SDS at the same time as public spending cuts related to austerity was a major factor. For participants in this study, the possibilities for choice and control were determined by the restructuring of learning disability services, discussed in chapter six, contributing towards SDS being conflated with cuts and closures.

Despite the lack of evidence of choice and control in practice, the implementation of SDS had contributed towards changing narratives around social care. Participants knew they were meant to have choice and control, and this contributed towards their dissatisfaction as they perceived a massive gap between policy rhetoric and personal experience, as discussed in chapter five.

Although the concept of choice and control is strongly associated with SDS, both in policy discourse and in participants' narratives, choice is highly contested, as discussed in chapter three. There is evidence to suggest that choice and control contribute towards improved outcomes (Rabiee and Glendinning, 2010), however various factors constrain individual choice, as noted in chapter three. For example, factors which determine choice include: the availability of alternatives and information (Rabiee and Glendinning, 2010); and individual capacity and budget allocation (Lloyd, 2010). Additionally, the concept of 'choice' is problematic because it implies that everyone is equally able to make choices and neglects the existence of wider inequalities, discussed in chapter three. For participants in this study, choice was constrained by various factors, including: the availability of alternatives; not having the information and support required to exercise choice; interdependencies in relationships; and the effects of ageing and impairment.

The local implementation of SDS resulted in direct and indirect limits on choice and control. As discussed in chapter five, participants reported being unable to fully participate in assessments or make informed choices, and in some cases, the possibilities over which they could make decisions were restricted by others. Examples of restricting choice and control included: not giving people the option of having the budget paid gross or net of the client contribution; determining the availability of services through direct provision or commissioning; and controlling the availability of information, discussed in chapter five.

Disabled people are a diverse group and some may value choice and control more than others (Roulstone and Morgan, 2009: 343). As the discussion in chapter three suggests, choice is not necessarily a pre-requisite of good care; collaborative relationships and continuity in support are often highly valued and associated with good care (Roulstone and Morgan, 2009; Mol, 2008).

Despite some initial high hopes, overwhelmingly, participants had come to feel that SDS had been imposed upon them, thus negating the potential for empowerment and in conflict with ‘choice and control’, as discussed in chapter five. Participants’ experience of SDS had not lived up to expectations; instead it reinforced their lack of power and control, contributing to feelings of anger and distrust towards policymakers and professionals. Thus, whilst SDS has been successful in embedding choice and control in social care discourse, ultimately there was little evidence of choice and control in practice .

The discussion above outlines the findings in relation to the three main research questions, and reveals a vast gap in policy and practice. The next section sets out the main findings of this study, and what this means for policy.

8.3. Main Findings

This section sets out the main findings of the study, and considers what this means for policy. The findings relate to three related areas, discussed below. First, this study provides evidence of a vast gap between SDS policy and practice, second, it demonstrates the importance of collective spaces for this group, and third, it illustrates the absence of care in social care policy.

8.3.1. Gap in SDS policy and practice

This study found little evidence of SDS values and principles, and suggests this was a key factor in the gap between policy and practice. Throughout the data, it was clear that the values and principles, and underpinning ethos, set out in legislation and guidance had not been embedded throughout the process. The findings of this study therefore suggest that further research is needed to consider how SDS values and principles are evident, or not, at all levels of policymaking and delivery, as discussed later in this chapter.

The gap in SDS policy and practice was evident in relation to: the association with cuts and closures; the shift from collective services to individual support in the community; experiences of choice and control; shift in power; and co-production in practice. These issues are discussed below.

SDS associated with cuts and closures

Throughout this thesis it is noted that SDS implementation took place alongside the restructuring of learning disability services and day centre closures. As outlined in chapter five, the local authority viewed personalisation as a way in which they could make budget savings (Main, 2014) and participants were well aware of this. For this group, SDS assessment meant lower budgets and fewer support hours, and more family care and household expenses. SDS was therefore inextricably linked to cuts and closures, however budgets cuts and more tailored services are contradictory goals (Needham, 2014).

Whilst SDS policy discourse was characterised by empowerment, in practice, SDS was experienced as disempowering. The negative consequences of SDS implementation for participants include: major disruption to family lives and routines; fewer opportunities for people with learning disabilities; and additional work and stress for carers.

This study provides evidence of the impact of public spending cuts on individual and family lives. If the transformation of social care promised by national government is to be achieved, policy needs to acknowledge and address the funding of social care.

From collective services to individual support in the community

This study highlights a clear gap in policy and practice in relation to the shift from collective services to individual support in the community associated with personalisation, discussed throughout this thesis. The shift from collective services is highly evident in the widespread closure of day centres in Glasgow, but there is little evidence that individual support in the community has emerged in its place.

Several factors appear to have contributed to this gap in policy and practice. First, individual support in the community requires both facilities and support for people with learning disabilities to participate. Participants reported a lack of appropriate facilities and support, largely associated with funding constraints. Second, contested understandings of inclusion and community mean people with learning disabilities were effectively segregated within mainstream environments, including community centres. Third, communities can be hostile places for people with learning disabilities, evidenced by the prevalence of assault and abuse; policy needs to address this at both local and national levels. Finally, and importantly, the shift from collective services to individual support in the community is not necessarily what individuals and families want. Participants in this study wanted to be able to exercise choice and control over their support, and that often meant being able to attend a day centre, or specialist groups, where they could be with other people with learning disabilities. For family carers, individual support in the community was not necessarily relevant; they simply wanted good quality and reliable services they could trust.

Little evidence of choice and control in practice

This study found a clear gap between policy and practice in relation to choice and control. As discussed earlier in this chapter, there was little evidence of choice and control in practice, although narratives of choice and control had been embedded in social care discourse. This study highlights contested issues in relation to choice and control, and notes that people are not equally able to exercise choice and control. For example, for participants in this study, interdependencies in relationships and the effects of ageing and impairment could limit opportunities for choice and control. Additionally, choice was constrained by local policy implementation; for example, the availability of alternatives and not having the support required to exercise choice. This highlights the effects of unintended consequences and local variance associated with the Scottish approach to policymaking.

Power shift from professionals

As noted in chapter three, personalisation is associated with a shift in power from professionals to individuals and families. This study found that this shift has not yet transpired, and proposes that this was associated with the policy values and principles not being embedded throughout the SDS process, as noted above.

The closure of day centres, discussed in chapter six, provided clear evidence of persistent power inequalities. Within the context of shifting power to individuals and families, somewhat ironically, it was the perspectives of powerful professionals which drove the closure of day centres. As Needham (2014) notes, the views of those who opposed day centre closures were dismissed and discredited by powerful decision makers. For participants in this study, ultimately this reinforced their lack of power.

This study suggests that the power shift associated with personalisation is largely rhetoric since it neglects fundamental power inequalities. Any genuine attempt to transfer power from professionals to individuals and families requires acknowledging and addressing powerlessness and vulnerability.

Co-production in practice

This study found a clear gap in policy and practice associated with co-production. Notably, this study challenges the largely uncritical adoption of 'co-production' in policy design and delivery. This has implications for SDS as well as the Scottish approach to policymaking more broadly, discussed later in this chapter.

8.3.2. Collective spaces and specialist groups

This study found that there was strong support for maintaining collective spaces, including day centres, and specialist groups for people with learning disabilities. This is an important finding because day centres are largely no longer seen as appropriate places for the care and support of people with learning disabilities (Power, 2014), as discussed in chapter two. The disability movement is generally critical of day centres because of associations with segregation and institutionalisation (Needham, 2014). As noted throughout this thesis, the dominant narrative in support for people with learning disabilities is individual support in the community. These are important critiques, however this study adds nuance to the debate by illustrating the perspectives of people who have attended day centres for most of their adult lives and, importantly, the impact on the lives of disabled people and their families when this support is withdrawn.

As discussed in chapter six, day centre closures had resulted in substantial distress and disruption. It was particularly difficult for people with learning disabilities to understand and adjust to the change to long-established routines, and this was associated with impairment effects (Thomas, 1999). Importantly, the closures had resulted in the loss of longstanding friendships and relationships. These issues, together with the complicated, unreliable and reduced support arrangements which largely replaced day centres, had resulted in additional physical and emotional work for carers.

In contrast with professional and political narratives about day centres contributing towards the segregation and exclusion of disabled people, as outlined in chapter two, participants' narratives demonstrated the important role of day centres, and collective spaces more broadly, in the lives of many people with learning disabilities and their families. One of the most important and overlooked functions of day centres was that of being a place of inclusion; this was particularly important because public places could be hostile and risky environments, discussed in chapter seven, and participants experienced few opportunities for inclusion. Relatedly, carers strongly felt the day centres were part of the local community, as well as a community within themselves, where disabled people and their families and support staff experienced belonging. Furthermore, there was a clear gap between perceptions of day centres by those outwith and within the day centre community, and families were deeply hurt and angry about the comparison of day centres to long stay institutions, discussed in chapter six.

As a result of the closure of day centres and reduced service provision, there were far fewer opportunities to establish and maintain friendships and relationships outwith the family. Participants with learning disabilities generally needed support from others to establish and maintain friendships and relationships. The loss of collective spaces meant that the onus was on families to provide this support, however this assumed that families were able and willing to take on this additional responsibility. Thus, the findings of this study suggest that opportunities for – and support to participate in – social activities, friendships and relationships need to be prioritised as new models of care and support emerge.

8.3.3. The absence of care in social care policy

Drawing on Tronto's (1993) and Rogers' (2016) conceptualisations of care, this study found a lack of care in social care policy. Analysis of the data revealed several areas where care was absent in practice, and service provision was experienced as 'care-less' (Rogers, 2016). This was in contrast to participants' narratives of family care and day centres, where ethics of care (Tronto, 1993) was highly evident, and services were experienced as 'care-full' (Rogers, 2016). As discussed in chapter two, Tronto (1993) outlined four phases of care (caring about; caring for; care giving; and care receiving) and associated moral values (attentiveness; responsibility; competence; and responsiveness), and proposed that good care requires all four phases to work together.

Participants' experiences of the SDS assessment process, discussed in chapter five, demonstrated the absence of all four phases of care, illustrating a lack of care for, and about, the intended recipients of social care policy. Additionally, the widespread closure of day centres and apparent disregard for the opinions and perspectives of the people who attended day centres and their families, discussed in chapter six, suggests a lack of caring about and caring for (Tronto, 1993) the needs of this group. Participants' experiences of 'personalised' service provision, involving poor quality services and activities, and additional work for carers, further demonstrated the absence of caring about, caring for, care giving, and care receiving (Tronto, 1993). Moreover, the discussion highlighted ‘care-less’ spaces (Rogers, 2016), in which participants had experienced poor-quality services and a lack of support.

As discussed in chapter two, ethics of care uncovers the implicit values and assumptions which underpin policy (Sevenhuijsen, 2004) and demonstrates that care is a fundamental part of human experience (Tronto, 1993; Sevenhuijsen, 1998), which demands a collective response (Barnes, 2012). Thus, Barnes (2012: 171) has called for the inclusion of care in the policy process, discussed in chapter two. By demonstrating the absence of care in social care policy in practice, this study provides further evidence to support the need for ethics of care throughout the policymaking process. This is an important and timely finding as the incorporation of kindness in Scotland’s National Performance Framework (Scottish Government, 2018d) and the emerging body of literature which calls for the inclusion of kindness and emotions in policy (for example, see Unwin, 2018) suggests the beginning of a policy shift which recognises and acknowledges human relations and connectedness.

The discussion above demonstrates the main findings of this study, notably: the vast gap between SDS policy and practice; the importance of collective spaces for people with learning disabilities; and the absence of care in social care policy. The next section moves on to consider the originality of this study and its important contribution to knowledge.

8.4. Originality and Contribution to Knowledge

There are many aspects of this study which are original and which make an important contribution to knowledge. The main areas of originality and contribution to knowledge relate to the following four aspects, discussed below. First, this study provides the most comprehensive picture of SDS implementation to date. Second, it uncovers meanings and experiences of personalisation for people with learning disabilities and their families. Third, this study challenges the largely uncritical adoption of 'co-production' in policy design and delivery, and fourth, it questions commonly held assumptions about choice and control.

8.4.1. Comprehensive picture of SDS implementation

There is little existing evidence in relation to SDS implementation and the experiences of people who require social care support, noted in chapter three. This study contributes towards addressing this gap, providing an in-depth critique of SDS implementation and illustrating the impact for participants. This study provides evidence that the transformation of social care, discussed in chapter three, has not yet transpired, and highlights contributory factors.

This study was concerned with understanding how policy change played out within family lives, focusing on the experiences of people with learning disabilities aged 30 and over, and their families, living in Glasgow. This thesis provides an in-depth study of this group and shows the impact of SDS implementation on the daily lives of participants. In contrast with policy narratives of choice and control, this study reveals that this group felt disempowered by the SDS assessment process, and they experienced its implementation in terms of restricting choices, increasing isolation, and reducing opportunities for independent living.

Notably, this study includes the perspectives of people with learning disabilities *and* their families. This was important for several reasons, including the neglect of the experiences of this group in existing literature, discussed in chapter four, and the often vital role of family support for people with learning disabilities, discussed in chapter two. Relatedly, this in-depth study highlights the social-relational context within which policy change, and specifically SDS implementation, was experienced. For participants in this study, experiences of SDS assessment and implementation were framed within the context of the local restructuring of learning disability services and day centre closures. Importantly, this study also provides an original contribution to knowledge in this field by highlighting the intersection of health, ageing, caring, and reduced support networks in participants' experiences of SDS implementation.

As noted in chapter three, there is very little evidence on SDS implementation in Scotland to date, and it is not possible to ascertain the extent and effectiveness of SDS policy from the current data. The limited existing research has tended to focus on professionals' perspectives (Manthorpe et al, 2015), although there have been some small quantitative studies (for example: SDSS, 2016; LDAS 2016a), and pilot studies (for example: Witcher, 2014) which focus on the perspectives of individuals who use services. This thesis contributes towards addressing the gap in knowledge in relation to SDS by providing an in-depth study of the impact of SDS implementation on the daily lives of people with learning disabilities aged 30 and over, and their families, living in Glasgow.

Relatedly, this study contributes to knowledge concerning the transformation of social care in Scotland (Scottish Government, 2018a), as discussed in chapter three. It was clear from participants' experiences that the power shift associated with personalisation has not yet transpired. As noted earlier in this chapter, this study found little evidence of SDS values and principles, discussed in chapter three. Importantly, this thesis identifies some of the barriers to the transformation of social care, discussed later in this section, including: the meaning of personalisation for people with learning disabilities and their families; the largely uncritical adoption of ‘co-production’ in policy design and delivery; and assumptions about choice and control. As noted earlier in this chapter, this study is important within the current policy context; the ten-year strategy for SDS (Scottish Government, 2010: 2) is approaching its end, and a new programme to reform adult social care in Scotland is under development (Scottish Government, 2018a: 21; Scottish Government, 2018b: 69).

Moreover, this study offers an important contribution to debates around personalisation, which have dominated discussion in social care across OECD countries over the past decade (see Needham and Dickinson (2017); Christensen and Pilling (2014). Importantly, it presents the voices and experiences of people with learning disabilities, who are often absent from these debates. Alongside Australia’s National Disability Insurance Scheme, Scotland’s SDS policy is one of the broadest attempts at personalised social care, and its focus on co-production at the heart of policy makes it distinctive from other international approaches. This research is therefore important in presenting a critical account of its users.

8.4.2. Meanings and experiences of personalisation for people with learning disabilities and their families

This study further contributes to knowledge by shedding light on the meanings and experiences of personalisation for people with learning disabilities and their families. As noted throughout this thesis, personalisation is associated with a shift from collective services to individual support in the community (Power, 2014) however this was not what many participants in this study wanted from personalisation. This group wanted to have *real* choice and control over their support, including having the option to attend day centres or specialist groups; they wanted to have opportunities to be with friends and to pursue interests. Additionally, family carers wanted good quality, reliable services, and to feel that their family members were safe and happy.

As discussed in chapter two, personalisation is associated with the highly contentious widespread closure of day centres for people with learning disabilities. In contrast with critiques from within the disability movement, there is some research to suggest that day centres are highly valued by many people with learning disabilities and their families (Needham, 2014; Hall, 2011). This study contributes towards this small body of existing evidence by demonstrating the importance of day centres in the lives of participants, and highlighting the opposing views held by those within and outwith the day centre community. Furthermore, this study provides empirical evidence to support Needham's (2014) analysis of 'recurring stories' in day centre closures, as it illustrates that the views of people who attended the centres and their families were dismissed and discredited by powerful decision makers.

This study also highlights the role of 'impairment effects' (Thomas, 1999) in adjusting to changes to long-established routines. Analysis of participants' narratives revealed distress and disruption, and additional work for carers. Importantly, this study draws attention to the emotional impact of relationships lost as a result of day centre closures, and suggests that decision makers either do not sufficiently understand, or do not value, the needs of many people with learning disabilities in relation to support networks and relationships.

As noted above, personalisation is associated with individual support in the community, and it was clear from the data that this had not transpired. In many ways, day centres had been replaced by community centres, but this did not mean people were included in the community. In contrast with the policy narrative of choice and control, participants' narratives suggested that those attending community centres did so because of a lack of alternative options.

The policy shift from specialist services to support in ‘mainstream’ places neglects the barriers to inclusion in the community for people with learning disabilities, discussed in chapter two. The prevalence of abuse and assault of people with learning disabilities (Hall, 2011; Williams, 2013; Macdonald, 2015) is well-documented, and several studies have noted that communities are hostile places for many people with learning disabilities (Hamilton et al, 2017; Hall, 2011; Power and Bartlett, 2018). This study contributes to this body of existing knowledge by illustrating participants’ experiences of hostile communities and, additionally, highlighting the impact for carers. Parents of people with learning disabilities are often portrayed as over-protective (Power, 2014; Bigby, 2012; Breitenbach, 2001; Bowey and McGlaughlin, 2007); this study also demonstrates the emotional impact on parents when their sons and daughters experience abuse and assault, and suggests that this impacts upon carers’ desire to protect their children from harm. In addition, recent high-profile incidents where people with learning disabilities had been subject to serious, and sometimes fatal, failings in social care understandably exacerbated carers’ fears about safety.

This study also demonstrates how personalisation is associated with more responsibility for carers, and suggests that this assumes that people are able and willing to take this on. SDS assessment and implementation had resulted in additional emotional and practical caring work; the intersection of ageing, health, and reduced support networks meant that the additional responsibility could be particularly burdensome in some cases.

8.4.3. ‘Co-production’ in policy design and delivery

This study further contributes to knowledge by challenging the largely uncritical adoption of ‘co-production’ in policy design and delivery. The concept of co-production is strongly evident in all aspects of SDS, discussed in chapter three. This thesis contributes to knowledge in this area by highlighting: fundamental power inequalities; the role of relationships; the absence of co-production in practice; and local implementation. Whilst the focus here is participants' experiences of SDS implementation, it has broader implications because the concept of co-production is associated with the Scottish approach to policymaking, discussed in chapter three.

Narratives of co-production neglect the existence of fundamental power inequalities, which this study demonstrates. For example, as discussed in chapter five, rather than the SDS assessment process being equal and collaborative, it was disempowering for participants because it heightened feelings of fear and vulnerability. Policy guidance emphasises the importance of collaboration and equal partnerships (Scottish Government, 2014a), but the data showed this was not a relationship of equals. Participants were dependent on services and worried about what would happen if budgets or services were withdrawn; ultimately, the local authority had the power to provide or withdraw these resources. This study also highlights that power operates at multiple levels; participants believed social workers were being constrained by management and institutional structures. Despite the policy narrative of co-production and equal partnerships, ultimately power lay with those who controlled resources.

This study also draws attention to the importance of relationships in co-production, and suggests that the context of SDS implementation in Glasgow was not conducive to building good working relationships. As noted throughout the discussion of the interview data, the extent of the conflict over the closure of day centres had resulted in extremely acrimonious relationships. This had left many families feeling distrustful, disappointed and disempowered, while contributing towards participants' views of decision makers as detached and uncaring. This study also illustrated participants' experiences of SDS assessment, which were detrimental to fostering the positive, trusting relationships required for successful co-production.

In addition to the conflict between families and the local authority in relation to the restructuring of learning disability services and implementation of SDS, this study highlights that participants had decades of experience of negotiating with professionals about care and support, and the legacy of previous conflict was a lack of trust. Furthermore, longstanding social work resourcing issues, together with the decimation of social care funding as a result of austerity, meant participants did not have relationships with known social workers. Thus, participants entered into the SDS assessment process with little trust in professionals or the social care system, and there was no evidence in the data to suggest that SDS implementation acknowledged or addressed this.

Despite the concept of co-production being strongly evident in all aspects of SDS policy, this study found no evidence of co-production in practice, and suggests that the ethos of SDS had not been embedded throughout the policymaking process. For example, participants believed that budget decisions were being made on the basis of cost savings, and that individual social workers had little say. Ultimately, it was felt that decisions were being made at a higher level, by people completely removed from the recipients of policy, and where the impact of those decisions was felt less acutely.

This study further highlights issues concerning local policy implementation. Consistent with the Scottish Approach, discussed in chapter three, SDS implementation and processes are delegated by the Scottish Government to individual local authorities. One of the challenges associated with the Scottish approach is the risk of local policies emerging (Cairney et al, 2016); this study provides empirical evidence of the gap between national policy and SDS *as implemented* for this group. As noted in chapter five, those participants who had undertaken extensive research in an effort to understand SDS were particularly frustrated and angry because they observed a massive gap between policy and practice, but felt powerless to challenge the local authority.

Co-production is promoted by the government in terms of '…sharing of power between professionals and people using services…' (Coutts, 2019: 4). It is clear from this study that the power shift required to support co-production in SDS implementation had not transpired.

8.4.4. Assumptions about choice and control

This thesis further contributes to knowledge by challenging commonly held assumptions about choice and control in relation to personalisation. As noted earlier in this chapter, this study shows that the implementation of SDS had not resulted in more choice and control for participants in this study, despite its prevalence in policy discourse.

Whilst choice is highly contested, as discussed in chapter three, this study demonstrates that the implementation of SDS had contributed towards changing narratives around social care. Participants knew they were meant to have choice and control. As a result, this contributed towards their dissatisfaction as they perceived a massive gap between policy rhetoric and personal experience, as discussed in chapter five.

This study also provides empirical evidence of the ways in which choice and control can be constrained by local implementation. For participants in this study, choice was constrained by not having the information and support required to exercise choice and the lack of suitable alternatives to choose from.

This study also illustrates additional factors which constrained choice for this group, including the effects of ageing and impairment.

Importantly, this study shows that participants had come to feel that SDS had been imposed upon them, despite their initial high hopes, in conflict with policy narratives of choice and control, as discussed in chapter five. Thus, whilst SDS has been successful in embedding choice and control in social care discourse, ultimately there was little evidence of this in practice.

The social model of disability underpins disability policy in Scotland (Scottish Government, 2016). The influence of the social model in policy development is evident in relation to the concept of independent living and the associated drive for choice and control (as discussed in chapter three). Importantly, the social model has the power to change lives because it transforms the relationship between disabled people and society from gratitude to entitlement (discussed in chapter two). Notwithstanding the profound impact of the social model in the lives of disabled people and its significance in policy development, it has been contested by many writers within Sociology and Disability Studies (Thomas, 2004), and is critiqued for neglecting the experiences of people with learning disabilities (Williams, 2013; Chappell 1998; Chappell et al, 2001; Rogers, 2016) (discussed in chapter two). Analysis of the data in this study suggests that SDS policy and practice neglected impairment effects (Thomas, 1999) associated with learning disability (discussed in chapter five and six). Thus, the application of the social model to SDS policy has not had the intended effect of shifting power and control to people with a learning disability in Glasgow. More work is required to embed the spirit of the social model in this policy field.

The discussion above demonstrates the originality of this study and its important contribution to knowledge, in terms of social care policy in Scotland and also more broadly. In addition to providing a case study of SDS implementation for people with learning disabilities in Glasgow, the discussion in this section demonstrates the thesis' wider contribution to international debates around personalisation. The discussion of meanings and experiences of personalisation for people with learning disabilities and their families highlights this significant area, demonstrating the continued importance of day centres and the ways in which the perspectives of disabled people and their families are dismissed by powerful professionals. These are crucial findings within the current policy context, which promotes narratives of user empowerment and privileges support in the 'community' over collective spaces, and this study contributes to discussions set out by Hall (2011) and Power (2014) over the loss of collective spaces for people with learning disabilities. The thesis' wider contribution to knowledge is further evident in the discussion of 'co-production' in policy design and delivery as it highlights fundamental power inequalities and the role of relationships, challenging the largely uncritical adoption of 'co-production' in policy design and delivery. Furthermore, this thesis contributes to knowledge through its critique of commonly held assumptions about choice and control, evidenced by the lack of choice and control experienced by participants. The next section moves on to consider the limitations of the study, and proposes areas for further research.

8.5. Study Limitations and Further Research

This section begins with a discussion of the limitations of the study, highlighting methodological issues which are not easily overcome and reflections on the methods adopted. It then moves on to suggest a range of areas for further research, including: ageing; caring and support; personalised care and support; and SDS values and principles.

8.5.1. Limitations

As discussed throughout this thesis, this study set out to explore the experiences of a specific group, in a specific location, at a specific time. The theoretical and practical considerations which informed and determined my approach are set out in chapter four. Notably, this qualitative study was not designed to be representative; it was designed to gather rich narratives about personal lives (Spencer et al, 2003) from the perspectives of people whose lives were affected by changes to social care policy. Thus, this study provides very detailed insight into the experiences of people with learning disabilities, aged 30 and over, and their families in Glasgow, and is one of very few in-depth studies of SDS in Scotland.

It was clear from participants' narratives that daily lives and living arrangements were subject to change, particularly as parents aged and become less able to provide support. For example, three participants had moved into supported accommodation following the death of a parent. Furthermore, this data was collected at a relatively early stage in SDS implementation (see timeline in chapter one), and it is to be expected that processes and services would evolve over time. Together, this suggests a need for longitudinal research to explore how care and support change over time, and highlight how policy and practice might best support the changing needs of this group.

A particular challenge in this study was gaining access to participants as family members and organisations have acted as gatekeepers, reflecting power inequalities and support needs. As discussed in chapter four, there were several factors outwith my control which may have affected the willingness or ability of organisations to assist with recruitment. For example, organisations did not have the time or resources to actively assist with recruitment, and their preference for distributing flyers or using social media inevitably excludes particular groups. Additionally, as noted throughout this thesis, relationships between families, service providers and the local authority were extremely tense and the topic of this study was very emotive; it was reported that some people declined to participate because they were '... *feart it would get back to social work'*.

Contested issues in relation to participatory and inclusive research are discussed at length in chapter four. Whilst this study set out to be as inclusive and accessible as possible, in practice, the research design was largely determined by practical considerations, as discussed in chapter four. Some of the ways in which I attempted to make the research inclusive and accessible were: adapting my approach in response to feedback and individual needs; and producing easy read information. However, there are inherent difficulties in ensuring the perspectives of people with learning disabilities, and particularly those with more complex needs, are included in research, and this is a notable limitation of this study. Whilst I took an individual approach to communication, often involving family members or support workers, I acknowledge that the research design was not completely accessible to everyone, and in some cases I heard only from carers because their family member was deemed to not have capacity to participate, as noted in chapter four.

Relatedly, interviews with people with learning disabilities tended to generate much shorter responses, discussed in chapter four. Whilst I was aware of this at the interview and analysis stages, and was keen to make sure these voices were not drowned out by carers' lengthier or more articulate narratives, the marked disparity in the volume and depth of data meant that this was not entirely successful. This highlights methodological issues in relation to carrying out research involving people with learning disabilities and their families, which are not easily overcome.

Reflections on methods

As illustrated above and discussed in detail in chapter four, there were a range of methodological challenges in this project and at times I found it extremely difficult and frustrating. I had not anticipated quite how challenging, complicated, and protracted the recruitment process would be, and my carefully thought out research design largely did not transpire; in practice, methods developed iteratively and decisions were often necessarily pragmatic (discussed further in chapter four).

Importantly, my attempts to ensure the research was inclusive and accessible for people with learning disabilities were not entirely successful, as acknowledged in the above discussion of the study limitations. Notably, the voices of participants with learning disabilities were often overshadowed by those of family carers, partly due to the use of family group interviews, and I was acutely aware of this in the analysis of the data (discussed in chapter four). Undertaking more interviews, or focus groups, exclusively with people with learning disabilities may have helped to mitigate this issue, however (as discussed above and in chapter four), recruitment was extremely difficult and I felt I had exhausted all possible options.

In undertaking this project, I have learned about the complex and messy reality and practical considerations in undertaking qualitative research involving families and relationships and people with learning disabilities. As discussed in chapter four, there are inherent challenges in undertaking research involving multiple related participants. Negotiating the different, and sometimes conflicting, needs and wishes of people with learning disabilities and family carers was a particular challenge in this study; for example, several short interviews may have been more suitable for participants with learning disabilities, but less acceptable for family carers (as discussed in chapter four). In addition to the technical skills and academic knowledge gained in undertaking this project, I have learned that attentiveness, flexibility and compromise are also essential research skills.

8.5.2. Further research

This study highlights a range of issues which demand further research, associated with three main areas: ageing, caring and support; personalised care and support; and SDS values and principles.

Ageing, caring and support

This study illustrates how policy change plays out within family lives, focused on the experiences of people with learning disabilities aged 30 and over, and their families, in Glasgow. As noted in chapter four, this was not the intention when I began the PhD; the topic emerged from initial engagement with relevant literature and informal discussions with disabled people, carers and workers. The change in topic reflected a pressing issue for this group, as the implementation of SDS coincided with the restructuring of learning disability services and day centre closures.

As discussed earlier in this chapter, this study makes an original and important contribution to knowledge. Notably, it provides an in-depth critique of SDS implementation and illustrates the meanings and experiences of personalisation for people with learning disabilities and their families. However, as noted in chapter two, there are several interrelated factors relevant to this particular group which frame experiences of social care policy and service provision, including: extended transitions to adulthood; the role played by families; and increased life expectancy and ageing.

The study limitations, set out above, propose a need for longitudinal research to explore how care and support changes over time and highlight how policy and practice might best support the changing needs of this group. Notwithstanding the original and important contribution to knowledge made by this study, it also suggests that the gap identified in my initial research proposal remains. Thus, this study suggests a need for further research to explore the experiences of people with learning disabilities and their families, which would document the challenges faced by families as individual members grow older, and contribute to understanding how ageing, caring and support intersect.

Personalised care and support

This study highlights a range of issues associated with personalised care and support which demand further research. These issues relate to: new models of care and support; inclusion and community; carers; and participation and co-production.

New models of care and support

This study found that the implementation of SDS, together with the restructuring of learning disability services in Glasgow, had resulted in an increase in the number of service providers, discussed in chapter six. This meant that some participants were being supported by a number of different organisations, resulting in carers managing complicated arrangements. Additionally, satisfaction with services varied, and it was clear that some were providing more person-centred services than others. There were strong critiques of 'one size fits all' activities, many of which appeared to be simply time-filling, and participants felt services were very much resource-led. Additionally, several family carers expressed concern about the high turnover of staff and the lack of engagement from some workers. This was important because participants highly valued relationships with workers.

The negative experiences outlined above suggest the need for further research to understand how new models of care and support reflect: the needs and wishes of people with learning disabilities and their families; and the aspirations set out in Scottish Government policy. Such a study could be designed to capture the perspectives of people who use services and their families, as well as those who deliver, manage and commission services.

Inclusion and community

As noted throughout this thesis, personalisation is associated with a shift from collective services to support and inclusion in the community. This study supports previous studies (Hamilton et al, 2017; Hall, 2011; Mencap, 2012) which have shown that many people with learning disabilities want to have the option to attend a day centre. This study suggests that there is a vast gap between perceptions of day centres by those outwith and within the day centre community, as noted in chapter six. Participants in this study placed high value on collective services, as noted earlier in this chapter, and it was clear that day centres and other specialist services had provided an important space for people to develop and maintain support networks.

The shift towards support in the community requires the provision of community facilities, as well as support for people with learning disabilities to participate in mainstream activities; however, this had not transpired. Notably, this study illustrates the continued segregation and exclusion of people with learning disabilities within mainstream settings. Crucially, however, this study also provides evidence of the prevalence of assault and abuse of people with learning disabilities – a major barrier to inclusion that is neglected in personalisation policy narratives.

The findings outlined above suggest the need for further research in two main areas. First, collaborative action research could address the barriers to inclusion within local communities. Such an approach would include people with learning disabilities and their families, as well as other people living within local communities. Second, a larger scale participatory study involving people with learning disabilities could demonstrate experiences of inclusion and community, providing further evidence to challenge the dominant narrative.

Carers

This study suggests that the combined effect of SDS implementation, restructuring of learning disability services, and austerity was additional work for carers. This related to: the SDS assessment process (chapter five); complicated and unreliable service provision (chapter six); disabled people spending more time at home (chapter seven); and assumptions that family carers could organise social opportunities (chapter seven). Thus, many of the carers in this study had effectively become care managers – a role most did not want. This study also highlighted additional costs associated with changes to social care policy and service provision, notably: the client contribution; activity costs; and buying in additional support.

The findings outlined above suggest the need for further research in two main areas. First, there is a need to understand the impact of changes to social care policy and service provision on carers, particularly older carers and carers of people with learning disabilities. Within the context of the Carers Act, such a study should explore what policy and services could do to support people to continue to care if they wish to do so. Second, but relatedly, this study suggests that there is a need for an economic evaluation of changes to social care policy and household finances. Such a study should consider the impact on socio-economic inequalities for this group, within the context of the long-term economic disadvantage experienced by disabled people and carers, as noted in chapter seven.

Participation and Co-production

As noted throughout this thesis, policy narratives of SDS emphasise the concepts of ‘co-production’ and ‘collaboration’. This study highlights power inequalities, and challenges the largely uncritical adoption of ‘co-production’ in policy design and delivery, as discussed earlier in this chapter. Notably, this study found that people with learning disabilities had very little involvement in SDS assessment. As discussed in chapter five, it was often carers who dealt with assessments and, perhaps relatedly, the SDS assessment process was largely not accessible for people with learning disabilities.

The findings outlined above suggest the need for further research in two main areas. First, a critical analysis of ‘co-production’ and ‘collaboration’ in SDS, which would consider issues of power and identify ways to mitigate inequalities. Second, a participatory study involving people with learning disabilities could identify good practice in SDS assessment processes. As noted in chapter five, assumptions that people could participate in meaningful ways – in a normative assessment process – neglected the nature of impairment; a participatory study could highlight accessible and inclusive assessment processes.

Values and principles

Throughout this thesis, it is noted that there was little evidence of SDS values and principles in practice. To some extent, the values and principles may have been compromised by funding constraints, discussed in chapter three. As noted in chapter five, participants’ narratives suggested that the ethos of SDS had not been enacted by policymakers at all levels, nor had it been embedded throughout the policymaking process. For example, participants were critical of the Resource Allocation System (RAS), and believed that budgets were resource-driven, rather than need-driven, as discussed in chapter five. Furthermore, as noted earlier in this chapter, although participants were familiar with the term ‘choice and control’ in relation to SDS, the implementation of SDS had not resulted in more choice and control for participants.

The findings outlined above suggest the need for further research in four main areas, discussed below: SDS implementation and practice; choice and control; Resource Allocation Systems; and social care resourcing.

SDS implementation and practice

Both the Scottish Government (2019a) and Audit Scotland (2017) acknowledge that it is difficult to accurately ascertain the extent to which SDS has been implemented throughout Scotland. The findings of this study suggest that a substantial gap exists between policy and practice, and that the transformation of social care associated with SDS has not yet transpired. These findings, together with the known evidence gap, suggest that further research is required to understand SDS implementation at the national level. A large-scale, mixed methods study could seek to understand how SDS values and principles have, or have not, been embedded in practice; for example, to what extent policy actors understand and demonstrate these values and principles in their work. Such a study would incorporate various perspectives, including: disabled people; carers; social care workers; social workers; service providers; and local authority officials.

Choice and control

Additionally, a smaller scale participatory study could seek to understand experiences of choice and control. Such a study could consider the barriers to choice and control experienced by people who require social care support, and identify ways to address these. As noted in chapter two, people who are assessed by the local authority as needing social care are entitled to exercise choice and control in relation to how their needs are met, even if they are not eligible for a budget. A study of choice and control could make an original and important contribution to knowledge and practice by considering the ways in which people are able to exercise choice and control, and ensure assessed needs are met, without a social care budget.

Resource Allocation Systems (RAS)

The experiences of participants in this study suggest several difficulties associated with the RAS, particularly in relation to the support needs of people with learning disabilities, as discussed in chapter five. Further research could contribute towards developing an alternative system which would better capture the complexity of social and emotional support needs, and incorporate the knowledge and expertise of disabled people, carers, and social workers.

Social care resourcing

Finally, economic modelling of social care demand and resourcing at the national level could contribute towards a strategic approach to achieving the aspiration set out in policy. This would consider the long-term financial implications of current and future demand and expectations in relation to social care. Deliberative methods could then be used to consider a range of alternative policy options and agree a strategic approach to meeting future demand and aspirations for social care in Scotland.

The discussion above set out the limitations of this study and proposed a range of issues highlighted by the study which demand further research. The next section concludes the thesis with an overview of the key findings and potential ways forward.

8.6. Conclusion

This thesis set out to explore the experiences of people with learning disabilities, and their families, at a time of considerable change to social care policy and service provision. My motivation to understand more about families' experiences of disability was rooted in my family's own 'biographical disruption' (Bury, 1982), and this particular topic emerged from engagement with relevant literature and informal discussions with disabled people, family carers and care workers. I adopted broadly feminist research methods in order to mitigate power differentials (Maynard, 1994) and acknowledge that this study is influenced by my personal and political feminist position in various ways. This includes, but is not limited to: the choice of research topic and questions; the ways in which I engaged with participants and collected data; and the ways in which I have analysed the data and presented the findings of this study.

The study was concerned with understanding how policy change played out within family lives, focusing on the experiences of people with learning disabilities aged 30 and over, and their families, living in Glasgow. The main research questions were:

1. In what ways have changes to social care policy affected the day-to-day lives of people with learning disabilities and their families?

2. How does the dominant policy discourse of 'Personalisation' reflect the needs and wishes of people with learning disabilities and their families?

3. In practice, does self-directed support policy increase choice and control for people with learning disabilities and their families?

This turned out to be an extremely challenging project, and some of these issues proved particularly difficult, if not impossible, to overcome. The process did not always go to plan and, in practice, the research design was largely determined by practical considerations. Additionally, there were very particular ethical challenges inherent in the research questions which were related to three main features of the study: it involved multiple related participants; it explored potentially sensitive issues; and it involved a group perceived as 'vulnerable'. Notwithstanding these challenges, I tried to make the research as inclusive and accessible as possible, without compromising on analytical rigour, and the thesis makes an original and important contribution to knowledge.

The key findings in this thesis relate to the vast gap between SDS policy and practice, and the importance of collective spaces. As the ten-year strategy for SDS (Scottish Government, 2010: 2) approaches its end, and the Scottish Government and COSLA develop a programme to reform adult social care (Scottish Government, 2018a: 21; Scottish Government, 2018b: 69), these are important findings.

This study suggests that the gap between policy and practice was associated with SDS values and principles not being embedded throughout the system. The four statutory principles of SDS are: collaboration; involvement; informed choice; and participation and dignity (Scottish Government, 2014a: 15-16). The values underpinning SDS include: respect; independence; fairness; safety; and freedom (Scottish Government, 2014a: 15). As illustrated earlier in this chapter, analysis of the interview data found substantial gaps between policy and practice in various aspects of SDS. Notably, this study highlights that the power shift associated with personalisation neglects fundamental power inequalities, and proposes that a real attempt to transfer power from professionals to individuals and families requires acknowledging and addressing issues of powerlessness and vulnerability.

Within the context of widespread discrimination and exclusion of people with learning disabilities in mainstream society, analysis of the interview data demonstrated continued support for collective spaces; these were places where participants experienced inclusion and community. The disability movement is generally critical of day centres (Needham, 2014), and they are largely no longer seen as appropriate places for the care and support of people with learning disabilities (Power, 2014). However, this study adds nuance to the debate by illustrating the perspectives of people who have attended day centres for most of their adult lives and, importantly, demonstrated the impact on the lives of disabled people and their families when this support is withdrawn. In doing so, this study reveals a vast gap between perceptions of day centres by those outwith and within the day centre community. Within the context of shifting power to individuals and families, somewhat ironically, it was the perspectives of powerful professionals which drove the closure of day centres, despite strong resistance from disabled people and their families.

It was clear from the data that the transformation of social care promised by SDS policy had yet to be achieved. As evidenced by Pearson and Ridley (2017), and noted throughout this thesis, the implementation of SDS at the same time as public spending cuts – related to austerity – was a major factor. This study provides evidence of the impact of public spending cuts on individual and family lives, and proposes that transformation cannot be achieved without addressing these important issues.

Furthermore, this study highlights how care and support changes over time, proposing that there is a need to understand how policy and practice might best support the changing needs of people with learning disabilities and their families as they grow older. Within the context of the longstanding exclusion and marginalisation of people with learning disabilities, as well as the challenges related to the intersection of ageing and caring, supporting relationships and wellbeing should be central to social care policy and practice.

Finally, the findings of this study suggest a need to understand and address the barriers to embedding SDS values and principles in order to tackle the gap between policy and practice. Relatedly, this demands critical analysis of the Scottish approach to policymaking, and commitment to mitigating power inequalities, if the aspiration to transform social care in Scotland is to be achieved.

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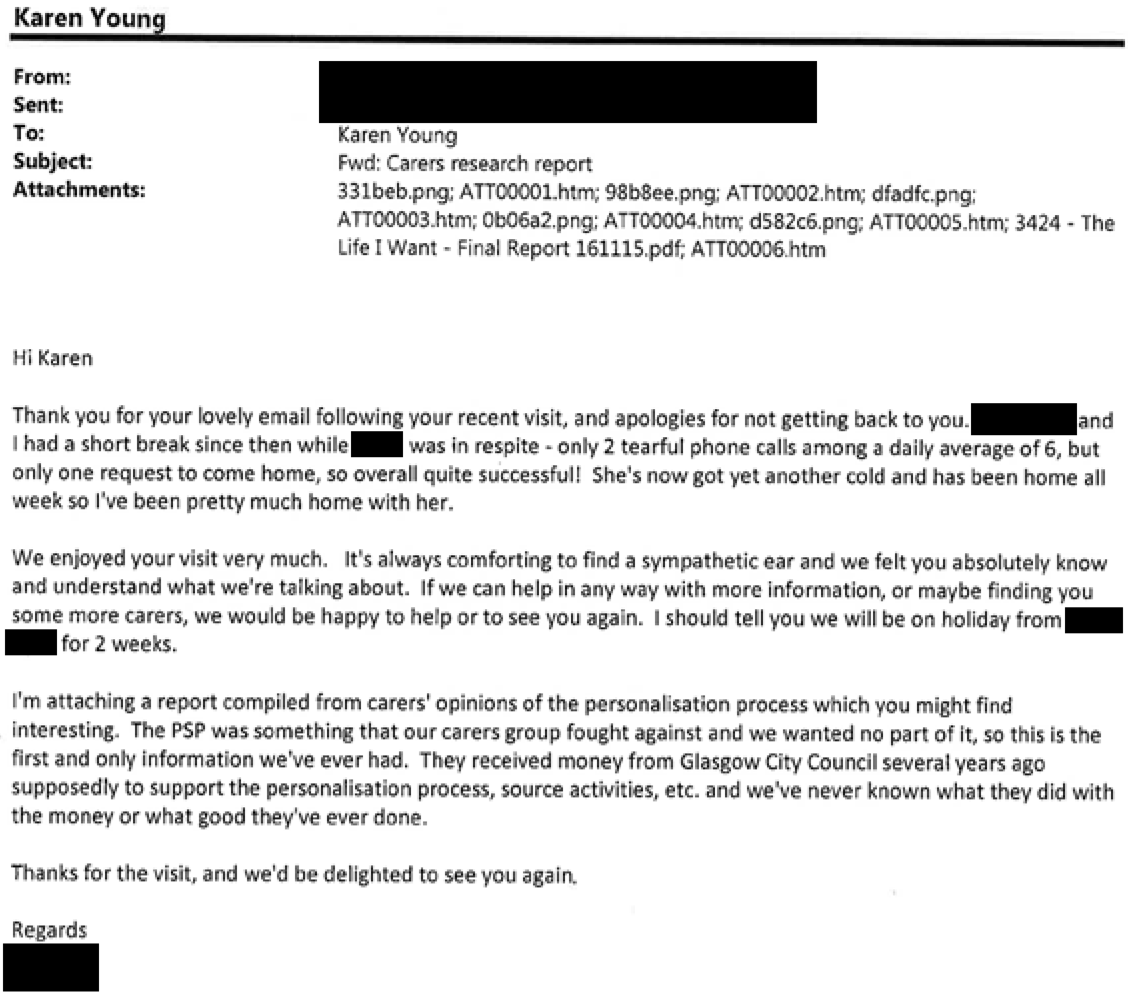
Appendix A - Email from Participant



Karen Young

From:
Sent: [redacted]
To: Karen Young
Subject: Fwd: Carers research report
Attachments: 331beb.png; ATT00001.htm; 98b8ee.png; ATT00002.htm; dfadfc.png; ATT00003.htm; 0b06a2.png; ATT00004.htm; d582c6.png; ATT00005.htm; 3424 - The Life I Want - Final Report 161115.pdf; ATT00006.htm

Hi Karen

Thank you for your lovely email following your recent visit, and apologies for not getting back to you. [redacted] and I had a short break since then while [redacted] was in respite - only 2 tearful phone calls among a daily average of 6, but only one request to come home, so overall quite successful! She's now got yet another cold and has been home all week so I've been pretty much home with her.

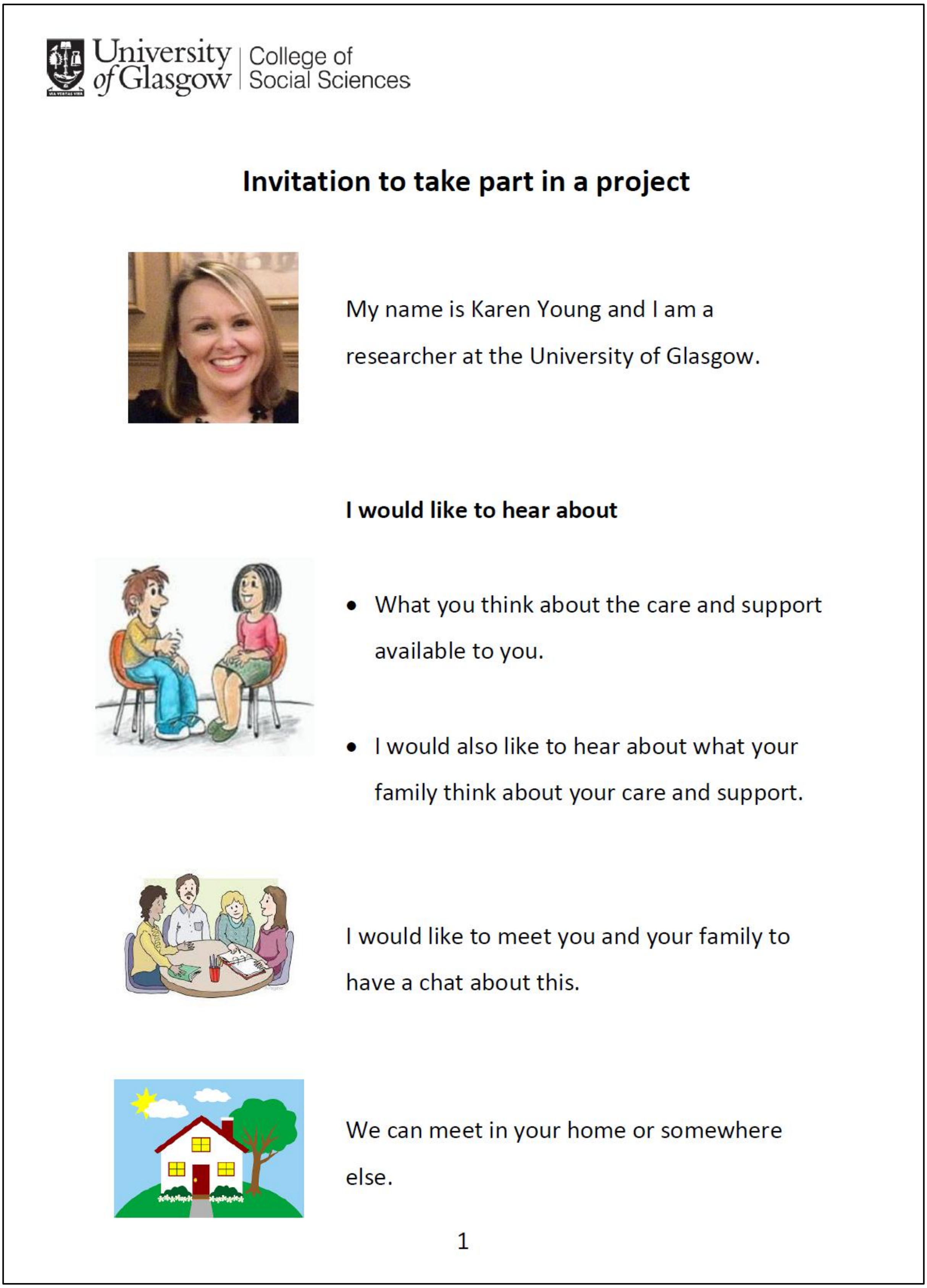
We enjoyed your visit very much. It's always comforting to find a sympathetic ear and we felt you absolutely know and understand what we're talking about. If we can help in any way with more information, or maybe finding you some more carers, we would be happy to help or to see you again. I should tell you we will be on holiday from [redacted] [redacted] for 2 weeks.

I'm attaching a report compiled from carers' opinions of the personalisation process which you might find interesting. The PSP was something that our carers group fought against and we wanted no part of it, so this is the first and only information we've ever had. They received money from Glasgow City Council several years ago supposedly to support the personalisation process, source activities, etc. and we've never known what they did with the money or what good they've ever done.

Thanks for the visit, and we'd be delighted to see you again.

Regards
[redacted]

Appendix B – Easy Read Information for Participants



University of Glasgow | College of Social Sciences

Invitation to take part in a project

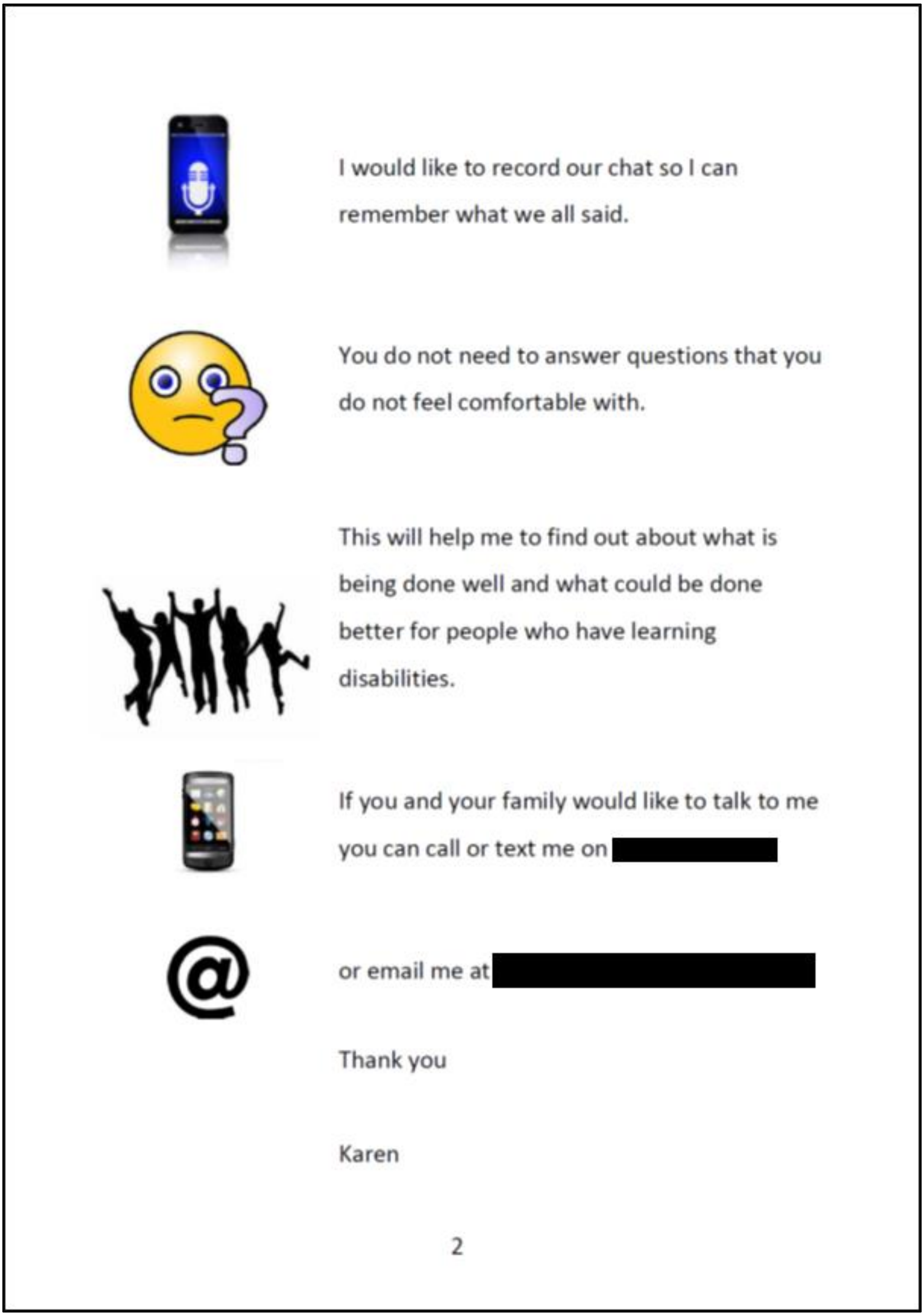
My name is Karen Young and I am a researcher at the University of Glasgow.

I would like to hear about

- What you think about the care and support available to you.
- I would also like to hear about what your family think about your care and support.

I would like to meet you and your family to have a chat about this.

We can meet in your home or somewhere else.



I would like to record our chat so I can remember what we all said.

You do not need to answer questions that you do not feel comfortable with.

This will help me to find out about what is being done well and what could be done better for people who have learning disabilities.

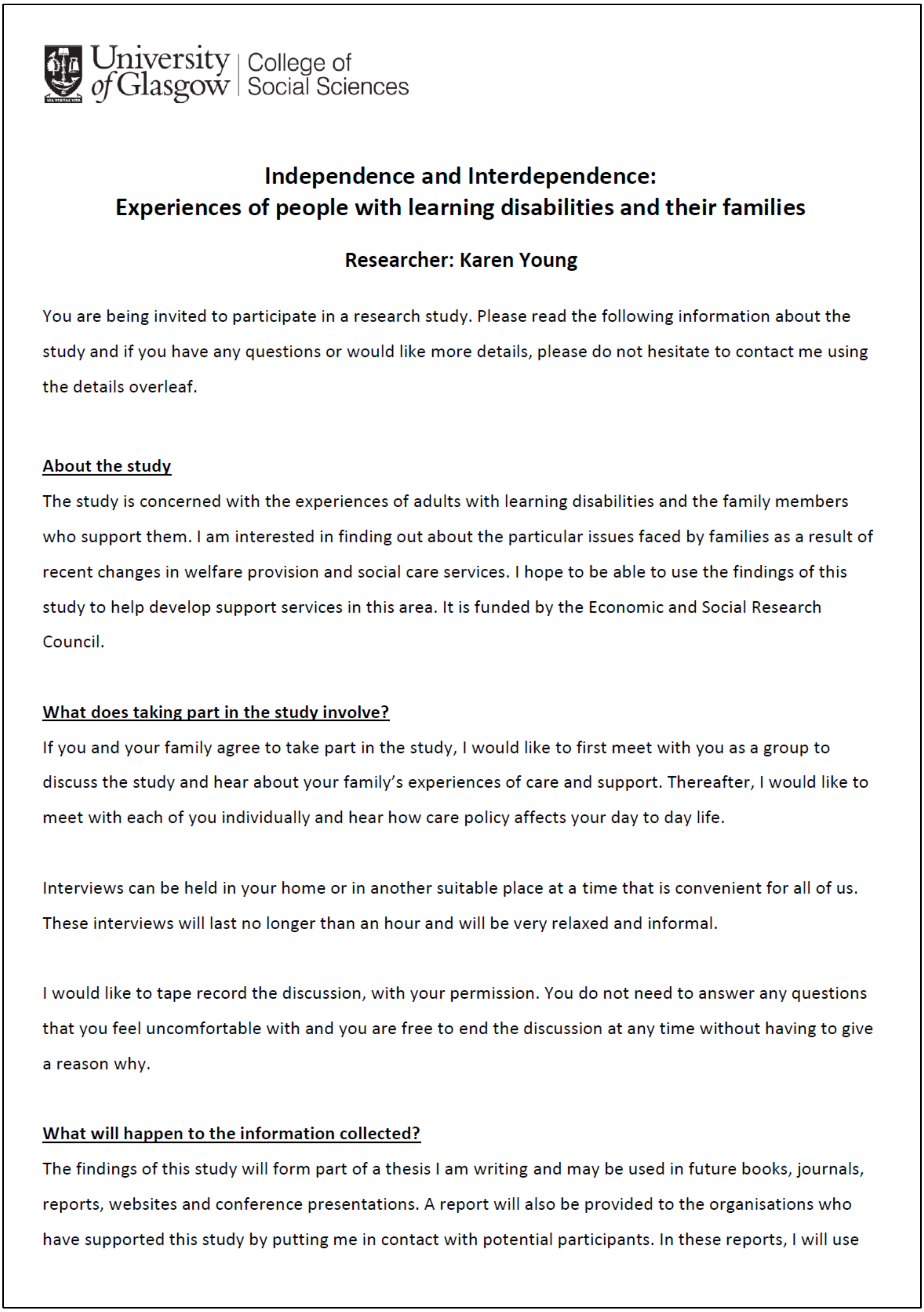
If you and your family would like to talk to me you can call or text me on [redacted]

or email me at [redacted]

Thank you

Karen

Appendix C – Information for Participants



University of Glasgow | College of Social Sciences

Independence and Interdependence:
Experiences of people with learning disabilities and their families

Researcher: Karen Young

You are being invited to participate in a research study. Please read the following information about the study and if you have any questions or would like more details, please do not hesitate to contact me using the details overleaf.

About the study

The study is concerned with the experiences of adults with learning disabilities and the family members who support them. I am interested in finding out about the particular issues faced by families as a result of recent changes in welfare provision and social care services. I hope to be able to use the findings of this study to help develop support services in this area. It is funded by the Economic and Social Research Council.

What does taking part in the study involve?

If you and your family agree to take part in the study, I would like to first meet with you as a group to discuss the study and hear about your family's experiences of care and support. Thereafter, I would like to meet with each of you individually and hear how care policy affects your day to day life.

Interviews can be held in your home or in another suitable place at a time that is convenient for all of us. These interviews will last no longer than an hour and will be very relaxed and informal.

I would like to tape record the discussion, with your permission. You do not need to answer any questions that you feel uncomfortable with and you are free to end the discussion at any time without having to give a reason why.

What will happen to the information collected?

The findings of this study will form part of a thesis I am writing and may be used in future books, journals, reports, websites and conference presentations. A report will also be provided to the organisations who have supported this study by putting me in contact with potential participants. In these reports, I will use some of the information you have given me, including direct quotes, however I will use false names for yourself and anyone else you might mention to protect your identity.

All information given will be treated confidentially and data will be stored securely and disposed of in accordance with University procedures and the requirements of the Data Protection Act (1998). However, in cases where you reveal details of harm towards yourself or others, I have an ethical obligation to pass this information on in order for you to receive the appropriate support. Additionally, any information you give me is not legally privileged, this means that the police/courts may be able to request the research data if such a situation (however unlikely) arises.

<u>Further questions or concerns</u>

If you have any questions about the research, you can contact me using the details below:

Karen Young
Strathclyde Centre for Disability Research
University of Glasgow
Adam Smith Building
Glasgow
G12 8RS
Mob. [redacted]
Email: [redacted]

If you have concerns about the conduct of the research, you can contact the following people:

Research Supervisor:
Professor Nick Watson
Strathclyde Centre for Disability Research
University of Glasgow
Adam Smith Building
Glasgow G12 8QQ
Tel: [redacted]
Email: [redacted]

Ethics Officer:
Dr Muir Houston
University of Glasgow
R223, St Andrew's Building
Glasgow
G3 6NH
[redacted]
Email: [redacted]

Appendix D – Easy Read Consent Form

University of Glasgow | College of Social Sciences

I would like to hear about what you think about care and support for people who have learning disabilities

- You do not have to answer any questions you do not like.
- You can stop talking to me at any time.

Do you want to talk to me about your care and support?

Please put a circle around your answer.

👍 **Yes** 👎 **No**

Can I record our chat?

Please put a circle around your answer.

👍 **Yes** 👎 **No**

Who else can I talk to about your care and support?

Please write their names in the box below.

Can I tell other people about your life? I will not tell them your name.

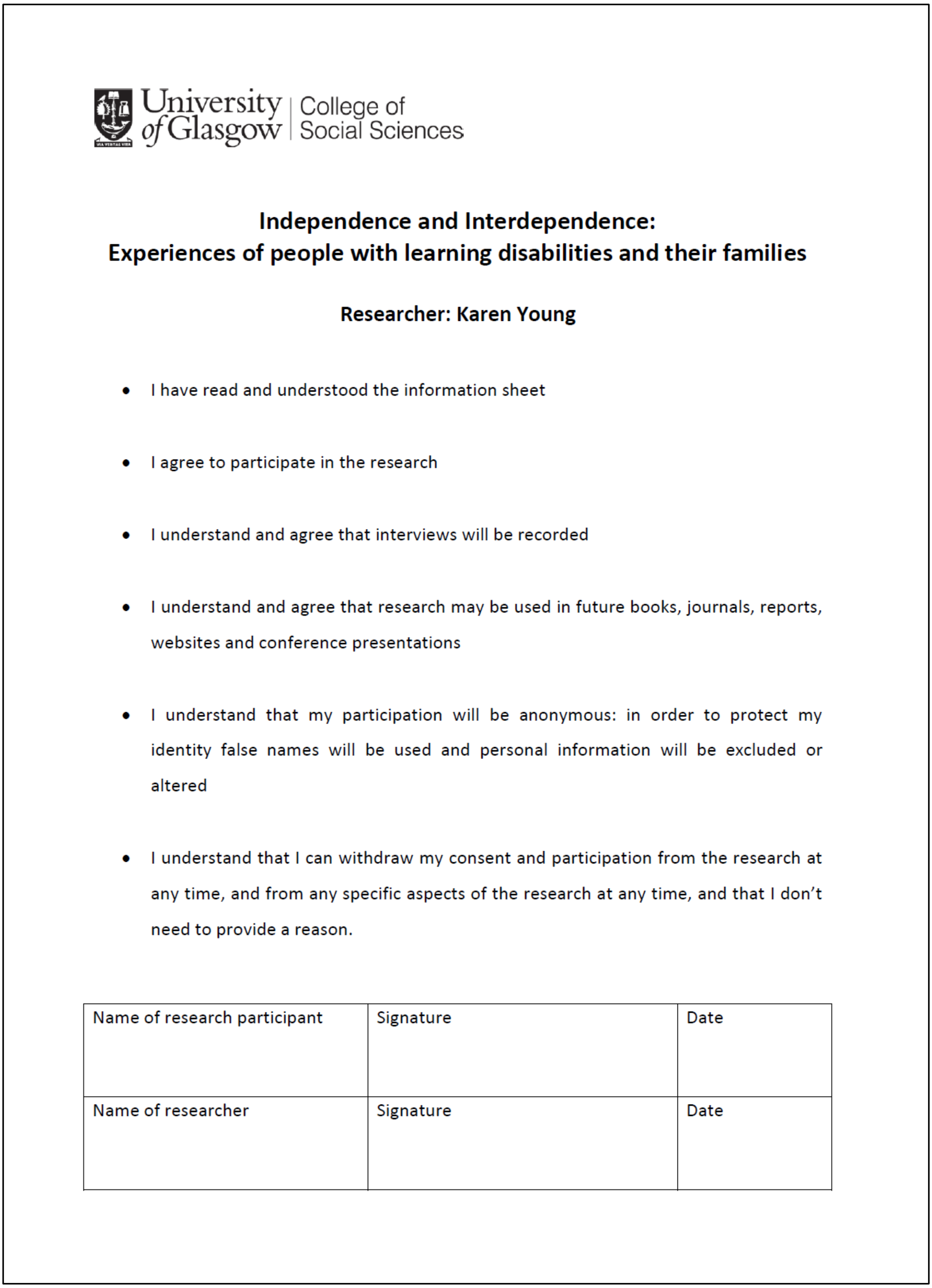
Please put a circle around your answer.

👍 Yes

👎 No

Please write your name in the box below.

Appendix E – Consent Form



University of Glasgow | College of Social Sciences

Independence and Interdependence:
Experiences of people with learning disabilities and their families

Researcher: Karen Young

- I have read and understood the information sheet
- I agree to participate in the research
- I understand and agree that interviews will be recorded
- I understand and agree that research may be used in future books, journals, reports, websites and conference presentations
- I understand that my participation will be anonymous: in order to protect my identity false names will be used and personal information will be excluded or altered
- I understand that I can withdraw my consent and participation from the research at any time, and from any specific aspects of the research at any time, and that I don't need to provide a reason.

Name of research participant	Signature	Date
Name of researcher	Signature	Date

Appendix F - Michelle's Drawing

Appendix G - Interview Summary

Family Groups	17

People with Learning Disabilities[45] (aged 30s – 50s)	13	
	Female	Male
	9	4

Family Members (aged 50s – 90s)	15			
	Female		Male	
	10		5	
	Mum	6	Dad	3
	Sister	4	Brother	1
			Partner	1

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[45] A further 5 people with learning disabilities were not included in the interviews (2F & 3M) as their family members advised that they would be unable to take part due to (see section 4.9).

Appendix H – Recruitment: excerpt from fieldnotes

I initially made contact with [large service provider organisation] via a service manager already known to me, who agreed to help with recruitment and asked for a letter they could give out to clients. I provided both a letter and information in easy read format for distribution to service users. However, when I contacted them again one month later, my contact advised me by email that they '…have sent the information you gave me along to two people I thought would be perfect for your research via our Chairperson…'. This confirmed my initial concerns about recruiting via service provider organisations; they had handpicked 'suitable' participants, they had approached family members in the first instance rather than the disabled person, and contact was made by the Chairperson, who had existing relationships with the families chosen. Whilst this may have been done with the best of intentions, it illustrates the implicit power which service providers, professionals and families have over the lives of people who have learning disabilities and provides some evidence of the difficulties in recruiting research participants from this difficult to access group.

Appendix I - Carers' Organisation Facebook Post

New appeal from student to assist with course research project:

How have the changes to services for people with learning disabilities affected the lives of disabled people and their families?

If you have a learning disability and you are aged 30 or over, I would like to hear what you and your family think about the care and support available to you.

My name is Karen Young and I am a PhD researcher at the University of Glasgow. If you are interested in taking part in this project or you would like to know more, you can call or text me on [redacted] or email me at:

[redacted]

Appendix J – Topic Guide

How have recent changes to care policy affected the day to day lives of people with learning disabilities and their families?

- *What does a ‘typical’ week look like?*
- *What’s changed?*
- *How do participants feel about it?*

Does SDS increase choice and control for people with learning disabilities and their families?

- *Perceptions of choice/control/independence?*
- *Is this important to individuals/families?*
- *How is policy/service change being experienced?*
- *How does independence/choice/control look & feel?*

How does SDS meet the needs of people with learning disabilities and their families?

- *Policy promises to enable folk to choose how they live their lives – how much choice do participants have (e.g. what to do/where to live/who with)?*
- *Health & wellbeing?*
- *Perceptions of quality of life (work/leisure/relationships, issues of risk?)*

How is the self-assessment process experienced?

- *Focus on user outcomes?*
- *Is support available & received? By & from whom?*
- *How are decisions negotiated/agreed? Equal partnership? Do folk feel listened to?*
- *Response to change?*

Appendix K – Coding Framework

1	**Assessments**
1.1	Involvement
1.2	Knowledge
1.3	Time
1.4	Relationships
1.5	Barriers
1.6	Misc.

2	**Budgets**
2.1	Cuts
2.2	Client contribution
2.3	RAS
2.4	Additional costs
2.5	Misc.

3	**Policy & Politics**
3.1	SDS implementation
3.2	Benefits
3.3	Glasgow CC
3.4	Conflict
3.5	Scot/UK govt
3.5	Misc.

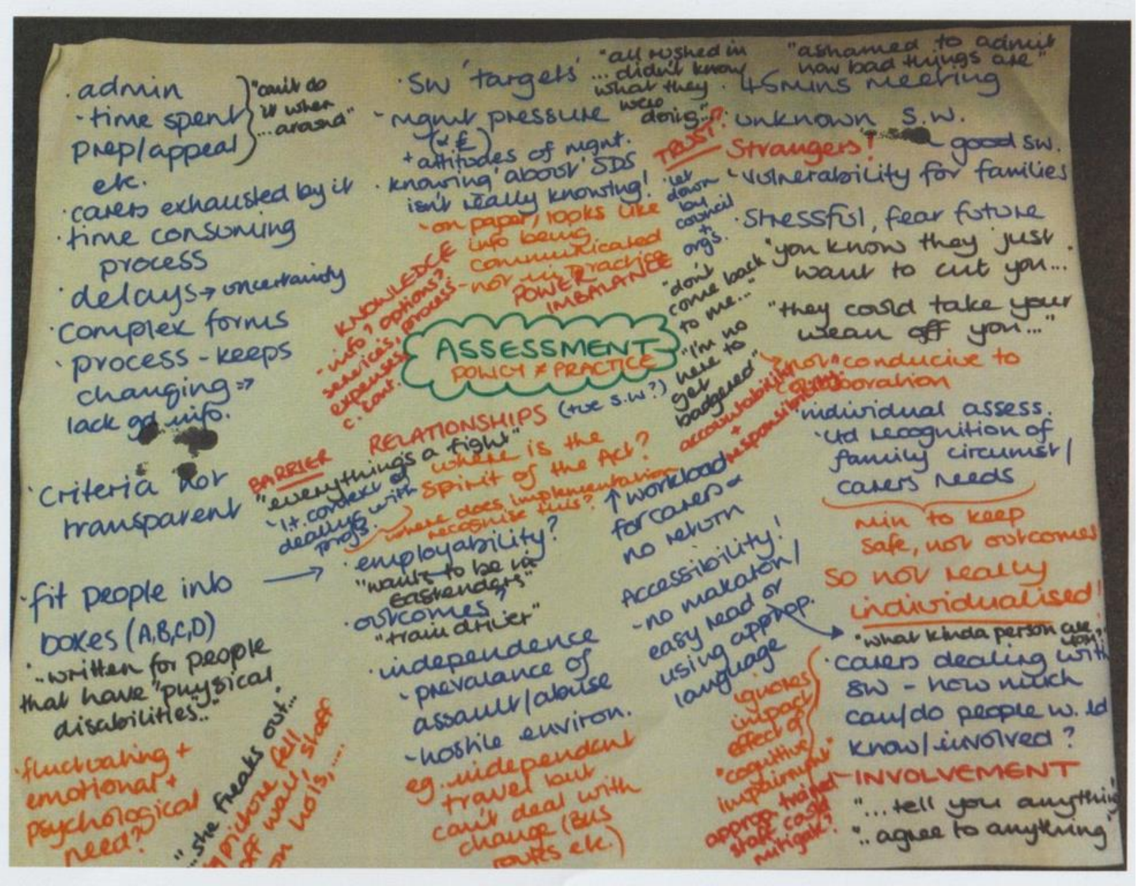
4	**Carers**
4.1	Assessments
4.2	Logistics
4.3	Lifecourse
4.4	Support
4.5	Misc.

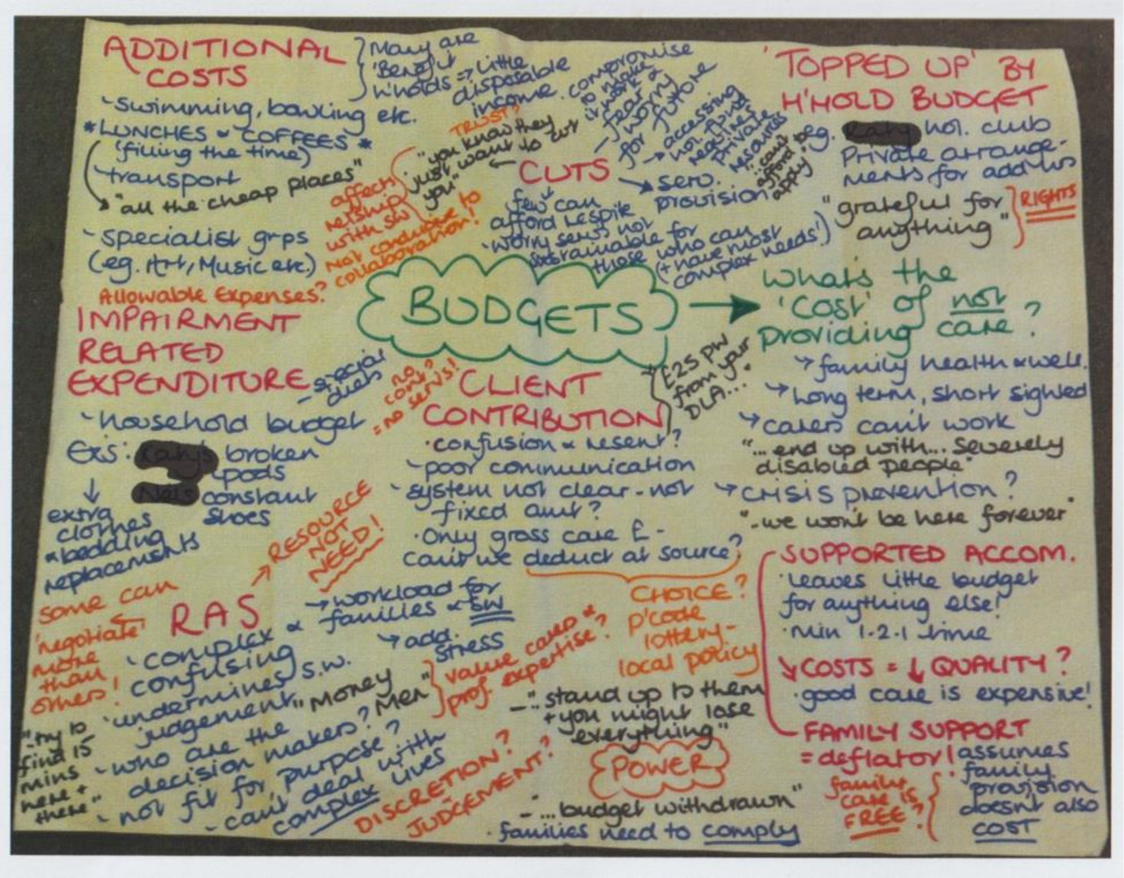
5	**Services**
5.1	Service providers
5.2	Community facilities
5.3	Staff
5.4	Failures
5.5	Relationships
5.6	Respite
5.7	Misc.

6	**Relationships**
6.1	Families
6.2	Friendships
6.3	Support workers
6.4	Social work
6.5	Health & education
6.6	Misc.

7	**Day Centres**
7.1	Friendships
7.2	Community
7.3	Activities
7.4	Buildings
7.5	Routines
7.6	Misc.

Appendix L – Mind maps





POLICY & POLITICS

SDS POLICY * 4 CHOICES? *
INCONSISTENT
BETWEEN LA'S
(+ [redacted]!)
ACCESSIBILITY
- RAS complex
- doesn't reflect need
- needs transparency (but also discretion?)
- holistic view

-ve perceptions
- std understanding of need - "getting your caring cut up..."

RESOURCE NOT NEED
NOT INDIVIDUAL PERSON CENTRED
MISINFORMED
no trust!

TIME CONSUMING NEGOTIATIONS
local area co-ordinators
"need a Philadelphia lawyer"

JOINED UP SOLUTIONS?
- community resources
- not listened to
- no legal aid to challenge
POWER

WHATS THE POINT OF SDS?
"just so you can get a PA..."
- answer to everything!
- folk don't want PAs - they want good services!

MPs! MSPs!

PRESSURE ON SOCIAL WORKER

CONFLICT WITH PROFS
- orgs are profiting
- profs think they're experts.

ALL TALK

"CHOICE?"
' can't use season ticket
"can't use budget for college" → that's education, not s.care."

where's the collaboration then?

POLICY ETHOS MISSING IN PRACTICE
- Values & Principles?
- "nobody actually cares"... safety
- Understand duty of care
↑ expectations + ↓ experience
"thought it was gonna be great!"

what's meant by 'choice' then?

IMPLEMENTATION RESOURCE LED IN PRACTICE
ACCOUNTABILITY

POLICY CONTEXT

WHAT IS THIS 'CARE'? NOT LIKE EDCARE!
not conducive to working together
NO TRUST
ON MY WAY
LET DOWN BY POLICYMAKERS

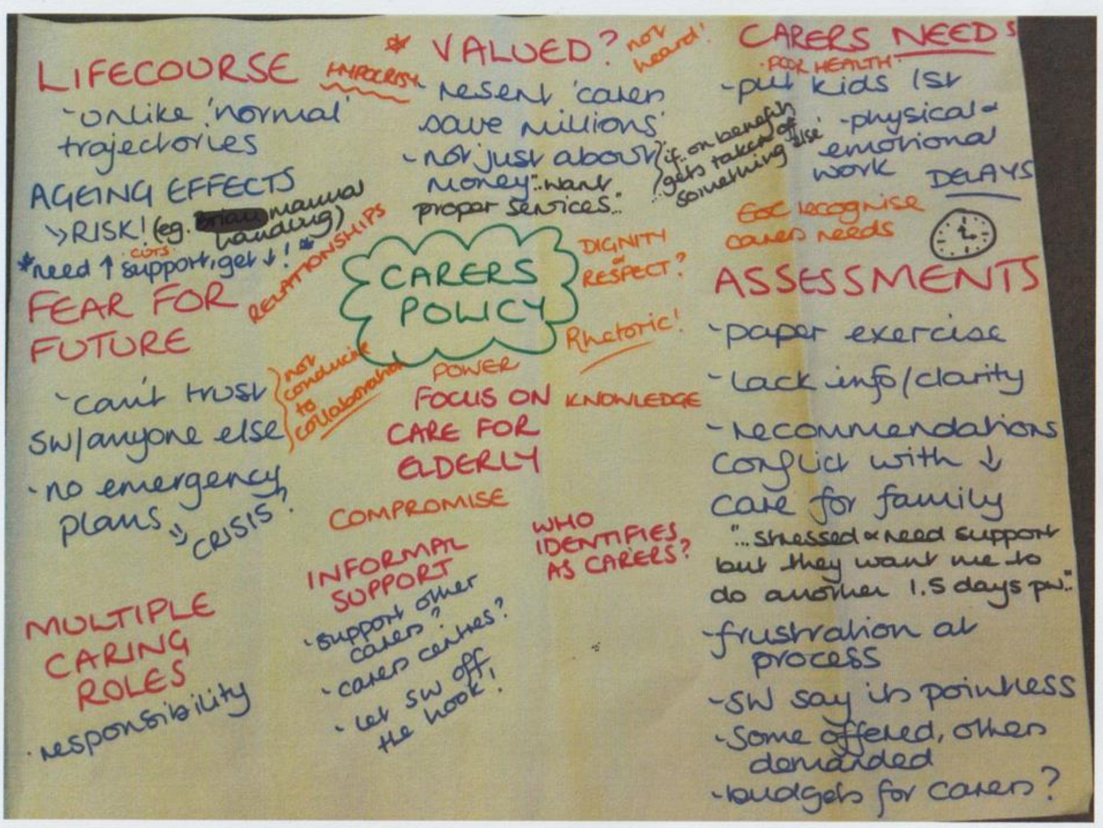
WORRY ABOUT BENEFIT CUTS
(eg. [redacted] + key cancelled)
- anxiety about future
NO choice + control!

GUARDIANSHIP
↓ CONTROL?
↑ segregation

who's in charge now?

AGE + EXP = REFLECTIONS
TIMES HAVE CHANGED...
- for better (eg Lennox castle, schools etc) + what if that's all you've known?
- worry though? - known v. diff. sits.
- ↑ inclusion ∵ (TV etc) language
- experienced long term exclusion (eg. special schools)
- lost not enough!
- expectations ↑
- importance of parents in setting up support
+ LD groups etc.

GLASGOW - CARING CITY?
- socialist history
- feel let down



CARERS POLICY

LIFECOURSE
- unlike 'normal' trajectories
AGEING EFFECTS
→ RISK! (eg. [redacted] manual handling)
* need ↑ support, get ↓! * cuts
FEAR FOR FUTURE
- can't trust SW/anyone else
- no emergency plans → CRISIS!

RELATIONSHIPS

not conducive to collaboration

HYPOCRISY

* VALUED? not heard!
resent 'carers save millions'
- not just about money" .. want proper services.."
if on benefits gets taken off something else

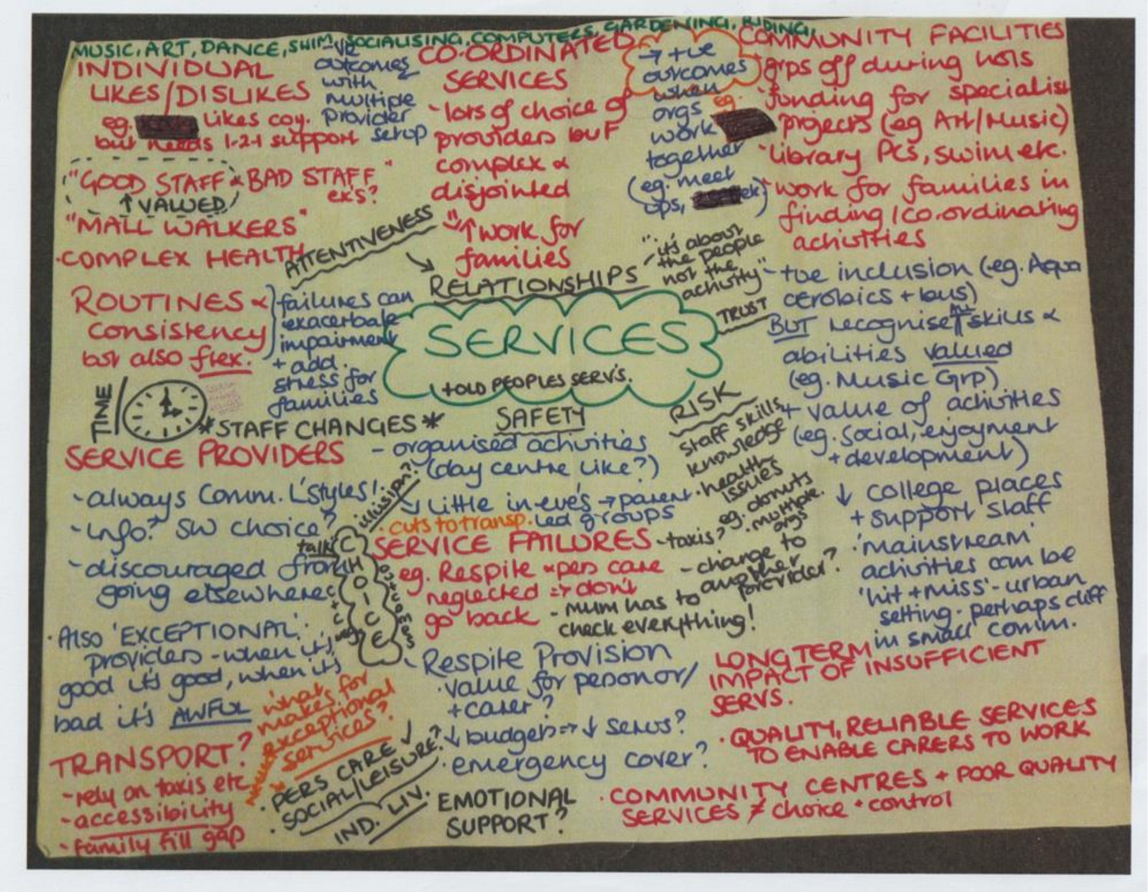
DIGNITY & RESPECT?
Rhetoric!
POWER
KNOWLEDGE
FOCUS ON CARE FOR ELDERLY
COMPROMISE
WHO IDENTIFIES AS CARERS?

MULTIPLE CARING ROLES
· responsibility

INFORMAL SUPPORT
· support other carers?
- carers centres?
- let SW off the hook!

CARERS NEEDS
· POOR HEALTH ·
- put kids 1st
- physical & emotional work
DELAYS
Ecc recognise carers needs

ASSESSMENTS
- paper exercise
- lack info/clarity
- recommendations conflict with ↓ care for family
"...stressed & need support but they want me to do another 1.5 days pw.."
- frustration at process
- SW say its pointless
- Some offered, others demanded
- budgets for carers?



MUSIC, ART, DANCE, SWIM, SOCIALISING, COMPUTERS, GARDENING, RIDING,

INDIVIDUAL LIKES/DISLIKES
eg. [redacted] likes coy. but needs 1-2-1 support

-ve outcomes with multiple provider setup

CO-ORDINATED SERVICES
- lots of choice of providers but complex & disjointed
- ↑work for families

→ +ve outcomes when orgs work together eg. [redacted] (eg. meet ups, [redacted] etc)

COMMUNITY FACILITIES
- grps off during hols
- funding for specialist projects (eg Art/Music)
- library PCs, swim etc.
- work for families in finding/co-ordinating activities

"GOOD STAFF & BAD STAFF" ex's?
↑VALUED
"MALL WALKERS"
·COMPLEX HEALTH

ATTENTIVENESS → RELATIONSHIPS

"...it's about the people not the activity"
- +ve inclusion (eg. Aqua aerobics + bus)
BUT recognise all skills & abilities valued (eg. Music Grp)

TRUST

ROUTINES & consistency but also flex.
failures can exacerbate impairment + add. stress for families

SERVICES
+OLD PEOPLES SERV'S.

TIME
STAFF CHANGES

SAFETY

RISK
staff skills + knowledge
·health issues
eg. donuts
·multiple orgs

+ value of activities (eg. social, enjoyment + development)

↓ college places + support staff

SERVICE PROVIDERS
- organised activities (day centre like?)
- always Comm. L'styles!
- Info? SW choice?
- discouraged from going elsewhere
- inclusion?
- ↓ little in eve's → parent-led groups
- cuts to transp.

talk
CHOICE
outcomes

SERVICE FAILURES - taxis?
eg. Respite & pers care neglected => don't go back
- change to another provider?
- mum has to check everything!

·'mainstream' activities can be 'hit + miss' - urban setting - perhaps diff in small comm.

·Also 'EXCEPTIONAL' providers - when it's good it's good, when it's bad it's AWFUL

what's for makes exceptional services?

- Respite Provision
·value for person or/ + carer?
↓ budgets => ↓ servs?
·emergency cover?

LONGTERM IMPACT OF INSUFFICIENT SERVS.

·QUALITY, RELIABLE SERVICES TO ENABLE CARERS TO WORK

·COMMUNITY CENTRES + POOR QUALITY SERVICES ≠ choice + control

TRANSPORT?
- rely on taxis etc
- accessibility
- family fill gap

·PERS CARE
·SOCIAL/LEISURE?
IND. LIV.

EMOTIONAL SUPPORT?

SUPPORT WORKERS

"it's the people that make it"

"they've got energy!"

- ↑valued 'good staff'
  *L.T. relships @centres +
- patience, consistent
- knowing individual
- working together → ↑skills (identifying activities, co-ordinating, inter-pers skills) yet caring work seen as low skilled, low status
- not just 'functional' (but good pers care important!)
- emotional support for fam.

RESPONSIBILITY

- working with family (eg. [redacted] ex's of driving)
- getting to know staff as people eg. family etc + vice versa

·also ex's of bad staff (eg. [redacted], not turning up, donuts) RISK

CARE
·time in family home? (eg. [redacted] enjoys chat + company) others reject home support

"couldn't cope without them"
"tells her things she doesn't tell me" (only person outside family she has relship with)
- hols
- health concerns & needs

TRUST
- friends/family like? "go for lunch 121 ·KFC!
"makes me feel safe"
"makes me feel safe"

RELATIONSHIPS
·[redacted] - works cos gd. supp → working together
"managing" distress/change?
ATTENTIVENESS

"[redacted] say 'whit lave we to do today'" - I decide
POWER?
CHOICE?
But not straightforward -eg [redacted] & E, [redacted] pics, campus visit

SOCIAL WORK
·not aware of help (was offered)
·some little prev. involvement → already felt let down
- good social workers
  - 'done her best'
  - 'on your side'?? "so nippy"
- LET DOWN
- few have relships
  - LT restructuring => not resourced for SDS?
- SW w/drawn from centres + specialist
  - 'deal with everything'
- job's not what expect
- 'threatened' to w/d budget
- short sighted "carers are terrified"

- undermined by system - value skills?
- mgmt. don't make decision. "Honeymen"
- POWER?
- under pressure
  ↑workload
  ·sympathy?
- need to trust them "telling... all your problems"
- conflict with Mgmt
  - not listened to
  - false consultation
  - disrespect

HEALTH & EDUCATION
"...I was very naive... didnae know anything aboot disability..." what help was available..."
- special schools, staff relships,
- "fight to get into s. school"
- lack support in formative years? (escort etc.)
- medics not listening
- ltd opportunities
- l.term health profs involved
- lack trust due to previous failures/lack of care
- serious health scares


DAY CENTRES
FRIENDSHIPS
- disposable?
- through school + centres
- peers + workers
INSTITUTIONS?'
LONG TERM (25yrs +)
- never known anything else
STABILITY & ROUTINE
· M-F "work"
POWER?
ACTIVITIES
& work exp (hairdressers asst, cafe, reception)
· arts & crafts, ...
· music, drama
· dance · outings
· choice (+ support to make choices)
· cuts ↓ activities ↓ no's? "ran it down"
· computers
COMMUNITY?
- conspiracy · making £
- consultation + campaigns
- peoplelist
- ucil
- enable
CONFLICT
POWER
"AGE"?
- not what young folk want?
- or not default
↑ options + opps
THERAPEUTIC?
& medical needs
eg. LD nurses, podiatrist, physio, ~~chiropodist~~,
+ therapy activities (eg. dance/exerc/trampoline etc)
'medicalise LD?
or recognise impair.?
"EXPERTS"
- no-one wants centres - says who?
- not listening to people + carers
not conducive to collaboration!
RELATIONSHIPS
→ many have gone to other bldg based servs.
GRIM?
"not so much the centres but the way they were run"
ATTENTIVENESS
EMOTIONAL IMPACT
families pick up ↑ emotional labour
- confusion
- distress
- fear
· "how do you explain it..."
BUSES
STAFF SKILLS & KNOWLEDGE
- importance of key workers
↘ worker condition
- long term staff (contrast to t/over in servs)
- know individuals & families
builds trust
CARE
DEVELOPMENT
"they brought her on"
· cafes + supermarkets
→ what happens when you take away building?
- NHU WALKERS
IMPORTANCE OF BUILDING/BASE
- safety, inspections,
- trust & responsibility
- place of safety + care?
"didn't need to be out & aboot all the time"
SEGREGATION
- only wheelchair users could get day service?
- don't have budget to go
"All down to money"
ISOLATED?
↓ ACTIVE
- physical + mental