IT’S PERSONAL
LIVED EXPERIENCES OF ADULT SOCIAL CARE AND SOCIAL WORK PRACTICE IN A POLICY CONTEXT OF PERSONALISATION

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Abstract

This study focuses on what can be learnt from lived experiences of adult social care and social work practice in England in a policy context of personalisation. The concept of personalisation is increasingly a key driving force in adult social care policy with significant implications for social work practice. In this study, psychosocial and participatory methods are purposefully combined, with lived experience and co-production placed at the centre of a unique qualitative methodology. A reflective learning group with people with lived experience is a core feature of the research design. The findings reveal some important learning for social workers. Firstly, a risk is identified that social workers working within a personalisation framework focused on independence and strengths might unconsciously collude with psychic defence mechanisms. Like those defences first identified by Menzies-Lyth (1960) they include individual and social defences against anxiety associated with unconscious fear and hatred of dependency. The findings also highlight a phenomenon that the researcher characterises as depersonalisation – a social care system that appears unreal, detached and emotionally numb. The need for emotionally engaged social workers capable of bearing reality is a suggested response to such phenomena in adult social care. It is proposed that social workers have an essential role to play in perceiving and responding to such defences and countering the adverse effects of depersonalisation. Drawing on Fairbairn's (1952) concept of 'mature dependence', the author argues that the social work role should include facilitating the developmental achievement of mature dependence for people accessing adult social care. Secondly, the findings reveal the need for better integration of a form of personalisation rooted in principles of self-directed support and relationship-based practice approaches in social work. Finally, a reorientation towards contribution-focused practice and an outline personalisation relationship-based practice model emerges from the findings. The draft model proposes that social work practice in adult social care in a policy context of personalisation should be focused on interdependence, choice and control, and reciprocity.

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Andrew J. Richardson
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List of abbreviations and acronyms

ABI	Acquired brain injury
ADASS	Association of Directors of Adult Social Services
BAME	Black Asian and minority ethnic
BASW	British Association of Social Workers
BNIM	Biographical narrative interpretive method
CAQDA	Computer-assisted qualitative data analysis
COS	Charity Organisation Society
CSA	Care and Support Alliance
DP	Direct Payment
DPO	Disabled Peoples' Organisation
DRUK	Disability Rights United Kingdom
DWP	Department for Work and Pensions
FANI	Free Association Narrative Interview
IB	Individual Budget
IBSEN	Individual Budgets Evaluation Network
IFSW	International Federation of Social Workers
ILF	Independent Living Fund
ILM	Independent Living Movement
JRF	Joseph Rowntree Foundation
LGA	Local Government Association

NAO	National Audit Office
NDIS	National Disability Insurance Scheme
NHS	National Health Service
NIMHE	National Institute for Mental Health in England
ONS	Office for National Statistics
PA	Personal Assistant
PB	Personal budget
POET	Personal Outcomes Evaluation Tool
PRLG	Personalisation Reflection and Learning Group
RCT	Randomised controlled trial
SCIE	Social Care Institute for Excellence
SDS	Self-directed support
SRA	Social Research Association
TLAP	Think Local Act Personal
UK	United Kingdom
UN	United Nations
UPAIS	Union of the Physically Impaired Against Segregation
UREC	University Research Ethics Committee

Chapter 1: Introduction

> *'…It's interesting that the [local personalisation transformation programme] has been going for two and a half years, and yet at the end of that process, we're still here arguing about what personalisation means. Maybe what the experience of it has done, is to give us ways of thinking about it and there aren't any simple answers, because it's a complex relationship.'*
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> ~Comment from Expert by Experience, PRLG meeting #1~

An Expert by Experience and a member of this research project's bespoke Personalisation Reflection and Learning Group (PRLG), summed up their views about personalisation at the group's first meeting in the quote featured above. As will become apparent in Chapter 2, it is striking how these observations, which in a few simple sentences draw attention to the slow pace of progress, the contested meaning of personalisation and its complexity, so closely accord with some aspects of a review of the existing literature on this subject. At the group's inception, and here at the beginning of my thesis, the wisdom associated with lived experience is apparent. I hope to demonstrate that by carefully listening to and reflecting upon what people with lived experience say about adult social care and social work practice in a policy context of personalisation has value and can guide social workers and others in making sense of personalisation and in navigating the connections and tensions associated with its fundamental tenets.

This chapter will explore my research journey and the rationale for the study. I begin by introducing myself and outlining my research journey, including relevant experiences from my personal and professional background that have informed my decision to research the subject of personalisation. In this regard, I adopt a stance that is consistent with principles of reflexivity that I aim to adhere to throughout this social work doctoral thesis. Here, I use the term reflexivity to refer to critical self-reflection and self-awareness about the impact of my background, assumptions, emotions and positionality situated within my social context (Finlay and Gough, 2003). I briefly demonstrate how such experiences influenced my methodological choices – ultimately leading me to construct a bespoke qualitative methodology, a purposeful bricoleur approach (Denzin and Lincoln, 2011), informed by a unique combination of psycho-social and participatory research methods. A reflective learning group with Experts by Experience, observation, and free-association narrative interview methods were used to generate a rich data corpus. A dynamic process of data generation and data analysis, with significant participatory features, was also part of the research design. A comprehensive account of my research methodology is provided in Chapter 3. Next, locating my own professional experiences and influences within a broader social care policy and social work context, I set out the rationale for my study. Then, I outline my research questions and provide some reflections on how they were conceived. Finally, I briefly describe the structure of my thesis, the intention of which is to provide a clear chapter by chapter guide for the reader.

About me

I am a social worker with mixed white European ancestry who was born in Australia. Based on my level of education and position in the labour market, I am likely considered middle class. I do not currently identify as a disabled person, a service user or carer. I, therefore, write about this subject from my position as a social work practitioner. Reflecting my commitment to reflexivity, anti-oppressive and anti-discriminatory practice (Banks, 2012; Dominelli, 2002; Thompson, 2016), I share aspects of my identity here and explore their relevance in later chapters insofar they relate to dynamics of power and how I have taken up my role as a researcher.

My research journey

I originally qualified as a social worker in Melbourne, Australia in 2005, before moving to London and taking up a social work role in local government in 2008. My social work degree, which I undertook alongside a Politics and Gender Studies degree in Melbourne, was a generic course, encompassing a range of theoretical perspectives informing practice with individuals, groups and communities. At the time, it was practice with communities and more radical and critical social work theoretical approaches that I was most drawn to (Ife, 2002; Adams, Dominelli and Payne, 2009; Fook, 2002; Mullaly, 1997). Such perspectives, I believed, most closely accorded with the social work values and ethics I subscribed to, in particular, those relating to human rights and social justice. My enduring professional and academic interest in community development, participatory and rights-based social work, has roots in my earlier social work training and anti-war, gay rights and environmental student activism in Australia.

This research endeavour subsequently, grew out of my experience as a social worker working in the area of adult social care in London. I was working as a social worker in a community learning disabilities team in an inner London local authority when personalisation was gaining traction, nationally and locally. In the ensuing decade, personalisation has held a prominent place in my professional and academic endeavours. Since 2007, when the *Putting People First* concordat declared personalisation as official government policy (England. HM Government, 2007), I have held several roles in which I gained insight into the policy and practice implications of personalisation for social work. This experience spans more than a decade, and includes direct social work practice in relation to assessment and support planning for personal budgets, supervision of staff and management of teams charged with setting up and reviewing personal budgets and direct payments, and project management of various personalisation, co-production and transformational change initiatives.

I initially embraced personalisation when it was first introduced in my workplace in 2008 because I considered it aligned with progressive social work values and had potential to advance human rights and social inclusion for disabled people, service users and carers. Early successes buoyed me. For example, I worked with a service user to secure a personal budget which allowed her to have a creative support plan, directly employ staff, pursue learning and leisure activities, and take a life-enhancing holiday overseas. Social workers currently working in frontline practice with adults, in particular, will most appreciate how the notion of a service user being funded by the local authority to have a holiday overseas was, and remains, extraordinary. Yet personalisation, at the time, both allowed and legitimised such creative possibilities. Other service users I worked with flourished when given a chance to design their support plans using person-centred planning (PCP) tools. In the early days of personalisation, I also arranged many personal budgets for family carers who had previously had no support or acknowledgement of their caring role. Such personal budgets allowed them to purchase products, services or experiences to help them to de-stress, relax and feel valued.

However, over time, I became more aware of some tensions and challenges associated with adult social care and social work practice in a policy context of personalisation. Austerity began to bite, and this was no doubt a factor, but I sensed that there were some more complex factors at play. I perceived a change in emphasis, and a widening gulf between the rhetoric of personalisation as espoused by policy-makers and other proponents of personalisation and, anecdotally, the lived reality of disabled people, service users and carers. Furthermore, I began to think that personalisation, at both a local and national level, was being interpreted in very different ways from the vision to which I had subscribed initially. I began to fear that I had been inadvertently complicit in a policy being promoted by politicians and policy-makers, whose neoliberal intentions were disguised as promoting choice and control for service users. Indeed, I began to fear that personalisation might be antithetical to the core social work values and ethics that I have long held to be fundamental. And yet, I continued to see first-hand the transformative power of self-directed support and co-production – enacted in the name of personalisation, in the lives of disabled people, service users and carers with whom I was working. As time went by, I felt a more pressing need to understand these tensions better, to know why they manifested, explore whether they can be reconciled, or whether they pointed to some fundamental flaws at the heart of personalisation as a concept. I concluded that understanding and giving voice to what personalisation means to service users, rooted in their actual lived experience, was necessary to restore meaning and focus to what felt like an increasingly slippery and elusive concept. This seemed an important undertaking for me personally, as someone who had championed both social work and personalisation for many years.

At the same time, my postgraduate training at the Tavistock Centre introduced me to contemporary psychoanalytic and psychodynamic theories and led me to appreciate the importance of unconscious processes, in individuals, groups and organisations. I had seen how psychoanalytic theory could be utilised to help make sense of challenging and fraught phenomena in the social work arena – for example in the area of child protection and familial child homicide (Rustin, 2005; Cooper, 2005). Utilising the theoretical works of Melanie Klein, I began to see that anxieties, defences and polarised, paranoid-schizoid (Klein, 1946) states of mind seemed to manifest in adult social care policy and practice. I wondered what defences against anxiety might be in operation in relation to personalisation in adult social care, like those observed to manifest in the area of nursing care outlined in the seminal study by Menzies-Lyth (1960). Also, drawing on the works of Cooper and Lousada (2005) and Dartington (2010) of which I will say more in Chapter 2, I reflected on the role of defended states of mind, in particular, those associated with independence and dependence concerning social work, adult social care and personalisation. So too the locating and occupying of a third position (Britton, 2004) as a possible way through the fractious and polarised all good or all bad debates about personalisation, whereby one can observe something more akin to reality, seemed necessary. What might be termed a psychoanalytic lens, seemed to open up possibilities for exploring and making sense of the more mixed, ambivalent and complex perspectives, thoughts and feelings that seemed to be obscured, marginalised, ignored, split off or denied in relation to adult social care and social work practice in a policy context of personalisation. It was, therefore, the coalescing of my professional experiences in adult social care with my exposure to psychoanalytic theories in my post-graduate studies that led me to embark on doctoral research with a focus on adult social care, social work and personalisation.

The rationale for the study

Personalisation has had wide-ranging impacts for adult social care and the social work profession. Some consider personalisation to be *the* principle underpinning contemporary social care policy in the UK (Wilson et al, 2011). According to Newman (2009, p.1), personalisation has evolved from a ‘twinkle in the eyes of a small number of people’ to now being considered mainstream. Needham (2011) goes further still, arguing that personalisation is a new policy orthodoxy, seemingly self-evident and irrefutable. More recently, Needham and Glasby (2014, p.3) declare that it is ‘one of the key themes of the past decade, and quite possibly one of the key agendas of the next ten years’. Focusing in particular on social work, Beresford (2014, p.1) asserts that personalisation is ‘without question the dominating idea and development currently in social work and social care’. What seems clear is that personalisation will remain a topic of relevance in adult social care for the foreseeable future. The significance of personalisation for the theory and practice of social work with adults is thus clearly evident. This thesis, therefore, has relevance in terms of social work policy and practice. Research in this area is therefore timely and necessary, if not essential; not least as the debates about personalisation have become so polarised, as Chapter 2 goes on to explore.

Trying to make sense of what I encountered when working as a social worker in a policy context of personalisation, as mentioned earlier, underpins my motivation for this research. Yet, while seeking to ground this study in the realities of service users’ lived experience stems from my own professional experiences, there appears a need to bring greater reality to bear more widely in relation to personalisation. Indeed, Think Local Act Personal (TLAP), the government-funded quasi-autonomous champion of personalisation and prominent voice in the sector, has highlighted concerns about a widening gap between the vision of personalisation and the realities of service users' experiences of social care: what they call the rhetoric-reality gap (TLAP, 2017, website). Furthermore, it is interesting to note that a flagship national programme for personalisation, led by TLAP, of which I was a project manager in a local authority context, is called *Making it Real*. On a surface level, TLAP is simply trying to highlight challenges associated with the implementation of personalisation, no doubt heightened by austerity. Yet TLAP's focus on reality and talk of making it real may also point to an unconscious desire by a leading organisation charged with championing personalisation to engage in a more realistic, more integrated or depressive position (Klein, 1946) exploration of personalisation. This would, by necessity, be rooted in the realities of service users' lived experiences.

In late 2017, Simon Stevens, independent disability and inclusion consultant and service user, outlined his fears that personalisation is dying because the current generation of Social Care professionals have forgotten what it is (Stevens, 2017). Stevens' challenge is sobering and underlines the despair now felt by many disabled people and service users, whose experience of adult social care is now anything but personalised. Yet, I am not sure that social workers and other social care professionals have forgotten what personalisation is. I am more inclined to think that many never fully understood what it was, and for a large part of my time working in the area of adult social care, I would have included myself among those confused by personalisation. The concept of personalisation can be elusive, so too the raft of terminology that comes within its ambit. There is a veritable quagmire of jargon that necessitates a jargon buster (TLAP, 2018a) to help service users, carers and social work professionals alike to make sense to personalisation. Furthermore, as members of the PRLG also highlighted in their first meeting, and what is borne out in the literature, personalisation is complex and can give rise to fierce arguments about its meaning. This issue may lead to some challenging questions, for example: Has there ever been a clear and shared meaning for the concept of personalisation in both adult social care and social work practice? What different meanings might different stakeholders give to the terms, independence, choice and control? What might be learnt from the lived experience of having a personal budget? While taxing, immersion in the complex and vexed debates about personalisation, nonetheless helped to shape and refine my research questions. At the very least, I concluded that research focused on gaining a greater understanding of what personalisation is, rooted in the lived experience of disabled people, service users and carers, is an important and necessary task for the social work profession. Indeed, this thesis aims to illuminate complexity associated with personalisation and to chart a path forward for social work practice in adult social care.

Research questions

The research questions guiding this doctoral research include an over-arching primary question and three subsidiary questions as follows:

Primary:

1. What can be learnt from what services users say about their experiences of personalisation?

Subsidiary:

2. What are the range of meanings of personalisation that adult social care service users ascribe to this concept when given an opportunity to explore their lived experience in depth?

3. What might be the connections and tensions, conscious and unconscious, between the lived experience of adult social care service users, social work practice and the concepts of independence, choice and other key tenets of personalisation policy?
4. How do the principles of personalisation accord with the realities of services users' lived experience and contemporary social work practice with adults in England?

A preliminary version of research questions first emerged from my own curiosity, and at times bewilderment, about my experiences of seeking to implement personalisation policy in an adult social care department, as discussed earlier. I was keen to try to make sense of my experiences, in particular feelings of confusion, apprehension and anxiety, and the research questions reflect these objectives. I felt that a focus on lived experience of service users would help me to gain greater clarity about personalisation and my role and practice as a social worker in this area of practice. This is why I decided that I needed to work with service users to explore personalisation. My research design, set out in detail in Chapter 3, is an attempt to achieve this. Overall my research questions did not change, and remained relevant throughout the data collection and analysis stages, with only minor modifications. The nature of the modifications and the reasons for making them are outlined in Chapter 3.

A note on terminology

Throughout this document, I use the term disabled people, the preferred term in England as it emphasises how people are disabled by society (Shakespeare, 2018). Where appropriate, I will also use the term people with learning difficulties, again the preferred term among such groups in England for people that many internationally refer to as people with intellectual disabilities (Shakespeare, 2018). I also use the term service user to refer to any person who receives care and support services. While it has its limitations, this term is widely used in adult social care. I use it here also in an attempt to be inclusive, as many service users of adult social care would not consider themselves to be, nor refer to themselves as, a disabled person. Finally, I use the term carer to refer to a person who provides unpaid care and support to a partner, family member or friend.

In addition, at this early juncture, for the sake of terminological clarity, the reader is advised that I am using a definition described by Williams and Tyson (2010) which differentiates personalisation as a broader change in the culture and ethos of public services from the terms self-directed support and individual budgets. So too, in accordance with Williams and Tyson (2010), the term self-directed support refers here to the operating system for social care, pioneered by the organisation *In Control*, which puts the service user at the centre of the assessment and support planning processes. Personal budgets, an iteration of earlier individual budgets, refers to money that is allocated to a person to meet assessed social care needs (TLAP, 2018a).

Structure of the thesis

The thesis is structured in chapters and a summary of each of the proceeding chapters is set out below.

Chapter 2: Literature review

This chapter sets the scene by presenting a comprehensive review of the literature about personalisation in relation to adult social care and social work. This is focused principally on England, though some international sources are used where appropriate. Pertinent contemporary and historical context related to social care and social work with adults in England is included in the literature review. Various aspects of personalisation are explored in-depth, including factors associated with its development and meanings. Debates and perspectives from various commentators and theorists are included in this exploration. Empirical studies, evaluative research, and grey literature are reviewed throughout, with a particular emphasis placed on the identification and presentation of research findings focused on service user perspectives and experiences of personalisation.

Chapter 3: Methodology

In this chapter, the methodological paradigms that influenced the research are explored. This is situated within a wider discussion about research methodology. My research design, a multi-method psycho-social participatory study, is then outlined. I set out what research methods I used and the rationale for using them. I describe how my methodology comprises a qualitative approach consisting of two principal elements: a reflective learning group with Experts by Experience, the PRLG, and semi-structured psycho-social interviews with service users of adult social care. The components of my data corpus are described, along with the methods and framework used for data analysis. Consideration of ethical issues and research validity, reliability and generalisability of the findings also features in this chapter.

Chapter 4: Findings

This chapter sets out the findings. Pen portraits of the research participants are presented, followed by an account of the key themes of the research that emerged from a cross-case thematic analysis. The key themes are illustrated throughout with examples from the participant interviews, the PRLG meetings, and my own observations.

Chapter 5: Discussion

This chapter presents an exploration and theorisation of the key findings. What can be learnt from the findings is explored, with particular consideration of implications for social work practice. For this task, several theoretical concepts are drawn upon.

Chapter 6: Conclusions

This final chapter returns to the research questions, draws together the findings and offers some concluding comments on the topic. Applications for social work practice are identified and made explicit. Possible areas for further research are also outlined. A model of practice is offered. A critical appraisal of the research, with reference to ethics and limitations of the research, is presented. Plans for dissemination and some final personal reflections are also offered in this chapter.

Chapter summary

In this chapter, I have outlined the research topic and introduced myself. I have briefly charted the personal and professional journey that led me to pursue research on the subject of personalisation. I have set out a rationale for the study, rooted in my own professional experiences as a social worker working within the adult social care system in England during the period in which personalisation became a chief driving force in social care policy and practice. I have described how personalisation is considered by many commentators to be highly significant for both social care and social work. Drawing on contributions from a number of key commentators, I have set out how personalisation is a contentious topic, and have shared my view that it is necessary to bring reality to bear on the subject by considering lived experiences of disabled people, service users and carers. My research questions also featured in this chapter, both primary and subsidiary. Finally, I have included a brief summary of each chapter in this thesis.

Chapter 2: Literature review

Introduction

In this chapter, I explore the current literature about adult social care, social work and personalisation. The purpose is to provide context for my research, address the research questions set out in Chapter 1, ascertain what can be learnt from the existing body of literature and to synthesise and summarise this learning. Firstly, I outline how I have approached this literature review, including setting out the rationale underlying the inclusion criteria. Then, by way of context, I analyse historical and contemporary developments in social care and social work with adults in England, including key legislation. I explore current models of social work practice in adult social care. Personalisation, how it is defined, its development and historical influences and antecedents are set out, along with technical terms associated with it. Here, the focus is on those concepts and tools that are utilised in adult social care by social workers such as self-directed support, direct payments and individual/personal budgets. I explore studies that reveal service users' views and experiences with particular attention to studies anchored in the lived experience of service users. Evaluative studies focused on personal budgets are identified as a key source of evidence informing the development of personalisation as a policy. The learning from such studies is summarised and examined. I also consider what the literature reveals about social work practitioner perspectives and experiences of adult social care and social work in a policy context of personalisation. Where relevant, tensions, gaps and debates associated with adult social care, social work and personalisation are examined.

My approach

I have completed this literature review with reference to the guidelines outlined by David and Sutton (2011, p.66), whereby I seek to meet the requirement to 'focus, find, catalogue and evaluate'. My inclusion criteria have been flexible but have comprised the following core elements. The search strategy included research and documentation relating to adult social care, social work and personalisation. It was not necessary to apply a restricted timeframe to the search. However, in line with good academic practice it will be apparent that much of the literature included is from circa 2000 to the present, therefore remaining current and relevant. The literature includes peer-reviewed journal articles, published studies and scholarly texts as well as a variety of sources deemed grey literature, namely reports, blogs, government white papers and policy documents in line with current scholarly convention (GreyNet, 2019). I mainly restrict my review to items published in the UK, England in particular, as this is where the study took place (London and Southeast England) and where my professional social work experience has taken place. I have, however, included some relevant international sources, to aid a comparative analysis, where appropriate. As Prandini (2018) observes, personalisation is occurring in many parts of the world besides England, including but not limited to the United States, Australia, Germany, Scandinavia, Italy and the Netherlands. Furthermore, Pozzoli (2018a), focusing on the Italian experience, indicates that vouchers and budgets in the name of personalisation have been part of the Italian care sector for almost twenty years. Such contributions suggest that there are some developments in adult social care that are characterised as personalisation with potential opportunities for learning and comparison.

My method for collecting literature comprises the use of academic databases, reviewing journals, books and web-based research, including generalist search engines and specialist research-focused search engines. The databases I have used include EBSCO Academic Search, PsycINFO, Tavistock and Portman NHS Foundation Trust Library: Discovery (EBSCOhost) and One-Stop-Shop for Journals, the British Library catalogue and Google Scholar. An initial literature review was undertaken as part of my research proposal. Following this initial collection of available materials in the early stages of my research, I have periodically conducted an EBSCO search to identify and collect any new works that have been published on the topic. Where available, I have filed electronic copies of the materials collected on my personal computer. I have also obtained, where possible, copies of critical books on the subject of adult social care, social work and personalisation.

My initial focus was concerned with what the existing literature tells us about service users' views and experiences of adult social care, social work and personalisation. I have included literature that is intended to set up a framework for later chapters, particularly the findings and discussion chapters. This includes literature that defines and illuminates technical terms that are referred to in the findings and discussion chapters, including direct payments, self-directed support and personal/individual budgets. Published research reports have been individually screened to ascertain if they could help to answer my research questions. Additionally, I have made use of the Critical Appraisal Skills Programme checklist (CASP, 2018) and the key questions suggested by Orme and Shemmings (2010), which include drawing attention to relevance, ethics and generalisability. Such tools have guided my inclusion criteria but are not rigidly applied. Indeed, it should be noted that I have afforded two kinds of studies a higher priority for inclusion. Prioritised items include peer-reviewed journal articles, owing to the editorial standards and academic rigour, and any studies or reports on the subject matter of adult social care, social work and personalisation, focusing in particular on lived experience.

In approaching the task of evaluating the literature and indeed in my thesis as a whole, I have employed a psychoanalytic lens informed by my training at the Tavistock Centre. Psychoanalytic theory informs both my approach, my reflections and how I critically engage with the material. This approach is rooted in a broad range of concepts and principles associated with psychoanalysis including notions of the unconscious and mechanisms of defence against anxiety and psychic pain, in individuals, groups, institutions and wider society (Bateman, Brown and Pedder, 2010; Bateman and Holmes,1995). I have sought to attend to both that which is explicit, known or conscious, and that which might be below the surface, or unconscious. This includes consideration of that which might be unconsciously known in the literature, but not yet able to be consciously thought about – a stance that may be analogous to the notion of the 'unthought known' (Bollas, 1987).

The psychosocial concept of the defended researcher, in which one's own defences and emotional responses as a researcher are acknowledged and considered valuable rather than a hindrance (Hollway and Jefferson, 2013) bears emphasising, as I have held it in mind whilst undertaking the literature review and in analysing my findings. Similarly, I subscribe to the view that my subjectivity includes the use of defensive processes, which manifests across all aspects of the research endeavour, including in relation to selection and analysis of the existing literature. I consider that continuous reflection and supervision, in which there is space to note and explore feeling responses, is important and it was therefore a key component of the literature review. Related to this and owing to the psychosocial nature of the study, I have made reference and links to my own experience throughout the literature review where relevant.

Adult social care in England

For the purposes of this research, adult social care refers to help and support provided to adults and includes people with a disability or long-term illness, sensory impairment or mental health condition. The support can be provided in various ways. For example, adult social care can include residential care, home care, personal assistants, day services, short breaks, the provision of aids and adaptations and personal budgets. According to Duffy (2014a), the system under which adult social care operates does so according to a Professional Gift Model, in which tax-funded services are gifted by professionals to individuals who satisfy specified eligibility and assessment criteria. Duffy (ibid) contrasts the model with a citizenship model, arguing that support should not be a professional's gift but a citizen's entitlement. Notions of professional control, service user passivity and limited choice and control are characteristics of the Professional Gift Model. Despite policy and legislative changes to the adult social care system in line with personalisation, in my professional experience, the key characteristics of this model remain.

Legislative developments in social care and the modern welfare state can be helpful in understanding the emergence of the current social care system in England (Burton, Toscano and Zonouzi, 2012; Gardner, 2011; Glasby and Littlechild, 2009). The period following the end of the Second World War was particularly significant in terms of the introduction of a welfare state in the United Kingdom, with the repeal of the Poor Law system and introduction of the *National Assistance Act 1948* (Burton, Toscano and Zonouzi, 2012). Since this period, a succession of legislation has developed in tandem with key policy. Until 2014, the main statute governing adult social care in the community, or community care, was the *NHS and Community Care Act 1990*. According to Brammer (2010, p.406), the essential aim of the *Act* and related policy was ‘to enable people to continue to live in their own homes rather than move by necessity into residential settings’. The *Community Care (Direct Payments) Act 1996* is considered a significant milestone, and a disability rights movement campaign victory, which established the legislative foundations for direct payments (Oliver, Sapey and Thomas, 2012; Glasby and Littlechild, 2009). Oliver, Sapey and Thomas (2012, p.5) suggest that following this, ‘direct payments, and putting the users of social services in control became a cornerstone of social care policies’.

Turning to the present day, adult social care in England now operates under the legal framework as set out in the *Care Act 2014*. The passing of the *Act* is an important development in the area of adult social care in England with implications for social work practice. This landmark legislation modernised and consolidated most of the existing law in the area of adult social care (In Control, 2015). Commentators have described the *Act* as ushering in significant reforms to adult social work and heralding the biggest change to adult social care law since the *National Assistance Act 1948* (Community Care, 2014a). The Association of Directors of Adult Social Services (ADASS) hail the *Care Act 2014* as putting the right to a Personal Budget and self-directed support into primary legislation for the first time and furthermore note that the

Act's regulations and guidance set out that personalisation and self-directed support is now the expected norm of the care and support system in England (ADASS, 2017). The *Act* sets out several duties and responsibilities relating to how adult social care should be organised and delivered by local authorities (England. Department of Health and Social Care, 2016). A prominent feature of the *Act* is its focus on preventing and delaying people developing a need for care and support and improving people's independence (ibid). The *Act* also stipulates that care and support provided by local authorities should be personalised and places care and support planning and personal budgets on a legal footing alongside what was an existing legal right to direct payments (ibid). An important point to underline is that charging for care and financial assessments remain central to adult social care law with key provisions outlined in the *Act*. Unlike the NHS, which is free at the point of need, adult social care is means-tested and subject to care charges.

It is difficult to obtain precise data about the number of people using adult social care in England. One reason for this is that local authorities report requests for adult social care along with short term and long term service provision (NHS Digital, 2018). The total number of adults receiving long term support is reported to be 857,770 in England in 2017/18 (NHS Digital, 2018). However, there were also over 1.8 million new requests for adult social care support from 1.3 million new people during this same period (NHS Digital, 2018). People who receive short term support may require it on more than one occasion per year and each time is counted as a new request (Full Fact, 2017). It is also notable that there has been a decrease in the number of people receiving long term care each year since 2015-16, the majority of whom are people over the age of 65 (NHS Digital, 2018). Notwithstanding this decrease and the difficulty in obtaining precise data, there is widespread agreement that demands on adult social care will increase in coming years (Local Government Association, 2018a; ADASS, 2018; Care and Support Alliance, 2018; Disability Rights UK, 2018a).

An examination of the current literature pertaining to adult social care, social work and personalisation reveals a number of challenges that are impacting the sector, service users and practitioners. Polling conducted by the Local Government Association (2018b) highlights widely held misconceptions about adult social care in England, including a significant number of people thinking that social care is provided by the NHS and is free at the point of access. In addition, the population of England is getting older (Office for National Statistics, 2017) and there is an increased demand for adult social care associated with the ageing population. It is estimated that the number of disabled older people (who are unable to perform at least one instrumental activity of daily living or having difficulty with performing or are unable to perform without help at least one activity of daily living) will increase by 67 per cent from 2015 to 2040 (National Audit Office, 2018b). At the same time as this expected increase in demand, the UK government’s policy of austerity has resulted in unprecedented cuts to adult social care budgets (CSA, 2018). Austerity refers to a fiscal policy adopted by the UK government that has focused on a drastic programme of reductions in public spending intended to reduce the size a budget deficit and the role of the welfare state (O’hara, 2014). Some local authorities, such as Northamptonshire, have declared bankruptcy and others, such as East Sussex County Council, are cutting services to the legal minimum (Butler, 2018). Austerity is having a major impact on adult social care services, staff and service users. As will become apparent in my findings chapter, it was a source of considerable anxiety for many of my research participants.

As I write, the impact of austerity has led to what is now widely regarded as a crisis in social care. There is mounting evidence that underlines this assertion. In 2017/2018, the Care and Support Alliance (CSA), which represents over eighty of Britain's leading charities, carried out a survey with nearly 4000 people which revealed the depth of the crisis in social care. The report found that the £6.3 billion that has been taken out of adult social care in real terms since 2010 has led to a widespread absence of care for an estimated 1.2 million older and disabled people (CSA, 2018). Likewise, a 2012 report from the *Hardest Hit coalition*, a group representing over 90 disabled people's organisations and charities, found that disabled people have experienced a massive drop in income associated with cuts to benefits, with many being wrongly labelled 'fit for work' (Kaye and Baker, 2012). So too, a Joseph Rowntree Foundation report about the impact of the cuts found that they 'have hit the poorest people and places the hardest, with those least able to cope with service withdrawal bearing the brunt' (Joseph Rowntree Foundation, 2015). According to Duffy (2014b), disabled people with a lower income who use social care services are the most disproportionality affected by austerity. This is due to over fifty per cent of the cuts associated with austerity falling in just two areas: welfare benefits and local government. Local government is responsible for social care in England, and since 2010 there has been a 49.1 per cent real-terms reduction of funding for local government (National Audit Office, 2018b). Added to this, the rights of disabled people, as enshrined in the UN Convention on the Rights of Persons with Disabilities, to which the UK is a signatory, are being compromised by austerity. An official United Nations inquiry in 2016 determined that austerity-related reforms in the UK had disproportionally and adversely affected the rights of disabled people and had resulted in ‘grave or systematic [rights] violations’ (United Nations, 2016). Perhaps most alarmingly, a 2017 study found that austerity is associated with increased mortality. The authors of this report found that there were 45,000 more deaths than would have been expected in the first four years of austerity and they projected there would be an additional 152,000 deaths by 2020 (Watkins, Wulaningsih, Da Zhou, et al, 2017). They conclude that ‘spending constraints, especially public expenditure on social care, are associated with a substantial mortality gap’ (ibid, 2017, p.1).

Adult social care and social work in England – historical context

It is somewhat difficult to separate social work as a profession from the wider welfare state, not least of all because the roots of social work pre-date the later emergence of a distinct professional identity. Nonetheless, according to Beresford (2014, p.2), the history of social work and social care is chequered and both have been ‘devalued, underfunded, neglected, stigmatised and misunderstood’. This somewhat bleak characterisation has resonance with my own professional experiences of social work and social care over the last decade. Yet it is also possible to discern greater complexity in the historical account, certainly in the profession’s much earlier history, not least of all the debates about the role of the state and individual responsibility (Horner, 2006) that endure to the present day and that have relevance to the focus of this thesis: adult social care, social work and personalisation.

According to Wilson et al (2011), the origins of the social work profession in England lie in both the Charity Organisation Society (COS) and settlement movements, which were based, respectively, on individual and collective responses to problems (Wilson et al, 2011). Likewise, Gardner (2011) maintains that the roots of the profession can be traced to the development of the COS in 1869, adding that COS assessments were used to determine if people were worthy or unworthy of assistance. Drawing on thousands of archived case files, Peel's (2012, p.99) compelling account of COS workers' approach to assessments, attests to the centrality of determining worthiness, not least of all accounts in which the people living in poverty in London are characterised as dim, ugly, misshapen, disfigured and disarrayed, too fat or too thin and repulsive. Notions of who is worthy or unworthy or, relatedly, who is deserving and undeserving are clearly incongruent with contemporary social work ethics. Yet, Horner (2006) argues that the matter is more complicated than it might first appear, claiming that COS leaders also championed individualism, self-reliance, self-help groups, community education, mutuality and self-determination (Horner, 2006). Many of these notions are those that might be associated with good social work practice and personalisation. There are many tensions and debates associated with adult social care, social work and personalisation, and what the early history of social work suggests is that some debates, for example, those related to the role of the state and individual responsibility, are not new and are not solely associated with personalisation.

Social work with adults in England

I now focus on the contemporary context for social work practice with adults in England. Firstly, it is important to establish that social work in England is a regulated profession that operates within a statutory framework. Social work practice is typically organised as practice with children (and families) and practice with adults. Social work practice with adults can include working with service users in a number of areas: mental health, substance misuse, learning disabilities, physical disabilities and long term health conditions. Such areas can be practice specialisms for social workers, with different theories and practice approaches more prevalent, for example, the use of motivational interviewing (Miller and Rollnick, 1991) in the area of substance use, or person-centred planning (Sanderson, 2000; O'Brien, 2013) in learning disabilities services. As I will explain in my methodology chapter, while my research is intended to have relevance across all areas of adult social care, people with lived experience associated with learning disabilities and physical disabilities are more strongly represented in the interviews and in the membership of the reflective learning group. This reflects my professional experience of social work with adults and the professional contacts and networks that I was able to utilise to recruit to the study.

As social work regulation is devolved in the UK, social workers are regulated by separate bodies in England, Scotland, Northern Ireland and Wales. In 2019, the regulator in England, the Health and Care Professions Council was replaced by a new body, Social Work England. Social Work England is described as an independent public protection body that sets professional, education and training standards for social workers (British Association of Social Workers, 2019). Such professional, education and training standards include provisions related to personalisation. Social workers are expected to perform their duties, for example, in line with eligibility and service provision requirements relating to personal budgets outlined in the *Care Act 2014*, the Professional Capabilities Framework (BASW, 2018) and the Knowledge and

Skills Statement for social workers in Adult Services (England. Department of Health, 2015). Included in the latter are explicit requirements for social workers to have a good understanding of personalisation and person-centred practice (England. Department of Health, 2015).

Models of social work practice with adults

I will now describe some common features of social work practice with adults in England and what might be considered the prevailing model of practice, as this is important context for subsequent chapters. In line with the psychosocial orientation of this thesis, I will ground this in my own experience, whilst also drawing on relevant literature. There are inherent limitations of my objective to identify and describe the current model of social work practice in adult social care. This is because there is no single model of social work practice but rather a large and expanding set of ideas that are variously defined as models, theories, approaches and perspectives (Maclean and Harrison, 2015; Payne, 2014; Wilson et al, 2011). The demarcation between theories and models is not sharply defined and I concur with Maclean and Harrison (2015) who emphasise the inter-relationship between theories and models in social work. As outlined earlier in this chapter, a Professional Gift Model (Duffy, 2014a) characterises the adult social care system in England. While the system of adult social care and models of social work practice are different, social work practice with adults nonetheless takes place within this system and model. In my view, the adult social care system as it is currently constituted runs counter to both core social work values (BASW, 2014) and notions of citizenship.

Nonetheless, the global definition of the social work profession as outlined by the International Federation of Social Workers (2014, no page number) asserts that social work is a practice-based profession that is 'underpinned by theories of social work, social sciences, humanities and indigenous knowledge'. In my experience of social work in adult social care in England, theories most commonly used in practice include those concerned with human growth and development (Erikson 1950; Bowlby, 1988), systems and ecological perspectives, notably Bronfenbrenner (1979) and models of assessment and needs (Smale, Biehal and Marsh, 1993; Maslow, 1970). Also, in the area of learning disabilities, in which I worked as a social worker for several years, theories of normalisation and role valorisation (Wolfensberger, 1972; Wolfensberger, 1983; O'Brien and Lyle O'Brien, 1998), which will be explored in further detail later in this chapter, were very influential.

Parker and Bradley (2010) describe the social work process as being comprised of assessment, planning, intervention and review. While not a model, assessment, planning, intervention and review might be understood as a framework within which adult social work typically takes place in a statutory context. My experience as a social worker in a statutory adult social care setting in England is that social work roles and tasks were focused on these processes, shaped and mandated by the legal framework underpinning them, notably the *NHS and Community Care Act 1990* and later the *Care Act 2014*. As might be expected in a context where the Professional Gift Model (Duffy, 2014a) predominates, a significant focus of social work in adult social care in England is concerned with assessing for eligibility and rationing of funded services (Lymbery and Postle, 2010). This previously took place under the Fair Access to Care Services (FACS) criteria and now under *Care Act 2014* eligibility criteria. The focus on rationing is borne out in my own social work experience in adult social care, where the tasks of assessment and review were particularly concerned with addressing questions of eligibility. Another prevailing feature of social work practice in adult social care is safeguarding. Safeguarding is increasingly considered a core function of social work practice in adult social care, with statutory duties and organisational infrastructure, notably Safeguarding Adults' Boards, instituted following care scandals and subsequent inquiries in residential and NHS settings (Graham et al, 2016; Lymbery and Postle, 2010). In my experience, much of contemporary social work practice in adult social care is focused on safeguarding and it is challenging to reconcile the tension between promoting autonomy and the duty to safeguard and protect. Safeguarding would often predominate in social work practice in adult social care settings that I worked in, perhaps due to the activation of organisational and professional anxieties and defences (Menzies-Lyth, 1960).

There have been growing critiques in the last decade about 'care management', a model of social work practice associated with community care policy which entails a care manager (social worker) commissioning and having oversight of services provided to a service user (Wilson et al, 2011). A care management approach is typically short term, involves minimal direct contact and limits the capacity for the formation of a relationship between the social worker and the service user. This was the predominant model of social work that I encountered when I first began working in an English adult social care department in a local authority in 2008. Horder (2002, p.114) argues that care management is an individualising model that 'implicitly downplays the significance of relationships, personal contacts and continuity of care... emotional needs of users may be neglected'. Care management might, therefore, be characterised as a deliberately de-personalised approach to social work practice. While I was employed in a local authority adult social care department, my job title was changed from Care Manager to social worker, which marked a shift away from a care management model. Despite a care management model being widely abandoned, more general concerns about stultifying managerialist approaches in social work persist; what Maclean, Finch and Tedam (2018, p.95) suggest could be described as ‘conveyor belt social work’, which prioritises case management, accountability, targets and evidence-based practice. As I shall explore later in this thesis, characteristics of a care management model and its depersonalising impacts may endure, albeit in a system now ostensibly committed to its opposite.

Alternative theoretical and practice approaches have gained traction in the last decade, not least of all relationship-based practice approaches (Ruch, Turney and Ward, 2018; Hennessey, 2011; Megele, 2015) which build on earlier psychoanalytic and psychosocial social work models, notably Hollis (1964). I have found such approaches instrumental in my practice as a social worker, as they helped me to identify and examine my feelings and responses as well as inter-subjective dynamics occurring between myself and people with whom I was working. These models emphasise the centrality of the relationship between social workers and service users (Ingram and Smith, 2018). Personalisation and relationship-based practice approaches would appear to share a common set of aims and values. I am inclined therefore to agree with Parkinson (2010, p.250), who asserts the congruence between personalisation and relationship-based social work and the potential for psychoanalytically informed social work practice to help ‘navigate the pitfalls and possibilities of personalisation’.

Strengths-based or asset-based approaches to social work practice with adults have been promoted by sector leaders in recent years (England. Department of Health and Social Care, 2019; Hardy, 2018; England. Department of Health, 2017). Such approaches place greater emphasis on collaborative working with service users, with a focus in particular on their strengths, resilience and potential (TLAP, 2018b) and envisage social workers enabling service users ‘to identify their personal assets and local systems of support, and build on these to find sustainable solutions’ (England. Department of Health, 2017, p.4). They also seek to shift away from deficits being the focus in assessment and intervention processes (England. Department of Health and Social Care, 2019). While their own roundtable report stipulates that a strengths-based social work approach to working with adults is not yet a fully formed set of ideas, prominent sector leaders, including Lyn Romeo, Chief Social Worker for Adults and Tony Hunter, Chief Executive of the Social Care Institute for Excellence (SCIE) have nonetheless declared their support and ambition that such approaches should underpin social work practice (England. Department for Health, 2017).

New post-qualifying standards for social work Practice Supervisors in adult social care (2018) stipulate that Practice Supervisors should encourage practitioners to adopt strengths and asset-based approaches (England. Department of Health and Social Care, 2018b). Slasberg and Beresford (2017, p.269) are dismissive of strengths-based social work practice, characterising it as ‘the current elixir’ sought by a social care system that is in crisis and in search of a ‘miracle cure that will painlessly transform it into a system both personalised and that will cost less’. They caution that ‘good practice cannot change the system’, which in their view is structurally deficient (Slasberg and Beresford, 2017, p.272). The need for critical engagement with strengths and asset-based approaches might also entail an examination of how such approaches can unconsciously collude with psychic defence mechanisms associated with fear and hatred of disability (Dartington, 2010; Cooper and Lousada, 2005) and fear of our own dependency needs and actual or potential weakness. Such issues are evident in my data and I will, therefore, explore them in greater depth in the findings and discussion chapters.

Finally, there is a recovery orientation in mental health policy which seeks to focus professional activity on recovery from mental ill-health (Leamy et al, 2011). In the recovery approach, which underpins social work practice in mental health services, efforts are focused on addressing psychosocial factors such as relationships, social inclusion, financial security and housing (Mental Health Foundation, 2018). It is frequently acknowledged that this focus on recovery does not mean that one’s mental illness will be cured in the way that one may recover from a physical health problem (Leamy, 2011; TLAP, 2018b; Mental Health Foundation, 2018), which would suggest that there is a need to manage expectations associated with recovery among service users, families and policy-makers. How the recovery approach intersects with personalisation policy and practice is not a particular focus of my research, but is a possible area for future inquiry.

Personalisation is…

One of the primary aims of my research at its inception, reflected in my research questions, was to gain an understanding from people with lived experience about what personalisation means to them. As a starting point, it is important to set out how personalisation is defined in the literature and policy documentation. To begin, a jargon buster, produced by SCIE/TLAP defines personalisation as follows:

> A way of thinking about care and support services that puts you at the centre of the process of working out what your needs are, choosing what support you need and having control over your life. It is about you as an individual, not about groups of people whose needs are assumed to be similar, or about the needs of organisations (TLAP, 2018a).

This seemingly simple definition belies the highly contested and confusing territory that one encounters when reviewing the literature in this area. It nonetheless provides a starting point for understanding what meaning personalisation holds in the minds of policy-makers and government officials. According to Lymbery and Postle (2010), personalisation was introduced by Leadbeater (2004) as a new idea for public services based on the principle that service users should have more choice and control over services and how they are provided. Several principles, policies and concepts, including self-directed support, co-production and personal budgets and notions of choice and independence, typically fall within the ambit of, and at times are conflated with, personalisation. I acknowledge that the term personalisation was not used at the time when some new models of service delivery which now come under the personalisation umbrella, such as self-directed support, were first being developed (Duffy, 2014a). Notwithstanding this limitation, general definitions of personalisation identified as part of the literature review will be set out in this section, followed by descriptions of key related concepts that inform social work practice in adult social care.

Parkinson (2010, p.247) suggests that ‘instead of thinking about services, the philosophy of personalisation invites us to start with the needs, wishes and capacities of the individual person’. According to Beresford (2014, p.1), personalisation is ‘a term that has no clear or agreed meaning and does not have a place in many established dictionaries’. Gardner (2011, p.18) argues that personalisation is both a ‘way of thinking and a way of doing’ that is guided by an underlying philosophy and principles including self-determination, dignity and choice. As Needham (2011, p.4) discovered in her analysis of personalisation policy, in place of a clear definition, there appeared to be a set of stories being told about how personalisation has transformed the lives of service users, which together ‘constituted a narrative of public service reform’. Some observers point to policy documents such as *Putting People First* (England. HM Government, 2007) and *Independence, Well-being and Choice* (England. Department of Health, 2005) for a definition (Hamilton et al, 2016; Lymbery, 2014). While for Needham and Glasby (2014, p.4) personalisation is ‘broadly (and often poorly defined)’ but with two key mechanisms: direct payments and personal budgets. Pozzoli (2018b) describes personalisation as both a vision and a toolkit – the latter comprised of self-directed-support, direct payments, person-centred-planning and personal budgets. This thinking follows a similar line to that earlier advanced by Duffy (2010) who identified three meanings of personalisation as follows:

> 1. rhetorical – personalisation is sometimes used to describe a positive direction for public service reform;
> 2. technological – personalisation is sometimes used as a generic term for one or more of the specific technologies or practices that are referred to by advocates of personalisation; and

> 3. policy – personalisation is sometimes used to describe a set of government initiatives that are justified in terms of personalisation.
> (Duffy, 2010, p. 254)

The technologies that Duffy (2010) refers to include direct payments, self-directed support and individual budgets. Each of these technologies has its own definitions and characteristics which are important to grasp when formulating a more comprehensive understanding of personalisation.

Defining technical terms associated with social work practice in a policy context of personalisation.

I will now define and describe the key characteristics of some of those technical terms related to personalisation. This broad overview is intended to provide relevant background information and context for key concepts that are referred to in the findings and discussion chapters, in particular: direct payments, self-directed support, individual/personal budgets and person-centred planning.

Direct payments are cash payments in lieu of directly provided services, paid directly to the individual or someone acting on their behalf, that are available for individuals who have been assessed as being eligible for council-funded social care (Glasby and Littlechild, 2009; Wilson et al, 2011; TLAP, 2018a). Direct payments were formally introduced by the *Community Care (Direct Payments) Act 1996* and it, along with subsequent legislative developments pertaining to direct payments and more widely, have been succeeded by the *Care Act 2014* (England. Department of Health and

Social Care, 2016). Direct payments are intended to provide greater choice, control and flexibility to people using adult social care services. A key usage of direct payments, which is relevant to some participants in my study, is using them to recruit and directly employ care workers who are often referred to as Personal Assistants (PA’s). When using direct payments to employ staff in this way, social care service users become employers and must meet all responsibilities associated with being an employer. There are services available to support people to discharge these responsibilities and I managed one such service for a period when employed by a local authority. As a manager of a direct payments support service, I saw first-hand people benefitting from direct payments in terms of increased self-confidence and improved satisfaction with care and support arrangements.

As I outlined in the introductory chapter, the term self-directed support refers to the operating system for social care, pioneered by the organisation *In Control* (Williams and Tyson, 2010). According to Gardner (2011), notions of self-assessment, support planning and review are key characteristics of self-directed support. Self-directed support, as conceived and espoused by Duffy (1996; 2013; 2018) is concerned with rights, freedom, participation and citizenship and giving people as much control as possible over the help they need. Furthermore, self-directed support aims to do away with the Professional Gift Model of service delivery and is organised around a Citizenship Model in which citizens are in control of their own lives, are part of a community, have entitlements to support and shape the support they need (Duffy, 2018). Shaping the support needed includes up-front or an early indication of entitlement to a personal budget. Indeed, finding out how much money someone is entitled to is the first of seven steps that *In Control* espouse as part of self-directed support, followed by making a plan, getting the plan agreed, organising the money, organising support, living life and seeing how it worked (In Control, 2011). Self-directed support was piloted alongside the existing social care system in my workplace when I was working as a social worker in adult social care. It is somewhat difficult to separate my experience of self-directed support from my later experience of personal budgets. Still, I do recollect being drawn to the principles of self-directed support, not least of all because the focus on citizenship accorded well with my rights-based approach to social work. However, self-directed support seemed to meet with some organisational barriers in my workplace quickly. For example, self-assessment was soon re-named supported self-assessment. The reasons given by managers of this change was that it better reflected the reality, which was that social workers were helping people to complete self-assessment forms and continued to have a crucial role in determining eligibility by validating (screening and approving) self-assessment forms.

A personal budget refers to money that is allocated to a person to meet assessed social care needs and can be taken as a direct payment, managed by a local authority or sometimes a mixture of the two (TLAP, 2018a). Personal budgets using social care funds were first called individual budgets and were developed by *In Control* (Glasby and Littlechild, 2009). Individual budgets came to refer to a single pot that included multiple funding streams, following Department of Health pilots (Glasby and Littlechild, 2009). Assessing eligibility for and reviewing personal budgets is a large part of social work practice in adult social care, now under the auspices of the Care Act 2014. *Care Act 2014* statutory guidance stipulates that the process and practice of personal budgets should follow the *In Control* principles of self-directed support (England. Department of Health and Social Care, 2018a). Social workers have a prominent role in the personal budget processes of assessment, resource allocation, support planning and review. This was certainly the case in the local authority in which I worked. However, practice is likely to vary across the country, with roles for unqualified (non-social work) staff and the voluntary sector, to a greater or lesser extent.

Notwithstanding the *Care Act 2014* statutory guidance, in my social work experience principles of self-directed support were not central to personal budget processes and systems. This is true for notions of self-assessment as outlined above, but also concerning the requirement to provide an up-front or early indication of entitlement to a personal budget. As with many local authorities, work was undertaken in my place of work to develop a Resource Allocation System (RAS) which is a system used to decide how much money people get for their support (TLAP, 2018a). This was a protracted and dispiriting process because in my experience the budget produced by the RAS was often lower than required or was changed or overturned by managers or a funding panel. Financial assessments for care charges would also impede the ability to provide an early indication of entitlement to a personal budget. In short, it was challenging to provide a clear indicative budget to service users in line with the principles of self-directed support, by virtue of organisational processes and systems.

Finally, person-centred planning is described as a process of ‘continual listening and learning; focused on what is important to someone now, and for the future’ (Sanderson, 2000, p. 2). It is associated with a broader set of person-centred approaches and the social inclusion movement, which is explored in more depth later in this chapter.

Independent living and the social model of disability

The movement for independent living and the social model of disability are precursors to and have been influential in, the development of personalisation and the models and technologies that pre-date it. Understanding personalisation in adult social care and the implications for social work practice requires that they are examined. Independent living is a philosophy associated with the disability rights movement and the social model of disability (Morris, 1991; Charlton, 1998). Wilson et al (2011, p.711) explain that independent living is based on the ‘principle that disabled people have control and choice over their own lives and are able to enjoy the same civil rights as non-disabled people’. The three basic principles of independent living are: ‘those who know best the needs of disabled people, and how to meet those needs, are disabled people; the needs of disabled people can best be met by comprehensive programmes which provide a variety of services; disabled people should be fully integrated into their community’ (Morris, 1998, p.172). The social model of disability, which originates from the UK, emerged from radical ideas first advanced by the Union of the Physically Impaired Against Segregation (UPIAS). UPIAS held that it is society that disables 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, quoted in Oliver, Sapey and Thomas, 2012, p.16). Since its inception, the social model of disability has steadily grown in popularity in both England and internationally and is considered to be a reaction to the dominant, pathologising medical model of disability (Oliver, 1996).

Notwithstanding its ubiquity, the social model of disability does have its detractors. Morris (1991) calls for reform of the model, critiquing its tendency to deny bodily experience and its insistence that all restrictions are socially created. Shakespeare (2006) is more strident in his criticism, questioning the dichotomy between impairment and disability and other fundamental tenets of the model, ultimately concluding the model is flawed. These polarised positions and the possibility that some painful aspects of disability might be denied suggest the need for a psychoanalytic approach of the kind that informs this thesis and the model that emerges from it in the concluding chapter.

In my professional experience, knowledge of the disability rights movement, and particularly awareness of the social model of disability, have been essential tools when working as a social work practitioner with disabled people. Despite the critiques noted above, the social model can provide a necessary rebalancing for people who have internalised profound experiences of oppression associated with society's, often unconscious, fear and hatred of disability (Dartington, 2010; Cooper and Lousada, 2005). Indeed, a similar view is shared by Morris (2014), who expresses concern that often disabled people have no knowledge of the history and principles of the movement for independent living and their experiences of personalisation, direct payments and personal budgets are at the hands of professionals whose practice is not based on principles of independent living but rather determined more by bureaucratic procedures. While the movement for independent living and the social model of disability have been influential in the development of personalisation, they are not the only influences. The social inclusion movement is, for example, another important influence that merits examination. However, before examining this I will further explore complexities associated with the notion of independence in the area of personalisation and social care more widely.

Dependency and independence

The meaning and goals associated with the pursuit of independence are somewhat more ambiguous than the rights-based philosophy of the movement for independent living as articulated above. Independent living and independence are often conflated and confused in adult social care, social work and personalisation policy discourse. Indeed, this issue coming into contact with the realities of lived experience is apparent in my findings as set out in Chapter 4. Wilson et al (2011, p.520) situate independence as a policy objective within a wider context of contemporary social policy and note ‘the interaction of the themes of independence, dependence and interdependence are not fully worked out [in social care policy]...’ and identify ‘a lack of reality’ concerning the policy. Similarly, Ferguson (2012, p.57) argues that there is a ‘very shallow and debased understanding of dependence and independence that lies at the heart of some influential versions of personalisation’, particularly an individual rights model. In short, it is essential to understand that the pursuit of independence can be markedly different from the pursuit of independent living as first conceptualised by the American Independent Living Movement (ILM) and subsequently adopted by UK-based disability activists (Barnes, 2012). Perhaps there is awareness of the potential for the concept to be misunderstood and misused, as definitions of independent living sometimes explicitly seek to ground the notion in reality. Dickenson and Glasby (2010, p.8), for example, assert that independent living ‘does not mean doing everything yourself – in practice, no one is truly independent, and we are all interdependent on others to meet our needs as human beings’. Not only does the literature support my aforementioned contention that independent living and independence are often conflated and confused in adult social care, social work and personalisation policy discourse, so too do the findings of my research which are set out and explored in Chapters 4 and 5.

Recognising more realistic notions of independence and the concept of interdependence are crucial elements of the model that emerges from my research that is featured in Chapter 6.

Dartington (2010, pp.41 - 45) provides an illuminating critique of independence and an ‘associated unconscious denigration of dependency’ and cites Bion, who asserted that ‘man is a dependent creature no matter how autonomous he becomes’ (Bion, no date, cited in Dartington, 2010, p.41). Similarly, Cooper and Lousada (2005, p.194) observe that we (as individuals and society) fear being enslaved, drained and depleted if we ‘allow real contact with a deprived, dependent, helpless population’. It would seem important to hold in mind the potential that there may be an unconscious denigration of dependency when independence and self-reliance are held to be the stated goals of social work in adult social care, issues that might be amplified by personalisation policy. Some empirical studies have explored these notions within social work practice settings. For example, Foster (2010), using an observational and psychosocial interview methodology, found that fear of dependency was apparent in the social work teams included in her study about self-directed support. This, and other factors, she argues, functioned to curtail the necessary creativity required for the successful implementation of self-directed support. So too, Sowerby (2010) concludes from his study the necessity for relationship-based social work, including the place of therapeutic dependency, within a self-directed support model of personalisation. Also, Holloway and Fryson (2015) in their critique of personalisation and social work practice with people with Acquired Brain Injury (ABI) via the use of composite case studies, determinedly challenge what they characterise as simplistic notions of autonomy associated with personalisation that run counter to their practice-based knowledge of

ABI. Notwithstanding some apparent misconceptions about the social work role within a self-directed support model, the authors do appear to be drawing attention to the dependency needs of people with ABI and issuing a plea for these needs to be recognised.

Social inclusion movement

The social inclusion movement has its roots in theories of normalisation and social role valorisation and is concerned with countering social devaluation and enabling people to have valued roles in the community (Wolfensberger, 1972; Wolfensberger, 1983; O'Brien and Lyle O'Brien, 1998). According to Flynn and Lemay (1999, p.3), principles of normalisation and social role valorisation have been of central importance in shaping human service policies and practices around the world and in the UK, and have 'brought about an enormous change in services, particularly for people with developmental disabilities'. Indeed, the two concepts are inextricably linked, as Wolfensberger (1983, p.234) proposed that normalisation be called social role valorisation, asserting that the 'highest goal of the principle of normalisation has recently been clarified to be the establishment, enhancement, or defence of the social role(s) of a person or group…'. The social inclusion movement gained traction and a higher profile as social care policy shifted from institutional care for people with learning disabilities, mainly through the closure of long-stay hospitals, to more inclusive approaches (Gardner, 2011). Keilty and Woodley (2013, p.93) provide a vivid and moving account of the experiences of survivors of one such institution, Prudhoe Hospital, underlining the horrors and injustices of institutionalisation by asserting in their conclusion that there is 'no going back'.

The principles of normalisation and social role valorisation are the antecedents of more contemporary person-centred practices (Sanderson, 2000; O'Brien, 2013), which I am familiar with from my work as a social worker in a learning disabilities team in a local authority. According to Gardner (2011), such person-centred approaches have had a significant impact on the development of personalisation. Person-centred planning was formally adopted as government policy in England via the Department of Health (2001) white paper *Valuing People,* and an explicit objective was included in the *Putting People First* concordat that stipulated 'Person-centred planning and self-directed support [are] to become mainstream…' (England. HM Government, 2007, p.3). O'Brien (2013) provides some evocative reflections about the potential of person-centred planning processes to impact all involved in them.

> Gathering to affirm a person in their interdependence awakens those engaged to their mutual presence, wonder and plight. This collective awakening demands and guides action as people make time to facilitate expressions of higher purpose, recognize possibilities and coordinate commitments to move toward a better community future (O'Brien, 2013, p.1).

O'Brien's (2013) emphasis on interdependence outlined here in his conception of person-centred planning is notable because it is both uncommon and accords with the lived experience of my research participants, as I will demonstrate in the findings chapter.

Personalisation and social work practice

The values and ethics of contemporary social work practice are rooted in notions of social justice, human rights and anti-oppressive practice (Banks, 2012; Dominelli, 2002; Thompson, 2016). Indeed, the global definition of the social work profession states that ‘Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work’ (British Association of Social Workers, 2014, p.5). Furthermore, the BASW code of ethics includes several principles that align with the key tenets of personalisation and self-directed support, including: ‘upholding and promoting human dignity and well-being’; ‘respecting the right to self-determination’; ‘promoting the right to participation’ and ‘treating each person as a whole’ and ‘identifying and developing strengths’ (BASW, 2014, p.7). Such principles accord with human rights, notably with the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006).

For Duffy (2010), the congruence between the social justice ideals embraced by social work and personalisation is clear.

> The technologies of personalisation simply are social work, social work in action; for what is social work if it is not the effort to develop, share and implement practices that promote social justice for people whose citizenship is threatened? (Duffy, 2010, p.265)

Principles of dignity, self-determination and human rights are central to personalisation, at least conceptions of personalisation based upon a self-directed support model. There are, however, some challenges and tensions associated with personalisation, self-directed support and social work. As I will set out in more detail in my methodology chapter, it is my view, informed by my practice experiences as a social worker with adults and as a doctoral researcher, that a focus on the lived experiences of service users provides a vehicle to navigate and address these issues.

There have been some concerns expressed about the role and place of social work within personalisation. Lymbery (2014) argues that the role of social work in personalisation was never made explicit and indeed was over-generalised and unspecific, with much made of the potential under self-directed support for service user self-assessment to free up social work time spent on assessment, and allow a greater focus on support, brokerage, advocacy, early intervention, social inclusion and safeguarding. Furthermore, he points out that despite promises of a ‘rosy future’ for social work within personalisation from some government bodies, the realities of practice are that the numbers of social workers are being rapidly reduced and social work roles are being increasingly restricted and eroded (Lymbery, 2014). Furthermore, he argues that the ‘failure to locate social work as central to personalisation’ is associated with interrelated factors, namely the state-mediated, politically-dominated nature of the profession, austerity and managerialism, leading to a rupturing of what he calls the ‘bureau-professional compact’, in which professional autonomy has been ceded in exchange for job security (ibid, p. 802). There are similar questions about the role of social work in the National Disability Insurance Scheme (NDIS), a large-scale personalisation scheme, in Australia. Brophy et al (2015) contend that while the intersections between personalisation, recovery and social work are well identified in theory and practice, the role of social workers within the NDIS remains unclear.

Balancing risk and the choice and control central to self-directed support is another tension that can be a challenge for social workers. Carr (2008) argues that:

> ‘Positive risk-taking’ or ‘risk enablement’ is central to the philosophy behind self-directed support and personal budgets, but social care practitioners can be concerned about how to both empower the individual and fulfil their duty of care (Carr, 2008, p. vi).

Stevens et al (2016) carried out research in three local authority adult social care departments in England, which explored links between adult safeguarding and personalisation. Consistent with Carr (2008), findings included how social work practitioners described a tension between policy objectives, for example increasing the uptake of direct payments, and their exercise of discretion to assess and manage risks (Stevens et al, 2016).

Risk-averse practice is not unique to the area of self-directed support, direct payments or personal budgets, but rather characterises contemporary social work practice with both adults and children and families. Indeed, according to the seminal *Demos* child protection pamphlet on risk, The Risk Factor (Cooper, Hetherington and Katz, 2003, p.23), there has been ‘widespread growth of a culture of risk-aversion in the welfare state and society at large; that has resulted in an institutionalised social preoccupation with performance monitoring, quality assurance and the centralised policy control of professional standards and behaviour’. This cultural context is important in understanding what might at first appear to be practice-level barriers to the successful implementation of personalisation. The need to balance safeguarding and personalisation is liable to organisational and professional anxieties associated with the culture of risk aversion that Cooper, Hetherington and Katz (2003) assert now permeates the welfare state and society at large. As a social worker in local government, my professional autonomy was regularly curtailed, if not undermined, by onerous financial monitoring of direct payments and restrictions on the usage of personal budgets imposed at an organisational level that might be understood as manifestations of a culture of risk aversion.

Since the advent of personal budgets in adult social care, social workers have raised concerns about increased bureaucracy and paperwork. In a special report in Community Care (2011, p.4), the trade magazine for the social care industry, it was reported that social workers are losing faith in personalisation, leading with the headline: ‘In 2009, 67% of you thought personal budgets would benefit service users, last year it was 51%, now it's 41%’. The report revealed that growing numbers of social workers felt that personalisation was impeding their ability to support service users, had increased paperwork and it was reported that there were growing concerns over the extent to which service users had genuine choice and control (Community Care, 2011, p.5). The views of social workers outlined here appear to mirror some of the experiences of service users about their experiences of personal budgets, detailed in evaluative research and national surveys, explored later in this chapter. Slasberg, Beresford and Schofield (2012) attribute such issues to the self-directed support approach to personal budgets, claiming it has been a costly distraction that is having a negative impact at a practice level.

> We concluded our first article with the view that self-directed support was failing to deliver either personal budgets or

> personalisation… However, it is even more serious than that as it is becoming evident that it is causing significant damage. This is not only in terms of wasted resources through the growth in a bureaucracy that has no value, but also in terms of driving further wedges between practitioners and service users (Slasberg, Beresford and Schofield, 2012, p.103).

Such strident criticism appears to fail to consider the impact of other influences, not least of all the aforementioned culture of risk aversion in adult social care (Cooper, Hetherington and Katz, 2003). Furthermore, the extent to which a self-directed support model might result in increased bureaucracy and paperwork over and above other models and approaches that fall within the personalisation umbrella is debatable. It seems erroneous to single out and condemn self-directed support, not least of all because it is an approach rooted in principles of social justice and citizenship that so closely accords with the values and ethics of social work. This is an example of where the importance of disentangling self-directed support, personal budgets and personalisation is necessary so that the actual issues can be more clearly identified.

There have been concerns about what is happening in relation to personal budgets for service users and social workers alike. Wilberforce et al (2014) found high levels of stress among social workers involved in delivering individual budgets (referred to as individual budgets in the study) in the English individual budget pilot sites. In fact, social workers were twice as likely to be at risk of stress compared to those with no people with personal budgets on their caseload (Wilberforce et al, 2014). While personal budgets and the bureaucracy and paperwork associated with them can be a source of stress for social workers, some studies identified positive experiences of personalisation, including social work practice within a self-directed support model. Williams and Tyson (2010), for example, investigated the impact of self-directed support on social work practitioners by facilitating a one-day workshop using person-centred planning tools. Among other findings, self-directed support had enabled participants to 'do "real social work", reconnecting with the values and practice which were obscured by care management' (Williams and Tyson, 2010, p.319). The methodological approach taken in this study is novel and appears to give voice to some important social work practitioner experiences. The principles and approach of self-directed support would appear to be much more strongly evident in this study and this raises questions about the extent to which self-directed support might be more congruent with social work and acceptable to social work practitioners compared to models of individual and personal budgets which are less firmly anchored in self-directed support. Related to this, it suggests a need to distinguish between genuine models of self-directed support and those that falsely purport to be so. My own experience as a social worker was characterised by encounters with both versions of self-directed support.

Personalisation – evaluative studies

There is a sizeable body of grey literature about personalisation that has focused on measuring and improving the effectiveness of the technologies that have come to be associated with it. In England, this includes studies about self-directed support, individual/personal budgets and direct payments. Glasby (2014) observes the notable extent to which evidence is variously invoked, demanded or derided, by proponents and critics of personalisation alike. It is perhaps not surprising that personalisation appears to have been subject to the same trend observed to have taken place across social work research more widely, namely what Ruch and Julkunen (2016, p.16) describe as a ‘government-led, evidence-based practice movement… [with an] emphasis on narrow definitions of research evidence and a preoccupation with determining “what works” in practice from a positivistic epistemological perspective’. Given that much of the evaluative research claims to represent service users’ experiences of direct payments, personal budgets and self-directed support, and has been drawn upon to develop and extend personalisation as a policy in adult social care, it merits some examination.

One high profile and large scale study, led by the Individual Budgets Evaluation Network (IBSEN), has been particularly influential in shaping the development of individual budgets and later, personal budgets (Glendinning et al, 2008). The study was an evaluation, using a randomised controlled trial (RCT) research design, of individual budgets that were piloted in thirteen local authorities across England between 2005 and 2007 (Tisdall, 2011). Being an RCT, widely considered gold standard or superior to other types of research by the evidence-based practice movement, is the likely reason why this study gained such a high profile and influence. Besides being an RCT, the IBSEN study had many features which indicate a robust and ethical research design, including a service user and carer advisory group, albeit infrequently convened in my view for a seemingly well-funded and resourced study of such a considerable scale. The study found that individual budgets were generally welcomed by service users because they offered more choice and control over support arrangements than conventional social care arrangements. There were some variations in outcomes, with highest satisfaction amongst mental health service users and physically disabled working-age people, and lowest amongst older people (Tisdall, 2011). While the study identifies these variations in outcomes, it offers little to aide an understanding of why they manifested.

Findings from the IBSEN studies presage enduring debates about the efficacy of personalisation for all user groups, not least of older people, whom West and Needham (2017) characterise as the ‘unexceptional exception’. This might be understood as an issue of generalisability but also could relate to the possibility of defences against anxiety being at play. An apparent inability by policy-makers and sector leaders to appropriately perceive and digest some painful realities about the limitations of what personalisation can achieve in adult social care is suggestive of defences against anxiety (Menzies-Lyth, 1960). This is something that I will consider in more depth in the discussion chapter. Finally, the study identified bureaucratic, organisational and cultural challenges for staff associated with implementing individual budgets as well as legal and accountability barriers associated with integrating resources, such as those with different NHS and local authority funding streams (Glendinning et al, 2008). The parallels here with the contemporary trends is striking, not least of all the focus on changing staffing practices via strengths-based practice approaches.

Evaluations of direct payments attest to high satisfaction rates compared to conventional services, particularly in relation to having choice and control over support and reliability of support (Zarb and Nadash, 1994; Spandler, 2004; Witcher et al, 2000). Despite these positive outcomes, direct payments uptake in social care, in general, remains low (NAOb, 2018). Also, consistent with the findings noted above regarding lower satisfaction of individual budgets among older people (Tisdall, 2011), there are differences in uptake of direct payments among different service user groups with approximately 24 per cent of younger people with a disability receiving a direct payment compared to 10 per cent of older people (West and Needham, 2017).

Some studies focused on self-directed support have been widely cited and were influential in the development of individual and personal budgets (Poll et al, 2006; Poll and Duffy, 2008; Tyson et al, 2010). Such studies were published by *In Control* and were focused on the impact of self-directed support, over three phases spanning 2003 to 2009 (Glasby, 2014). Poll et al (2006) describe the first phase in which six local authorities piloted self-directed support focused on people with learning disabilities and cautiously conclude that the pilot project had been associated with important improvements in participants' lives. This and other positive conclusions are cautiously drawn by the authors owing to the small sample size and the difference between learning from a pilot and a formal evaluation of an intervention which might be expected from traditional research design (Poll et al, 2006). The subsequent *In Control* studies draw on progressively larger samples, and Tyson et al (2010) present aggregated findings from phase two and three, which included the following:

> More than two-thirds of people using Personal Budgets reported that the control they had over their support (66%) and their overall quality of life (68%) had improved since they took up a Personal Budget. A majority reported spending more time with people they wanted to (58%), taking a more active role in their local community (58%), feeling that they were supported with more dignity (55%), and feeling in better health (51%) since they took up a Personal Budget (Tyson et al, 2010, p. 140).

While the findings are positive, Tisdall (2011) highlights that the data is not subdivided into service user groups and it is, therefore, difficult to identify different experiences which would appear important given the different outcomes for some groups of service users highlighted earlier.

The Personal Outcomes Evaluation Tool (POET) is an influential annual survey developed by *In Control* and the *Centre for Disability Research* at Lancaster University that measures the experiences of people receiving personalised care and support via personal budgets (In Control, 2017). Some commentators, notably, Slasberg, Beresford and Schofield (2013), question the reliability of the survey findings for various reasons, including the size and nature of the sample, and survey design. Indeed, Beresford (2009; 2012) and Slasberg, Beresford and Schofield (2012; 2013), have long raised concerns about the evidence base underpinning personalisation, and specifically in relation to personal budgets. While compelling, it is important to understand that such concerns about the evidence base underpinning personalisation form part of a wider and sustained critique of the contemporary adult social care system, particularly the relationship between needs and resources, what they call the 'eligibility question' (Slasberg and Beresford, 2016, p.969).

Annual findings, commencing with the first published POET survey report in 2011, typically find that service users report positive experiences associated with having a personal budget, and unsatisfactory experiences of the process (In Control, 2011; In Control, 2017). While never explicit, such findings and associated calls to focus on the need to change the practice of social workers for the policy of personalisation to work, currently expressed under the guise of strengths-based practice, to my mind reveal the fault lines that Briggs (2005) identifies in relation to social work research. This includes the predominance of research produced by policy, and the dearth emerging from social work practice, associated with a split between policy-makers, practitioners and researchers. Perhaps too, the wedge between professional experience and research, a limitation Briggs (2005) associates with evidence-based practice, is revealed. Indeed, the body of evaluative research appears to highlight the gap between the policy and practice of personalisation. In my view the body of evaluative research associated with personalisation, in which surveys and questionnaires using Likert scales to measure outcomes and satisfaction predominate, does not adequately capture the detail and complexities of service users' experience. Glasby (2014, p.263) affirms the importance of service users' lived experiences of direct payments and personal budgets, which he suggests should be reframed as 'human testimony' and not dismissed as anecdotal evidence. As I will set out in more detail in my methodology chapter, it is my view, informed by my practice experiences as a social worker with adults and as a doctoral researcher, that a focus on the lived experiences of service users provides the vehicle that addresses these issues.

Learning from lived experience

One might expect that there would be a wealth of user-led or service user-focused research, focused on the lived experience of adult social care and social work in a policy context of personalisation of the kind called for by influential commentators (Hunt, 1981; Oliver, 1990; Morris, 1991; Beresford and Carr, 2012). Yet, besides the evaluative studies and surveys explored above, there are few published studies which include or reveal the lived experiences and views of service users. This may reflect structural barriers associated with the evidence-based practice movement, which curtail or fail to recognise participatory, emancipatory and service user-led approaches to research. I explore here some notable examples that I have however identified. Tew et al (2015) undertook in-depth interviews with 53 participants as part of a national study about the implementation of personal budgets in mental health. The central importance of service user views and experiences from different service user groups, in this case mental health, is demonstrated by this study. Findings include the importance of co-production and peer-support processes being key to personal budgets supporting positive outcomes for people with mental health conditions, and that resource allocation needs to take account of fluctuating needs (Tew et al, 2015). Similarly, drawing on service user accounts of personalisation in mental health services, as part of a national study about the implementation of personal budgets in mental health, Hamilton et al (2016, pp.719-720) found that ‘a key factor enabling personal budgets to support empowerment and recovery was reported to be the quality and continuity of the professional relationship’. Such findings appear to support the need for social work relationship-based practice approaches (Ruch, Turney and Ward, 2018; Hennessey, 2011; Megele, 2015). The views of service users are central to the findings presented in both these studies.

Brophy et al (2015) conducted a study in Australia with 41 people about individualised funding packages in anticipation of the launch of the NDIS. They reported that a key finding was the value that participants placed on relationships with support workers and case managers [social workers]. One participant said:

> A caseworker, yeah… at the moment that’s what I think I really need… because I’m so much on my own and there’s no-one really I can open up to. You know, I would like to be able to have

> a full on conversation for at least once a week with somebody or
> once a fortnight. (Brophy et al, 2015, p.108)

Notwithstanding an important limitation that the authors identify, namely 'asking participants to anticipate choices they would make in an, as yet, unfamiliar system' (Brophy et al, 2015, p.113), the study is strengthened methodologically in my view because it is anchored in, and reflects, the reality of the lived experiences of service users. As I will set out in Chapter 3, I made similar efforts to ground my study in lived experience, in particular via the inclusion of a co-research group with Experts by Experience and the focus on the lived experiences of interview participants as core elements of my research design.

However, some studies purport to include the views of service users but exhibit problematic research design. For example, a scoping study by Brookes et al (2015) included a survey of local authorities along with interviews and focus groups with both staff and service users to explore the progress of the implementation of personalisation and to identify innovative practice. Their findings are presented, however, as high-level themes and local authority case studies, whereby it is not possible to separately discern the, possibly different, views of service user participants. In addition, a qualitative study using semi-structured in-depth interviews by Larkin (2014), focusing on the experiences of carers, found that personal budgets can improve the carer-service user relationship. In addition, findings in the study about carers' experiences of personal budgets appear to accord with the aforementioned findings of largely positive outcomes for service users reported in the POET survey and evaluative studies. A limitation of this study, however, is the lack of clarity of what is being compared with the current personal budget of participants and how many, if any, of the sample, took their personal budget as a direct payment.

Another prominent exception to the lack of service user focused or led research is the Standards We Expect Project by Glynn and Beresford et al (2008). It is a collaborative research project, based on a participatory methodology about person-centred support. Note that Beresford et al (2011) recast personalisation as person-centred support which they say is based on the ideas of person-centred planning and independent living; this adds, in my view, to the terminological confusion associated with personalisation. Nonetheless, this novel qualitative research involved 245 people, including over 100 service users, 39 relatives and carers and over 100 social care staff, of which nine were managers (Fleming et al, 2014). There are some interesting views captured in the original 2008 report. For example, in relation to choice and control, participants emphasised the importance of 'being in charge of your life; being able to change your support if it does not work out for you; having support to make decisions; having the chance to learn about making decisions' (Glynn and Beresford et al, 2008, p.15). I highlight this example here because it is quite a nuanced take on choice that emphasises support to exercise choice and control in a manner and to an extent that is not generally reflected in personalisation discourse and policy guidance. It suggests that the project's collaborative methodology generated complex findings relating to key aspects and experiences of personalisation. A similar engagement with complexity is evident in the account from Sowerby (2010), based on his discussions with people with learning disabilities about their understanding and experiences of personalisation. Sowerby observes:

> A consistent message was that Personalisation/self-directed support (SDS) did not feel very real. It was all taking too long, which resonated with their experience with (and disappointment about) direct payments. Some reported their family carer's view that it was all taking a long time to get sorted. I did not find any coherent understanding of Personalisation/SDS. (Sowerby, 2010, p.273)

The literature review suggests that when research includes the views and experiences of service users, findings appear to be more nuanced and grounded in the realities of lived experience. This discovery informed my methodological decision to place lived experience of service users and collaboration with Experts by Experience at the centre of my research design. I will provide a full description of my research design and further justification of my methodology in the next chapter.

Furthermore, the literature review combined with the findings that emerge from my research led me to the discovery of some limitations in current models of social work practice and the need for a new relationship-based practice model for social work in a policy context of personalisation. The literature suggests there is much in common between the values and ethics of social work and self-directed support, but there appears to be a lack of integration between relationship-based practice and self-directed support approaches. The literature review and my findings suggest that integration of the two approaches might provide a model of social work practice that better reflects the needs and priorities of people with lived experiences of adult social care. Relationship-based practice approaches provide conceptual tools for understanding and responding to the complexities of dependence and independence and defences against anxiety that social workers in adult social care must face. Self-directed support provides a framework for social work practice that focuses on rights-based, participatory, citizenship-focused practice in adult social care. A model of social work practice that seeks to integrate such approaches is proposed in Chapter 6.

Chapter summary

In this chapter, I have explored the existing literature about adult social care and social work in a policy context of personalisation. A range of literature has been examined, including peer-reviewed journal articles, published studies, evaluative studies, scholarly texts and grey literature. I have highlighted what the literature reveals about service user views and experiences in particular and provided descriptions of the technical terms associated with personalisation that are explored in the findings and discussion chapters. The current social care system is revealed as a Professional Gift Model in which social work in a policy context of personalisation is taking place. Findings from evaluative research, where personal budgets and service user experiences of them are taken to be a measure of personalisation, in general, indicate that service users welcome notions of choice and control associated with personalisation. There are some variations in the evaluative research literature, namely the extent to which positive outcomes are generalisable across all service user groups. The literature suggests that social work and personalisation share a common value base when personalisation follows the tenets of self-directed support. There are however tensions for social workers associated with balancing the requirement to support autonomy and the duty to safeguard and protect. Organisational and practitioner anxiety associated with dependency and associated concerns about unrealistic notions of independence in adult social care emerge as themes from the literature. In addition, there appears to be a correlation across the available literature between unsatisfactory experiences of the processes associated with a personal budget and messages emanating from front line social work practice about increased bureaucracy and paperwork.

Overall, a review of the literature suggests that there is a lack of research which includes service users' views and experiences, and certainly few studies that can claim to have a participatory or transformative research design. Where service user views and experiences are sought and included, findings appear richer and provide a more accurate account of the realities of lived experiences of adult social care and social work in a policy context of personalisation. My literature review has yielded no examples of where a combined psychosocial and participatory approach has been taken to research adult social care and social work in a policy context of personalisation.

Finally, the literature reveals that there is much in common between the core values and ethics of social work and self-directed support. Relationship-based practice provides some conceptual tools for managing complexity pertaining to dependence and independence in adult social care, however there is a lack of integration between relationship-based social work and self-directed support approaches. There appears to be much in common between the approaches, along with some important features of each that has the potential to strengthen social work practice if better aligned.

Chapter 3: Methodology

Introduction

In Chapter 1 I outlined how my professional experiences of social work and adult social care in a policy context of personalisation underpin my motivation for this study. Using my own professional experiences as a starting point, I wanted to bring greater clarity to the subject of personalisation and to understand and make sense of some of the tensions and contradictions I was encountering in my work as a social worker in adult social care. My initial thoughts were that the best way to go about this was to learn from lived experiences of service users. Therefore, I decided that I needed to identify research methods that could assist in realising this objective. In this chapter, I will set out my journey in terms of methodology and how and why I developed the methodological framework that has informed and guided the research. Details of the methodological foundations of the research, the data collection and data analysis methods used, and the theoretical justification for selecting such methods from the many available is set out in this chapter.

My research design, a multi-method qualitative approach comprised of two principal elements shall be outlined: a reflective learning group with Experts by Experience, the PRLG (Personalisation Reflection and Learning Group), and semi-structured psycho-social interviews with service users of adult social care. Throughout this chapter, I intend to consider matters of researcher positionality and reflexivity concerning the methodology and research methods utilised. This is consistent with psycho-social approaches (Clarke and Hoggett, 2009; Wengraf and Chamberlayne, 2006; Wengraf 2008; Hollway and Jefferson, 2013). Furthermore, in line with the psycho-social nature of this study, I will highlight my lived experiences of the methodology, including as a defended researcher (Hollway and Jefferson, 2013) throughout this chapter. So too, I explore ethical issues inherent in research with human subjects and in particular service users of adult social care, both in a general sense and with particular reference to my experiences undertaking this research. I set out the ethical frameworks that have guided and informed this research. Finally, attention is given to issues of sampling, validity and generalisability of the findings.

Summary of the research methodology

My doctoral research is a multi-method psycho-social participatory study. The two main research methods comprised a participatory reflective learning group with Experts by Experience and semi-structured psycho-social interviews with service users of adult social care. It is important to highlight that I adopted a double-interview approach, sequenced to allow a meeting of the PRLG to take place between the first and second interview. I consider the research design to be novel because psycho-social and participatory research methods originate from different qualitative traditions and are not typically combined. In this regard, I adopted a stance analogous to that of a ‘qualitative-researcher-as-bricoleur’, as outlined in Chapter 1, and was prepared to make use of and deploy the materials/methodologies at hand in a purposeful manner and, if required, invent new ones (Denzin and Lincoln, 2011, p.4). Throughout the research journey I also recorded my observations and reflections in a research journal. These research components yielded three separate data sets. These methods were adopted to enhance the validity of the results by allowing for complementarity (Greene et al, 2008, cited in David and Sutton, 2011). The diagram below, Figure 1, provides a visual representation of the research design and emphases the relationship between the three components. The point at which they intersect is the position that I occupied as a researcher, a position from which I was able to make links and integrate the perspectives and learning from each component. Later in this chapter, I shall describe in greater detail the individual components of the research design.

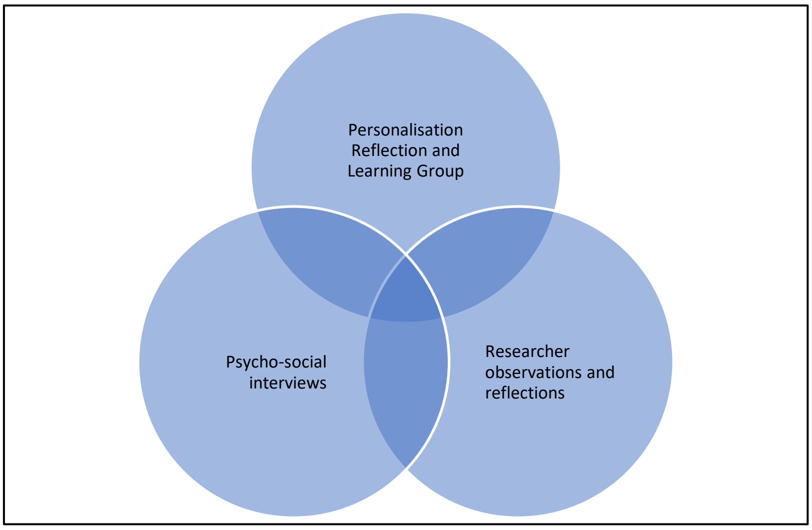


Figure 1 Research design

The development of my methodological framework

Several personal and professional influences contributed to the methodological framework that underpins this study. My post-qualifying professional experiences as a social worker in adult social care led me to seek out theories and approaches beyond those that were taught as part of my qualifying degree that could help me to best support service users. Like many social workers, I was also seeking theoretical concepts and tools to help build my professional resilience. Bower (2005, p.3) notes that ‘there is a hole in the middle of social work where a comprehensive, coherent model of human personality and emotional development should be’ and asserts that ‘[p]sychoanalysis covers a wide area of human experience; it also has well-researched interventions in the areas of human behaviour which concern social work’. The hole that Bower posits is one that I recognise. In my practice as a social worker in adult social care I often felt ill-equipped to make sense of and bear many strong emotions, others and my own, that I encountered when working with service users of adult social care. My post-qualifying training at the Tavistock Centre and the psychoanalytic theories and techniques that I learnt strongly influenced my decision to undertake a psycho-social study. Psychoanalytic concepts, theories and principles informing psycho-social approaches, including this study, comprise Freudian notions of the unconscious and repression (Freud, 1900, 1915); Kleinian theory in relation to anxiety and psychic pain, mechanisms of defence and projective identification (Klein, 1988a, 1988b); and notions of transference and countertransference (Heimann, 1950). Also, my personal experience as a client of psychoanalytic psychotherapy, in which I came to appreciate its value in treating symptoms of anxiety and depression, informed the development of my methodological framework. I might, therefore, be regarded as having lived experience of the psychoanalytic theories used in my study, and psycho-social studies more generally. To be explicit, my position is that of a proponent of the utility and benefits of psychoanalytic concepts for individual therapy, professional practice and research, grounded in my own personal and professional experiences.

As outlined in Chapter 1, I began working as a statutory social worker in adult social care at the time when personalisation and individual budgets were being piloted. Like other social workers working in adult social care at the time, I received extensive training, policy and practice guidance about personalisation and personalised approaches in adult social care. Among other features, such guidance emphasised working in a manner consistent with principles of co-production and encouraged a shift in the power dynamics between professionals and service users (Carr, 2008; TLAP, 2018). While I was drawn to such notions, I was also somewhat apprehensive about the extent to which power could be shared more equally with service users within the current system of adult social care and curious about the tensions and challenges associated with such an approach.

Co-production recasts a service user as an Expert by Experience. For the purposes of my research, this is an important conceptual shift in terminology, which seeks to value lived experience and place this on a more equal footing with practitioners' practice-based experience. As was the case for many of my social work colleagues in 2007/2008, such principles resonated with my professional values and vision for how I wanted to practice social work. Principles of co-production thus became core to my social work practice. Co-production was also an approach that I championed in my later role as a project manager for a personalisation transformational change programme in a local authority. Co-production was an approach that I valued as I had seen the transformative potential of it both for organisations and for service users. My observations were that my local authority benefitted from co-production in terms of better design and development of services by virtue of being more attuned to the needs and preferences of local people. I also observed that co-production positively impacted on the self-worth and confidence of service users. I also enjoyed working with people in a co-production framework; it was professionally rewarding. Carr's (2014) critique about the exclusion of people with lived experience in the development of personalisation policy that I encountered when undertaking a review of the literature, Chapter 2, was also influential in my determination to use co-production principles to include people with lived experience prominently in my research. When conceiving my research design, I was therefore committed to including research methods anchored in principles of co-production and this led me to explore participatory research methods.

Participatory research methods seek to address issues of participation and inclusion, in particular by strengthening the voice and autonomy of people defined as vulnerable (Aldridge, 2016, p.7). In this respect they may be regarded as transformative. Participatory research approaches have the potential to promote active involvement in research by those who, in other typical research processes, may be regarded simply as ‘objects of the research’ (Aldridge, 2016, p.8). However, not all kinds of participation are transformative. At worst, according to Arnstein (1969), participation can be an empty ritual from which others profit. This is also true of participatory approaches to research. Likewise, research *on* disabled people by non-disabled people has frequently been criticised as oppressive (Hunt, 1981; Oliver, 1990; Morris, 1991). Indeed, in developing my research proposal I was somewhat shocked to discover that an earlier research study in a residential institution for disabled people, later a book, undertaken by senior clinicians from the Tavistock Centre, *A Life Apart* (Miller and Gwynne, 1972) is often cited as an example of oppressive research on disabled people (Morris, 1991; Barnes and Mercer, 1997). Paul Hunt, a social model of disability advocate, founding member of Union for the Physically Impaired Against Segregation (UPIAS) and one of the residents of the institution, denounced the psychoanalytically orientated Tavistock researchers as ‘the parasite people’ (Hunt, 1981, p.37). I was keen to avoid being experienced as oppressive and possibly, parasitic, and this was one factor that informed my decision to include participatory approaches in my research design.

I came to the view that participatory, and transformative, research methods of Action Research and Cooperative Inquiry, align closely with the social work values and ethics of social justice and human rights (British Association of Social Workers, 2014). Reason (1994, p.1) defines Action Research as a participative process of inquiry in which 'people engage together to explore some significant aspect of their lives, to understand it better and to transform their action so as to meet their purposes more fully'. Action Research, therefore, involves people in a process of change and is a form of learning for those involved (Winter and Munn-Giddings, 2001, p.5). Co-operative Inquiry is a form of Action Research in which 'all participants work together in an inquiry group as co-researchers and co-subjects' (Heron and Reason, 2008, p.366). The assertion made by Heron (1999, p.340), the founder of Co-operative Inquiry, that '[t]o do research on people rather than with people is to treat them as less than people' resonated with me strongly and is analogous to the principle 'Nothing about us without us!' (Charlton, 1998, p.3). At the formative stages of my research I was determined that my approach would be informed, as much as possible, by the values, ethical stance and design methods espoused by such participatory approaches.

When my doctoral proposal was approved, the methodological approach outlined in this chapter, namely a multi-method psycho-social, participatory approach, was encouraged by the registration board. However, the board cautioned me of the difficulties and practical challenges associated with the inclusion of participatory methods in the research design. Likewise, my supervisors also harboured concerns about how the PRLG and involvement of Experts by Experience in the research design might present challenges in terms of remaining focused on the fulfilment of the academic requirements of the doctoral programme. I had to hold firm to my conviction that it was important to retain such features of my research design. As I will outline later in this chapter, there were indeed difficulties and challenges associated with these aspects of my research design, and my study may have been less taxing and emotionally demanding had I opted for a simpler, more conventional psycho-social approach. However, what I hope will become apparent to the reader in subsequent chapters is the value that the PRLG, in particular, added to the study.

As indicated earlier, I settled on a multi-method research design that brings together psycho-social and participatory approaches. While my research design differs markedly from standard Cooperative Inquiry or Action Research methods I have incorporated aspects of them, and their emancipatory values, into my approach. In later chapters I will explore the limitations of my approach, and the extent to which my research design meets the transformative ideals to which I aspired. Nonetheless, at this juncture, it can be noted that the influence of participatory methodologies in the research design is evident by both the inclusion of and prominence afforded to, a reflective learning group with Experts by Experience in the study.

Finally, it bears highlighting that as a social work practitioner undertaking a professional doctorate with a focus on practice, I considered that it was important that the methodological framework underpinning the study was theoretically and ethically congruent with anti-oppressive and reflexive approaches to social work practice (Banks, 2012; Dominelli, 2002; Thompson, 2016). Anti-oppressive and anti-discriminatory approaches to social work practice ‘stress the need to engage service users on the basis of their position in personal and political power dynamics that may disadvantage, marginalise and oppress them’ (Wilson et al, 2011, p.708). Principles of reflexivity and ability to be critically self-reflective and to identify personal biases are a core feature of contemporary social work practice, particularly relationship-based approaches (Ruch, Turney and Ward, 2018; Wilson et al, 2011) and critical social work practice (Adams, Dominelli and Payne, 2009). In relation to research, reflexivity places a focus on the relationship *between* the researcher and the research subjects and emphasises that the researcher is an ‘integral part of the research process, not separate from it’ (Coghlan and Brannick, 2010, p.42). In developing my research design I concluded that such requirements would be satisfied by the adoption of a psycho-social approach, as they place a similar emphasis on inter-subjective processes, as I will go on to explore later in this chapter.

Methodological foundations: A qualitative study

As outlined above, my research utilises a combination of qualitative psycho-social and participatory research methods. The details of how such methods were applied are outlined in depth later in this chapter. Here, I will set out a justification for such a methodology. Qualitative and quantitative research methods hold very different assumptions about the role of researchers and how research should be conducted. At times such debates are so heated and polarised that they are described as the paradigm wars (Bryman, 2008). As a practitioner-researcher, at times I found it difficult to navigate my own path through these complex and fraught methodological debates. I drew on social work values and ethics (BASW, 2014) and my practice experiences to help guide me. I noted that quantitative research methods are typically associated with a positivist ontology, which comes from the natural sciences and privileges objectivity (Kara, 2017, p.43). I decided that a positivist research paradigm and its associated quantitative methods for the collection of data which can be counted and put on a numerical scale (David and Sutton, 2011, p.82), would not be the best approach for me as a social worker to gather data focused on subjective lived experience. From its inception, the notion of lived experience has been central to my doctoral research. Indeed, it features in the title I have given to this thesis. According to Adams and Manen (2008 cited in Given, 2008. p. 616), the term lived experience derives from the German *Erlebris* – 'experience as we live through it and recognise it as a particular type of experience'. Boylorn (2008 cited in Given, 2008, p.489) conceptualises the exploration of lived experience in qualitative research as 'a representation and understanding of a researcher or research subject's human experiences, choices, and options and how those factors influence one's perception of knowledge'. An examination of lived experience therefore suggests the need for a qualitative approach, though the topic of examination in this study may well benefit from additional research concerned with quantitative data.

The stance that I adopted is based on the proposition that there is a theoretical and philosophical affinity between qualitative methodologies and social work (Shaw and Gould, 2002). Furthermore, qualitative research focuses on the experiences of people and stresses their uniqueness in a similar way to which personalisation is premised upon the notion of individual uniqueness and preferences. In this regard, the important community development principle of the 'integrity of the process', whereby the process itself must reflect the outcome sought, which has guided my practice as a social worker since qualifying, is instructive (Ife, 2002, p.122). My stance is that a research project focused on adult social care, social work and personalisation could only be undertaken with integrity by utilising qualitative methods which, at the very least, have the potential to take account of and recognise the uniqueness and complexity of individual experience. While the methodological frameworks and methods informing my research place it squarely in the qualitative camp, I think sensible the notion advanced by Bryman (1988) that qualitative and quantitative approaches should be understood as part of a spectrum, rather than divergent. In this regard I think it bears highlighting that some studies that use quantitative methods have been gathered and appraised and form an important part of my literature review chapter, for example Tisdall (2011) and Tyson et al (2010).

A psycho-social methodology

Psycho-social studies is considered a new paradigm of cross-disciplinary scholarship situated at the juncture where psychological and social theory intersect (Clarke and Hoggett, 2009, p.1). The notion of using psychoanalytic concepts and principles to research beneath the surface, and in doing so considering 'unconscious communications, dynamics, and defences that exist in the research environment' is a key tenet of psycho-social studies (Clarke and Hoggett, 2009, p.2). In common with the approach of psycho-social studies, my study sought to make use of psychoanalytic concepts and principles to explore experiences of social care and social work in a policy context of personalisation. Indeed, one of my subsidiary research questions is focused on exploring the connections and tensions, conscious and unconscious, between the lived experience of adult social care service users, social work practice and the concepts of independence, choice and other key tenets of personalisation policy.

My psycho-social study has the features of 'intensive reflexivity' and a focus on 'emotional and relational processes' which are defining characteristics of practice-near research (Froggett and Briggs, 2012, p.1). As Cooper (2009, p.432) highlights, practice-near research of this kind can be deeply affecting and intense and requires methodologies ‘that can help us with the intensity and epistemological uncertainties that arise from such research encounters’. Grounding the research design in principles of psychoanalysis, as previously outlined, seemed to be necessary to make sense of the strong feelings that would inevitably be evoked in me, as the researcher, undertaking practice-near research of this kind.

My study draws heavily on the approaches, principles and learning outlined by Hollway and Jefferson (2013) whose psycho-social research, which focused initially on fear of crime, has been developed into an influential qualitative research method. Multiple practice-near studies have drawn on the approach of Hollway and Jefferson (2013) in an effort to get close to the social and emotional complexities of service user and practitioner experience, notably Boyle, Kernohan, and Rush (2009), Gregor, Hingley-Jones, and Davidson (2015) and Guest (2012). In common with these researchers I too have adopted the method to examine the social and emotional complexities of service user and practitioner experiences, focused on adult social care and social work in a policy context of personalisation. What makes my study different is combining the approach with participatory research methods. No psycho-social study of which I am aware includes a group like the PRLG as such a prominent and influential feature of the research design.

Core to the psycho-social approach of Hollway and Jefferson (2013) are the concepts of the defended subject and defended researcher. The Free Association Narrative Interview (FANI) method, developed by Hollway and Jefferson (2013), provides a means of theorising how defences can operate in relation to conflicts and threats, and for understanding how this can affect both the interviewee's and researcher's investment in certain discourses (Hollway and Jefferson, 2013). Such notions proved highly useful in helping me as a researcher to make sense of my thoughts and feelings, in line with my reflexive stance, that arose due to the practice-near nature of my study. Respecting, accommodating and seeking to understand these defences, rather than denying them, was considered both important and inevitable given this study's practice-near and reflexive methodological orientations. Hollway and Jefferson (2013, p.3) assert 'If we wish to do justice to the complexity of our subjects an interpretive approach is unavoidable' and crucially they add '[A]s long as this approach to knowing people through their accounts is applied to the researcher as well as the researched'. The researcher must therefore also be prepared to examine themselves. This stance is analogous to the notion of reflexivity and is consistent with the principles of anti-oppressive social work practice (Banks, 2012; Dominelli, 2002; Thompson, 2016). Axiological concerns, namely the values that the researcher brings to the endeavour, can be appropriately engaged with by adopting this approach. This is important because I accept the notion that as a researcher I am part of the research story and cannot claim to be value-free. This stance also assists in ensuring the validity of the data.

In subscribing to such notions of the research subject and researcher, my study also shares the wider theoretical stance and research paradigm that underpins the work of Hollway and Jefferson (2013). This includes the notion that research subjects cannot be known except through another subject; that research subjects cannot be understood without knowledge of their experiences in the world and that there is a relationship between research subjects' representations and their experiences (Hollway and Jefferson, 2013). The research paradigm underpinning such positions is known as critical realism. Critical realism is a philosophical and methodological framework and an alternative paradigm to positivism, interpretivism and constructivism (Archer et al, 2016). Developed by Roy Bhaskar in collaboration with a number of British social theorists critical realism is concerned with ontology – the philosophical study of being – and allows for an independent reality (Kara, 2017) and rejection of the epistemic fallacy, the notion that reality is conflated with our knowledge of it (Bhaskar, 2008). Hollway and Jefferson (2013) explain how critical realism can help to overcome a critique associated with interpretivism: the 'hermeneutical circle' (Denzin, 1989, p.141). This refers to the problem of there being no end to interpretative processes and it is relevant because such processes are core to psycho-social methods, including those advanced by Hollway and Jefferson (2013), and used in this study.

Before arriving at the psycho-social approach to interviewing adopted as part of my study, I considered the merits of two methods in particular: the Biographical Narrative Interpretative Interview Method (BNIM) (Wengraf and Chamberlayne, 2006; Wengraf, 2008) and FANI, which was developed by the aforementioned psycho-social researchers Hollway and Jefferson (2013). These approaches, rooted in the narrative tradition, emphasise unconscious dynamics and inter-subjectivity between the researcher and researched or interviewer and interviewee (Clarke and Hoggett, 2009, p.9). Fritz Schütze, a German sociologist, is thought to have developed the original work that became the Biographical Interpretive Method, which was further refined by Gabrielle Rosenthal (Bornat, 2008, p.346). The main theoretical principle underpinning the method is that there is a *Gestalt* (a whole or an order) informing each person's life

(Hollway and Jefferson, 2013). Contemporary Biographical Interpretive methods, such as BNIM and FANI, prioritise eliciting biographical narratives in an uninterrupted way and emphasise a distinction between the ‘told story’ and the ‘lived life’ (Clarke and Hoggett, 2009, p.11). In their adaption of BNIM, Hollway and Jefferson (2013) refer to the *Gestalt* as the interviewee’s ‘meaning-frame’ (p.32). FANI seeks to elicit the interviewee’s meaning frame via the use of four guiding principles adapted from BNIM: use of open-ended questions, eliciting stories, avoiding why questions and using respondents’ ordering and phrasing (Hollway and Jefferson, 2013).

In relation to this study, the FANI method was considered the appropriate interview method to draw upon in particular because it seemed less rigid in its approach to questioning than BNIM. I anticipated that the subject matter would have a personal meaning grounded in the subjective, and perhaps sensitive, experience of being a service user and that I might need to be more active in the interviews than a BNIM approach, in particular, would sanction. However, as a defended researcher (Hollway and Jefferson, 2013), I was also aware of the need to be able to tolerate silence if this occurred. The four guiding principles used in the FANI approach (Hollway and Jefferson, 2013), outlined above, were adopted and used as part of my interviewing method. I valued that they are framed as guiding principles rather than strict rules to be rigidly adhered to when applying the method. In common with the FANI method I also adopted the double-interview approach and, as mentioned earlier in the chapter, this allowed for a PRLG meeting to be scheduled between the first and second interview.

Research questions

Here, I shall provide a reminder of my research questions, introduced in Chapter 1, and the rationale underpinning them.

Primary:

1. What can be learnt from what services users say about their experiences of personalisation?

Subsidiary:

2. What are the range of meanings of personalisation that adult social care service users ascribe to this concept when given an opportunity to explore their lived experience in depth?
3. What might be the connections and tensions, conscious and unconscious, between the lived experience of adult social care service users, social work practice and the concepts of 'independence', ‘choice’ and other key tenets of personalisation policy?
4. How do the principles of personalisation accord with the realities of service users’ lived experience and contemporary social work practice with adults in England?

My research questions reflect the qualitative orientation of the research. They are concerned with exploring subjective, lived experience. Here, there is clear accord between my research questions and psycho-social methodological approaches. The research questions focus on the views and experiences of service users of adult social care, rather than other actors in the field, for example, policy-makers, managers and social work practitioners. Here my research questions privilege service user perspectives, which in turn have informed the participatory elements of my research design, in particular, the establishment of the PRLG. My positionality regarding my views about the utility of psychoanalytic theory is also evident in the research questions, as I am explicit in my intention to reveal and explore ‘unconscious forces at play in the development and practice of personalisation policy’.

In the main, my research questions have remained relevant throughout the research process. However, as noted in Chapter 1, I did make some minor modifications. The modifications included a widening of the scope of my primary research question to focus more on what service users say about their experiences of social work and adult social care, rather than a narrower focus on the meaning they ascribe to the concept of personalisation. This change came about following discussions with PRLG members and is indicative of the participatory methodologies informing the research, and how I responded to participant feedback. Reflecting now, I wonder too if I may have been unconsciously defending against the need to examine myself and my profession by initially focusing the interview questions more on personalisation than social care and social work. As a defended researcher (Hollway and Jefferson, 2013), this is certainly possible. Having a PRLG meeting between the first and second psycho-social interview with each participant was important to help overcome such issues. The double interview approach and the sequencing whereby the PRLG reflected upon each research encounter I had with participants, helped me to overcome challenges associated with being a defended researcher (Hollway and Jefferson, 2013), adding rigour and validity to the findings. Figure 2, featured below, provides a visual representation of the process described above.

The research design: The components

Earlier in the chapter I explained that my research design is comprised of a reflective learning group with Experts by Experience and semi-structured psycho-social interviews with service users of adult social care. These two main research methods were supplemented by the recording of my reflections and observations in a research journal. In this section I shall describe these methods in greater depth. Figure 2, below, provides a visual representation of the research design described in this chapter, highlighting the interface between the PRLG and the interviews, the processes involved and the roles and functions of the PLRG and me as researcher.

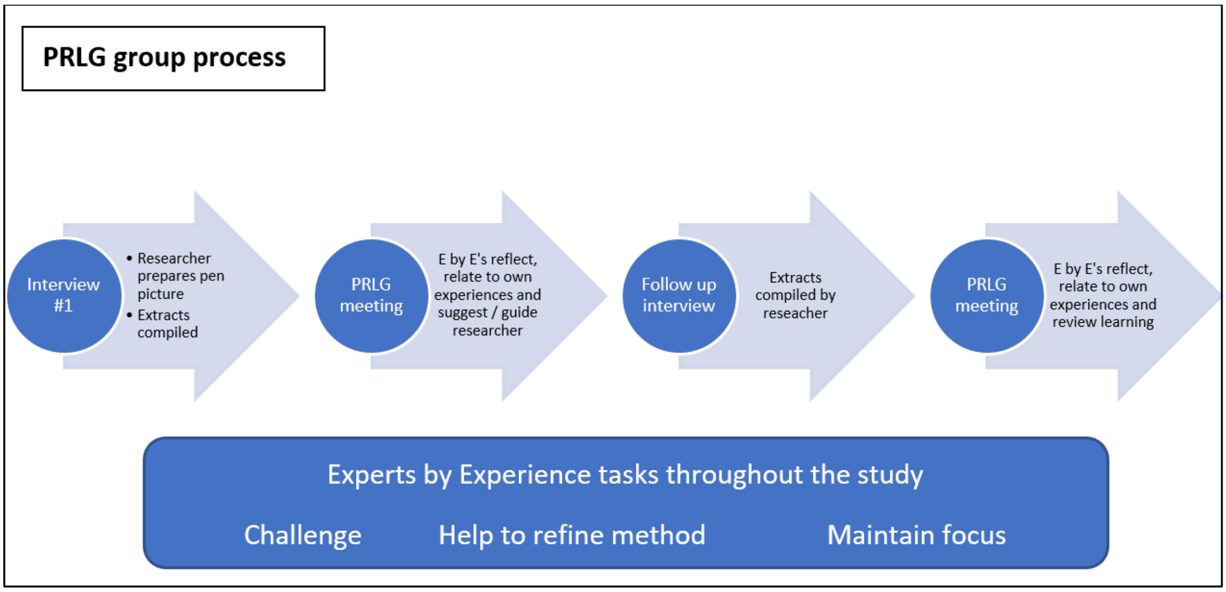


Figure 2 PRLG: process and roles

The Personalisation Reflection and Learning Group (PRLG)

At an early stage of the research, I established a Personalisation Reflection and Learning Group (PRLG) that included five Experts by Experience who had experience of, and an interest in, adult social care in a policy context of personalisation. As indicated earlier in the chapter, this aspect of the research design has characteristics informed by Action Research and Co-operative Inquiry (Reason, 1994; Heron and Reason, 2008) as well as the co-research group that features in Symonds et al (2018) study about experiences of social care assessments. Members of the PRLG were recruited from the borough in which I was employed as a Project Manager at the time. The group was facilitated by an independent facilitator who had relevant skills and experience in service user participation and qualitative research approaches. The independent facilitator and I had worked with the group members on a local personalisation transformation programme, so we all knew one another, albeit in different roles. The nature of our relationship was one grounded in principles of co-production: namely respect, reciprocity, mutuality and a firm belief that people who use services have assets and have skills (TLAP, 2018a). Nonetheless, ethical considerations were attended to, as outlined later in this chapter.

PRLG members were selected based on the following inclusion criteria:

- Over the age of 18.
- Current or recent experience of adult social care.
- An interest in adult social care and personalisation.
- Availability to participate in 2-hour reflective discussion meetings every four to six weeks over a six to 12 month period.
- Some experience of participating in meetings, groups or committees.
- Capacity to read (by any means), understand and consent to participate in the research.

Ten people were invited to join the PRLG; five took up the opportunity following attendance at a briefing session facilitated by myself and the independent facilitator. It was not necessary to exclude anyone that wanted to participate. I elaborate further on the recruitment process related to the PRLG in the ethical considerations section later in this chapter.

The group were an important source of data. At regular meetings, in dialogue with other group members, the group were tasked with making use of their own and shared lived experiences of adult social care and personalisation to reflect on extracts from the interviews. As well as generating data, the PRLG comprised the principal method for data analysis for the research. In meetings of the PRLG, anonymised extracts of interviews with service users of adult social care were analysed by the group, following a structured format. Ground rules were set for the meetings, which included maintaining confidentiality, respecting others' opinions and sharing any response – all contributions were considered relevant. The facilitator was briefed before each meeting and de-briefed after the meeting. I provided the facilitator with guidelines about the desired style of facilitation and prompt questions to guide the discussion. At meetings, the group were seated together with the independent facilitator, and I was seated outside of the circle. See the meeting layout in the diagram, Figure 3, above.

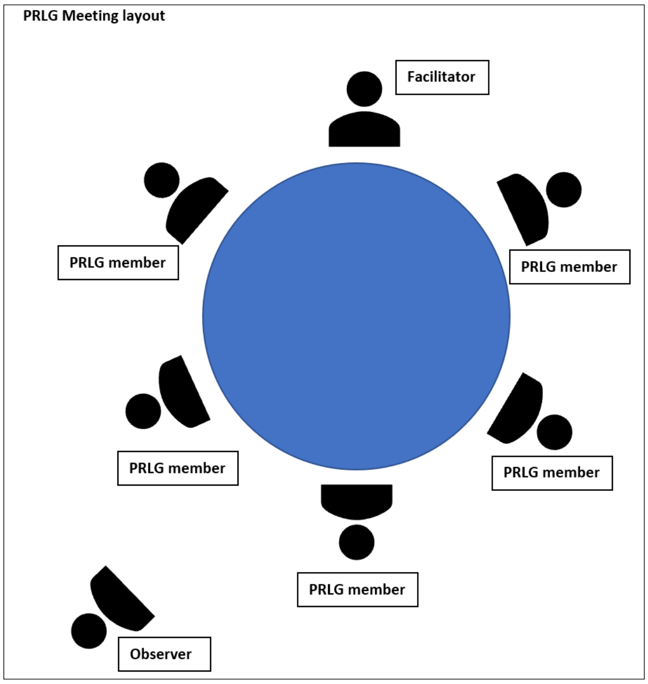


Figure 3 PRLG meeting layout

During meetings, the intention was to encourage the group to reflect on the material in a manner similar to free association in psychoanalysis, and to foster a creative atmosphere in which the frustration of not knowing could be tolerated. In addition to sharing their own perspectives, associations and responses to the interview data, the group were also encouraged to suggest questions for follow-up interviews, to challenge the researcher, to help maintain a focus on important issues for service users of adult social care, and to help to refine the research methods. A detailed exposition of the PRLG-led data analysis is provided later in this chapter.

These reflective functions of the PRLG are based on approaches to learning and teaching that I was exposed to as part of my post-qualifying training at the Tavistock Centre, in particular Work Discussion and Infant Observation. Briefly, Infant Observation was introduced as a core element of psychoanalytic psychotherapy training in 1948 by Esther Bick at the Tavistock Clinic (Hingley-Jones, Parkinson and Allain, 2017, p.23). Work Discussion also has origins in psychoanalytic psychotherapy training at the Tavistock Centre (Rustin and Bradley, 2008). The methods are rooted in the work of a number of pre-eminent individuals who worked at the Tavistock Clinic, including Wilfred Bion, known for his work on groups (1961) and John Bowlby, founder of attachment theory (1988). Both Infant Observation and Work Discussion involve compiling and sharing with a group a written account of a particular work experience or dilemma. In the group discussion the presenter withdraws from the discussion after presenting their written account and the group has to bear the frustration of not knowing and if it can be tolerated, this ‘negative capability’ can foster greater creativity amongst the group and a richer understanding of the material presented. First conceived by Keats, and applied to psychoanalysis by Bion (1970), the notion of negative capability, refers to the capacity to be ‘capable of being in uncertainties, mysteries, doubts, without any irritable reaching after fact and reason’ (Keats, 1899, p.277). Importantly, the observation task for both Work Discussion and Infant Observation often involves having to bear considerable anxiety and a struggle to remain in an observer role. At PRLG meetings I adopted an observer role and made intentional efforts to attend to both conscious and unconscious communications including my thoughts and feeling responses and to value this as valuable data. So too my approach of presenting interview extracts, written accounts, from the interviews to the PRLG and hearing and contemplating many different and valid perspectives about the material presented is also based on my experiences as a participant in Work Discussion and Infant Observation seminars at the Tavistock Centre.

My experience as an observer during PRLG meetings was emotionally demanding. A range of perspectives and emotions would be shared at the meetings. They were often intense with some heated debates occurring or people sharing painful associations and memories. I did not think that it would be easy work at all, but I was not expecting the PLRG to be such demanding emotional labour. I was frequently aware of my own feelings of wanting to escape the meetings and of feelings of anxiety in my body. I had to work hard to contain such anxieties and to avoid enacting the defences of a defended researcher. These feelings would be heightened when the PRLG were exploring subjects related to disability, dependency, loss and grief, and suicide. Feelings of anger, frustration and despair at the experiences of people needing social care and social work support were frequently expressed by group members at PRLG meetings. These and many other painful subjects that are often defended against emerged in the meetings in response to sharing extracts of the interviews with people about their experiences of adult social care and social work in a policy context of personalisation.

The PRLG met seven times over a period of seven months. Meetings typically lasted two hours, with a short break after an hour. Meetings were recorded using an audio recording device and transcribed within two weeks by the independent facilitator. I then read the transcripts in full to ensure the accuracy of the transcription. As outlined above, I took an observer role such as that described by Hingley-Jones, Parkinson and Allain (2017) during the meetings, and recorded notes about my observations and responses to the group process and discussion in my research journal. I also recorded reflections that occurred to me at any point after the meetings. The group was broadly reflective of the borough in which the group was based, including three women and two men, from an age range of approximately 25-80 and with a range of white European ethnicities. The group included people with experiences of physical disability, sight loss, learning disability and mental health conditions. To protect the identity of group members, I will not reveal further demographic details. Also, on the question of anonymity, as will become apparent when outlining the findings in Chapter 4, I have anonymised specific contributions of PRLG members with a designation P, denoting person, i.e. P1, P2, etc.

The psycho-social interviews

Semi-structured, psycho-social interviews were undertaken with eight people who each had experience of adult social care. Each participant was interviewed twice, with on average a period of two to four weeks between the initial and follow-up interview. Interviewees were selected based on the following inclusion criteria:

- Over the age of 18.
- Self-identified service user of adult social care in England (current or recent past).

- Outside of the borough in which the researcher was employed at the time of the research.
- Interviewee availability for two interviews of between 60 to 120 minutes approximately.
- Capacity to read (by any means), understand and consent to participate in the research.

The research sample is diverse with respect to age, gender and ethnicity (see Table 1). It was my intention to have a diversity of experience in the research sample, but with no specific requirement for the sample to be representative of particular groups. To have achieved a fully representative sample in terms of impairments would have required a much larger sample and study. However, a larger study would have meant sacrificing depth for breadth. Due to anonymity considerations associated with having a small sample, I have kept specific identifying details to a minimum, minimised the inclusion of more specific identifying details and extensively disguised participants' details when presenting the findings in Chapter 4. In doing so, I have sought to balance anonymity considerations with maintaining an accurate approximation to the diversity and characteristics of the overall sample, in respect of age, gender and ethnicity in particular.

It should be noted that during the recruitment and interview processes, I did not actively seek to identify and categorise the research participants on the basis of their impairment or disability. I am not suggesting I was not curious, nor that I may not have made some assumptions about this upon meeting the participants. However, consciously, I sought to adopt a stance that was congruent with Independent Living philosophy, attempting to see participants as people and citizens first (Beresford and Carr, 2012). In describing the participants I have replicated the language they employed themselves, with several different terms featured including impairment, condition or disability. In this regard, I have sought to respect individual preferences pertaining to terminology, as suggested by Shakespeare (2018). People with learning difficulties comprise more than half of the research participants. The use of an Easy Read flyer may have made participation in the research more accessible and appealing to people with learning difficulties. Easy Read, which combines simple words with pictures, is commonly used by people with learning difficulties and organisations supporting them. Both plain English and Easy Read flyers were developed and used for recruitment purposes (see Appendix 1 and 2). One family carer participated in the interviews with their adult son. Two participants with physical impairments and one with a visual impairment participated in the interviews. Two participants described some experiences of mental ill-health and past use of mental health services, though this was in addition to what they considered to be their primary condition or disability.

Table 1 Interview participant demographics: Summary data

Interview participant demographics: summary data				
Age range	**Gender**	**Ethnicity**	**Impairment/s or role**	**Recruitment source**
18-25 (2)	Male (3)	Asian British (1)	Visual impairment (1)	Responded to e-flyer (2)
25-40 (1)	Female (5)	White British (5)	Learning difficulty (4)	Personalisation professional network
40-55 (3)		Black British (2)	Carer for a person with a learning difficulty (1)	Social work event (1)
60-75 (2)			Mental health condition (1)	Learning difficulty charity (3)
			Physical condition (2)	

Participants were recruited from a number of sources, including professional, formal and informal networks and social work events. The promotional flyers were circulated via online forums dedicated to personalisation, self-directed support and service user participation. Social media was used, including Twitter and LinkedIn, to promote the research opportunity. The strategy was successful, with the sample target of eight interviewees being met. As with the PRLG meetings, the interviews were recorded using an audio recording device and transcribed within two weeks by a professional transcriber. I then read the transcripts in full to ensure the accuracy of the transcription. I kept a research journal and recorded reflections immediately after the interviews and any that subsequently emerged following the interviews. Reflections from the interviews and PRLG meetings were used when analysing the data.

As outlined earlier in the chapter, the interview method was informed by the free-association narrative interview method as described by Hollway and Jefferson (2013). I sought to follow as closely as possible the principles that underpin the free-association narrative approach. I used open-ended questions and allowed space for interviewees to respond without interruption. I had three main questions, which were very broad and open, in line with the principles espoused by Hollway and Jefferson (2013). I also had prompting questions, which I could draw on if required. I encouraged interviewees to tell their stories, at their own pace; and when responding or asking questions, I would do so using their ordering and phrasing. I was flexible in my approach, allowing myself to be interested in and guided by what interviewees decided to share. Adherence to the above principles was in order to foster a safe environment conducive to free association for participants and the generation of unconscious data. However, I did not strictly follow the method devised by Hollway and Jefferson (2013) and adapted it for my research. I was, for example, more active with participants with learning difficulties, who sometimes needed more prompting during the interview. Nonetheless, I would characterise the interview technique as psycho-social, not least because I was both interested in, and attuned to, unconscious processes with interview participants and myself during the interviews.

The following questions were set out in an interview schedule which was not shared with participants, but rather functioned as a prompt or guide for me during the interviews.

INTERVIEW SCHEDULE

Interview duration between one and two hours.

Two interviews – approximately two weeks apart to allow for PRLG meeting in between.

1st Interview.

Main questions:

Could you tell me about your experiences of personalisation?

What does personalisation mean to you?

Could you tell me about your experiences as a service user of adult social care?

Prompting questions:

- What's important to you?
- What does independence mean to you?
- What does choice mean to you?
- Can you tell me about your experience of having a personal budget?
- What does co-production mean to you?

2nd Interview – questions shaped by PRLG reflections and suggestions.

Data analysis

Having set out the methods that I used for gathering data, I now attend to the matter of data analysis. Here, I summarise the components of my data corpus and outline the methodological influences that informed my approach to data analysis. I describe the method I developed and employed to analyse the research data. In doing so, I make links to the aforementioned methodological influences explicit and also seek to highlight any modifications to such methods and any distinct or novel characteristics of the methods I employed.

The data corpus

The research produced a rich data corpus comprised of three interrelated data sets: data from the PRLG meetings; data from the in-depth interviews; along with my own documented reflections. The data items that make up the data sets include transcripts from seven PRLG meetings and 14 individual in-depth interviews. Together, this amounted to 27 hours of audio recording. Also, as noted earlier I made observation notes of PRLG meetings and kept a research journal throughout the research journey, from inception to writing up the thesis. Not only was the journal a useful tool in support of my reflexive methodological approach, but it also provided a useful account of my journey as a researcher and the evolution of the research undertaking. It too forms an integral part of the data corpus. In describing the data I gathered in this way, I am drawing on the framework outlined by Braun and Clarke (2006) which, in my view, provides some useful definitions and a clear way of conceptualising research data which distinguishes between the data corpus, data sets and data items. In summary, my data sets comprised the following:

1. Data from 14 psycho-social interviews (initial and follow up) with eight interview participants (seven service users and one family carer).

2. PRLG reflections and analysis of interview data from seven two-hour group meetings.

3. Researcher observation notes of PRLG reflections and journal reflections of interview data and PRLG meetings.

Please see below (Figure 4) for a diagrammatical representation of the data sets and the relationship between them.

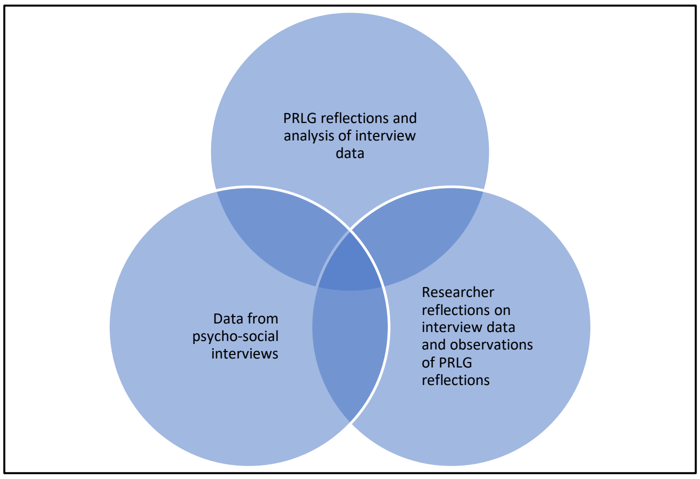


Figure 1 Data sets

Data analysis: Theoretical foundations

Owing to the participatory psycho-social research design it is not easy to clearly demarcate the research phases of data generation, collection and analysis. The study is characterised by a dynamic process of data generation and data analysis occurring at key phases of the research. Consistent with the broader methodological foundations of the research, the approach taken to data analysis is comprised of a participatory psycho-social approach followed by a cross-case thematic analysis. A retroductive reasoning approach (Blaikie, 1993) underpins my data analysis. Such an approach offers an alternative position to what can be a stark methodological divide between deductive and inductive reasoning. Unlike a deductive approach, this study did not begin from a declared theoretically-driven hypothesis and also did not seek to develop theory from the data as would be expected via an inductive approach (Mabry, 2008). I acknowledge that my own conceptualisations and implicit personal theories about subjects of adult social care, social work and personalisation, along with the cluster of psychodynamic concepts already outlined, mean that this study was to some extent theoretically driven. This is however accommodated by retroduction. According to Blaikie (1993, p.168), retroduction involves ‘the construction of hypothetical models as a way of uncovering the real structures and mechanisms that are assumed to produce empirical phenomena’. A dialectical engagement between the findings and theory is, therefore, key to a retroductive approach and this is reflected in the dynamic reflexive processes of data generation and analysis that are core features of this study’s research design.

As Aldridge (2016, p.122) notes, ‘conventionally, the responsibility for analysing and interpreting data falls on the academic researcher’. In such conventional approaches, the expert knowledge and skills of the researcher are privileged. Conversely, participatory methodologies provide opportunities to equalise or re-configure the researcher-participant dichotomy, including in relation to data analysis (Aldridge, 2016, p.134). Such approaches and methods also align with the principles of co-production. Importantly, co-production recognises the interplay of knowledge generation, where contributions from people who use services and professionals or researchers are equally valued. In terms of data analysis, co-production can help to ensure that research remains focused on what is most relevant and important to people who have direct lived experience of services. Affording the PLRG and the Experts by Experience a prominent role in data generation and analysis reflects the influence of participatory approaches in my research design. The PRLG was intended to enhance the validity of the research findings by analysing the data with people with lived experience. Members of the PRLG were encouraged to relate the material to their own experiences, and to take an active role in the application of a retroductive approach to data analysis, by identifying further lines of inquiry and formulating questions for follow-up interviews. The PRLG also helped to facilitate reflection of my own hunches, assumptions and perspectives. The PRLG can be said to have constituted a continuous learning and reflection cycle throughout the research, akin to an Action Learning framework, such as the spiral of action learning cycle (Coghlan and Brannick, 2010) and double-loop learning (Argyris and Schön, 1974). This aspect of the research design aligns with my retroductive reasoning approach, which is based on ‘cyclic or spiral processes rather than linear logic’ (Blaikie, 1993, p.162).

The FANI method was especially influential in terms of my approach to data analysis. In arranging an initial and follow-up interview, I followed the double interview approach, employed by Hollway and Jefferson (2013). This allowed for a preliminary reading and reflection of the interview and data, in collaboration with the members of the PRLG, and the subsequent testing of emergent hunches and provisional hypotheses with my supervisors. In addition, the questions that guided reflective discussions at the PRLG meetings were modelled on the guiding questions that Hollway and Jefferson (2013) offer for analysing the data: What do we notice?; Why do we notice what we notice?; How can we interpret what we notice?; How can we know that our interpretation is the 'right' one? (Hollway and Jefferson, 2013, p.51).

The key principle of Gestalt (Hollway and Jefferson, 2013) in narrative approaches was highly influential in my approach to data analysis. The notion, when applied to data analysis, emphasises the importance of seeking a holistic interpretation of data and its proponents decry the fragmentation of data that results from code and retrieve methods of data analysis, including computer-assisted qualitative data analysis (CAQDA) (Hollway and Jefferson, 2013, p.63). This illuminates further the rationale behind my decision to not adopt a rigid code and retrieve form of thematic analysis. So too, my decision to abandon an early attempt to code my data using NVivo (a popular CAQDA) followed the realisation that my data was feeling fragmented and distant. Instead, I sought to approach each data element, an interview or a PRLG meeting, in an holistic way.

I shall now briefly outline the key tenets of thematic analysis and how it was applied in my research. Thematic analysis generally entails coding, slicing and comparing different segments of data, identifying and exploring patterns in the data and connections between codes and themes (Kara, 2017, p.178). Braun and Clarke (2006, p.6) explain that thematic analysis is a qualitative method for ‘identifying, analysing and reporting patterns (themes) within data’. They consider thematic analysis to be a particularly flexible form of qualitative data analysis that is essentially independent of theory and epistemology that can be applied across a range of theoretical and epistemological approaches that can ‘potentially provide a rich and detailed, yet complex account of data’ (Braun and Clarke, 2006, p.5).

Thematic analysis informed the early identification of themes and choice of extracts that were presented to the PRLG, and also was used for the later cross-case thematic analysis. My use of thematic analysis was similar to the approach taken by Lonbay and Brandon (2017), whereby themes are mapped to specific research questions. Furthermore, I used latent thematic analysis, which goes beyond the semantic content of the data to 'identify or examine underlying ideas, assumptions, and conceptualisations – and ideologies – that are theorised as shaping or informing the semantic content of the data' (Braun and Clarke, 2006, p.13). Latent thematic analysis aligns with my wider methodological influences, particularly psychoanalysis and psycho-social approaches. An approach to thematic analysis that relies on the application of a strict formula by someone with specific expertise and conducting the analysis via the use of qualitative analysis software would seem likely to impede and curtail participatory research approaches. It would, therefore, have been incongruent with my research design. I adopted a flexible form of thematic analysis, as espoused by Braun and Clarke (2006), informed by participatory and psycho-social approaches and not the application of a rigid coding formula.

Method of data analysis

While my research yielded three data sets there is a clear relationship between them, as indicated in Diagram 4. It bears emphasising my position as researcher at the point of intersection of the data sets. My role in this position has been one of observing, contemplating and integrating the various perspectives, feelings and experiences that make up the data sets. Below I set out the sequential steps involved in the analysis of the research data. This includes the PRLG's analysis of the data generated in the in-depth interviews that I conducted, my observations and reflections and my subsequent analysis of the data generated by the PRLG's analysis. This might be considered an intensively reflexive process of data analysis.

1. Firstly, I made notes of my reflections after the individual in-depth interviews in a research journal. I recorded my feelings and any particular aspects of the interview that I had been especially affected by, or that I thought interesting or puzzling.
2. Within two to four weeks of the interview, I undertook a preliminary reading of the full interview transcript. I made use of my initial responses to the interview in my research journal to select interview extracts for presentation to the PRLG. A sample transcript is included in Appendix 8. Typically, three to four interview extracts were selected, which amounted to three to four single sides of A4 paper. An example is included in Appendix 3. During this process, I also made notes of initial themes that seemed to be emerging from the data.
3. During PRLG meetings, the independent facilitator would read the anonymised extracts to the group and would then facilitate reflection on the extracts with reference to the following questions: What do you notice? (initial thoughts/feelings/responses); What do you think personalisation means to this person? How does it fit (or not) with your experience or understanding of personalisation and why? What can we learn from this interview?
4. The facilitator would then provide a pen picture about the interviewee to the group, which might include, their approximate age, gender and ethnicity, their life circumstances, self-defined impairment and some emergent themes that I had identified following my initial reading and reflections of the interview. An opportunity would then be provided for the group to respond to this additional material and to make any other observations or contributions.

5. Towards the end of the discussion, the group would be invited to consider any suggested questions for the follow-up interview (where applicable).

6. At the end of the PRLG discussion, I would come out of the observer role and provide group members with an opportunity to ask me any questions. This was also recorded and included in the data set for each meeting. There was a tea break in the middle of the meeting before the group would reconvene and repeat the process with another selection of extracts from another interview. No more than two interview participants were discussed during a meeting of the group.

7. Once all the interviews and PRLG meetings concluded, I used a thematic analysis approach to collate all of the preliminary themes that appeared to be emerging from the data – both from my journal reflections, my initial reading, and the PRLG meetings. After several months, the data corpus in its entirety was revisited, and a cross-case thematic analysis undertaken using Braun and Clarke’s (2006) guide to conducting a thematic analysis. The transcripts of the individual in-depth interviews were read several times, together with the corresponding PRLG reflective discussion of the interview and my journal observation notes. Learning from several data validation activities, namely presentations at conferences and events was also undertaken, details of which are set out in further detail in the next section. The themes that emerged from the cross-case thematic analysis that form the basis of the research findings are set out in a table in Appendix 9.

Revisiting the data for the purposes of the cross-case analysis was a challenge because it would transport me back to the charged emotional experiences of the PRLG and interviews. At times I was unable to bear the emotions that would be stirred and would delay the task. Likewise, in one instance I realised when I re-read an interview transcript that I could not remember a significant and painful event that a participant had shared with me. Reflecting on this experience with reference to the notion of the defended researcher (Hollway and Jefferson, 2013) it would appear that forgetting was an unconscious way of defending myself against the psychic pain I had encountered in the interview.

Finally, it should be noted that regular supervision with my doctoral supervisors was an important aspect of the research design. Further analysis of emergent findings was explored with my supervisors and a space was also provided to explore my feelings and experiences of the research and the data with reference to social work and psychoanalytic concepts. By virtue of the emotionally demanding nature of my practice-near research (Froggett and Briggs, 2012), regular psychoanalytically-informed supervision not only supported the study's reflexive epistemology but was also self-preserving.

Ethical considerations

I now explore the ethical considerations associated with my research. There are ethical issues inherent in any research. Ethics has been described as the 'rules of conduct of a particular activity' (Kara, 2017, p. 29), and while ethics are relevant to a wide range of areas, there are particular ethical dilemmas, considerations and requirements associated with research, in particular research with human subjects. Iphofen (2011, p.7) contends that behaving ethically when undertaking research requires planning 'a route through a moral maze'. Indeed, designing my route has been a complex process, not least of all because I have sought to adopt a bespoke multi-method research design. David and Sutton (2011, p.53) assert that 'research involving human subjects needs to be ethical in its selection (design), in its conduct and in the use/distribution of its findings'. The task of ensuring ethics across these areas is likely to be more complex where a multi-method approach is taken over a tried and tested or more manualised methodology.

As has been noted previously in this chapter, participatory methodologies informed the research design. Such methodologies strengthened the ethical credentials of the research by keeping me focused on the priorities of people who use services. Coughlin and Ackerson (2017, p.57) assert that approaches of this nature reduce the likelihood of irrelevant or insensitive research, and that 'inclusion of community members in the research team as equal partners helps to protect the community from harm and exploitation and supports self-determination'. Criticisms about research *on* vulnerable or disabled people, whereby research participants are treated as mere objects of research, underline the need for additional sensitivity and careful consideration about ethical matters in social work research. Aldridge (2016) describes a pertinent, significant ethical dilemma associated with efforts to design more participatory and inclusive research.

> The challenge for the researcher (and practitioner) planning to work with vulnerable or marginalised people in more inclusive ways […] is to adopt approaches that recognise their competency and agency – aligned conceptually and epistemologically to contemporary shifts in understanding about rights and needs – while at the same time that work within research governance and ethical frameworks and classifications that define them as vulnerable (Aldridge, 2016, p.4).

The ethical dilemma of how to design inclusive and empowering research with service users of adult social care, who are deemed vulnerable in research frameworks and to whom I have a professional responsibility as a social worker, is one that I grappled with during the research. Including the PRLG in the research design, and giving a prominent role to Experts by Experience was instituted to address such concerns. In my view, it added rigour to the research undertaking and reflected the participatory principles informing the research design. I was guided by the principle of researching with people rather than on people. I welcomed and invited critique of the research design and my role and approach to the research from the Experts by Experience; while this may not have always been easy to hear and bear, it is my view that such an approach enhanced the validity of the data, and is more congruent with core social work values and ethics (BASW, 2014).

Social work ethics guide my practice as a social worker, and they also provided a solid foundation to guide me as a practitioner-researcher. Being an ethical social worker is, according to Banks (2012, pp 4-5) ‘an ongoing project that entails a process of critical reflexivity’. Indeed, Banks (2016, p.35) suggests that this ‘ethics work’ is core to social work. Many of the principles associated with research ethics are also core ethical practice principles for social workers, such as maintaining confidentiality, obtaining informed consent, and exercising authority appropriately. The British Association of Social Workers (2014, p. 13) Code of Ethics for Social Workers includes an ethical practice principle which stipulates that social workers should ‘facilitate and contribute to evaluation and research [and] should analyse and evaluate the quality and outcomes of their practice with people who use social work services’. Thus, in conducting research as a social worker on the subject of adult social care and social work in a policy context of personalisation with services users of adult social care, I have attempted to meet this requirement of my profession’s code of ethics.

As explored earlier in this chapter, psycho-social methods, including my methodological approach, use psychoanalytic theory and principles. There are many criticisms levelled at psychoanalytic theory, and particularly its key figures, including Sigmund Freud and Melanie Klein, but perhaps most relevant to my research and its ethical framework, are criticisms about its potential to be pathologising and individualising (Maclean and Harrison, 2015), thereby paying insufficient attention to the social context of problems (Mullaly, 1997). There are possible tensions therefore between the participatory methodologies informing my research, the social model of disability which seeks to highlight the social context of disability, and psychoanalytic approaches. However, I have given these criticisms due consideration and have concluded that they do not appear to take account of more contemporary developments in psychoanalytic theory and practice. Psychoanalysis is a dynamic discipline that has evolved and developed considerably since it was first founded in the late 19th Century. Contemporary psychoanalysis is engaged in more progressive theorisation and practice, regarding diversity and the social context of problems. Notable examples include Mitchell (1974), Eichenbaum and Orbach (1983), Butler (1990, 2004), Fanon (1952), Akhtar (1999), Clarke (2003), Lowe (2013) and Ryan (2017). It bears highlighting that psychoanalytic examination of the welfare state and social care policy and practice (Hoggett, 1992, 2009; Armstrong and Rustin, 2015) including theorising social and institutional responses to dependency and vulnerability (Cooper and Lousada, 2005; Dartington, 2010), are highly relevant to progressive critical thought and practice concerning adult social care and social work. Indeed, as will be apparent in subsequent chapters, such notions have been fundamental to my theorisation of the study's findings about lived experiences of adult social care and social work in a policy context of personalisation.

One final ethical consideration relates to the interpretation of interview data. Bornat (2008) raises a concern related to biographical interpretative and narrative approaches, of the kind that influenced my interviewing and data analysis. She asks ‘How far is it ethical to subject another person’s life to interpretation if the process and outcome are likely to be unrecognisable to them? How acceptable is an interpretation in which there is no possibility of continuing the dialogue and discussion, particularly where the data originated in an interview relationship?’ (Bornat, 2008, p.354). These are important and pertinent questions, though I would suggest that such questions could appropriately be asked of a range of research methods, not just biographical interpretative and narrative approaches. Bornat (2008, p.354) concludes that ‘we risk an over-interpretation which rather than emphasising the qualities of the original teller, eclipses them and puts the interpreter in a position of authority and control’. While I do not agree with this forceful critique and the premise that interpretation necessarily entails authority and control, I think it ethically prudent to be cautious about over-interpretation, insofar as it involves obscuring the voice of research participants; though perhaps it would be better to characterise it as reflexively deficient as opposed to over-interpretation. Nonetheless, I think it is important to take steps to mitigate one’s power as a researcher. Perhaps such concerns may have been mitigated to some extent in my research by my use of a multi-method approach, which blends both participatory and psycho-social approaches.

It should further be noted that ethical considerations informed my decision to not apply a pure Free Association Narrative Interview approach to the interviews. I was more active in the interviews than might be expected if the method had been applied strictly. Questions in the interview schedule were not solely framed to elicit stories but also focused on participants describing personal meanings of subjects and experiences. This variation was an attempt to co-create or share meaning making with participants, which I felt to be congruent with the participatory research methods and principles and their associated ethical underpinnings. Similarly, consistent with the lived experience approach, my focus on lived experience via the use of psycho-social, narrative interviewing is based on an exploration and comparison of people as complex individuals, and not a ‘critique of individual lives’ (Boylorn 2008 cited in Given, 2008, p.490).

Informed consent and confidentiality

As a practitioner-researcher, it was important to me that I considered how participants’ disabilities or other factors, such as class or experiences of exclusion and discrimination, might manifest as barriers to both full and equal participation in the research, and also barriers to voicing concerns about any aspect of the research and their participation. In the role of researcher, I recognised that I have and will be vested with more power and authority than the participants and that I would need to take steps to mitigate how this might affect the requirement to obtain informed consent. Obtaining informed consent from research participants is a core aspect of research ethics. The views of Iphofen (2011) about informed consent guided my approach. He asserts that there is a fluidity to consenting and that it is not a ‘once-and-for-all act – it is not an event, it is a process’ (ibid, p.67). Participant Information and Consent forms (see Appendices 4-6) were developed and used, which included key information about the research, a description of the research topic, details about the confidentiality of data and contact details for the researcher and the University Research Ethics Committee. Participant Information and Consent forms were sent in advance via email, and all participants were given the opportunity to ask any questions before signing the form. Issues of informed consent and anonymity were discussed with all participants, and the voluntary nature of participating in the research was emphasised, along with the option to withdraw from the research at any time without any adverse consequences for the participant. As part of the process of obtaining informed consent, potential participants were also advised that there was a risk that participation might evoke painful feelings and memories and that I would signpost them for support if required. This measure was instituted as part of my commitment to safeguard the well-being of participants and to avoid harm. Signed consent forms were obtained from all participants, both for the PRLG and the interviews before they participated in the research. Demonstrating my commitment to approaching informed consent as a process rather than an event, at the end of the first interview, participants were given the option to decline participation in a follow-up interview. PRLG members, with whom I had a pre-existing non-dependent professional relationship (as participants in an earlier co-production initiative), were given the opportunity to attend a briefing session about the opportunity, which included an overview of the approach, theoretical background and an outline of the Participant Information and Consent Forms. Participants were then given time to think about their decision and offered the opportunity to speak to someone independent in the department (Social Services) to ask questions. These steps were intended to address any concerns about how our pre-existing relationship might compromise their ability to give informed consent. A copy of the signed Participant Information and Consent form was returned to the participant via email.

Participant inclusion criteria included a requirement that participants had the capacity to read (by any means), understand and consent to participate in the research. Easy Read versions of the Participant Information and Consent Forms were created and used for research participants who had mild learning difficulties (see Appendix 4). In terms of research ethics, this was an important consideration to both enhance accessibility and to ensure informed consent was appropriately obtained. So, while people lacking consent to participate in the research were not included in the research, it was not assumed that people with mild learning difficulties would lack the capacity to consent. In this regard, the statutory principles of the *Mental Capacity Act 2005* were adhered to, notably Principle 1, ‘A person must be assumed to have capacity unless it is established that he lacks capacity’ and Principle 2, ‘A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success’ (Graham and Cowley, 2015, pp.40-44). I also met the Social Research Association (SRA) Ethics Guidelines which assert that researchers have a responsibility to enable participation of groups who might otherwise be excluded for reasons of communication, disability, comprehension or expense (SRA, 2003).

Confidentiality and anonymity are important considerations for research with human subjects. I was mindful that my research topic might entail participants sharing private and sensitive information. To ensure confidentiality and anonymity requirements for participants in my research I took a number of steps. Firstly, interviews were held in private locations of the participants’ choosing, either in participants’ homes, at my University campus, or in a room in a community centre. Electronic recordings were password-protected, stored securely and saved with non-identifying file names. Once transcription and data analysis processes were completed, the electronic recordings were deleted. Transcriptions were anonymised, with no identifying details included. I have redacted what I consider to be some particularly sensitive aspects of the sample interview transcript included in Appendix 8. In this regard, I have chosen to exercise my practitioner-researcher prerogative for what I consider to be an ethical decision taken in the best interests of the research participant. I have used pseudonyms in this thesis and, due to the small sample size, I have limited the inclusion of detailed demographic data to enhance anonymity further. I discussed limitations to confidentiality with all participants, and this was also included in the Participant Information and Consent form. This included explaining the limitations to confidentiality where disclosure of imminent harm to self or others may occur during participation in an interview or PRLG meeting.

Ethical approvals

I obtained ethical approval from the University of East London University Research Ethics Committee (UREC) by completing a detailed application form and ethics checklist. My ethics application outlined details of my proposed research, an overview of the methodology, an explanation about how I would identify, approach and recruit participants, the exclusion/inclusion criteria and a risk assessment and risk management plan. Participant Information and Consent Forms, including an Easy Read version, were submitted to and approved by the UREC. A copy of the permission letter is located in Appendix 7.

I also sought and obtained Research Governance approval from two local authorities, one being my former employer in which the PRLG was based and the other a borough that required this step before they would share the research flyer with their social work staff. Obtaining Research Governance approval entailed sending my proposal, UREC approval and associated forms to the research governance lead, who reviewed the documentation in line with the local authority's own guidelines for research. A recommendation was made that an independent facilitator be appointed for PRLG meetings. This recommendation was adopted and built into the research design. Research Governance approval was subsequently granted.

Ethics is, however, not just a matter of filling in the necessary forms, ticking boxes, and gaining approvals. In relation to social work, there is a risk of research being experienced as oppressive by disabled people and service users and subject to robust criticism (Hunt, 1981; Oliver, 1990; Morris, 1991; Beresford and Carr, 2012). As stated at the beginning of this chapter, the notion of 'nothing about us without us' reflects the ethical underpinnings of this study and the ethical demand that research embodies inclusivity and participation. Consideration of ethical matters was required throughout the entire research process. This included consideration at an early stage of a research design that was congruent with social work values and ethics. It also entailed ongoing reflections on the extent to which the approach to fieldwork, data collection and analysis was consistent with principles of co-production, how my power as a researcher manifested, and the extent to which I was balancing the tensions between the different research methods and influences which informed the study. Such matters will be explored in greater depth in Chapter 6.

Quality: Validity, reliability and generalisability

Considerations relating to research validity, reliability and generalisability are an expected requirement of quality in relation to qualitative research (Gibbs, 2007).

There are several features of this study’s research design which are intended to enhance the validity and reliability of the findings. Here I consider the validity of my research, along with other quality measures, using the five key questions devised by Orme and Shemmings (2010), which they stipulate should be asked as part of a critical appraisal of social work research.

1. How relevant is the study to the review question?

The research question is focused on an exploration of lived experiences of adult social care and social work in a policy context of personalisation in England. As the findings demonstrate, the study succeeds in eliciting details of the participants’ lived experiences of adult social care and social work that personalisation is intended to impact. The study is therefore relevant to the review question.

2. How much information does it contribute?

Psychosocial interviews were conducted to gather the lived experiences of adult social care and social work in a policy context of personalisation from eight people. Information from such interviews, along with the reflections and responses from the PRLG and my observations are included in the study. The sample size may be considered small, and therefore have less breadth compared to a larger scale qualitative study, or had a quantitative methodology been utilised. However, the data and findings have depth, and the study presents a rich body of information, including the views and experiences of people who are seldom heard in research. The information included in this study is, therefore, both bountiful and unique.

3. How trustworthy are its findings?

The findings have been subject to a rigorous process of validation, not least of all by the central role that the PRLG played in data analysis. Having extracts from the psychosocial interviews analysed and reflected upon by the PLRG, alongside my researcher observation and reflections, ensured that emergent themes and hypotheses were subject to exploration and corroboration by a group with lived experience of adult social care and social work in a policy context of personalisation. In this regard, there is a similarity with the function of the research panel used in BNIM, as the PLRG played a role in helping me as a researcher to 'overcome blind spots and defended subjectivity' (Wengraf, 2008, p.15). The use of an independent facilitator at the PRLG meeting allowed me to take an observer role, and my observations and reflections were included as a data set. In this way, there are three data sets as part of the overall data corpus which provide for corroboration and confirmation of findings from several perspectives. The psycho-social interview method that I used entailed having two interviews with the same participant – a first and follow-up interview. This allowed for the gathering of additional data and had clarification and confirmatory functions. It also meant that hypotheses could be explored and further lines of inquiry, devised in collaboration with the PLRG, could be followed up.

During the data analysis and write-up phases of the research, I secured opportunities to present aspects of my preliminary findings and methodology at the following three conferences:

- Social Work, Education and Development Conference, Dublin, Ireland, 4th –7th July, 2018.
- IFSW European Conference, Reykjavik, Iceland, 28th – 30th May, 2017.

- Camden and Islington Social Work Research Forum, London, 6th December, 2016.

These events provided opportunities to share preliminary findings and to get feedback about the study. It bears highlighting that the research forum event comprised a group of approximately twenty-five social workers from London in which preliminary findings from the cross-case analysis were co-presented with two Experts by Experience from the PRLG. The feedback I received from workshop participants and conference delegates helped me to clarify the themes further and confirmed that they were of interest and have relevance to a wide range of people. Copies of the presentations are located in the appendices (see Appendix 10, 11 and 12). Attending such conferences also formed part of a dissemination strategy, which is outlined in Chapter 6.

4. How generalisable are its findings?

While the research is a small-scale qualitative study that makes no claims to generalisability, the findings nonetheless have wider relevance beyond gaining some understanding of the views and experiences of the research participants.

5. Was it conducted ethically?

Ethical features of the research design have been set out in the preceding section of this chapter. Further reflections on ethical matters as they arose during all phases of the research are explored in Chapter 6. At this juncture, I can confirm that the research was conducted in line with the requirements of the University of East London University Research Ethics Committee (UREC), the SRA and BASW codes of ethics.

Chapter summary

In this chapter, I have provided an overview of my methodology. I have explained that my research is a multi-method qualitative study and that the methodological approach is psycho-social and participatory. The research methods used have been set out, including psycho-social interviews based on Hollway and Jefferson’s (2013) FANI method and a participatory reflection and learning group with Experts by Experience, the PRLG. I have outlined how the PRLG played significant roles in data generation and analysis. I have described my data corpus, including three data sets: data from the PRLG meetings and data from the in-depth interviews along with my own documented reflections. I have set out my approach to data analysis and in doing so have highlighted that the processes of data collection and data analysis were intensively reflexive processes, with a clear relationship between the data generated from the interviews and the PRLG. I have considered matters relating to quality: validity, reliability and generalisability using the five key questions devised by Orme and Shemmings (2010). Finally, I have outlined the ethical considerations associated with my research within a broader exploration of ethics, and especially ethics associated with research involving human subjects. This has included a focus on issues of informed consent and confidentiality. I have outlined how my use of particular methods relates to research ethics, in particular by highlighting the ethical credentials associated with participatory methods, and how I sought to adapt features of narrative and biographical interpretative methods to achieve better alignment with my ethical stance. In the next chapter, I will document the findings from my research.

Chapter 4: Findings

Introduction

This chapter documents the findings from the research. This includes data from the psycho-social interviews and from the reflective discussions and analysis of the interviews by the PRLG, along with my documented observations and reflections during the data collection phase of the research. To begin, pen portrait summaries of the interview participants are presented, which includes some brief descriptive details of each person. The pen portraits draw on the material across the first and second interviews with each interview participant to summarise their views and lived experiences of adult social care and social work practice in a policy context of personalisation. Then, key themes from the cross-case thematic analysis, which is featured Appendix 9, are presented. The themes are then explored in-depth and illustrated throughout with direct quotations from both the interviews and the PLRG group discussion. Finally, a chapter summary draws together and summarises the findings, laying the foundations for an in-depth discussion and theorisation in Chapter 5.

Pen portraits

Pen portraits for the eight interview participants Mandy, Roger, Ginnie, Carol, Nigel, John and Mike and Karen are set out below. As indicated in Chapter 3, interview participants' actual names have been replaced by pseudonyms, and their accounts have been anonymised to safeguard confidentiality in line with social work and research ethics (Banks, 2012; Kara, 2017). Mike and Karen are presented together as they took part in a joint interview, whereby Karen supported Mike's participation but also offered her views and experiences as a family carer. Informed by Hollway and Jefferson (2013, p.32), the intention of including pen portraits in this way is to make the participants come alive for the reader and, consistent with the theoretical principle of *gestalt*, to provide a substitute whole, allowing the reader to have a more meaningful grasp of the person. In this section, direct quotations, are extensively used as deliberate device to privilege the voice of research participants in line with my stated commitment to participatory research (Aldridge, 2016; Kara, 2017) and are intended to convey participants' lived experiences more clearly.

Mandy

Mandy is a Black British woman in her mid-20s. She is a writer and a student of creative arts. She volunteers with two organisations that provide art workshops for disabled children. She has a progressive medical condition and is a wheelchair user. Mandy lives in her own flat, has a personal budget and uses direct payments to employ several Personal Assistants (PAs) who help to meet her care and support needs.

Mandy's mother was her main carer up until the age of 20. Up to this point, Mandy was living at home and was unknown to the local adult social services team. Mandy was not able to continue living at her mother's house because it was no longer accessible. Mandy's initial contact and experience of assessment were challenging, and there were significant delays in having an assessment and getting support put in place. Mandy thought that social services struggled to understand how she had not needed help before and why her mother was not able to support her more. Mandy regrets 'playing down' her condition when she first contacted social services and learnt that it is best to not ‘big up’ what you can do. Mandy realised in her later interactions with social services that she needed to tell them not about everything she can do, but what it is like on her worst day. Mandy was frustrated and dismayed with ‘panel’ (local authority social care funding panel), who she said would ‘shoot down’ social workers asking for more hours on her behalf. Mandy feels that over time she has better learnt how to navigate the system, including the use of relevant jargon and terminology.

Mandy experienced a year of appeals about her personal budget and, during this time, a lack of responses to her emails and phones calls in which she was seeking an update from her social worker. During this period, Mandy had a fall in her bathroom, broke her leg and was hospitalised for three weeks. In her own words, this was a ‘very traumatising experience’ for Mandy. When discharged from hospital, support from a care agency was put in place as part of reablement. According to Mandy, not only was the care regimented and ‘a revolving door of carers’, but Mandy also explained how the carers seemed to hate their jobs, and how they left her feeling disgusting. Mandy described being reduced to ‘bodily functions’. Mandy contrasted ‘agency’ care with what she could arrange with direct payments. She spoke favourably of direct payments, which she now has, while acknowledging the responsibilities they entail. For Mandy, PAs are experienced like friends, so for her shared interests are more important in terms of PA recruitment than professional experience.

Mandy spoke about her disability being taboo in her African cultural background, how it can be seen as a family curse, and how there is a focus on trying to fix it or find a cure. Mandy contrasted this with the notion of living with, and having adaptations for, disability. Hope, prayer and optimism characterised some of her family’s responses to her condition. Mandy’s mother had difficulty accepting that Mandy’s condition was not going to improve. Similarly, Mandy felt that her social worker was not able to understand her condition and failed to present her case to panel in a way that they would understand her needs. Mandy was angry about austerity and felt that the government was wilfully providing inadequate care in the hope that people would die off.

Roger

Roger, a British Asian man in his mid-60s, has recently retired after having a long and successful career as a senior manager in a leading British company. He is married, has adult children and lives in his own home. Roger has a visual impairment. He is passionate about rights and equal opportunities, particularly for disabled job seekers, and is on the board of trustees of several charities. Roger does not have a personal budget; his care and support needs are met largely via informal carers. In the past, he has received rehabilitation and mobility advice from the local social services Sensory team.

Roger spoke about the struggle to come to terms with his sight loss. He talked about his experience of shock, denial and sadness associated with losing his sight at the age of 17. Looking back, he thought that he could have benefitted from having counselling to help him work through the experience. He also thought that coaching, mentoring and more tailored flexible support could be helpful for people with sight loss, particularly in the early stages of diagnosis. He thought there was a need for positive support at critical times to deal with difficult feelings. Roger also spoke about frequent encounters throughout his life, in education and employment in particular, with people’s assumptions and low expectations. He thought this was a common experience for people with sight loss. Roger’s recent retirement, and the loss of his role and social status associated with work, put him more acutely in touch with these earlier painful feelings. This he referred to as his ‘cycle of experience’. Roger emphasised the negative impact that low expectations can have on one’s self-esteem.

Roger’s more recent experiences with social services have been disappointing. He described how he has been trying to get some help to explore a new mobility aid as what he currently uses is no longer fit for purpose and is causing him pain. He experienced the service as unresponsive, inaccessible and rejecting. Eventually, he sought help from a fellow charity trustee to obtain the contact details to write to a senior manager in the local authority to get a response to his inquiry.

Roger also emphasised the importance of informal care and support structures, notably his family and friends. Roger emphasised notions of reciprocity in such relationships. He described how important it is for him to be able to give back to people, and to the community more widely. Roger described how when at university and in his former workplace he would informally mentor people that provided him with the support he needed associated with his sight loss. Roger felt proud that many people who he supported went on to progress in their careers.

Roger described the impact of his Asian cultural background on his experience of having sight loss. This included a negative impact on family status, religious beliefs such as ‘you are blind because of the bad karma you created’, and experiences of being over-protected and ‘smothered’ by people who assume that you are not capable of doing anything, and need protection. Status, progression in life, self-sufficiency and how one is perceived by society were also emphasised by Roger and he associated these values with his cultural background.

The next three participants, Ginnie, Carol and Nigel, all use their personal budget to access support from a local centre-based charitable organisation for people with learning disabilities, disguised in the data set as ‘the centre’. The centre provides a range of centre-based group activities, life skills courses, exercise classes, art and music classes, excursions and community-based activities and access to work and employment-related support. Group activities at the centre are organised according to a timetable, and service users typically attend a set number of days, between one to five per week. The centre also has an outreach project which provides one-to-one support to facilitate access to the community, health services, learning and employment opportunities, and to assist in meeting other activities of daily living.

Ginnie

Ginnie is a white British woman in her early 50s. Ginnie leads a full and busy life which includes volunteer work, regular social activities with friends and active involvement in the centre, which she attends several days a week. Ginnie thought it was important that I, and others, understood that she had a learning disability and preferred this term to ‘learning difficulty’. Ginnie lives in her own flat. One of her siblings moved in after the death of her mother around five years ago. Ginnie has a personal budget that she uses to pay for one to one and group support from the centre.

Ginnie associated personalisation with her personal budget, and in particular the support she receives from the centre. Ginnie spoke very favourably of the support she receives from the centre. She described it as a ‘lovely charity’ and the staff as ‘fantastic’. Ginnie outlined how the people who use the service are called members rather than clients or service users. Ginnie explained that there are some members at the centre who are her best friends, and who she calls her brothers and sisters. Ginnie appeared to take pride in being an active member of the centre and in taking on more senior roles and tasks, such as working on reception and collating lunch orders. She also told me about opportunities to be involved in European Union funded projects which culminated in her travelling to, and presenting at, a conference in a European capital. Ginnie outlined her schedule of activities at the centre and how she makes some choices of activities but also trusts the staff to plan things for her.

Ginnie explained to me some of the detailed aspects of her personal budget. She told me she receives a statement every month from the council, and how she is required to pay a charge towards the cost of her service. While at times she was a bit confused about the mechanics of her personal budget, she explained that she uses the personal budget to pay for her transport to and support at the centre – which she attends for three days a week.

Ginnie explained that she started receiving services in her own right from the Council after her mother had died. Prior to that time, it appears that she lived with her mother, and they largely met each other’s care and support needs without support from the local authority. Ginnie explained that she had been a carer for her mother for ten years before she died. She said that the centre had provided emotional support after the death of her mother and this was very important to her.

Ginnie explained that having her own flat, looking after herself, and keeping safe were things that were important to her. Ginnie said she loved having her own flat and appeared to be very proud of it. She had a new kitchen fitted recently and was looking forward to starting cooking more herself soon. Ginnie said she valued having choice in her life, but sometimes felt that her siblings boss her around and tell her what to do. She was not happy, but also somewhat resigned to the idea of her siblings imposing rules and restrictions on her freedom.

Carol

Carol is a Black British woman in her late 50s. Carol has grown-up children and lives alone. She has two cats. Despite having some physical health problems and long term conditions which affect her mobility, Carol enjoys a range of hobbies and creative pursuits, including swimming, poetry, pottery, drawing and playing the guitar. She enjoys making other people laugh. Carol does not like labels, particularly those applied to people about mental health. Carol has a personal budget, which she uses to access support from the centre for three days a week, and also receives some support from mental health services.

Carol has had a hard life. She has felt let down and hurt by the council, social workers and other professionals many times in her early years, and throughout her adult life. She told me about some painful experiences of loss. She reiterated several times that she does not trust authority figures, and is aware that this is because of her past experiences.

Carol was not familiar with the terms personalisation or person-centred support. She appeared to be apprehensive about the notion of personalisation. Carol was keen to convey the complexity of her lived experience to me. Carol also raised concerns about the government and the political direction of the country. She spoke about privatisation and was concerned about public buildings and facilities being sold off. She was worried about people who need housing and support not getting it while the ‘rich get richer’.

Carol highly valued the support she receives from the centre. She described the centre as like her home and spoke about how the staff and other service users at the centre are like her family. She described the centre as a lifeline and said she feels loved and wanted at the centre. To emphasise the point, she said she wants to ‘marry the centre’. Carol also spoke about how she sometimes worries about the staff and wants to make sure they are okay. She said that sometimes she will offer them hugs. She told me about a resource centre she used to attend years ago, when she lived in another area, that was closed down, and the loss in particular of someone involved with the centre with whom she had enjoyed spending time.

Carol told me she had to look after herself from a young age and associated this experience with the notion of independence. She also associated independence with needing to be patient, learning, and needing inspiration. Carol told me that she does not like to be told what to do. Carol also emphasised how important support is to help her achieve her potential. She told me she wants to do a sponsored swim to raise money for the centre and felt that she could do the lengths with somebody alongside her.

Nigel

Nigel is a white British man in his early 30s. Nigel prides himself in being a creative person. Nigel lives at home with his parents and younger sister. He attends the centre one day per week, and is also undertaking supported employment training in a local shop. He is a dancer, and actively involved with a number of dance companies for people with learning difficulties. He has been on dance tours, nationally and internationally. He also enjoys yoga, fashion, going to the gym and photography. Nigel likes elegant things, and said he wants to be rich and posh.

Nigel feels things quite strongly. He has had experiences of bullying, and said he does not always find it easy to fit in. Sometimes these experiences make him feel angry. He told me about a time when he got so angry that he broke some people’s possessions. He regrets what happened and the financial repercussions – he had to pay for the damage that was caused. He spoke about the freedom to be himself and express himself as being very important. Nigel was upset by the EU referendum result, which was announced the day before we met and was worried about the implications of the vote for the future of the country.

Nigel was not familiar with the terms personalisation or person-centred support. He was clear that independent living was important to him. Nigel frequently made references to being independent and independent living. By this, he meant making choices about and having control over his day-to-day life, as well as bigger choices about his life direction and career. Nigel’s goal is progressively to have more and more control in his life. For Nigel being able to travel by himself on public transport is important. He said that being clean, looking good, and making choices about what he wears were also important to him.

Nigel said that he receives direct payments, and has a social worker that he sees approximately once per year. He was a bit unclear on the details of his personal budget/direct payments, but thought that they funded some of his activities. Nigel said that he does not have a personal assistant or support worker, as he can do most things himself. Nigel spoke about the support he receives from his family, but was also very keen to emphasise that he also helps them and wants to take care of them more in the future. Being able to look after his family and also his friends was important to Nigel. Nigel spoke about past difficulties managing his own finances and accruing debts. He explained that his father is now in charge of his finances. He said his mother helps him with food shopping, and he helps her with meal planning for the family.

Nigel outlined his typical weekly schedule. He told me he wakes up early to do his chores and prepare for the day. He travels by himself to his dance company for rehearsals – typically three days a week. He attends the centre and works in the café when not with his dance company. In the evenings, he will sometimes go to the gym. He said that on the weekends, he enjoys having a posh breakfast, and will treat himself by drinking orange juice from a wine glass.

John

John is a white British man in his early 40s. John feels lucky about the life chances he has had, and the life that he is currently living. John enjoys working, volunteering, visiting family, socialising with friends, sporting activities and being able to use his income to buy ‘bits and pieces’ and pay for meals for his PAs when they are out. John grew up in a working-class family. He has a progressive hereditary impairment, and is a wheelchair user. He lives in his own home and has direct payments which allow him to receive support from a large team of personal assistants PAs. John’s family are important to him, and he explained that his parents have always been very proactive and supportive of the choices he made in life. John has many years of experience as a service user of adult social care. He is also working as an advocate for service users of adult social care – providing a range of information, guidance and support to his clients. John is a disability rights activist and will sometimes attend demonstrations.

John has extensive knowledge of and a keen interest and commitment to the concept of personalisation. John spoke about how important it is for him to be able to make choices about who supports him in particular. He outlined experiences before having direct payments, when the care and support were impersonal, restrictive and inadequate. Now, with direct payments, John is able to recruit and train his own staff in a manner that works best for him. This includes a preference when recruiting that candidates have no prior experience as a PA or as a carer in a formally trained setting, along with a preference for male staff. John has also gained increasing confidence in addressing any staffing issues that arise, including giving corrective feedback if work is not completed to an agreed standard.

Since the advent of austerity, John has seen a deterioration in his client’s experiences of adult social care along with his own experiences. John has seen multiple instances where assessment and review processes are experienced as punitive and stressful by people. In addition, John has seen support plans become more and more restrictive which is contrary to the foundational principles of direct payments and forces people to ‘break the rules’. John feels that how many of his clients are treated in the current adult social care system is unjust. John feels very confident supporting his clients but is very anxious when he has to engage with assessment and review processes for himself. John was keen to convey that support is vital in him being able to contribute and achieve what he does in his personal and professional life. Fear that this support might be withdrawn or reduced is triggered when social services instigate assessment and review processes. At such times John described feeling like a jellyfish: ‘no bones in it. Or anything. No substance. Just floating along, at the whim of currents of other people’.

While direct payments are highly valued by John, he did have a significant difficulty associated with employing his own PAs a few years ago. John was emotionally bullied by a PA for a protracted period. The PA undermined John’s confidence, and it was difficult to terminate their contract. Despite the difficulties associated with this experience, John says he learnt a great deal, and the experience has proven useful in term of him being able to draw on this learning to support his clients with direct payments facing similar staffing issues in his current job.

John values the social model of disability and if asked what his disability is says that he replies, ‘society’. John thinks that the concept of personalisation is a very good idea, and thinks that the idea has not been given enough of a chance to work. He was keen to widen the focus of personalisation beyond social care and, citing the requirement for reasonable adjustments under the Equality Act, how there should be a shift from demanding support to demanding rights.

Mike and Karen

Mike is a white British man in his early 30s. Mike lives in his own flat, and is supported by a team of Personal Assistants employed via direct payments. Mike has a busy schedule that includes a variety of work-based and social activities. Mike is supported to be as independent as possible. His PAs support him to go shopping, plan meals and keep his flat clean and tidy. Mike enjoys DJ-ing, swimming, rock climbing and going on holidays with family and friends. Mike has learning difficulties and epilepsy. Mike was supported to take part in the interviews by his mother, Karen. Mike and Karen shared Mike's experiences by working through a PowerPoint presentation that charted his experience of self-directed support, and by sharing several of Mike's person-centred planning tools.

Mike had direct payments from children's services before his transition to adult services. When preparing to leave his specialist school, a group of family, friends and professionals was set up as a 'circle of support' and completed a PATH with Mike (a PATH is a more visual planning tool which helps to identify goals and make a plan for achieving them). Mike also became part of an *In Control* self-directed support pilot around this time. One of Mike's primary objectives was to live independently in his own flat (with support). After some protracted delays, Mike achieved this objective and moved into his own flat, in the same town as his family. Mike's care and support arrangements work well, but he does find it hard to recruit suitable PAs in the area he lives.

According to Karen, direct payments have helped Mike to have more flexibility and higher quality care and support arrangements than with traditional services. However, he has had the current budget for nearly a decade, and in that time it has never been uplifted. Increased staffing salaries and increases in staffing on-costs, such as the requirement to make pension contributions, mean there is a shortfall in his available budget. His family manage this budget shortfall by covering some shifts in an unpaid capacity. Mike was affected by the closure of the Independent Living Fund (ILF); a portion of his budget was previously funded by the ILF. Karen has observed increasing restrictions on permissible uses of personal budgets. Mike’s use of his personal budget to purchase a gym membership was challenged by social services. Karen thinks using a personal budget to pay for a holiday, something possible in the early days of self-directed support, would definitely not be deemed acceptable now. Initially, Mike and Karen were encouraged by the local authority to share their story to help promote self-directed support which they have been happy to do. However, they are now wary of sharing his story publicly, because they are aware that people are no longer receiving the necessary level of funding to have a personal budget like Mike’s. There is a fear that what Mike has might be taken away. The effects of austerity have been challenging for Mike. Karen worries too about the impact of Brexit and how an economic downturn associated with Brexit might adversely impact disabled people.

While moving out of his family home to live independently in his own flat was an objective for Mike, it was not an easy process. The family needed to think carefully about how to support Mike to transition to his own, separate home. This included changing his old bedroom into a guest room and removing any of Mike’s possessions from the family home. This was necessary to help prevent Mike from not wanting to leave the family home when he came to visit. Karen acknowledged that Mike moving to his own flat was experienced as a loss for the family as well as for Mike. One of Mike’s current objectives is to increase his informal social support network. Mike also wants companionship.

Despite receiving a personal budget from adult social care, Mike has little contact with social workers. His service is infrequently reviewed, and he does not have an allocated social worker. A review of his personal budget is overdue. Karen has also noticed a change in the role of social workers since Mike was first involved with the *In Control* self-directed support pilot. At that time, the social worker was not focused on the cost of the personal budget, and was more enabling of the whole process. Since austerity, Karen has noticed that social workers are much more remote, and thinks that they seem to want to avoid getting close, as this will make it hard if they have to deliver difficult messages.

Key themes

The research design yielded a rich data corpus and provided many possibilities for in-depth exploration from multiple perspectives. The table in appendix 9 demonstrates that a sizeable number of themes related to adult social care and social work in a policy context of personalisation emerged from the cross-case thematic analysis. As outlined in Chapter 3, the PRLG had a key role in analysing the data; extracts of the interviews with all the interview participants were subject to group discussion and reflection. I make extensive use of the PRLG analysis, along with my observations, in this section. The themes have been subject to a retroductive process, in which emergent hypotheses, from the PRLG and from me as a researcher, were continuously tested against new data. The themes have been further organised and grouped to facilitate clarity. They are set out below.

Meanings of personalisation

Exploration of what range of meanings service users of adult social care ascribe to the concept of personalisation was one focus of my research. Indeed, it formed one of my subsidiary research questions. In reviewing a selection of extracts from each interview, the PRLG were tasked with identifying and reflecting upon what personalisation meant for each participant. Based on this approach, and as the cross-case analysis demonstrates (Appendix 9), it was apparent that several participants associated personalisation with personal budgets. Interview participants also spoke about topics that included choice and control, interdependence, relationships, reciprocity and austerity, which are explored in greater depth later in this chapter. In addition, interview participants were also asked a direct question about what meaning personalisation holds for them. Here, space was afforded to the views and perspectives expressed by interview participants concerning this specific question.

Echoing notions of choice and control, John defined personalisation as having support that is tailored to the individual.

> *John: For me, personalisation, in the purest form, means it's support that suits you; you have control of it, rather than something you fit into.*

Roger indicated that he was not very familiar with the term personalisation but had heard it being used. He related it to the achievement of potential.

> *Roger: Personalisation is not a term which I've come to be very familiar with, or used it in my own, sort of, experience a lot. I have heard of it, and I understand what it means, but I think I have kind of interpreted it to be about the individual, and how … how do you as an impaired individual … me, or anyone with that impairment, achieve their optimum potential.*

Roger also emphasised self-knowledge and an element of self-reliance as key aspects of his conception of personalisation: 'it is about you understanding how to help yourself'. His views might be thought to accord broadly with notions of independence and reciprocity.

Carol was not familiar with the term personalisation. She initially associated it with privatisation, and appeared wary of it. Later in the interview, Carol indicated that for her personalisation meant: ‘To be able to actually be you. Do what you want to do, sort of thing. To the best of your ability’. Carol also went on to talk about the importance of looking after yourself and others. Her views seem to include meanings of personalisation that relate to austerity, choice and control and reciprocity. Ginnie linked her experiences of personalisation to having a personal budget which enabled her to purchase support to help her to look after herself. There were some interesting perspectives about this which were explored by the PRLG.

> *P1: I think she’d made a good life for herself. And she has a personal budget, so I suppose … I think she’s made choices, she gets on with her [siblings], she lives with one of them, she goes wherever she wants, she likes this [centre] very much, she has her friends, she meets them outside and she goes to the social club, she meets them at home. And … um … she’s projecting an image of being content. So, I think for her, personalisation has meant that she can build up the life she wants, based on what’s on offer around her.*
>
> *P2: That sounds to me like a rather rosy picture of the life she’s got. She didn’t sound to me so sort of fulfilled as you were I think implying then, P1.*
>
> *P1: I felt she was fulfilled. But then, maybe, just because …*
>
> *P2: I think the thing that stuck in my mind was how many times she said – in different ways – if it wasn’t for this [centre], I don’t know where I’d be, I don’t know who I’d be, or what I’d be doing. You know, there was a sense that she almost wouldn’t exist, or would have disappeared, or collapsed, or disintegrated, if it weren’t for the [centre] holding her together. And it was almost, to my mind, as though the personal budget was just incidental to this. It just happened to be where some of the money came from; it*

> *wasn't that she was conscious of using it in any particular way.*
>
> *P1: That's why I qualified by saying: she's built a life for herself, using her personal budget, based on what she finds around her. So I wasn't saying she has the ideal life, I was saying based on what she finds around her, on offer. You don't usually get a thousand choices, you get maybe two choices or three choices … (PRLG, Meeting #4)*

Here, the PRLG, in dialogue, bring a significant degree of complexity to the analysis of what meanings personalisation may hold for Ginnie. The functions of her personal budget are explored. Not only are notions of choice and control emphasised, but also some unconscious functions of the centre, which she accesses with her personal budget, are explored. While her personal budget may indeed be incidental, the personalised care and support that the centre provides to Ginnie were thought by some members of the PRLG to hold her together and prevent disintegration. As I will explore further in Chapter 5, such ideas have resonance with the notion of 'holding' Winnicott (1964) in which the mother's provision of a trusting and safe holding environment enable a child's growth and development, later applied to therapy via a consistent therapeutic frame. Holding might, therefore, be one important meaning of personalisation for Ginnie, illuminated by the reflections of the PRLG.

Mandy was not familiar with the term personalisation, but had very clear views on the importance of service users having choice and exercising control over their care and support arrangements. She was strongly in favour of direct payments, which she contrasted with experiences of regimented agency support. The PRLG had very clear views on what meanings personalisation held for Mandy.

> *P3: It means that she can organise her life how she wants. I mean, she talked about going to Bath. Lucky her! And she did that by saving her hours. So, actually, sort of saying: do I want this, or do I want that. And that's the whole thing about direct payments; you can just kind of say: I'll just stay in my pyjamas all day tomorrow, or something; because that then means I can go to Bath at the weekend. Or something. And I think that she understands … she's learnt very quickly and understands pretty well how to kind of manage things. (PRLG, Meeting #5)*

Here one PRLG member explores banking hours and using direct payments flexibly. Another agrees, saying 'Yes, she's working the system in the very best sense of the word, I think'. So too another, who says 'I think the same … It means she can live more of the life she wants to live… [and] nobody wants regimented and institutionalised care in their own home' (PRLG, Meeting #5).

When asked directly what personalisation means to him, Mike replied 'Um… it means… belongs to me… that I just work'. It might be possible that Mike associated personalisation with notions of something being personal or that belongs to him. At the time, Karen thought that Mike might associate the term with the work (presentations) they have done together about his story of personalisation. The term or question may not have been understood. Karen and some members of the PRLG thought that was the case, while others felt that Mike was not able to express his views because Karen interrupted him and prevented him from expressing his views in the interview. While the direct question about personalisation no doubt had limitations, I felt that Mike was nonetheless able to communicate something of the meaning that personalisation held for him as an adjunct to the wider narrative about his experiences of personalisation and self-directed support across the two interviews.

It became apparent as my schedule of interviews progressed that questions pertaining to meaning, as in ‘what does personalisation mean to you?’, were at times experienced by participants as a test of knowledge. It seems that irrespective of how I put the question, it was at times heard by both interview participants and PRLG members as ‘what is the meaning of the term personalisation?’. Indeed, the use of the term personalisation and direct questions about it in the interviews was robustly criticised in early PRLG meetings, with one group member asserting ‘it’s like saying something in Icelandic, and expecting them to react to it!’ (PRLG, Meeting #2). This is an instance where the PRLG helped to guide me, as a researcher with an epistemological challenge, and that helped in refining my method. Importantly, my research design, as outlined in Chapter 3, whereby I conducted an interview, presented extracts for discussion and observation at the PRLG and then undertook a second interview, also allowed for refining, and indeed personalising, my approach with each interview participant. Notwithstanding my view that it was useful to discover that the term personalisation might be considered meaningless or jargon by participants, I resolved not to use the term personalisation or to ask a direct question about it in subsequent interviews, unless the interview participant had already used the term themselves or, as was the case with John, whom I knew worked in the area of disability advocacy, I judged it to be a suitable question.

Interdependence

As outlined in Chapter 2, the literature review established that independence is a concept that is often associated with personalisation, and sometimes conflated with notions of independent living. Views about independence featured prominently across the data sets, and the notion is frequently problematised by research participants. Moreover, an independence-dependence binary is sometimes explicitly challenged. Ginnie explained what independence means to her with reference to her flat, living her own private life, and the freedom to come and go in her own home as she pleases. She said that independence was important to her, suggested that there were limitations imposed on her independence by her family.

> *Ginnie: It means I can go out whenever I like. Like sometimes my friends… My friends not allowed in 'cause my place is being redecorated. So when they call for me, they got to wait downstairs, where I live. It means I can go in when I want. Whatever time I come in. Whatever time I go out. Yes.*
>
> *Researcher: And that sounds like it's important to you. To do that.*
>
> *Ginnie: Yes. Like, when I go out, I have to tell my [sibling], and I have to tell [them] what time I'll get in as well. My other [sibling]. My older [sibling].'*

Mandy had very clear views on the notion of independence in relation to social care.

> *Mandy: …. And what I think, especially in terms of social care… should be this idea that independence includes support. Like, it's not about going off and doing something on your own, but actually about you going off and doing something with the right support means you can do it.*

Mandy called independence a fallacy and explained that, for her, interdependence is a more realistic descriptor.

> *Mandy:… You know, the way a baby relies on its mother for food and changing and stuff; or an older person relies on someone to help them with their clothes, or to go out, or to remind them of things. We're all interdependent on one another.*

Mandy spoke of her frustration and dismay with panel, who would 'shoot down' social workers asking for more hours on her behalf. It is not the social care funding panel but rather 'panel', and appears unreal, numb and detached from reality. Panel is characterised by Mandy as a mean-spirited, aggressive, adversarial, naysayer.

> *Mandy: Oh my God, they were like … they'd take the case to Panel, and the Panel would always come back. And I think the … sometimes you can have a really great social worker, and also not so great social workers. And I think the great ones are the ones who understand your condition, and they know how to spin it in a way that Panel can't shoot down your points.*

The panel appears to struggle to perceive and accept Mandy's dependency needs. The following account gives some indication of this protracted process.

> *Mandy: …when I want to go to the library, I want to go to galleries, I want to go to workshops, and the Panel's response was: Oh, in the library, you can just ask a librarian. And I was like: did you tell them that when you go to the library, you can't*

> *ask a librarian to help you to the toilet? Yes, they can help you find books, do a bit of scanning, whatever …*
>
> *And … or … travelling: They were, like, you've got an electric wheelchair, so you'll be able to travel. And I was just, like [to her social worker] did you not tell them that public transport isn't accessible, or trains take too long to wait for, or buses when they come are packed with prams, you know … it can get quite … can become quite an anxiety and stressful experience using public transport in a wheelchair. Did you tell them any of this? Clearly, she didn't, she hadn't … I don't know, like, it felt like she wasn't good under pressure, or couldn't come back quickly with evidence. Maybe that was due to a lack of understanding of the nature of my condition.*

In Mandy's account, there appears to be a complex interplay between reality, aspiration, dependence and independence. When her social worker presents her case to the funding panel, its members appear unable to bear too much reality about the limitations of what Mandy cannot do without support. The need for help with using the toilet appears particularly contentious, perhaps made starker by the juxtaposition with everyday learning and leisure pursuits – such as going to an art gallery or using the library. Panel's refrain of 'can't you do it yourself' or 'can't someone else do it?' requires that a 'watertight' case be presented by the social worker. Perhaps the language here suggests the panel can't bear thinking about Mandy's need for help using the toilet – an unconscious wish that her bladder and bodily functions were controlled and watertight. Also, the humiliation of the social worker not able to present a watertight case at the outset or make the package work seems to be a factor influencing the outcome for Mandy.

Mandy also described the care she received following a period in a hospital as regimented and certainly not personalised. She said that the care package she was given at the time essentially reduced her to bodily functions and ‘at those calls, if you do not use the loo, you’ll have to hold it to the next call’ or risk falling again. Mandy explained that she experienced the care as a revolving door of faces, who let themselves in while she was confined to her bed.

> Mandy: …I had no say in who came. I was given a key safe, so carers could let themselves in as I wouldn’t be able to let them into the flat, as I was stuck in bed until they got me out of bed. So it was just this revolving door of faces, and it was … it was probably one of my lowest points in years.

Not only was the care regimented but Mandy also explains how the carers seemed to hate their job and how their responses to her dependency needs left her feeling disgusting.

> *Mandy: Such a revolving door of carers, who just didn’t want to be there. A lot them would say to each other, speak like I’m not in the room, they would talk about how much they hate the job, or they hate other clients […]*
> *… And it was just sort of my lowest point. Sort of, feeling like, not just a burden, but something more subtle, that it was disgusting, disgusting that I need to use the toilet, or need to empty my bowels, because they’d talk about how much they hated doing that with other clients. So they must hate doing that with me as well. Like, I was just sort of made to feel, like, you were … yeah … a disgusting burden.*

Mandy described how care agency staff would complain about their poor working conditions in front of her, and to her. At times, she said, the carers were rough. She also described how one carer refused to attend to her personal care needs fully.

> *Mandy: One carer did the top half of me, the other didn't want to do the bottom half. She just didn't do, couldn't clean in that area. But I couldn't just have a half-shower, like, I have to have a full shower, you have to clean there!*

These accounts of Mandy's experience stirred some difficult feelings in the PRLG. One member felt scared, 'Oh, as I say, it frightens the life out of me, dear God…' (PRLG, Meeting #7). Others talked about human rights, asserting that there are basic things that we should expect from society and highlighting how everyone has the potential to have an experience like Mandy.

> *P3: You're just one paycheque away from being homeless.*
>
> *P1: Yes. And society, I think, for her … society needs to address those needs, when they occur, to whoever they occur, because it could be the next person. It could be the person awarding the money who needs that help (PRLG, Meeting #6)*

Similarly, a discussion also took place in the PRLG which focused on the concern that Ginnie might be thought of as dependent on a centre-based service and that this might be cast as bad.

> *P1: … And as for the charity, it seems likes it is a big support to her. But it's not in a dependent way. Because I'm sure the*

> *fact that she goes to the charity, and makes use of what they offer, that helps the charity as well. So it's not so much dependence, as inter-dependence [emphasised again], rather than independence. (PRLG, Meeting #4).*

In the above quote, an independence-dependence binary is also challenged and the notion of interdependence again invoked. Likewise, John had a critical perspective on notions of independence. He hesitated when first using the word independent in the interview.

> *John: It could be allowing you to have a piece of equipment that helps you to … erm… be – I hate the word: independent – but independent in quotes, because I rely on my PA's for everything, but I say I'm fully independent.*

John goes on to explain the meaning he ascribes to the term independence.

> *John: For me, independence has always meant having the control. So, even though I can't do something, if I'm able to say to someone how I like it done, that's me being independent, because I'm just using another person's arms, or legs, or eyes, or something like that. But it's still me that's the person doing it.*

Here John talks about control and, like Mandy earlier, emphasises what is possible with appropriate support.

When asked what the term independence meant to him, Mike replied excitedly 'independence of the seas!', the name of a cruise ship in which he had been on holiday with his parents. With Karen's help, Mike explained that independence had meant that he was separated from his mother and father. It later became clear that the separation was experienced as a painful loss for both Mike and his parents. Careful planning and strategies were instituted to help manage the loss for Mike. This included measures to prevent him not wanting to return to his flat when visiting his parents' home; such as not referring to the family home as 'home' when speaking to him, and not keeping any of his possessions at the family home. In the second interview, 'independence of the seas' was again discussed between Mike and Karen. The following exchange is particularly poignant.

> *Karen: Because it's actually a name as well for that particular ship. It means, M, the ship is called the Ship of the Seas, it's free to go where it wants to go. It's not stopped from going places. So it's independent, it goes places. Without having to worry. So you go places, on your own.*
>
> *Mike: It's got little ships on the side…*

From a psychoanalytic perspective, this might be thought to convey something of the experience of separation between little ship (Mike) and big ship (mother/parents) symbolically. What Mike's account demonstrates is that there are painful aspects of independence – including experiences of separation and loss. Perhaps too, the little ships on the side, be they tugboats or lifeboats – both having an equally important and necessary relationship with the big ship, convey something of the reality and truth of interdependence.

The importance of relationships

The importance of relationships with professional staff is strongly emphasised across the data sets. All interview participants shared details about such relationships and, while the experiences are unique, there were some commonalities. Characteristics of such relationships included empathy, shared interests and honesty. Where the participant employed PAs, the nature of these relationships were highlighted, and there are some particular findings associated with PAs detailed below.

For Nigel, Ginnie and Carol, relationships with staff at the centre were very important. For Ginnie, sharing jokes, having a laugh, and talking about football with staff at the centre was important. Ginnie also highlighted the significance of her support worker at the centre who she sees for two hours a week.

> *Researcher: And what kind of support does he help you with?*
> *Ginnie: He helps me to sort out… I get nervous when I cross the road.*
> *Researcher: Yeah?*
> *Ginnie: I get into a panic. And you know, if I've got any problems, like if I've got any letters that need sorting out. I just meet up with him.*

Ginnie indicated that her support worker is providing empathic emotional support, associated with anxiety when crossing the road, along with helping her with more practical matters. She highlighted how crucial she felt the support was that she received from the centre.

> *Ginnie: My experience of being a member of [the centre] is so lovely. And friendly. If it wasn't for [the centre], and my support worker, and all the staff, I … I would not know where I'd be. And, that's true. That's the Gospel truth.*

Likewise, Carol affirmed how important the centre was to her.

> *Carol: If I'd have had the opportunity, I would have put wheels on … wheels on … magic roller skates under the building, so that wherever it goes, it goes with us.*

Carol said she calls the staff and members her family, and joked that she wanted to marry the centre. Carol's affection for the centre appears to include an attachment both to the staff and members, but also to the physical building itself.

Relationships were held to be central to adult social care social work and personalisation by the PRLG. In addition to being implicit in the discussion, such views were sometimes more overtly expressed during the analysis of the interview extracts. For example, one member asserted: 'What is important is the process, and the relationship between the providers and the person' (PRLG, Meeting #5); on another occasion, another group member mused: '… personalisation is about relationships really. With the staff, with professionals…' (PRLG, Meeting #3). The PRLG would also regularly suggest questions for the follow-up interview with a participant that focused on eliciting more detail about the nature and quality of relationships with service providers and PAs. In the case of the latter, there was a particular interest in understanding how issues of boundaries are managed in the relationship with PAs. The influence of such questions led to the gathering of the following data, which focuses on the intimate, and perhaps unique, relationship that can constellate between a PA and a direct payments employer/person receiving care and support.

Relationships with PAs, for those interview participants that had them, were highly significant. Mike's PAs are carefully recruited by Karen and inducted into the role by more senior PAs. Karen explained that she would not use agency support, noting that Mike can find too much change, including in his staff team, unsettling. Karen explained that having PAs also opened up possibilities for Mike to be more embedded in his community.

> *Karen: …the nice thing for M has been … this lady who is a support worker [PA], has a partner. And M and him have become really, really good friends. So instead of him effectively being supported by a workers' bank, he is actually becoming part of their community. So when Frank might go swimming with M, Lucy is still playing her roles for M, or if when they have a shift with Lucy, Frank's with his mates … [indistinct] football was happening … he would get invited … you cook for them, and they cook for you. [M interjects]*
> *… Friends getting together, rather than I'm paid to be with you, and it's going to be on those terms, so whilst if that was happening in a paid service, that wouldn't be seen as being correct … personalisation is about allowing him to explore … be independent … and be part of his community, in the way I would be…*

Mandy was very enthusiastic about sharing the benefits she experienced by employing PAs via direct payments.

> *Mandy: …And it is great, in the sense of delivery of care. I've got carers who like the job. They like me. They listen. They're patient. They've got all the right attributes to be a*

> *carer, even though one of them never had any care experience before. But was interested in care, and sort of felt like she was giving back. And I thought that's great because I need help … and … um … getting on personally.*

Mandy highlights the importance of the relationship with her PAs – noting that it is important that they like each other and get on well personally. Indeed, Mandy affords less importance to experience as a PA, as indicated above. Having shared interests is more important and it is on this basis that Mandy recruits her PAs. John appears to have adopted a similar approach to recruiting PAs.

> *John: … I choose my PAs preferably because they've had no PA experience, or they've had PA experience but not in a sort of formally trained setting. That way it's a discussion about how I need to be supported, rather than what the traditional way of supporting me is.*

Both Mandy and John talked about the complexity of their relationships with PAs. For Mandy, she defined the relationship with one of her main PAs as friendship and highlighted how they would see each other for social events and on special occasions such as birthdays. John had a different view, though he appeared to struggle to define the nature of what is clearly a complex relationship for him.

> *John: Er … I wouldn't class my PAs as friends in the type of way you phone up and have a chat outside of work hours, or you meet up outside of work hours. But I wouldn't class them as employees … I do class them as employees, obviously, but I wouldn't class them as workers who are just*

> *there to do a job. I like to make sure that they're happy in their job, you know … if we're going out somewhere, I'll make sure, you know, that I buy them the meal and stuff … So it's less of a … it's more of a … I don't know … a partner, but not a partner, if you know what I mean [chuckles].*

There are a variety of other professional staff that service users and carers may form relationships with when accessing NHS and social care services. The focus of this professional doctorate is social work, and it is relationships with social workers that I sought specifically to understand. The findings indicate that for some interview participants, social workers were experienced as remote and unimportant. This was the case for Mike, Ginnie and Nigel. There are also few accounts of positive relationships with social workers among the interview findings. For some participants, the adult social care system was overall experienced as dismissive, detached and inaccessible. In describing his efforts of trying to get support from social services, Roger explained that he was told by a duty social worker on the social care access helpline that there is no team called rehabilitation, and that he was not an 'open case'. He described how he was trying to be proactive in trying to access some support.

> *Researcher: The support that you needed … it didn't sound like you were asking for a lot ….*
> *Roger: No, no. All I was asking for … I've not accessed or experienced any new form of mobility aids. And I have been hearing that plenty of things have changed: I've been using this long cane since 1971. Have they changed in any way? Are there any sonic devices? Can I use something better? Because my right arm … is not very strong, and I get huge arm aches. And my feet are not as balanced … So I need to*

> *work out some different strategies for going out because I am losing … I am losing confidence to go out…*

Roger developed very low expectations and did not think he would get any support from social services, despite being aware that he was losing confidence and needed support.

As I explore in the later section about austerity, for some interview participants and members of the PRLG, contact from a social worker can be a source of considerable anxiety. However, Mandy highlighted a positive example with one particular social worker.

> *Mandy: She was really open with me. She was great. With the cuts at the minute, they're not thinking about you going out to meet friends. Or even going to uni. It's just about: what do you need – sadly – to survive.*

Mandy's account of her relationship with her social worker indicates the characteristics she thought important for someone in a social work role. According to Mandy, the social worker was very open and honest with her about how the system works and the realities of what one can expect from social services in a context of austerity.

Reciprocity

Notions of reciprocity and giving back featured prominently in the interview data. The theme was evident across all participant interviews. Roger spoke about the support he would get from colleagues who he would in turn informally mentor and characterised this as 'an investment we make, in each other'. Nigel frequently emphasised the importance of taking care of family and looking after family and friends. He also emphasised the reciprocal nature of his relationships with his family: ‘Yes, family is important. Because they want to help me, and I want to help them’.

Sharing Mike’s story about his experience of self-directed support was one way that Mike and Karen said they wanted to give back and help others to benefit from self-directed support as Mike had done. In addition, Mike took pride in making planters, shelves, a bed frame and other items for family and friends at a workshop he attended as part of a wood-work community project. Likewise, Carol highlighted how looking after others, including fellow service users and the staff at the centre was important for her. She said, ‘I just like to think I do my input [sic]’. Similarly, Mandy explained that she was a volunteer mentor for disabled children. She also set out her ambition to improve the self-esteem of disabled children by challenging the lack of positive disability representation in the arts.

> *Mandy: … I’ve always wanted to write for kids, at the back of my mind. I just didn’t know how. And I’ve gained a really great understanding of sort of the worries kids have, and particularly those with disabilities, who never see themselves in books or things like that. So, I would love to kind of take the experience that I’ve had, and tell a story about … that included disabled characters, but had nothing about … their disability getting in the way of things, but … yeah … something … whether it’s a book or a theatre piece … [chuckles lightly]*

Volunteering at the centre and a local charity shop was important for Ginnie. She told me how she would greet people and answer the phone on reception and appeared to take pride in the contributions she was making. Finally, John set out how he is a trustee, volunteer director and disability activist – roles he undertakes alongside paid employment because he considers himself lucky and wants to help other disabled people to secure their rights and entitlements.

The PRLG took the theme of reciprocity a step further in their analysis.

> *P2: And that led me to think, in terms of a social services organisation in a borough, it might be worth putting training funds and resources into training people to be better peer group supporters […] Because I think all of us with experience of living with a disabling condition, or with disabilities, have got things to give to people in the same situation or worse, new to it. [What was said] made me think of peer support. (PRLG, Meeting #3)*

In what appears to be linked to a realisation of the value of their own lived experience, notions of reciprocity are related to peer support. This has implications for social work practice, which I will explore, along with other implications arising from my research, in greater depth in Chapter 6.

Cultural and religious considerations

While the data set makes no claim to being representative, my sample includes participants from a number of different cultures, religions and ethnicities. An opportunity is therefore afforded to consider these important aspects of identity along with consideration of matters of intersectionality with disability and other aspects of lived experience associated with personalisation. There are some particular findings related to culture and religion that emerged from the data which are featured in this section.

Roger highlighted issues of over-protection and impacts of family social status associated with disability in some cultures.

> *Roger: … for some of the Asian cultures, some of the African cultures, dealing with any kind of disability is hugely, hugely problem-some, because you're dealing with part of your spiritual, your religious, and all those types of things. So… you'll be very protected; but not only you, your family will have impact on the social status, and all sorts of issues like that… as a blind person or any disability, you will not be able to operate to your optimisable, realisable, potential. You will be protected continuously: you'll not be allowed to go out, you're not allowed to do things by yourself...*

The impact of religion, in particular, the notion of karma was also something that Roger felt was important to be understood.

> *Roger: … in Hinduism, in Jainism, in Buddhism I think as well, is this thing you have to deal with that it's what you've done in a past life, in your …. Many of these religions think that you have a reincarnation, another form of life after your death; … you will have whatever karma's you've created …you have to deal with that... In some form, in some way. So many people will say you are [disabled] because of the karmas that you've created.*

Roger saw personalisation as related to an individual's progression through life stages. In sharing these experiences and views on culture and religion, Roger explained that he was trying to emphasise the need to consider all dimensions of a person's individual and social circumstances. Roger's contributions draw attention to possible tensions between the individualising aspects of personalisation as it manifests in England, and Asian and African cultural and religious perspectives.

Mandy shared her experiences of cultural understandings about disability. This related in particular to views about disability held by her mother who was born in Africa, the country unspecified in the findings due to anonymity considerations.

> *Mandy: …in [African country] it is still very taboo; it is seen as a family's curse, and there is this … this heavy thing about wanting to fix it. There isn't the idea of living with a disability – that's looked down upon as suffering. The person is suffering because [of] losing a limb, or they're blind, or can't do something. As opposed to the idea of living with it, adjusting … so having adaptations that help you live with it… and that's a lot of the time driven by religion. If something's wrong, you pray, it will change. But no matter how much you pray, with my condition, it's not improving … it is getting … there is clear evidence that it's getting worse. So my mum had to adjust her cultural views around constantly trying to fix me, but actually accepting that I need a wheelchair now. And that's not a bad thing, it's there to help.*

Mandy's account draws attention to cultural and religious views in which the focus in relation to disability is on finding a cure, which is antithetical to notions of accepting, adjusting to and living with a disability – all commonly held cultural assumptions about disability, at least at a policy level, in England. Here, psychic defence mechanisms rooted in notions of denial would appear to be manifesting at a social level, cloaked in culture and religion. Questions arise about how such cultural and religious views, notably an incessant focus on cure, are mediated by social workers focused on strengths-based and recovery-orientated approaches. This matter will be explored in further depth in the next chapter.

Austerity

Strong feelings and opinions related to austerity and cuts to social care budgets emerged as a ubiquitous theme across the data sets. Interview participants' lived experiences of adult social care and social work in a policy context of personalisation, appeared to be impacted by austerity in a variety of ways. For some this manifested in anxiety about valued and hard-won personalised support arrangements being taken away. This was the case, for example, for Mike and Karen.

> *Karen: And when personalisation came along, after having quite a difficult few years, in education, and the limitation, and the non-inclusive segregated society … when personalisation came along, wey-hey! [exclaims] This is what … finally … we can see a future here. And now, by austerity and even by the Brexit vote, it's slowly being … you know … honed down on, and made smaller and smaller…*
>
> *[…]*
>
> *Karen: I'm not trying to make it political. But every time the country has a knock, the more disadvantaged people in the country suffer as a result of that. Whether it's [because of] the bankers [laughs], or Brexit!*

Carol expressed concern about services being closed and made links with privatisation and a lack of affordable housing. She was candid about her lack of trust in the government.

> *Carol: Because the government's taking away …what do you call it? Resource centres. I don't know what else. And put a private house in. Or whatever. So that those who really need them, don't get it. Too many people living on the street that haven't got anywhere to go, or anything like that.*

Mandy argued that austerity was a deliberate policy aimed at eliminating people dependent on social care.

> *Mandy: That's what they hope; that people just die off… it all sounds very conspiracy, but it's not. People have died. People have died for lack of the adequate care, having benefits cut, and nothing happened. Simply … once they've died, they're buried and forgotten about. And that's what the cuts are for, they are hoping people die off. If people die off, there will be less people dependent on it.*

Members of the PRLG said they could understand the anxiety that interview participants were expressing about services being closed and social care support being withdrawn. One group member asserted 'you can't have personalisation when the safety net has gone' (PRLG, Meeting #2).

Interview participants also described a number of impacts that austerity appears to be having on how social workers are experienced. As mentioned in the previous section, for Mike, social workers were experienced as remote. Karen linked this to austerity and speculated that remaining distant from service users might be a way of protecting social workers from some difficult feelings.

> *Karen: …Since austerity, we've had a change of social worker, and we've also … they've had changes in management every few years. So no one ever gets close to you, because by getting close to you, I think it makes it difficult for delivering bad and difficult messages.*

In describing her experience of having a social care assessment, Mandy highlights how the gate-keeping function of social workers may be more pronounced in a context of austerity.

> *Mandy: I felt like I needed three people at the most recent assessment because if you don't say it right, you don't get the hours. And I don't know the jargon or the terminology … those golden nugget words which get you the support you need. Because if you don't say that, then they can kind of … it's very easy for Panel to then veto any sort of hours for social life.*

Mandy also spoke about how she learnt over time that when it comes to social care assessments, she needed to emphasise her needs and avoid talking about what she *can* do. This required an adjustment, as it was contrary to her normal approach in life.

> *Mandy: When you have a disability, there's no way, even in school and in everyday life, I'd go around telling people what I can't do. Or bigging that up, as well.*

It is clear that Mandy did not experience the process of assessment as supportive. John's experiences of assessment, like Mandy, are not positive. In fact, John, who otherwise considers himself robust, becomes highly anxious – like a jellyfish – at the prospect of having an assessment. John outlined his typical response when he receives a letter from a social worker about an assessment.

> *John: …when you receive a letter, then you're going to have an assessment. It starts the worry: Oh my God! Are they going to cut my care and support? You know. What demands are they going to put on me? Are they going to tell me that I have to use alternative services? Are they going to cut the support, so I'm going to have to make my PAs redundant? How am I going to pay for that? Who would I get in their place?*

John's experience resonated with some members of the PRLG. One group member spoke about the influence of austerity on the social work role.

> *P3: [T]he social worker's pretending to be your friend; when actually, you know they're trying to reduce your hours, because of the number of cuts that are going on. (PRLG, Meeting #5).*

However, another group member had a different view and contrasted their positive experience with a social worker with an unsettling experience of assessment with the Department for Work and Pensions (DWP).

> *P1: I had a social worker and I felt she was on my side. But when I went for an assessment at the DWP, I felt that I did*

> *get somebody who was there to catch me out, show me up, or worse than that. Not on my side. (PRLG, Meeting #5).*

This contribution from the PRLG led me to reflect upon parallels and differences between people's experiences of DWP and social services led processes of assessment and review. The notion that service users may not perceive the differences between these separate arms of government as clearly as professionals might, and the impact of this on their experiences of adult social care and social work in a policy context of personalisation, along with other practice implications that emerged in the findings, is explored in the next chapter.

Choice and control

Notions of choice and control over care and support arrangements were central to some participant's accounts of their lived experiences of personalisation. Mandy talked about how direct payments had given her more control and flexibility in arranging her care. Her view was that direct payments were far superior to agency care.

> *Mandy: It was with agency carers … um … I wasn't in control of it. Before that, I was using Direct Payments […] And I think I felt I had a lot more confidence, a lot more say … if I didn't like a carer, or I didn't get on with one […] I'm the one paying, so I had more say and control in my care…*

Having control of who provides her support and how the hours are arranged was important for Mandy.

> *Mandy: Essentially, you become an employer. So, I was, like: I will take all of that on if it means I can then dictate the hours and the people that work with me.*

Mandy asserted that direct payments indeed gave her more choice and control, ensured that she was at the centre of her care and support arrangements, and allowed her to avoid having regimented care.

> *Researcher: It sounds like Direct Payments has given you more choice and control.*
> *Mandy: Absolutely. That's where it comes from. If you let the council do the work, the paperwork and the … using agency … it will be regimented. And they rarely divert from the regiments. You're not at the centre of it, you have to adhere to it.*

Some interview participants spoke about the limitations of choice and control in their lives. For Ginnie, there was a contrast between her experiences and expectations of choice at the centre and being at home with her siblings.

> *Researcher: Do you feel you have choice and control?*
> *Ginnie: Yes.*
> *Researcher: In your life?*
> *Ginnie: Yes, I do. 'Cause I can do what I like. But my [siblings] still boss me around. But that's alright.*

Ginnie explained that her siblings tell her what time she needs to come home and she begrudgingly accepts this, though experiences it nonetheless as bossy. Ginnie was happy to allow the centre sometimes to present her with circumscribed choices or to make choices on her behalf, for example in relation to lunch choices or travel itineraries. She was however unhappy with her siblings imposing rules and restrictions on her freedom. The PRLG explored this matter with reference to their own experiences.

> *P1: I think it's normal behaviour to… whatever normal might be… to… it's perfectly acceptable if you live with somebody, to tell them where you're going, and when you'll be back. I think any couple or family would do that. If you didn't it would be a bit remiss, really. If you've got a relationship with somebody, as a family member, or partner, and you're going somewhere, you say: I'll be back later, I'm just going around to the library or something.*
>
> *P2: Yeah, I think the difference with this, though, P1, is the implication that if you said: I'll be back at eleven, they would say: no, no, you've got to be back at ten, or something.*
>
> *(PRLG, Meeting #4).*

What the PRLG appear to be grappling with might be considered the intersection of personalisation with cultural and social mores in the home/family context. The impact of Ginnie's learning disability appear to be a factor in the PRLG deliberations but is not made explicit. Like Ginnie, Nigel explained that there are some significant limitations to having choice and control in his life. His parents manage his money and his direct payments on his behalf. However, Nigel was clear that he was happy with this arrangement and that making 'proper, big choices' in his life was more important to him. Such choices related largely to his career, but he said he also valued being able to make day to day choices, such as choosing what he wears.

A final dimension to the theme of choice and control related to experiences of choice and control associated with personal budgets being curtailed. John spoke with incredulity about an instance where a service user he had supported in an advocacy role was denied a request to purchase a food processor with a personal budget, with social services instead insisting his needs would best be met by putting in place a daily one-hour visit from an agency carer to prepare meals. Mandy also talked about restrictions on her use of her personal budget, and her anxiety that if she were to break the rules by doing something with her personal budget not explicitly set out in her support plan, she would have her support withdrawn. I recorded in my research journal at the time that Mandy's experience seemed more akin to someone receiving welfare benefits fearing a benefit sanction. Some members of the PRLG felt frustrated when presented with Mandy's story and resolved that advocacy was necessary.

> *P4:* [interrupts] *I had an advocate and it was* good. *Because he did help me out. But I do think she should have someone there, so she understands the whole idea. I did feel quite she didn't understand -*
>
> *P3: In the beginning …*
>
> *P4: - the whole process. Because she did not know how many hours she could use. What I'm trying to say is: she should have gone through this step, got an advocate, or someone she knew … [indistinct few words] … but I do find she didn't know about this…*
>
> *(PRLG, Meeting #5).*

The findings suggest that there is a wide gulf between the rhetoric of choice and flexibility and the reality of restrictions on the use of personal budgets. The PRLG were concerned that this is confusing and unfair for service users.

John felt that people are 'being picked on by social services' who are determined to 'just give them the minimum'. He also talked about the impact of proscriptive support plans.

> *John: People are told, because they're given their support plans, people are told: this is the budget; this is how we've worked out your support! So, there's no sort of working out … I'd like to use my … to buy a blender, rather than having a care agency; or … it's all set out there; and it's all neatly calculated, you know. Mr X will have a bath on this day, and then after the bath, Mr X will have X prepared for him. So … [laughs] … I can't believe it myself, I really can't. So I tell people to take it with a pinch of salt, and you know, it's their life, they should do what they need to do.*

John emphasised how direct payments are supposed to be flexible, and how people are often left confused and anxious about deviating from their support plan. A member of the PRLG admitted that, like one of the interviewees, they also do not follow their support plan. Another member of the group questioned the assumption that social services were unaware of this.

> *P3: But I'm doing that as well, with my care plan, right. It's not done in the way that they think it's done.*
> *P2: [The interviewee], and you, P3, may be wrong about how much they are aware of, you know, the way you spend the money. (PRLG, Meeting #5).*

The findings suggest that service users appear to be getting confusing messages about permissible use of their personal budgets which are both unrealistic and appear to provoke different responses, ranging from anxiety to defiance.

Chapter summary

This chapter has set out the research findings. Firstly, pen portraits of the eight interview participants have been outlined: Mandy, Roger, Ginnie, Carol, Nigel, John and Mike and Karen. Then, drawing on findings from the cross-case analysis, and with illustrations from the psycho-social interviews and PRLG analysis, key themes have been set out. This began with an exploration of meanings of personalisation. The key themes then followed: Interdependence, the importance of relationships, reciprocity, cultural and religious considerations, austerity, and choice and control. In the findings, independence as a concept associated with personalisation was problematised with the notion of interdependence advanced as an alternative. Similarly, relationships with professional staff, including PAs, characterised by shared interests, mutuality, empathy and honesty, were identified as an important aspect of adult social care and social work in a policy context of personalisation. Reciprocity, the notion of giving back – both in relationships with professional staff, family and friends, and also more formally via volunteer and mentoring roles – was another key theme. Some cultural and religious considerations have been identified, which suggest a need to consider social work practice implications. Experiences of both having and of not having choice and control also featured prominently in the data. Direct payments were valued by those who had them, and all participants with a personal budget experienced some confusion about permissible usage. Austerity impacted on participants' lived experiences of adult social care and social work in a policy context of personalisation in a variety of ways, including anxiety associated with services being withdrawn, experiences of social workers as remote gate-keepers, and assessment and reviews processes as frightening. Finally, there was also anger about the impact of cuts on vulnerable people. These findings will be analysed and theorised in the next chapter.

Chapter 5: Discussion

Introduction

In this chapter, the key themes that have emerged from the cross-case thematic analysis, as outlined in the previous chapter, are analysed and theorised. Each of the key themes is explored in turn. The discussion draws on the analysis conducted with the Personalisation Reflective Learning Group (PRLG) and my associated observations as well as my subsequent reflections and analysis. Many of the theoretical frameworks that will be utilised have been foreshadowed in previous chapters. This includes: a broad psychoanalytic and psycho-social framework (Freud, 1900, 1915; Bateman, Brown and Pedder, 2010; Bateman and Holmes,1995, Clarke and Hoggett, 2009, Hollway and Jefferson, 2013); with a social work focus (Bower, 2005, Cooper and Lousada, 2005); relationship-based practice (Ruch, Turney and Ward, 2018; Hennessey, 2011; Megele, 2015); and theorisation of notions of dependency (Cooper and Lousada, 2005; Dartington, 2010). However, additional theoretical frameworks and concepts will be drawn upon where relevant to the discussion. The themes explored in this chapter inform the model for social work practice that I go on to propose in the conclusions chapter.

Theme 1: Interdependence

The findings relating to independence and dependence appear to highlight the prevalence of unconscious fear and denigration of dependency operating within an ostensibly personalised system of adult social care (Dartington, 2010; Cooper and Lousada, 2005). Research participants were wary, and at times dismissive, of the notion of independence. Those with lived experiences of adult social care and social work within a policy context of personalisation appear to have encountered and rejected the false notions of independence and dependence within the social care system that were explored in Chapter 2. Indeed, the findings in general and in respect of some participants specifically, challenge the notion of an independence/dependence binary, and assert the reality of a mixed or more integrated (middle) state, one that might be termed interdependence.

Interdependence is a term that is associated with social psychology; when used in that discipline it denotes a focus on relationships between people which is held to be as important as the people themselves (Kelley and Thibaut, 1978). It is also associated with systems theory, where meaning is located in the ‘connectedness and interdependence of apparently discrete and separate experiences and actions’ (Dartington, 2010, p.20). In addition to applying this theory to large and complex entities, such as a business or indeed an adult social care department, we can also think of a ‘person as a system’ (Dartington, 2010, p.20). As outlined in Chapter 2, the term is also used by O’Brien (2013) in relation to social role valorisation and person-centred support. The key characteristics of interdependence that emanate from the research data include notions of connectedness, mutual support and non-pathologised states of dependence. Interdependence in this regard closely approximates with Fairbairn’s (1952) definition of mature dependence. Mature dependence denotes a developmental progression from infantile dependence, characterised by a recognition of the other person as being separate (Gomez, 1997; Fairbairn, 1952). Mature dependence involves making choices on whom to depend, and a wish to give as well as to take (Gomez, 1997). The notion seems useful regardless of any perceived limitations of one’s capacity for lesser dependence, for example, an adult with a learning disability. Indeed, the findings from my research suggest that Ginnie, for example, an adult with a learning disability, requires both holding (Winnicott, 1964), but also has a wish to give to others in her network. By denoting it as a developmental achievement, Fairbairn’s notion of mature dependency highlights the reality of our adult dependency needs and affirms interdependence, not independence, as central to healthy adult development. Viewed in this light, policies and services perversely badged as personalisation but based on ‘shallow and debased’ notions of independence and dependence (Ferguson, 2012, p.57) may risk thwarting, rather than facilitating, service users’ developmental progression towards mature dependence.

Dependency and professional anxiety

The defensive techniques observed in a hospital nursing service by Menzies-Lyth (1960) also appear to be in operation in the adult social care services encountered by some interview participants. This observation is consistent with Cooper and Lees (2015) account of defences against anxiety in contemporary human service organisations. For Mandy, for example, the funding panel, and perhaps the social worker, appears unable to apprehend and think about the limitations of what she cannot do without support. As outlined in the findings chapter, the need for help with using the toilet appears particularly contentious and, at times, is essentially denied. Mandy’s dependency needs appear to be unbearable to many people that she encounters within the social care system. I am reminded of T.S Eliot’s poetic musing, ‘humankind cannot bear too much reality’ (Eliot, 1941, p.44-45). Defences against anxiety, at both an individual and organisational level, appear to be in operation. Two defences, in particular, seem evident. Firstly, the separation of the tasks of assessment from decision making and budget allocation seems designed to split up the service user/social worker relationship. Related to this, there appears to be detachment and denial of feelings, not least of all because the panel makes decisions about Mandy, including denying her support, without having met her. These defences are analogous to the splitting up the nurse/patient relationship and the detachment and denial of feelings described by Menzies-Lyth (1960). Also, the rationing anxiety that Cooper (2010) identifies as one of a set of new anxieties that build on Menzies-Lyth's (1960) original thesis, and is associated with the contemporary political and policy context, is relevant. In my experience as a social worker working in adult social care, I vividly recall experiences of presenting to funding panels and frustrations that panel members were remote decision-makers who seemed able to make harsh budgetary decisions that I would have to communicate to service users.

While Mandy's account is perhaps the starkest, detachment and denial of feelings is something that many participants experienced in their contact with the social care system. This includes social workers, who were often experienced as remote, distant and inaccessible. It is as if they, like all humankind, cannot bear too much reality. Psychic defence mechanisms are intended to protect people from painful psychological experiences that are unacceptable to consciousness (Bateman, Brown and Pedder, 2010). According to Klein (1946; 1988a; 1988b), such defences have roots originating in early infancy when an infant is slowly introduced to the realities of separateness and the falsity of omnipotence. I felt disappointment and shame in my profession when I heard these experiences. Social workers might be expected to have an advanced capacity for bearing psychological pain, but the findings suggest that many practitioners and social care departments are having difficulty dealing with the anxiety stirred by contact with dependency as well as the 'powerful range of extra-organisational forces and pressures' associated with the contemporary political and policy context (Cooper and Lees, 2015, p.239).

During the research fieldwork, I struggled with the emotions that were stirred in me. In some interviews, it was difficult to hear and to bear some of the painful stories that were being shared. At times, the painful material I encountered left me feeling variously shocked, outraged, angry, sad, anxious, guilty and depleted. For example, Mandy's account of her requests for additional help from social services being rebuked, and her subsequent fall, which resulted in a lengthy hospital admission, left me feeling shocked, angry and sad. Such reality was therefore hard for me to bear. Consistent with Hollway and Jefferson's (2013) notion of the defended researcher, my research journal reflections recorded during the fieldwork phase indicate a growing realisation that anxieties about my own dependency needs were being activated. I became aware of my propensity to deny my own dependency needs. I began to wonder about my initial interest in personalisation, and why I might have been an early adopter and champion of it. If a 'very shallow and debased understanding of dependence and independence' (Ferguson, 2012, p.57) has indeed been influential in personalisation policy, I wondered to what extent I was unconsciously drawn to these features, which might be thought of as defensive as well as lacking reality (Wilson et al, 2011). During the PRLG meetings, the group also seem to be working through, individually and collectively, some painful realities about life, of living with a disability or long term condition, and the shared reality of our dependency. While personalisation may be liable to defensive appropriation at a policy level, the findings suggest that the concept is not inherently antithetical to realistic and truthful conceptions of dependence and independence. The lived experiences of adult social care and social work in a policy context of personalisation featured in this research refute the independence/dependence binary and assert the reality of interdependence.

Denial and strengths-based practice

As outlined in the literature review, strength-based approaches as a practice model for social work have been gaining traction and have been promoted by sector leaders in recent years (England. Department of Health and Social Care, 2019; Hardy, 2018; England. Department of Health, 2017). Allied with the pursuit of unrealistic and unattainable states of independence, strengths-based approaches may risk denying or obscuring dependency needs. Indeed, might strength-based approaches be a new guise for the pursuit of independence in adult social care? Social work practitioners need to be alert to how a focus on strengths might unconsciously collude with their own psychic defence mechanisms that function to defend against painful encounters with dependency. As with my experience outlined earlier in this chapter, such encounters can be painful because they stir anxieties associated with one's past and, inevitable, future experiences of dependency. In this sense, strength-based approaches can function as a defence against anxiety, legitimised as a practice model. So too, a focus on strengths rather than deficits might imply that needs and dependency are weakness. While strengths-based approaches are somewhat vague, they nonetheless seek to focus practitioner attention on strengths, personal assets and sustainable solutions (England. Department of Health, 2017, p.4). The research findings suggest that strengths-based approaches may have some adverse implications for service users and disabled people who are learning to live with impairments, and who may be working through their own emotional and psychological processes of adjustment. Mandy, for example, explained how she would minimise her needs and overstate her capacity for independence in assessment processes. Strengths-based approaches offer little guidance to social work practitioners meeting with such phenomena. Indeed, they may be counterproductive if deployed reductively and translated into practice with questions during assessment processes such as: ‘what are your strengths?’ or ‘what are your assets?’ I contend that there are some challenges for social workers associated with strengths-based approaches, particularly in a context of austerity with limited resources amplifying local authorities’ gatekeeping functions.

Key implications for social work practice associated with this theme include the need to take a critical stance and problematise notions of independence and strengths-based approaches when encountered in personalisation policy and practice in adult social care. Interdependence is a notion that can help social work practitioners to overcome an independence/dependence binary. As outlined in Chapter 2, the notion of independent living describes a much more clearly defined set of principles that originate from the disability rights movement and that are likely to better accord with social work values. Social workers can play a positive role in facilitating service users’ development, including a developmental progression towards mature dependence, by acknowledging and facilitating interdependence.

Theme 2: The importance of relationships

Interdependence might be thought of as one manifestation of a broader principle that relationships must be central to lived experiences of adult social care and social work in a policy context of personalisation. Like the study by Brophy et al (2015) referred to in Chapter 2, the findings indicated that relationships, including supportive and empathic relationships with professionals, are valued by service users. In the case of Personal Assistants (PAs), for some of the participants, the relationship was held to be more important than professional experience. The nature of the relationship between a PA and a service user can be very intimate and seems to exist on the boundary between the personal and the professional. Reflecting on my professional experience as a social worker working in adult social care and before undertaking this research I did not fully appreciate the extent to which PA's were such important relationships to service users. Notions of professional roles and professional boundaries are challenged in the service user and PA relationship. More generally, the extent to which relationships and their importance are recognised as being central to personalisation, and particularly social work practice in a context of personalisation, is questionable. Yet, the findings suggest it is necessary to consider how relationships manifest and are experienced by service users and social workers alike, at both conscious and unconscious levels.

Ginnie, for example, provides an example of some unconscious characteristics of relationships. Ginnie appears to require from staff supporting her and her services a holding type function. As noted earlier in the chapter, holding in this regard refers to the nurturing and caring behaviour a mother engages in with her child that results in a sense of trust and safety (Winnicott, 1964). The capacity for holding in both a physical and psychological sense is associated with an essential maternal function named 'primary maternal pre-occupation' (Winnicott, 1964 in Symington, 1986, p.314). Holding can also refer to the supportive environment, both physical and psychological, that a therapist, a social worker or an organisation, can provide for a person. The centre also appears to function as a secure base for Ginnie, a concept associated with attachment theory which refers to a base from which a child ventures into the world, but that is available to return to if they become distressed or in need of comfort and support (Bowlby, 1988). Ginnie’s relationships with staff and her services are mediated by such unconscious dynamics. What can be learnt from Ginnie is that an ability to perceive and respectfully to engage with such unconscious dynamics is an important dimension of relationship-based social work practice. Moreover, personalisation is sometimes invoked by local authorities to justify cuts and closures of day centres (Needham, 2012). Indeed, for a period after qualifying as a social worker, I believed that day centres were retrograde institutions that impeded social inclusion. What Ginnie’s experience indicates is that centre-based support can provide important functions, including holding and a secure base, which may not be conscious, nor easy to discern. Ginnie is not the only example from the findings that attest to the centrality of relationships to participants’ lived experiences of adult social care and social work in a context of personalisation. Overall, the findings support Fairbairn’s (1952) contention that people have a fundamental need to relate to and connect with other people, a position which was a forerunner to attachment theory.

The research findings seem to confirm the relevance and utility of relationship-based practice approaches (Ruch, Turney and Ward, 2018; Hennessey, 2011; Megele, 2015) for adult social care and social work practice in a policy context of personalisation. However, they also suggest that such approaches are insufficiently embedded in social work practice. It would seem that the legacy of the individualising care management model, in which relationships are neglected endures (Horder, 2002). The question, however, is why the legacy of this model might endure? The slow pace of change of local authority systems might be a factor, but it seems an inadequate explanation.

There are questions about the extent to which the individualising nature of care management found resonance with some conceptions of personalisation that might also be characterised as individualising. Also, care management models could be conceptualised as a formalised manifestation of defensive practice, the function of which is to minimise contact with people and their dependency needs. In this regard, it is not simply enough to abandon such models; it is also important to equip practitioners with the theoretical tools and the support necessary to understand and process emotional responses associated with their work. A more clearly elaborated personalisation and relationship-based social work practice model is in my view required. In Chapter 6, drawing on the research findings, such a model is proposed.

Theme 3: Reciprocity

The research findings assert the importance of reciprocity. Indeed, it was central to participants' conceptions of personalisation. Reciprocity is a notion that is linked to relationships and interdependence. In a sense, these themes form part of the same schema. The implication is that enabling reciprocity as part of social work practice in a policy context of personalisation thus becomes an important focus, much like the imperative outlined earlier in this chapter about supporting service users' developmental progression towards mature dependence (Fairbairn, 1952).

The importance of reciprocity is also reflected more widely in the literature. There are links with reciprocity to principles of social inclusion and social role valorisation. The features of social role valorisation were outlined in Chapter 2, but it bears repetition that enabling people to have valued roles in the community and society is its primary objective (Wolfensberger, 1972; Wolfensberger, 1983; O'Brien and Lyle O'Brien, 1998). Similarly, Duffy (2010, p.263) includes 'contribution – giving to others through family and community' as one of the six keys to citizenship. Reciprocity is thus acknowledged to be an important constituent of citizenship. Members of the PRLG highlighted the potential for reciprocity to be enabled via peer support. The emphasis in this regard is not about replacing professional support with peer support, but rather that it can be an adjunct form of support that also enables people to help others by sharing their knowledge, skills and experience.

Reciprocity can, however, find expression in the professional relationship between social workers and service users. Indeed, this research project involved me as a professional and Experts by Experience engaged in a dynamic process of reciprocity via co-production. My reflections, as recorded in my research journal, indicate that it was sometimes challenging to balance my commitment to co-production with constraints associated with the academic requirements of my doctorate. Moreover, my learning from this experience is that allowing reciprocity in the direct professional relationship involves ceding power, being open and allowing oneself to not know in line with negative capability (Keats, 1899; Bion, 1970). I sometimes found it to be a challenging experience. Such an approach may also not sit neatly with notions of professionalism and professional authority. Yet my learning from this research is that the fruits of being able to take up such a position and to allow service users to guide, take the lead and share their knowledge and skills are plentiful for all involved. Reciprocity is something that service users want and require and is an important aspect of citizenship. The implication, therefore, is that social workers have a pivotal role to play in enabling reciprocity to be realised for service users of adult social care.

Contribution focused practice

In my view, current social work practice models do not adequately address service users' need for reciprocity, a need I prefer to call the 'reciprocity imperative'. Strengths-based approaches could conceivably satisfy the need for reciprocity, but as was discussed earlier in this chapter, some aspects of strengths-based approaches can be problematic. Loosely defined strengths-based approaches are liable to translation into social work practice via the crude identification of strengths, whilst unwittingly deriding dependency needs as weaknesses. For this reason, I propose a conceptual reorientation towards a focus on contribution. This is not simply semantic. In practice, this would entail a shift from the identification of strengths, to consideration of what and how a person can contribute as part of a support planning process. Such contributions might be to one's family, peers, local community, or society at large. Specific examples identified in the research include paid or volunteer work, peer support and sharing tasks or responsibilities with family members. Co-production, at any level, also provides opportunities for contributing, for example in the development of a support plan or in the design and commissioning of services. A focus on contribution provides a means for the development and utilisation of people's strengths, whilst avoiding some of the pitfalls associated with an explicit focus on strengths associated with strengths-based approaches. It is proposed that this approach, whilst still embryonic in its elaboration, be termed 'contribution focused practice'. In the concluding chapter, I will propose further research and development of this practice model for social work with adults.

Theme 4: Cultural and religious considerations

Thinking and talking about differences associated with race, cultural and religion can be emotionally charged and anxiety-laden (Lowe, 2013). Indeed, as a defended researcher who does not identify as BAME, I am aware that I offer these observations about culture and religion with some apprehension. Nonetheless, there are some findings related to culture and religion that may raise questions about the implicit cultural underpinnings associated with personalisation policy. Broadly, this could be understood as individualistic versus more familial or communal cultural orientations. While such an observation might be made about the social care system in general, the matter is under-theorised in relation to personalisation. However, critiques of personalisation that focus on its co-option by neoliberalism (Ferguson, 2007; 2012) do implicitly acknowledge that the policy reflects the UK cultural and social context. Also, the findings draw attention to different cultural and religious understandings and responses to disability and illness. Erroneous notions of independence and dependence, recovery and strengths-based approaches may unhelpfully intersect with unfavourable cultural assumptions about disability and illness. Such notions need not be central to the policy and practice of personalisation in adult social care. The implication for social work is that practitioners need to be alert to psychic defence mechanisms with individual service users and their families, including those that might have a cultural or religious basis. So too, practitioners need to adopt a critical stance in relation to recovery and strengths-based approaches and to be mindful that they may obscure needs during assessment processes. Approaching personalisation in this way as a social worker is consistent with anti-oppressive practice (Banks, 2012; Dominelli, 2002; Thompson, 2016).

Theme 5: Austerity

As I write, the findings indicated that austerity is having an adverse impact on research participants' experiences of adult social care. This is consistent with the literature on austerity and its impact, which was outlined in Chapter 2. It is clear that cuts are causing huge anxiety, and service users are struggling to keep and defend the support and services that they need and value. In some instances, there is fear that what has been gained by processes of self-directed support will be lost as support is reduced or withdrawn. Indeed, such was its ubiquity, it is perhaps difficult to decouple experiences of adult social care and social work in a policy context of personalisation from experiences of austerity in the findings. Going further, I would suggest that austerity appears to be having some perverse effects on service user experiences. Firstly, social care assessment and review processes for personal budgets can be experienced as punitive, frightening and adversarial. John's visceral description of feeling like a jellyfish: 'No bones in it. Or anything. No substance. Just floating along, at the whim of currents of other people' strongly conveys the emotional impact of austerity. It was certainly a very affecting experience for me to hear and bear. John's experience suggests that fundamental survival anxieties were being activated, and has parallels with Klein's (1946) paranoid-schizoid position. This early mental state which characterises the early months of infancy and that continues to a great or lesser extent and can be activated at times throughout life, is a constellation of anxieties in which feelings of disintegration predominate (Klein, 1946). Assessment and review processes that activate such profound anxiety clearly run counter to notions of personalisation. I experience feelings of anger and despair when reflecting on such experiences.

In my research journal reflections, when findings related to austerity started to emerge, I wondered at first to what extent social care assessments and reviews might be unconsciously associated with DWP assessment and review processes. Work capability assessments which are widely experienced by ill and disabled people as unfair and draconian are a key feature of many DWP-led assessment and review process (Disability News Service, 2019). Perhaps service users may not perceive the differences between separate arms of government as clearly as professionals might, and approach any assessment or review, including those associated with adult social care, with trepidation? Psychoanalytically this might be thought of as transference of feelings associated with the DWP onto the social care system (Heimann,1950).

However, this only accounts for part of the dynamic. In a context of austerity, the gate-keeping functions of assessment and review processes in adult social care appear to be amplified. Some research participants report experiences of assessment in which the assessor is focused on determining what the person can do for themselves, or who else within their family or friends' network can meet their needs. They report having to learn to 'play the game', to minimise their abilities and emphasise their needs in social care assessment and review processes to secure or retain the support they require. The notion of playing the game implies an element of deception. One risk is that service users who manage to secure the support they require may be left with some residual sense that they have done so by deception. Also, as I will explore later in this chapter, there is a wide gulf between the rhetoric of choice and control and the reality of restrictions on the use of personal budgets. The relevant point here is that this can be confusing to service users and leaves some people thinking they are covertly breaking the rules if they deviate from their written support plan. These experiences could undermine service users' self-esteem and sense of personal integrity, especially when coupled with the toxic psychological impact of benefit scrounger discourses (Baumberg et al, 2012). In addition, there is a risk of denying support to people who need it but are unable to understand the unspoken and nuanced rules of social care assessment and review processes. Furthermore, there is greater potential for notions of who is deserving and undeserving, long disavowed by social workers since the days of the COS (Peel, 2012), to inform assessment and review processes. Indeed, a social care system such as this might also be described as paranoid-schizoid (Klein, 1946). As austerity impacts the adult social care system, it appears to be adopting polarised all good (deserving) or all bad (undeserving) approaches to assessment and review processes. The perverse effects of austerity on a social care system ostensibly committed to personalisation are a profound challenge for social workers committed to ethical and rights-based practice.

Depersonalisation

The findings revealed countless instances where interview participants recounted experiences that seem to run counter to the whole philosophy of personalisation. Interview participants and members of the PRLG appear to be describing encounters with a social care system that appears unreal, detached from reality and emotionally numb. Such a phenomenon might best be characterised as depersonalisation. In psychiatry, depersonalisation refers to a mental health condition in which one experiences feelings of detachment and unreality (Baker et al, 2003). There is no clear theorisation of depersonalisation in personalisation discourse. While personalisation implicitly seeks to overcome depersonalisation by, for example, seeking to put the person at the centre of social care policy and service provision, there is little theoretical consideration of why depersonalisation manifests and why personalisation is not a normative state across the social care system. While it seems likely that depersonalisation, as described above, might be amplified by austerity, it also seems clear that the phenomenon pre-dates the advent of austerity. Other factors, therefore, need to be considered.

As outlined earlier in this chapter, defences against anxiety associated with dependency are a prominent feature of the adult social care system (Dartington, 2010; Cooper and Lousada, 2005). Depersonalisation, as it manifests in the social care system might, therefore, describe individual and organisational defences against anxiety associated with dependency. In this sense, depersonalisation functions to protect the system and the staff working within it from unbearable anxiety. My contention is that in order to realise personalisation we must be able to perceive and bear manifestations of depersonalisation and, more importantly, the pain and anxiety that it seeks to avoid and defend against. Currently, it seems that depersonalisation is not able to be perceived, let alone the more painful realities it functions to defend against. Furthermore, in order to overcome the widespread phenomenon of depersonalisation in the social care system, I would suggest that practitioners and organisations must be equipped with the necessary resources and skills. This includes the theoretical and practical tools to work with their own and others' anxiety that stem from psychoanalysis and relationship-based social work. Without such tools I am not sure that I would have been able to bear the encounters with emotional pain and distress that I encountered as a defended researcher. I have reflected upon my experience and cannot identify any instances during the research when I had a countertransference experience of depersonalisation. If there were instances when I became detached from reality or numbed, I am not aware of them. What I am aware of is how taxing it was to bear many of the emotions I encountered and how important the PRLG and my doctoral supervisors were in enabling me to continue with the research.

Theme 6: Choice and control

Whilst notions of choice and control over care and support arrangements are evident in the findings, they featured less prominently than one might expect from reading the literature and policy documentation about personalisation. Choice and control was nonetheless an important theme. Being able to make choices, including everyday choices, and being able to exercise control over care and support arrangements, was important to research participants. Direct payments, for those that had them, were highly valued. There appear to be some differences between how choices manifest and are negotiated in social care services (for example centre-based support), with a PA and in a family context. The findings suggest that the limitations of choice and control in the home/family context may be under-theorised in relation to personalisation. The findings also suggest that the prominence given to choice and control at a policy level is not necessarily translated into lived experiences of adult social care and social work in a policy context of personalisation. The rhetoric-reality gap identified in Chapter 1, appears to manifest, at least in part, as a gulf between the rhetoric of choice and control and the reality of restrictions on the use of personal budgets. Cuts to local authority budgets associated with austerity (Duffy 2014b; National Audit Office, 2018a) appear likely to be a driving force behind changing practice about permissible personal budget usage. While further research is necessary, the findings suggest that limitations to choice and control in the form of onerous restrictions on personal budget usage are being implemented by ‘street-level bureaucrats' (Lipsky, 2010, p.3), namely local authority officers who are rationing resources, including social work practitioners and managers. This is despite personalisation as social care policy, including personal budgets, being enshrined in law in the form of the *Care Act 2014*.

Notions of choice and control might also be overstated in personalisation discourse. Some other important aspects of personalisation identified as part of this research, including notions of interdependence and reciprocity, appear to receive much less attention in the literature. This may be due to choice as a concept being favourable to neo-liberal conceptions of personalisation (Ferguson, 2007; 2012). This is not to diminish the importance of choice and control, as it is nonetheless an important constituent of personalisation and the lived experiences of adult social care and social work that were explored in this research. However, the findings suggest that choice and control might best be thought of as one of several important dimensions of personalisation. Indeed, earlier conceptions of personalisation that I enthusiastically embraced as a frontline social worker, including *Putting People First* (2007), promoted notions of choice and control alongside developing and sustaining relationships and citizenship in line with self-directed support. Personalisation at its inception was a useful vehicle that brought these important concepts into the mainstream of the adult social care system. However, over time these important features of personalisation, which are highlighted in the research findings, appear to have been sidelined as the influence of self-directed support on the policy and practice of personalisation appears to have receded. As noted in Chapter 2, self-directed support can align well with social work practice that is rights-based, participatory and citizenship-focused. I now find myself thinking that personalisation that is not firmly anchored in a self-directed support approach is limited and less likely to accord with core social work values. Similarly, reflecting on the findings of my research I also find myself thinking that some of the limitations associated with social work practice in adult social care in a policy context of personalisation identified in this chapter, including unrealistic notions of dependence and independence, can be addressed by adopting a relationship-based practice approach. In the final chapter, I propose a model of social work practice in a context of personalisation that seeks to integrate and align the findings from the research with a relationship-based social work approach.

Chapter summary

In this chapter, I have discussed the key themes that emerged from the cross-case thematic analysis. The theme of interdependence as a key aspect of the lived experiences of adult social care and social work in a policy context of personalisation has been explored with reference to Fairbairn's (1952) notion of mature dependence. Drawing on the seminal study by Menzies Lyth (1960) and more contemporary developments of her original work, dependency and links to professional anxiety have also been explored. In line with the reflexive nature of this research, I have related this to the anxieties that I experienced in my role as researcher. Furthermore, I have considered the defensive functions of notions of independence that may have drawn me to personalisation because they had resonance with my own defensive structures. Relationships, as a key aspect of personalisation, have been explored. Strengths-based approaches and their place within personalisation have been examined in relation to denial and professional anxiety. In the discussion, the need for social workers to adopt a critical stance concerning strengths-based practice has been outlined. Moreover, an alternative approach has been proposed: contribution-focused practice. It has been argued that this approach avoids some of the pitfalls of strengths-based practice, whilst satisfying the reciprocity imperative of service users identified as part of this research.

The theme of austerity and its impact has been explored. Related to this, a phenomenon of depersonalisation that appears to manifest as a system-wide response to anxieties associated with dependency has been named and explored. It was described as ubiquitous in the research findings, but is under-theorised in personalisation discourse. A case has been made that depersonalisation needs to be perceived, and social workers equipped with theories and skills from relationship-based practice and psychoanalysis to work with it. Finally, choice and control as a concept, and its place in personalisation have been explored. While it is an important part of personalisation, its overemphasis in social care policy does not accord with the lived experiences of service users. Rather, it is one important aspect of personalisation that is mediated by relationships, and interacts with notions of reciprocity and interdependence. The over-emphasis of choice and control in personalisation policy may reflect a shift away from principles of self-directed support. My research findings suggest that the principles of self-directed support should be core to personalisation policy. Also, my research findings have led me to the view that there is scope for self-directed support and relationship-based social work to be aligned and integrated. In the next and final chapter, the main findings and implications are summarised, a model of practice is proposed, recommendations are set out and some personal reflections are outlined.

Chapter 6: Conclusions

Introduction

This chapter draws together and summarises the findings, returns to the research questions, and offers some concluding comments on what has been revealed by what service users say about their experiences of adult social care and social work in a policy context of personalisation. Firstly, the main research findings are summarised. As part of this, implications, particularly those related to social work arising from the research, are identified and made explicit. I explore what the findings and data say about the role of social work in adult social care in a policy context of personalisation. Informed by such findings, a tripartite personalisation relationship-based practice model is then set out. The model draws on learning from the research, with key practice points aimed at addressing and connecting interdependence, reciprocity and choice and control. Next, limitations of the research are identified and discussed, followed by some further reflections on ethical aspects of the research. Possible areas for further research are suggested and a dissemination strategy is outlined to ensure that learning from the research is shared and has an impact. Finally, some personal reflections about my experience of this doctoral research journey are offered.

Summary of main findings and implications for social work

Participatory, psycho-social methodology

The research design, comprising a blended participatory and psycho-social methodology, demonstrates how such approaches can be purposefully used together to generate rich data in an approach more consistent with transformative methods and principles of co-production. Also, the methodology show-cased its capacity to generate qualitative findings that have depth. The reflective learning group with Experts by Experience supported the objective that lived experience and co-production be prominent features of the research design. Such features of the research design may appeal to social workers as it is consistent with many of the profession’s core values and ethics. There is scope to further refine and develop the methodology as part of and for, future research.

Focus on lived experience

Personalisation is a concept that held several meanings for research participants and the reflective learning group of Experts by Experience. However, there is a distinction to be made between familiarity with personalisation as a jargon term and its intended definition, and what meanings it holds based on lived experience. The research demonstrates that a focus on lived experience can help to restore meaning and purpose to aspects of social work practice that have become detached from reality and obscured by jargon. Beyond social work practice in a policy context of personalisation, this may have more general relevance for social workers whose practice is often at the behest of managerialist incursion by virtue of its state-mediated, politically-dominated nature.

Problematise notions of independence

Unconscious fear and denigration of dependency (Cooper and Lousada, 2005; Dartington, 2010), can be expressed in personalisation policy and practice by the idealisation of independence along with a denial of dependency needs. It has been argued that such defences against anxiety (Menzies-Lyth, 1960) can thwart rather than facilitate service users' developmental progression towards mature dependence (Fairbairn, 1952). The research findings indicate that social workers need to take a critical stance whenever notions of independence are encountered in their practice.

Interdependence and relationship-based practice

Lived experiences of adult social care and social work in a policy context of personalisation point to interdependence as a more realistic and truthful conceptualisation of reality. Interdependence closely resembles Fairbairn's (1952) concept of mature dependence. By perceiving and acknowledging the reality of interdependence, social workers' need to make use of relationship-based practice frameworks in support of service users' developmental progression towards mature dependence. The study asserts the central and important role that relationship-based practice has for social work in a context of personalisation. Relationship-based practice approaches are necessary, but not sufficiently embedded in social work practice in adult social care.

The defensive functions of strength-based approaches

Strengths-based approaches, currently acknowledged to be vague, risk casting dependency and needs as weakness. A similar critique can be made about recovery-based approaches. Legitimised as a practice model, strengths-based approaches may deny and obscure dependency needs and unconsciously collude with practitioners' own defences against anxiety. In addition, strength-based and recovery-orientated approaches might collude with cultural and religious assumptions and prejudices about disability and illness. Strengths-based approaches might therefore disproportionately disadvantage BAME service users and their families, though further targeted research on this matter is required. Furthermore, practitioners need to be aware that the vagueness of strength-based approaches make them liable to managerialist appropriation and, at the current time in particular where austerity predominates, to the perverse effects of rationing anxiety (Cooper, 2010).

The reciprocity imperative and contribution-focused practice

Reciprocity, the ability to give as well as to receive and to contribute to others, is an often unrecognised priority for service users of adult social care. The research findings suggest that conceptions of personalisation need to embrace this ‘reciprocity imperative’ more clearly. Social workers have a positive role to play in facilitating reciprocity. This might entail adopting principles of co-production in all aspects of one’s work with a service user and their family and identifying and supporting peer support initiatives. In line with the reciprocity imperative, I have proposed that strengths-based approaches be re-orientated to focus more explicitly on what a service user can contribute. I have suggested that a new approach is required, which I have termed: contribution-focused practice. Further research to develop contribution-focused practice is recommended.

The impacts of austerity

Austerity is a source of considerable anxiety, and it is affecting service users’ lived experiences adult social care and social work in a policy context of personalisation. Assessments and reviews raise anxieties as service users anticipate cuts to their personal budgets. Social workers need to be aware of how much anxiety is generated by assessment and review processes. In my view, social workers have an ethical duty to oppose cuts to service users' care and support arrangements, both overtly and covertly. Alongside this, it is also necessary that social workers adopt relationship-based practice approaches which provide theoretical and practice tools to respond to anxieties associated with austerity appropriately.

Depersonalisation

Service users described frequent encounters with what I suggest be termed depersonalisation – an adult social care system that appears unreal, detached from reality, and emotionally numb. Personalisation as a concept offers little to understand such manifestations of what might be considered its very antithesis. A clearer theoretical framework for understanding and addressing depersonalisation is required. Some ideas have been proposed in this thesis, including consideration of individual and organisations defences against anxiety. I have also suggested that to achieve personalisation, it is necessary to perceive depersonalisation and the anxiety that it seeks to avoid and defend against. It is necessary to equip social workers with the necessary theoretical and practice tools to engage in this work. Psychoanalysis and relationship-based social work approaches can provide such tools, though a more clearly elaborated model for personalisation is required and is set out later in this chapter.

Choice and control

Having choice and control over one's care and support arrangements is an important part of personalisation. Lived experiences of adult social care and social work in a policy context of personalisation attest to this, however, they also indicate that choice and control is mediated by and interrelated with other important priorities, namely relationships, reciprocity and interdependence. Social workers need to ensure that they attend to all these priorities in their work with service users and their families. Having choice and control is one important aspect of personalisation that is liable to predominate, as it may favourably accord with neo-liberalism. Choice and control may, therefore, be overstated in personalisation discourse. In addition, notions of choice appear to manifest differently in a home/family context, and this is under-theorised in personalisation policy. Further research on how personalisation translates into a home/family context is recommended. Service users receive confusing messages about choice and control. It is the salient feature of personalisation rhetoric. However, restrictions on personal budget usage are often both numerous and onerous. Moreover, a lack of clarity predominates about permissible use of personal budgets and being able to make changes to one's support plan. In the absence of clarity, service users can be left confused and uncertain that they are acting in accordance with the rules of personal budgets. Social workers have a positive role to play in providing the clarity that service users require.

The role of social work in a policy context of personalisation

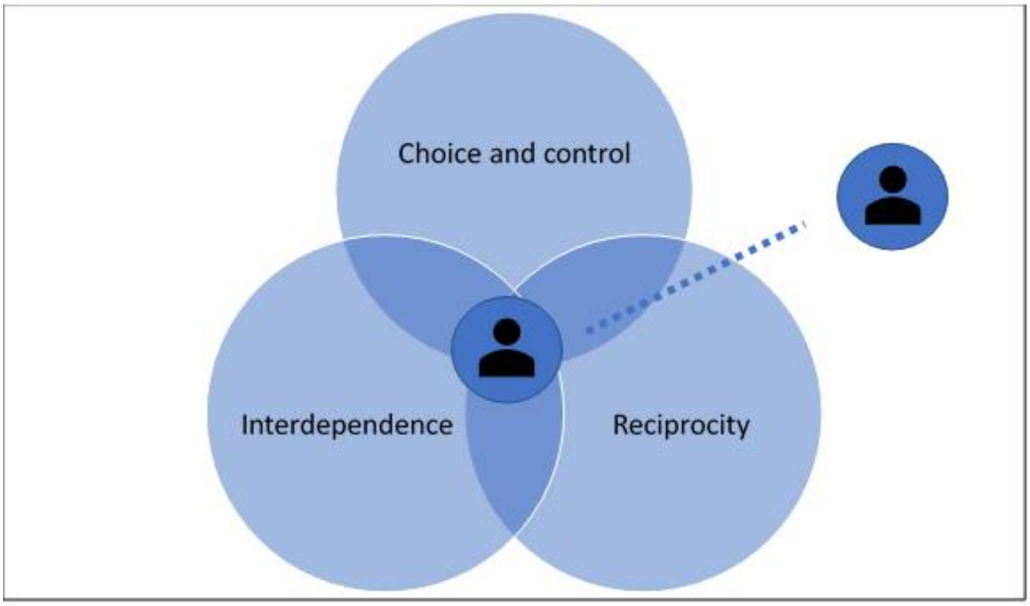
The data and findings highlight the important role of social work in adult social care in a policy context of personalisation. In Chapter 1, I set out my concerns and anxieties based on my own professional experiences of social work in adult social care. This included concern that personalisation may be antithetical to core social work values and ethics. This thesis has identified that anchoring personalisation more firmly in a self-directed support approach is more congruent with social work and this suggests a way forward for personalisation as a concept. However, social work also does not always live up to the ideals to which it aspires. The role of social workers as gatekeepers of resources in adult social care does not sit well within the model of personalisation I espouse here. Indeed, the data and findings reveal that the gate-keeping functions of social workers are met with disdain by research participants.

The findings explored in this chapter are instructive for the role of social work within an adult social care system committed to personalisation. The findings provide guidance for social workers in how to achieve the more realistic, more integrated or depressive position (Klein, 1946) approach to practice in adult social care in a policy context of personalisation that I suggested is required in the introductory chapter of this thesis. Social workers can enable choice and control for service users whilst asserting that it is only one aspect of personalisation. Social workers can put reciprocity at the centre of their practice, recognising that it is fundamental to service users' sense of self-worth and citizenship. Finally, social workers have a positive role to play in challenging unrealistic notions of independence, recognising and normalising and dependency and affirming the reality of interdependence. I now go on to develop these ideas into a proposed model of practice.

Personalisation: Relationship-based practice model

The research findings highlight some important aspects of personalisation that are instructive for social work practice. I propose an outline model below (Figure 5) that draws together three key and interrelated aspects of personalisation that social workers should attend to: choice and control, reciprocity and interdependence. The model will require further development and detailed elaboration. It is intended to provide a step towards the suggested integration of relationship-based practice with self-directed support, the need for which has been set out in this thesis. The development of a model for social work practice was an unexpected and unintended outcome of the research. The model sits within a relationship-based practice framework (Ruch, Turney and Ward, 2018; Hennessey, 2011; Megele, 2015). Relationship-based practice has been selected as a practice framework because of its congruence with the key theme: relationships. It also provides the necessary conceptual and practice tools for addressing each element of the tripartite model. The person at the centre of the model is intended to signify the service user and the person outside the Venn diagram the social worker. However, the social worker will need to meet the service where they are at in their developmental journey and the diagram is intended to convey the dynamic nature of the relationship between the social worker and the service user.

Figure 5 Personalisation: Relationship-based Social Work practice model



Key practice points for social workers for each element are as follows:

Choice and control

- Understand that choice and control is one part of personalisation
- Identify and enable choice and control (small and larger scale, with support)

- Recognise the differences and limitations of choice in family/services
- Be clear about the permissible uses of personal budgets

Reciprocity

- Recognise and affirm people’s need for reciprocity
- Collaboratively consider what can be contributed by the service user
- Value and facilitate all forms of contribution
- Use co-production in practice
- Identify opportunities for peer support

Interdependence

- Affirm the reality of interdependence
- Recognise and normalise dependency needs
- Support service users’ developmental progression towards mature dependence
- Continuously self-examine (with supervision/support as required) for defences against anxiety

The model accommodates the cultural and religious considerations necessary for anti-oppressive social work practice in a context of personalisation that were explored in Chapter 4. It does so by its focus on reciprocity and interdependence, which better reflects the diverse realities of service users’ lived experiences of adult social care and social work in a policy context of personalisation, is less individualistic and more collective and socially/family orientated. It is envisaged that this model can be a guide for social workers and can further evolve via an iterative process of learning and reflection.

Limitations

The research design facilitated a continuous process of challenge, reflection, learning and refinement of the research tools. Instances where the method has been refined have been outlined where relevant throughout this thesis. However, there are some particular limitations of the research which I have identified during this writing up phase. Firstly, in my approach to sampling and throughout this thesis, I have made no attempt to differentiate between experiences of adult social care and social work in a policy context of personalisation based on disability or impairment. Critiques levelled at research which fails to account for differences in the experience of some service user groups, such as older people (West and Needham, 2017), might therefore apply to this study. However, this might be more an issue of generalisability across all life-course stages, rather than disability or impairment. Such concerns might be addressed by including such considerations into the design of any future research of the model that has emerged from this research. Also, in terms of research design, I would have preferred an additional process of validation of the themes that emerged from the cross-case thematic analysis. Ideally, I would have liked to reconvene the PRLG and present the findings for discussion. This would also have been more consistent with principles of co-production, however, this was not possible due to time pressures and the difficulty of coordinating an additional group process after the agreed work of the PRLG had concluded.

Further reflections on ethical aspects

As outlined in Chapter 3, in devising my methodology, I had thought that the task of meeting research ethics requirements might be more complicated by virtue of my multi-method approach research design. Had I adopted a manualised methodology with a specified approach to research ethics, it may indeed have been simpler. However, there has been important learning associated with my approach. In Chapter 3, I set out how the research design aimed to follow principles of co-production and was informed by the ideals and methodologies of transformative and participatory research. In this section, I reflect upon the extent to which my research design met the transformative ideals to which I aspired, along with other ethical issues as they arose during the data collection, analysis and write up phases of the research. As the lead researcher, I acknowledge that I had authority and responsibilities that meant there was an unequal relationship with research participants – both the interview participants and the PRLG Experts by Experience. While there were some tensions, overall, my view is that the study largely succeeded in following principles of co-production, perhaps most clearly in the data analysis phase. The tensions included balancing the academic requirements associated with undertaking a professional doctorate with the research interests and priorities of the Experts by Experience. In terms of sequencing, the research proposal, in which the topic and research design are established, and ethical approval, were respectively submitted and granted before the first PRLG meeting could be convened. The notion that formalised research processes undermine more participatory methods is not unique to this study (Aldridge, 2016; McArdle and Reason, 2008). However, comparing this research design with a more conventional psycho-social study most clearly underlines the determined effort that has been made to pivot the research in a more participatory and transformative direction. The PRLG and the role of Experts by Experience, participatory elements that are central to the research design, are not characteristics of conventional psycho-social research studies. Involvement of participants in research processes can contribute to the ethical requirement to minimise harm (Ibhofen, 2011). The ethical credentials of psycho-social, or indeed other qualitative methods, could therefore be enhanced by adopting participatory features such as those included in this study. This research demonstrates that participatory methods and psycho-social methods can be effectively and ethically deployed in combination as part of an overall research design.

Specific issues that arose during the different research phases are now considered. During the data collection phase, on one occasion I was asked by an interview participant to provide some help to secure an increase to their personal budget. This risked blurring my role as a researcher and social worker; however, I resolved that it would be ethically permissible to provide some informal advice and guidance in a one-off, separate telephone conversation based on my knowledge of local authority social care systems. In doing so, I made clear the separate and limited nature of my support, and I sought to empower the person to advocate for themselves and to seek out advocacy and peer support services. In the data collection and analysis phase of the research, another ethical issue arose. An interview participant disclosed personal information of a sensitive nature. Despite having obtained consent from the participant, when I came to review the interview transcript, I considered the information to be of periphery relevance to the research but with the potential to be emotionally distressing if shared outside the confines of the researcher and participant relationship. In line with the research ethics requirement to do no harm (Social Research Association, 2003), I resolved to redact this information in the transcript and to exclude the information from the data set. During the write-up phase, some further ethical issues arose. Mindful of Bornat's (2008) concerns about over-interpretation, I decided to present the findings with extensive direct quotations from the interview participants and also the PRLG, where appropriate alongside my interpretations. In addition, in the pen-pictures, I sought to prioritise participants' own words about how they describe themselves and how they describe their condition, impairment or disability. Finally, with the ethical requirement to ensure anonymity and confidentiality in mind, I adopted broad categories with respect to age and ethnicity. At times I have changed some characteristics such as gender, age and ethnicity, in the interests of protecting confidentiality, but all such characteristics featured in the same ratios across the full interview data set. In this regard, I sought to balance research ethics, quality and reliability considerations.

Dissemination

As set out in Chapter 3, preliminary research findings were presented at a number of events and conferences, both regional and international. Not only did this provide an important source of data validation for the research it also provided an opportunity for dissemination of the research findings. Copies of the presentations and poster are located in the appendices (See Appendix 10, 11 and 12). Plans for further dissemination are as follows:

1. To enhance the accessibility of the research, I intend to produce plain English and Easy Read summaries of the research findings. Initially, these will be sent to the research participants, followed by circulation to my professional networks including the London Self-Directed Support Forum and the Centre for Social Work Practice.
2. To facilitate engagement, I will create infographics and data visualisation based on the research findings as suggested by Mollett et al (2017).
3. I will prepare a template PowerPoint presentation which will be adapted depending on the audience.

4. I will identify opportunities for dissemination at events and conferences.

5. I plan to write journal articles based on my research. I have a personal goal to have at least two articles prepared and submitted for review by the end of 2021. In the first instance I will submit my articles to the British Journal of Social Work, the Journal of Social Work Practice and Qualitative Social Work.

I will continue to identify other ways to disseminate the research findings.

Areas for further research

Some areas for further research have been proposed throughout this thesis. This includes testing and further development of the proposed Personalisation Relationship-based practice model with social work practitioners, further research to develop contribution-focused practice, research to explore how personalisation and notions of choice and control manifest in a home/family context and research about experiences of strengths and recovery-based approaches, particularly with BAME communities. Further research has also been proposed to develop and refine the blended participatory and psycho-social methodology utilised in this study. Also, I suggest further research that focuses on culture and gender insofar as it relates to lived experiences of adult social care and social work in a policy context of personalisation.

Personal reflections

My experience as a researcher of this topic has been variously illuminating, affirming and exhausting. Anchoring the research in lived experience no doubt added methodological rigour, but it also necessitated that I get close to people who shared some very painful feelings. These include people whose vulnerabilities, their dependency needs, had been coldly rebuked by a social care system that at times appears to be in the grip of what I have chosen to call depersonalisation. It also required that I reflect upon my own fears and anxieties associated with dependency. At times, this left me feeling despondent. I have learnt that practice-near research can be a very taxing endeavour. The research has changed my personal and professional understanding of personalisation. I learnt that having choice and control over care and support arrangements is important to service users, but more so are relationships and reciprocity. I learnt that people have a need to contribute and that this is often stymied for service users of adult social care. Such notions are marginalised in current personalisation policy and practice, perhaps due to the influences of neoliberalism, austerity and individualism. My experience might be characterised as an unfolding journey, in which the realities of personalisation, its pitfalls and potential, have been vividly and strikingly illuminated by my encounters with service users' lived experiences. The research design was based on a long-held principle, core to my identity as a social worker, that the process itself must reflect the outcome sought, thereby ensuring the 'integrity of the process' (Ife, 2002, p.122). To put this into practice, and for it to yield such bountiful research findings, has been affirming, both personally and professionally. However, the responsibility I have felt as custodian of the data, to the participants and the Experts by Experience who have generously contributed so much to this thesis, has frequently weighed heavily upon me. At this juncture, as the end of the journey comes into focus, my exhaustion is matched in equal measure by my steadfast determination that what I have learnt about lived experiences of adult social care and social work in a policy context of personalisation be shared.

Chapter summary

In this chapter I have summarised the main findings from the research and set out various implications for social work. I have reflected on the role of social work in a policy context of personalisation. Recommendations have been made in relation to social work practice, culminating in the presentation of a tripartite personalisation relationship-based practice model which focuses on interdependence, reciprocity and choice and control. Areas for further research have been identified. These include: further development of research methodologies which combine participatory and psycho-social research, contribution focused practice, BAME experiences of strengths and recovery based approaches and experiences of personalisation in the context of home/family. Limitations of the research and reflections on ethical aspect of the study have been presented. A detailed dissemination strategy has also been outlined to ensure that the research findings are shared widely and have an impact. Finally, I set out some personal reflections about my experience of the research.

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Appendices

Appendix1: Research recruitment flyer

Appendix 2: Research recruitment flyer (Easy Read)

Appendix 3: Extracts (sample)

Appendix 4: Participant information and consent form (Easy Read)

Appendix 5: Participant information and consent form (Interviews)

Appendix 6: Participant information and consent form (PRLG)

Appendix 7: University Research Ethics Committee (UREC) approval

Appendix 8: Sample interview transcript

Appendix 9: Cross case thematic analysis themes

Appendix 10: Poster presentation, ISFW European Social Work conference, Reykjavik Iceland, 28th – 30th May 2017

Appendix 11: Camden and Islington Social Work Research Forum slide pack, London, UK, 28th February 2017

Appendix 12: Presentation slide pack, SWSD Social Work conference, Dublin, Ireland, 4th – 7th July 2018

Appendix1: Research recruitment flyer

The Tavistock and Portman NHS
NHS Foundation Trust

PERSONALISATION

UEL
University of East London

Now recruiting!

WHAT?

- An exciting research project about personalisation is taking place in 2016. The project is about personalisation and finding out what it means to service users.
- If you have experience of Adult Social Care you can take part. This might include having a personal budget or experience of 'personalisation'.
- You will be invited to take part in two **confidential** interviews to share your views and experiences.
- The project is part of a Doctoral Research programme being undertaken by Andrew Richardson, a qualified Social Worker and personalisation project manager.
- A group of service users and carers from Islington with an interest in personalisation are involved in the project and will be helping to reflect on and analyse the results.
- The research has received ethical approval from the University of East London (UEL) and is based at the Tavistock Centre.

Share Your Experience!

WHY?

- Personalisation is jargon. We need to understand what it really means.
- Personalisation seems like a great idea. But is it?
- The research will be used to develop policy guidance to support service users of Adult Social Care. You can help to make a positive difference!

WHEN?

- The research will start in January 2016 with interviews taking place throughout the year. The interviews will be arranged at times and locations that suit you.

NEXT STEPS…

- For more information and to register your interest please contact **Andrew Richardson** by email: andrewj.richardson@gmail.com or phone: 0791 381 8524
- You will be provided with more information, including a detailed participant information sheet and consent form.

Appendix 2: Research recruitment flyer (Easy Read)

The Tavistock and Portman NHS
NHS Foundation Trust

PERSONALISATION

UEL
University of East London

Get involved in Research

What we are doing

An exciting **research project**

The project is about **personalisation**

We want to **find out what personalisation means** to people who use services

If you have **experience of Adult Social Care** you can take part

You will be invited to **take part in two interviews**
You can tell us
- what you think
- about your experiences

The interview will be **confidential**
This means what is said will be **private**

Why we are doing it

Personalisation is **jargon**
We need to **understand what it really means**

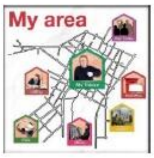
Personalisation **seems like a great idea**
We want to **find out if it really is a great idea**

The research will be used to **develop policy guidance**
It will help to **support people who use Adult Social Care**

You can **help** to **make a difference**

When it will happen

The research will start in January 2016



We will arrange interviews at **times** and **places** that suit you

What you can do next

For more information and to tell us if you are interested contact

Andrew Richardson
Andrew is a social worker and a personalisation project manager

[redacted] ☎ [redacted]

We will give you **more information**
We will give you a **consent form**

The research has consent from the **University of East London**

The research is based at the **Tavistock Centre**

Appendix 3: Extracts (sample)

First Interview with J, 7th Nov 2016

Extract number: 1

AR	**Ok. Excellent. Ok.** **So, the first question is … can you tell me about your experiences of personalisation?**
J	Yeah. I mean, I've been extremely lucky, because from a sort of younger age, even before direct payments came into place, I was told about the fact that you could get payment. So I had been given … um … a service … one hour, four times a day; one hour with the local home helps and care agency. Well, then I was told: actually, that might not be the thing that suits you best, have a think about *this* …
AR	**Uh-huh.**
J	So, right from ... ooh … I don't know … '93 or something like that, when I'd moved into my new flat, I was told about this possibility of having things done in a way that suited *you*, rather than just fitting into a system. So my experiences have been having practically all the control of the support I need, including … um … being able to choose who helps me, when they help me, who I employ … So after that first, initial home help thing, that went on for a couple of years, since then I've always had personalised support.
AR	**Right. Ok.** **So, how do you understand it, then? Because the idea of personalisation – it's the focus of my research – I'm interested to know what it means to people; how they understand it; but perhaps what it means in their lives.**
J	Ok. So, for me, personalisation in the purest form, means it's support that suits *you* [emphasised]; you have control of it, rather than something you fit into … And it could be by allowing you to … um … learn a new way of doing something; it could be by allowing you to have a piece of equipment that helps you to … erm … be – I hate the word: *independent* – but *independent* in quotes, because I rely on my PA's for everything; but I say I'm fully independent. So, it's having that choice about how you're supported, and being able to think about what it is you need help with, and the various different ways you could have that. And being able to choose which suits you best.
AR	**Right, ok.**
J	Facilitated to do that.
AR	**Ok. And you said you hate the word *independent*. I'd be quite interested if you could say a little bit more about that.**
J[chuckles]	Sure, ok. For me, independence has always meant having the control. So, even though I can't do something, if I'm able to say to someone how I like it done, that's me being

	independent, because I'm just using another person's arms, or legs, or eyes, or something like that. But it's still *me* that's the person doing it.
AR	**Yeah.**
J	But, nowadays, you hear so much that doing something independently is doing something without help. So, I think, unfortunately, the sort of rhetoric of the era is taken away from you being the person who's in control, to you not being a burden on society. Doing things yourself, without having to resort to some type of social care, or even … well … not having to rely on anyone other than yourself.

Extract number: 2

J	I wouldn't say there's personalisation. At all.
AR	**In adult social care?**
J	In adult social care, no. I … I would say that my experience about that, in general, has been where I work; my experience of having friends who live near me and myself, it seems to be better where I live, than where I work. But I wouldn't … I wouldn't … use the word personalisation at all, to be honest. It's: care; care and support.
AR	**Is it helpful to think about personalisation at all, as an idea, as a concept, do you think?**
J	Yes. I mean, you look at the Care Act guidance … I keep going back, and it says that the disabled person is the one that's the expert; they understand their own needs; and … er … social care staff should pay attention to that, give that consideration. But, in reality, it's … they still have the final say, and it's: this is what the arrangements in this local authority are: go to this agency, or you have a direct payment; but the direct payments are also fairly limited, because we're not allowing you scope with your support plan. I think it's paternalism, rather than wanting to be restrictive.

Extract number: 3

AR	**… What is the key learning, do you think, for social workers, based on your experience?**
J	I think probably they need to learn about what they actually *are* doing. And how it … how it differs from what they're supposed to be doing.
AR	**OK.**
J	So … the interpretation of the Care Act … you interpret it one way, I interpret it the other way … you know, it's interpreted your way, because that suits the funders and

	stuff, but doesn't suit disabled people. They're the ones you're supposed to be serving. So, how do disabled people interpret that? How are your actions affecting the confidence of the people that you're supposedly helping? How are your preconceptions affecting what the person really believes they'll be able to do? Because, you know, I have heard people say: oh, you won't be able to manage a direct payment; we'll just get you settled up with this agency. Well, why would this person, at this stage, even be saying: you won't be able to manage it? Why are they not saying: This is what's involved … what would you have difficulties with? Do you think there's someone that could take that on? Looking at solving problems, rather than saying: this is a problem, therefore we're not going to do anything about it. And the way they talk to people. I think … I think the biggest thing for me, as a disabled person, who uses services and has to go through the assessment processes, is my … when I'm contacted by social services, I'm like a jellyfish. [Loudly, emotionally] *Oh my God, there's going to come round, they're going to say … Oh my gosh, they're going to take away all my support! I'm not going to be able …* And I *work* in the field; and I support other people. And then social workers will say: people shouldn't feel *worried*; it's a good opportunity for people to explain the difficulties, and coming together, and identifying the difficulties, and coming up with the solution. But the reality is: you get a letter from the social services: you're a nervous wreck.

Pen picture profile

White British man.

Age circa 45.

Wheelchair user.

Works in a user-led organisation – providing guidance and support to service users.

I have chosen to not include more identifying details to protect anonymity.

Second Interview with M, 7th Nov 2016

Extract number: 1

AR	**… I thought I might give you an opportunity ... if you had any reflections on the [first] interview?**
M	Yeah, a little bit. I had … my mum raised a really interesting point. Like, there's a very distinct difference between the NHS and social services.
AR	**Yeah.**
M	And that … because this whole year's been so testing, with me and my health, that also this chronic ulcer… chronic pain .. this … [indistinct word] was sort of … the fault of the NHS's side, but the fracture is from social services' side. In our mind, it was sort of blurred, because of this year and how hard it's been. It's just blurred. Oh, this is all social services' … I'm like, no! It gets to a point where it, like, changes, so that had I had an adequate care package and support, there would have been someone at night to support me to go to the loo. I may have still fallen, but I might not have fallen and fractured my leg. And … and then … obviously had I not had a cast, that would never have led to an ulcer and hospital. So, it's almost like different things, the emotion … that the NHS and social services are different things. They are not the same. And that's just an interesting thought my mum sort of came up with. And, it's … oh yeah, it's true, actually.

Extract number: 2

AR	**Mmm, mmm.** **The next question … following that really … The group asked … how could the system be improved?**
M [exclaims]	Oh, God! They need more funding, clearly. That's the biggest one. That the cuts have been unethical. The cuts have been so unethical, but people who have made the cuts have not thought about the people living on this, using this, that with more money – with *less* money – they are hoping some of them will die off. That is the truth of the matter, to be honest. So … um … so, like, really lame analogy: but the idea of … you have a home, you have a job, everything's fine. You lose your job, you can't pay the rent, become homeless. You become homeless, you're cold, you're frustrated, you're sad, depressed, you take drugs, you drink, you drink to try and stay warm in the winter … you either freeze to death, or you die of an overdose. The house that you're living in just gets rented by someone else.
AR	**Mmm.**
M	That's what they hope; that people just die off. That's how they shed off … [clattering and clanking of wheelchair, turns off music] … it all sounds very

	conspiracy, but it's not. People have died. People have died for lack of the adequate care, having benefits cut, and nothing happened. Simply … once they're died, they're buried, and forgotten about. And that's what the cuts are for, they are hoping people die off. If people die off, there will be less people dependent on it. Um …

Extract number: 3

AR	**And what about, then, the relationship with the staff [PA's], and having to manage any conflict?**
M	Yeah. So, managing conflict for me, I try and always do it head-on. I mean, I think I was … I shied away when it was X Council in control of it. I don't know why, but I think because I've taken up the responsibility of employing, a little bit of confidence to say: because I'm paying you to do a level of care, if you're not doing that, then we need to address it. Why? Is there something going on in their personal life, or something? And if they can't commit, I can let them go, I can terminate the contract. [takes a deep breath]
AR	**Have you done that before?**
M	Fortunately not. I've only got two carers at the minute. I'm still trying to recruit more. But I'm sure that will happen in the future. And, because caring for me is my life. I cannot not take it seriously. And I think if I was ever in that position, I'd … yeah, I'd have to … it would be difficult … I'd call on my friends and family for advice and support; but I would have to do it. Because I don't want someone who I'm paying, or who X Council paying, to come in my house, and sort of disrespect me, or not deliver care to a certain standard. Because that affects me. It affects me not just physically, but emotionally as well. And I'm not going to sort of tolerate that. Yeah.

Pen picture profile (reminder)

Young woman – early 20's.

She's Black British.

She's studying creative arts.

She's a wheelchair user. Has a progressive physical health condition.

Lives in her own flat. Has a PB (direct payments)

Appendix 4: Participant information and consent form (Easy Read)

The Tavistock and Portman NHS
NHS Foundation Trust

UEL
University of East London

Information Sheet
Details about the research

Who is doing the research

University of East London
Tavistock & Portman NHS Foundation Trust
120 Belsize Lane
NW3 5BA

The University Research Ethics Committee has approved this research

If you have any questions, contact

Catherine Fieulleteau
Ethics Integrity Manager
Graduate School, EB 1.43
University of East London, Docklands Campus
E16 2RD

020 8223 6683 researchethics@uel.ac.uk

The Principal Investigator
The investigator is the person who does the research

His name is Andrew Richardson

c/o Tavistock Centre
120 Belsize Lane
NW3 5BA

[redacted]

Consent to Participate in a Research Study

This information will help you to think about and decide if you want to be part of this research

The name of the project

It's personal
Personalisation and what it means to service users

What the project is about

The research wants to understand more about **what personalisation means to people who use services**

You are invited to take part in this study to share your **views** and **experiences** of personalisation

There will be **2 interviews**
The interviews will be informal
This means they will be in a relaxed style

Each interview will be **about 2 hours**

What you say will be recorded

We will ask you about your **views** and **experience**

You will have time to **think** about these things

Some of the things you think about may make you feel **emotional**
This means feeling sad or happy or a mixture of feelings

Before the interview we will give you contact details of someone you can talk to about this

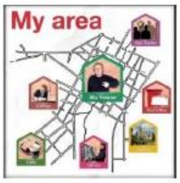
Confidentiality
We will keep your information **confidential**
This means we **will not share it with other people**

Data Protection Act 1998

We will do this through the Data Protection Act 1998 and University's Data Protection Policy

What you say in the interview will be **confidential**

Location
The research is based at the **Tavistock Centre**
They are working with the University of East London



Interviews will be held in a place that suits you

Things to remember

You **do not have to take part** in this study

If you do want to take part, you can **stop at any time**
We will not ask why you want to stop
Nothing bad will happen if you stop

This research will **not change anything** about the services you get

Consent to take part in the Programme

Consent means to **agree to do something**

The project is called
It's personal
Personalisation and what it means to service users

Name of researcher
Andrew Richardson

c/o Tavistock Centre
120 Belsize Lane
NW3 5BA

[redacted]

Please tick the boxes below

I have read the information leaflet about the research ☑ ☐

I have been **asked to take part** in this research ☑ ☐

I have been given have a **copy of the information** to keep ☑ ☐

I have been told what the **research is about** ☑ ☐

I have had the chance to **ask questions** about this information ☑ ☐

I understand what it being **planned** ☑ ☐

I know **what I will have to do** ☑ ☐

Data Protection Act 1998

I understand that my involvement in this study, and the data collected from this research, will be handled in agreement with the **Data Protection Act 1998**
This means my information will be kept safe ☑ ☐

If there are any **safeguarding** issues I know that my confidentiality may have to be broken ☑ ☐

I understand that **I will be interviewed** ☑ ☐

The interviews **will be recorded**
I have been told what will happen to the recordings once the research is finished ☑ ☐

I understand that some **quotes** and a **case study** from my interviews **may be published in the final report**
Quotes are things people say ☑ ☐

I understand that **my name will not be on the report** ☑ ☐

I understand that **my voice might be recognised** on the recordings ☑ ☐

I understand what is learned will be **shared with me** ☑ ☐

The final report **may be published** in professional journals ☑☐

I **agree** to be involved in the study
It has been **fully explained to me** ☑☐

I know that any information **can be used** in relevant publications ☑☐

I know that I can **stop being involved** at any time
I will not have to give a reason for this ☑☐

	**Print your name**
	**Sign your name**
	Investigators name **Andrew Richardson**
	**Sign**
	**Date**

Appendix 5: Participant information and consent form (Interviews)

The Tavistock and Portman NHS
NHS Foundation Trust

Participant Information Sheet (INTERVIEWS)

University of East London

Tavistock and Portman NHS Foundation Trust,
120 Belsize Lane
London, NW3 5BA

University Research Ethics Committee

This research has received formal approval from UREC. If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:

Catherine Fieulleteau, Ethics Integrity Manager, Graduate School, EB 1.43
University of East London, Docklands Campus, London E16 2RD
(Telephone: 020 8223 6683, Email: researchethics@uel.ac.uk).

The Principal Researcher

Andrew Richardson
c/o Tavistock Centre, 120 Belsize Lane
London, NW3 5BA, Tel: 0791 381 8524

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Project Title

It's personal. Personalisation and what it means to service users.

Project Description

The research aims to better understand **what personalisation means to service users**. You are invited to take part in this study to share your **views** and **experiences** of personalisation. Participants will take part in 2 in-depth interviews, spaced approximately 6 weeks apart. The interviews are not expected to take more than 1.5/2 hours each and will be recorded using an electronic recording device. The interviews will be informal and the questions asked will be very open and intended to provide a respectful and thoughtful space for you to explore your thoughts and experiences. The second interview is a follow up, which will allow for further in-depth exploration of any themes that might have come up in the first interview. Participation in the interviews may stir some difficult emotions. You will be given contact details for appropriate support before the interviews commence.

Confidentiality of the Data

Your confidential information including the interview recording and transcript will be handled in accordance with the requirements of the Data Protection Act 1998 and in accordance with the University's Data Protection Policy. Your interview will be anonymised to preserve confidentiality and will form part of the research data that will inform the results and conclusions of the research. As the sample size is small it means that there are implications and limitations to anonymity which the researcher will discuss with you.

Location

The research is based at the Tavistock Centre. Interviews will be held in a suitable location that is convenient to you.

Disclaimer

You are not obliged to take part in this study, and are free to withdraw at any time. Should you choose to withdraw from the programme you may do so without disadvantage to yourself and without any obligation to give a reason. Participation or non-participation in the research has no impact whatsoever on the continuation of any services you currently receive.

UNIVERSITY OF EAST LONDON

Consent to Participate in an Experimental Programme Involving the Use of Human Participants (INTERVIEWS)

Title of Project: It's personal. Personalisation and what it means to service users.
Name of Researcher: Andrew Richardson
c/o Tavistock Centre, 120 Belsize Lane
London, NW3 5BA, Tel: 0791 381 8524

- ☐ I have the read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.
- ☐ I understand that my involvement in this study, and in particular data from this research, will be handled in accordance with the Data Protection Act 1998. It has been explained to me what will happen once the research has been completed.
- ☐ I understand that there are limitations to confidentiality where disclosure of imminent harm to self and/or others may occur.
- ☐ I understand that I will be interviewed and that the interviews will be recorded using an electronic recording device and stored securely.
- ☐ I understand that some quotes and a case study from my interviews may be published anonymously in the final report.
- ☐ I understand that the small sample size means that there are implications and limitations to anonymity.
- ☐ I understand that the findings will be presented to me during analysis and that the final report may be published in professional journals.
- ☐ I hereby freely and fully consent to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications.
- ☐ Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS) …………………………………………………………………….

Participant's Signature ……………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS) …………………………………………………………………..

Researcher's Signature ……………………………… Date: …………………………

Appendix 6: Participant information and consent form (PRLG)

The Tavistock and Portman NHS
NHS Foundation Trust

Participant Information Sheet (Personalisation Reflection and Learning Group PRLG)

University of East London

Tavistock and Portman NHS Foundation Trust,
120 Belsize Lane
London, NW3 5BA

University Research Ethics Committee

This research has received formal approval from UREC. If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:

Catherine Fieulleteau, Ethics Integrity Manager, Graduate School, EB 1.43
University of East London, Docklands Campus, London E16 2RD
(Telephone: 020 8223 6683, Email: researchethics@uel.ac.uk).

The Principal Researcher

Andrew Richardson
c/o Tavistock Centre, 120 Belsize Lane, London, NW3 5BA, Tel: 0791 381 8524

Consent to Participate in a Research Study

The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study.

Project Title

It’s personal. Personalisation and what it means to service users.

Project Description

The research aims to better understand **what personalisation means to service users**. You are invited to take part in this study to share your **views** and **experiences** of personalisation. Participants will join a small Personalisation Reflection and Learning Group (PRLG) that will include service users of adult social care (Experts by Experience), academic research staff and social care professionals. All members of the PRLG will have an interest in the research focus: personalisation and what it means to service users. The PRLG will function as a reflective learning group and will be facilitated by the lead researcher (Andrew Richardson). The PRLG will assist in the formulation of questions that will be used as part of the research interviews, engage in analysis and discussion about research data (including anonymised interview data) and will share their reflections about personalisation policy in particular in relation to the interview data. The PRLG will meet regularly (approximately every 6 weeks) for a period of at least 12 months during the research project. PRLG meetings will be approximately 2 hours and will be held in an appropriate, accessible and convenient location. Participation in the PRLG provides a unique opportunity to contribute to academic research and analysis of personalisation policy. The PRLG will aim to be a supportive and empowering experience, however, it is possible that participation may stir some difficult emotions. You will be given contact details for appropriate support as appropriate.

Confidentiality of the Data

Your confidential information relating to your participation in the PRLG will adhere to the requirements of the Data Protection Act 1998 and the University’s Data Protection Policy. Any views or contributions that you make will be anonymised to preserve confidentiality and will form part of the research data that will inform the results and conclusions of the research. As the sample size is small it means that there are implications and limitations to anonymity which the researcher will discuss with you.

Location

The research is based at the Tavistock Centre. PRLG meetings will be held in a suitable location that is convenient to you.

Disclaimer

You are not obliged to take part in this study, and are free to withdraw at any time. Should you choose to withdraw from the programme you may do so without disadvantage to yourself and without any obligation to give a reason. Participation or non-participation in the research has no impact whatsoever on the continuation of any services you currently receive.

UNIVERSITY OF EAST LONDON

Consent to Participate in an Experimental Programme Involving the Use of Human Participants. (Personalisation Reflection and Learning Group PRLG)

Title of Project: It's personal. Personalisation and what it means to service users.
Name of Researcher: Andrew Richardson
c/o Tavistock Centre, 120 Belsize Lane
London, NW3 5BA, Tel: 0791 381 8524

- ☐ I have the read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.
- ☐ I understand that my involvement in this study, and in particular data from this research, will be handled in accordance with the Data Protection Act 1998. It has been explained to me what will happen once the research has been completed.
- ☐ I understand that there are limitations to confidentiality where disclosure of imminent harm to self and/or others may occur.
- ☐ I understand that I will be part of a reflective learning group and that my contributions will form part of the research data.
- ☐ I understand that some quotes and contributions may be published anonymously in the final report.
- ☐ I understand that the small sample size means that there are implications and limitations to anonymity.
- ☐ I understand that the findings will be presented to me during analysis and that the final report may be published in professional journals.
- ☐ I hereby freely and fully consent to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications.
- ☐ Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

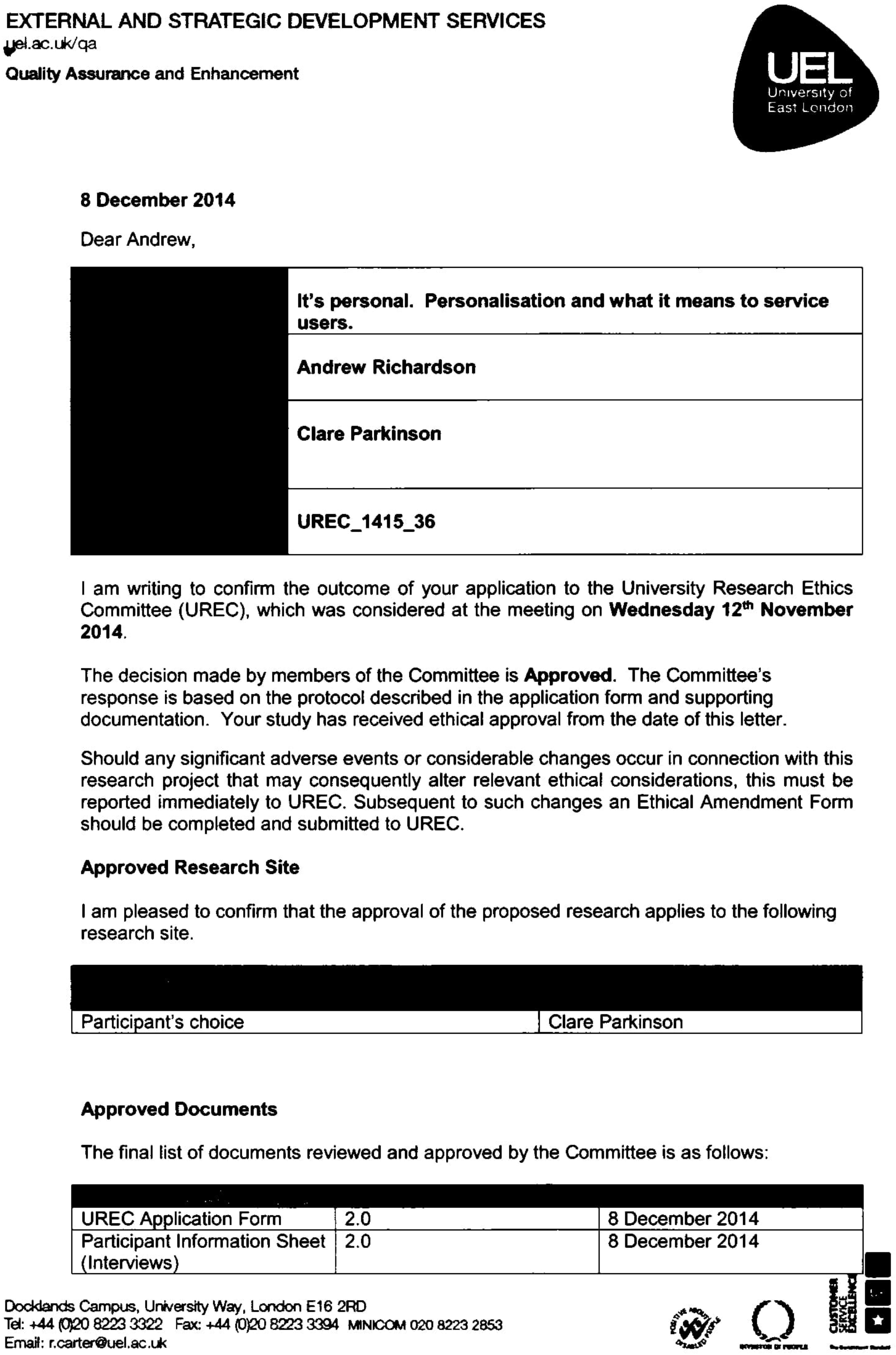
Participant's Name (BLOCK CAPITALS) …………………………………………………………………….

Participant's Signature ……………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS) …………………………………………………………………..

Researcher's Signature …………………………………… Date: …………………………..

Appendix 7: University Research Ethics Committee (UREC) approval



EXTERNAL AND STRATEGIC DEVELOPMENT SERVICES
uel.ac.uk/qa
Quality Assurance and Enhancement

8 December 2014

Dear Andrew,

[redacted]	**It's personal. Personalisation and what it means to service users.**
[redacted]	**Andrew Richardson**
[redacted]	**Clare Parkinson**
[redacted]	**UREC_1415_36**

I am writing to confirm the outcome of your application to the University Research Ethics Committee (UREC), which was considered at the meeting on **Wednesday 12th November 2014**.

The decision made by members of the Committee is **Approved**. The Committee's response is based on the protocol described in the application form and supporting documentation. Your study has received ethical approval from the date of this letter.

Should any significant adverse events or considerable changes occur in connection with this research project that may consequently alter relevant ethical considerations, this must be reported immediately to UREC. Subsequent to such changes an Ethical Amendment Form should be completed and submitted to UREC.

Approved Research Site

I am pleased to confirm that the approval of the proposed research applies to the following research site.

[redacted]	[redacted]
Participant's choice	Clare Parkinson

Approved Documents

The final list of documents reviewed and approved by the Committee is as follows:

[redacted]	[redacted]	[redacted]
UREC Application Form	2.0	8 December 2014
Participant Information Sheet (Interviews)	2.0	8 December 2014

Docklands Campus, University Way, London E16 2RD
Tel: +44 (0)20 8223 3322 Fax: +44 (0)20 8223 3394 MINICOM 020 8223 2853
Email: r.carter@uel.ac.uk

Participant Information Sheet (Personalisation Reflection & Learning Group PRLG)	2.0	8 December 2014
Consent Form (Interviews)	1.0	29 October 2014
Consent Form (Personalisation Reflection & Learning Group PRLG)	1.0	29 October 2014

Approval is given on the understanding that the UEL Code of Good Practice in Research is adhered to.

Please ensure you retain this letter for your records.

With the Committee's best wishes for the success of this project.

Yours sincerely,

Catherine Fieulleteau
Ethics Integrity Manager
University Research Ethics Committee (UREC)
Email: **researchethics@uel.ac.uk**

Appendix 8: Sample interview transcript

TRANSCRIPTION

TITLE : First interview with M

DATE OF RECORDING: 23 September 2016

NUMBER OF SPEAKERS: 2 Speakers

TRANSCRIPT STYLE: Intelligent Verbatim

FILE DURATION: 1 hour 20 minutes

SPEAKERS:

ANDREW RICHARDSON: AR
INTERVIEWEE: M

AR	**Ok. So I'm interested in hearing about your experiences. So I wonder if you just want to tell me about your experience of adult social care …**
M	Ok. So, I think what happened … my primary carer was my mum, so she sort of cared for me … main carer up until about 20. And I was living at home, so I wasn't even known to the adult social services team. So then when I could no longer live at my mum's house, because it wasn't accessible, and it was preventing me from getting a wheelchair, and I had to move out, is when I presented myself to adult social services. And it was a bit of a kerfuffle. Because they were, like, so how were you coping all these years with us not having any case, or record of you … So it was my mum caring for me … why can't she continue? Because she's older, moving out … so there was all this sort of … a bit of delay of them, like, having to do an assessment, find out about my condition because they had no prior history; and then when I first moved into the flat, I was definitely more able, so I could still do some … but here, I didn't have a carer at all … still my mum, my siblings, dropping by to help me with things. But I was sort of coping, and being able to take care of myself.
AR	**Uh-huh.**
M	And it was the next year, because I've got a progressive condition, that it really worsened. The second year after moving. I became more reliant on my wheelchair, struggling with everyday things: making meals, getting out of bed … um … and that's when, again, I got back in touch with adult social services. I was … like … I need help. More day-to-day help, now. And I had another assessment, and they gave me a rather … which I hadn't realised, because I was still very … When, going into the assessment, which in retrospect, or … um … like, rather, even in hindsight with what I've learnt … what I know now is that you're not meant to kind of big-up the stuff you can do … {laughs] … so I was trying to make it sound like I didn't need much help, just a very little bit of help …
AR	**Yeah.**
M	So they gave me a very small care package.
AR	**So, you were approaching it in a way where you were telling them everything you *could* do?**
M	Yeah. Precisely. And not trying to deflect from the stuff that I couldn't do. I made the mistake of telling them my mum still came to support me, so they only gave me a care package of four hours … um … um … and then I started working, which was making it really difficult. Because I only had four hours at home. And my mum went back to work full time, and moved out, so she wasn't around as much to help me. So there was this really sort of difficult period of not having enough care: no one being around to support me, while trying to work as well. And then … it wasn't until I brought it up at work, that I was struggling to come in and things, or I knew that I hadn't showered, I might call in sick – I didn't want to go to work without having a shower – so they were like: is your health really

	getting bad? I sort of confided in someone that no, it's just I'm not getting enough care at home. So they put me in touch with their … because I work for the [progressive condition] Campaign ...
AR	**Yeah. Yeah.**
M	So they knew about my condition. They also had advocacy, because they know how difficult it is to get adequate care packages for clients with varying degrees of [progressive condition], some more severe than mine, some less so. So they've had to advocate for a lot of people. It's a common thing. So I got one of them to sort of put me in touch with the advocacy team, who helped writing supporting letters to social workers and others to understand what my condition was. And that bumped up the four hours to 18 hours.
AR	**Ok …**
M	And then with 18, I was sort of making it work. I was still having quite a lot of support from home. And with that 18 still finding it not enough, and with looking into doing a Masters, 'cause the job just wasn't really for me … um … so when I got accepted onto a course, I was going to do this Masters, I was, like, I need more hours, hours of support around uni … they were like: Unis have true disabled students allowance, you're entitled to certain number of things including non-medical help; but that didn't mean, if I was in uni, if I needed a trip to the loo, or help to use a non-disabled loo … they're there for non-medical support: note-taking, research, libraries, that sort of thing.
AR	**So when you say: *they* said … was it social services? They said you could get this support from the university?**
M	Yeah, yeah. And then being told by the university, that's not the case. You *can*, but not for personal care.
AR	**Right.**
M	*That* should have been covered by the local authority. So I went back to them, had another assessment, and the 18 got bumped up to 22.5. And then … and then, they just wouldn't budget from there. I spent about a year appealing, and they wouldn't budget from 22.5, they wouldn't increase it. I found it simply wasn't enough. And …
AR	**What were the responses from the …**
M	Oh my God, they were like … they'd take the case to Panel, and the Panel would always come back. And I think the … sometimes you can have a really great social worker, and also not so great social workers. And I think the great ones are the ones who understand your condition, and they know how to spin it in a way that Panel can't shoot down your points.
AR	**Yeah.**

M	About why you need a certain number of hours. And the social worker I had at the time … I'd been through one or two social workers, during that whole span of about three years … the second social worker I had definitely wasn't as good as the first, and she just didn't understand my condition. Like … when Panel raises these points, how to shoot it down with evidence or acknowledge an understanding about my condition … So when I do research out of school, when I want to go to the library, I want to go to galleries, I want to go to workshops, and the Panel's response was: Oh, in the library, you can just ask a librarian. And I was like: did you tell them that when you go to the library, you can't ask a librarian to help you to the toilet? Yes, they can help you find books, do a bit of scanning, whatever … but if there's a bit of a queue, or if time is limited with whoever I'm with … like, whoever I'm with should be able to help me do all of these things. Let's go find the book, print these pages, scan this … as well as: use the loo, get some lunch. Panel's response was: Librarian could just support me. I was, like, yeah, but she didn't report, she didn't tell me what she said to Panel … And … or … travelling: They were, like, you've got an electric wheelchair, so you'll be able to travel. And I was just, like, did you not tell them that public transport isn't accessible, or trains take too long to wait for, or buses when they come are packed with prams, you know … it can get quite … can become quite an anxiety and stressful experience using public transport in a wheelchair. Did you tell them any of this? Clearly she didn't, she hadn't … I don't know, like, it felt like she wasn't good under pressure, or couldn't come back quickly with evidence. Maybe that was due to lack of understanding of the nature of my condition. Because, yeah, she told me everything that Panel said, but not what she said to try and show them that I do need extra hours. That 22.5 is not enough.
AR [softly]	**Mmm. Mmm.**
M	And we went back and forth to Panel again for …. what felt like a year, it could have been only about six months, and there's only a certain number of times you can go to Panel … but her manager was, like, you need to have a watertight case before you go to Panel to present to them. You can't come back again and say: it's still not working, it's still not working …they'll be wondering: what are you doing with the care package, if it's still not working? Kind of thing. And during that year of appeals, the social workers sort of, like, not getting back in touch with me. So I'd send emails, leave voicemails, and she would never get back in touch with me. It was just like, in a couple of months, she got back to me once. She said: I got your emails, and if had time to respond … and it wasn't like I was pestering – I'd send, like, one email a month. And I'd leave one phone call, maybe once a fortnight. So I wasn't … I definitely wasn't, in hindsight, becoming a nuisance, calling every day, that sort of thing. But she just stopped replying to my emails and calls.
AR	**Yeah.**

M	And then during this time, when I was waiting to hear back from her, was when I fractured my knee, at the end of last year … um … partly down to … I did need more hours, and because there isn't anyone at night. I could still, at the time, get in and out of bed myself, use the toilet. But it wasn't safe to be doing that, when there was no one around. And I had to use the loo … there's carpet all around the flat … I've fallen quite regularly, and I wear a pendant, because of my falling. But I've never fallen in the bathroom before, where there's no carpet … just a thin lino, with pure concrete underneath. So when I fell, the way that I fall, sort of like a sack of potatoes, just landed really badly on it, and fractured my patella, called … pressed my pendant, because I'm always wearing that, for the ambulance to come and help me up, and stuff.
AR [in background]	**Yeah, yeah.**
M	And then when they came to help me up, I couldn't stand on my leg, being told at two in the morning that I'd broken my leg. And I'd never broken a bone in my body before … um … and it was a very traumatising experience. Because, even in hospital … I was in hospital for three weeks, because I couldn't be released home, because my care package wasn't adequate enough for somebody to be around to support me. Because now that I'd fractured my knee, I would need someone to support me with every little thing.
AR [in background]	**Yeah.**
M	I'd need help to get in and out of bed; I'd need help to reach my medicines; I'd need help for every meal; I'd need help to shower; get dressed. A lot of these tasks, I could still do myself, prior to the fracture. But I would not able to do now, with the leg cast as well.
AR	**Yeah.**
M	So I was in hospital for three weeks, whilst they were trying to … well, I was given an emergency care package though the social services that are tied to the hospital. And they managed to get it from 22.5 to 31.5. And that … I'd have visits, not here all the time … in the morning to get out of bed, to get dressed, washed, have some meals … so it became, like, really regimented. To have someone come at nine, someone come at one, someone come at four, someone come at eight …
AR	**Yes.**
M	And the social worker there, in the hospital at the time, I thought she was really nice, because she asked me, she wanted me to have input into the way that my care package is given … delivered. However, little did I know, she sort of ignored everything I said … she asked, like, what time would you like the bed call? I said: nine, ten? And it was eight o'clock.

	So when I had … when it was safe enough to discharge me home, my care package would start, this new care package. It was with agency carers … um … I wasn't in control of it. Before that, I was using Direct Payments: I was paying agencies. And I think I felt I had a lot more confidence, a lot more say … if I didn't like a carer, or I didn't get on with one, I could send … I could call the agency and say I don't want this person. I'm the one paying, so I had more say and control in my care.
AR	**Mmm.**
M	But this time around, I had no say in who came. I was given a key safe, so carers could let themselves in as I wouldn't be able to let them into the flat, as I was stuck in bed until they got me out of bed. So it was just this revolving door of faces, and it was … it was probably one of my lowest points in years. Because … um … with this particular agency, which Local Authority later on sort of terminated their contract with, because they were so bad. Such a revolving door of carers, who just didn't want to be there. A lot them would say to each other, speak like I'm not in the room, they would talk about how much they hate the job, or they hate other clients …
AR	**In front of you?**
M	In front of you. And it was just sort of my lowest point. Sort of, feeling like, not just a burden, but something more subtle, that it was disgusting, disgusting that I need to use the toilet, or need to empty my bowels, because they'd talk about how much they hated doing that with other clients. So they must hate doing that with me as well. Like, I was just sort of made to feel, like, you were … yeah … a disgusting burden. It also happened that when I fractured my knee, the timing couldn't have been worse … my mum was going to [African country] because my grandma was ill, so she wasn't going to be around. My younger sister was at Southampton at uni. My older [sibling] works full time, so she was only ever around on some evenings, and most weekends. My younger [sibling] was doing his A-levels. It was, like, having … some of his exams are in January, so he was in revision mode, so I couldn't call upon on him much, and … but luckily, people like Alice [best guess], who doesn't live too far … she became a great, sort of, very great comfort during that time. She would help me into bed later, so I wouldn't go bed at eight. I mean, they were expecting that I was in bed at eight, and wake up at nine the next morning. So, over 12 hours in bed, without being able to use the toilet. That's mental. So, she'd like come round about ten, eleven … but even Alice works full time as well, she's a teacher. So, she'd come and help put me to bed a bit later, help me use the loo … I really … it was one of those times, apart from being my darkest moments, it made me realise how many great supportive friends I had around me who will come, bring better meals, keep me company during the evenings or something, when they're free.

	When something like that happens, like, you have to sound the alarm bells, you have to tell everyone. Which I didn't usually do. Back then, when something was wrong, I just usually go to my mum. But she was like, this time, ring the alarm bells, let everyone know. And everyone wanted to come see me, almost like every day …
AR	**Yeah…?!**
M	Yeah. Because of the kind of carers that I had, they were not good at all, they basically refused to make any other sort of meal at all, that wasn't a ready meal. And ready meals are disgusting. So I had friends bringing me meals that would last two or three days; and then another friend would bring me a meal that would last two or three days, just needed to be heated up in the microwave … and, yeah, my friends really rallied around! They rallied around when I was stuck in hospital, and they rallied around me when I was home. For, like, two months … yeah, and by this time … this was nearing when I was getting the cast off … hoping that the care package, if I could keep the hours, but have the flexibility of what I had before … I was getting in contact with the hospital. The hospital social services lady … because I was still … um … in recovery …
AR [in background]	**Yeah.**
M	I was under Local Authority social services, but [NHS hospital] social services … and so she was, like, sort of, ok … I understand, I need to discuss this with my manager, I'll get back to you … that I'd like to keep these hours, but have the flexibility of being able to say when, at what times, for how long, and stuff. Within the framework of the 31.5 hours. And she sort of, like, she sort of was stringing me along for about two months, saying … she told me when she was going to go to Panel, how long it would take to get the result, and she would give me a call. And I waited all that time, and didn't hear back from her. So I gave the office a call, and they said she's on annual leave for week or two. And I'm, like, what? Ok, maybe someone in the office will know what was the outcome of the Panel, and stuff, and this was about … this is after I'd gotten the cast off, so now just in knee brace, and having intensive physio ..
AR	**Uh-huh.**
M	Um … and they were, like, I'll check the system … no, there's been nothing to Panel, she couldn't have been able to go to Panel, our manager's … she said: I'll give you a call back. She came back, like ten minutes later. She said: no, couldn't have gone to Panel, our manager's not aware of this. She says she'll check online on the system. She says my file hasn't been updated since the day I was discharged, which was about two months ago. Um … so this particular worker had just been fobbing me off, just to get me off the phone line, like. And I was *incredibly* hurt. And someone who works at the hospital, who's a friend of mine, a physio, she said: make a complaint. Which I did. But, didn't hear anything from

	[NHS hospital]. Apparently that's quite normal! 'Cause [NHS hospital] are very … have lots of problems. I'm probably not the only one complaining that they get … they have a lot of systematic failings … um … yeah …
A [softly]	**Gosh!**
M	So I'm, like, well, ok. Then the job was to find out whether … whose got my care package, essentially Local Authority are saying they don't have it, [NHS hospital] are saying: once you're discharged, it's out of their hands …The care package was essentially in limbo for about … because it only got sorted in about June/July … so was in limbo February, March, April, May … about four months. Nobody could tell you who … where it was. Then, eventually, when it was given back to Local Authority, then there was a waiting list of about two months again before you were assigned a social worker, because they're so inundated, no one gets assessments or re-assessments. Then I was given a social worker. It was great. And by this time, I'd had input for the carer of my leg; I'd had input from the adult trauma team, adult community …?
AR	**Rehab?**
M	Adult community rehab team …yes! [both chuckle] So I had input there, people who understood my condition; had physios under [NHS hospital] who understood my condition; and an OT at Local Authority, who I'd been with a year before while waiting to get adaptations doneto the bathroom, so she understood my condition. But when I had the re-assessment, they were all present; because there was no way, like, I'm doing this again on my own, and nothing coming of it.
AR	**Did you organise that to happen?**
M	Yeah. Well … sort of all of us did. Like, once you get assigned a social worker, let us know when the re-assessment is, and we'll all try to schedule to be present.
AR	**Ok.**
M	Because my mum couldn't be coming, because she works full time. So they were all present on that day. Took notes. They inputted into my mobility, the level of my mobility, why I needed certain things, the nature of my condition. So this social worker left with a really clear knowledge of my level of need.
AR	**Yeah.**
M	And … um … when … it had to go to Panel … in under two weeks. It was the quickest I'd ever been assessed: to go to Panel and then to hear an outcome, all within the space of two weeks … quite alarmed me, how quick it was. And she managed to get it from 31.5 to 37, which the Local Authority Panel … is notoriously stingy [short laugh] … but it was … 37 is a much better place to be in, than 31, or the 22 previously.

AR	**Or the four … at the beginning …**
M	Or the four, yeah [Laughs loudly]. So that's what I've been working with now. I was like: I don't want to work with agencies, I want to take on the responsibility of a Direct Payment; tell me, show me what to do, which essentially they have been. Technically, yes, it's a lot of admin. But once you get into the flow of it, once you get into the routine of what you need to do, it is pretty straightforward. And I can always call if I'm confused about anything; I'm allowed … I've got a direct payments officer, so I can always call her and say: I'm not sure if I'm supposed to pay someone this month, or: I haven't recorded this; how do I pay sick leave, holiday pay, whatever. Essentially, you become an employer. So, I was, like: I will take all of that on, if it means I can then dictate the hours, and the people that work with me. So that … was definitely not easy – the recruitment process and all that stuff – but the new social worker and the direct payments officer were so encouraging, that they made me feel like I could do it. Once you get a handle on it … you've done it once, it will become easier. Before you know it, a year has passed, and you've been doing it … yeah … so that's sort of … to present day …
AR	**Ok. Well, thank you. I think that's a really coherent narrative, as well. I was struck by that – how you came to talk it through, and remember it all. I mean, as well as all the jargon throughout, which you've picked up on: knowing about Panel, review and assessment, and all that kind of process. Which I guess you wouldn't have known …something you've learnt as you've gone along.**
M	Yeah, absolutely. Definitely. Like, in a roundabout way … K … who's one of my new carers, I've had her for about five weeks now, and it was just the idea, like … had I not broken my knee, I would never have known or understood about the bureaucracy. That's not to say that I'm happy that it happened, but, like, I can take into account that sometimes certain things have to happen, for other things to happen.
AR	**Yeah. Do you think it was preventable, though, the knee?**
M	Um … we did put that in writing in the … what was sent to Panel. Because we sent, like, a pack of stuff. Me, and one of the OTs wrote a really long report, like, detailing my childhood, and also explaining why my mum can no longer be my primary carer, and … um … we did sort of leave it ambiguous about whether or not the fall could have been prevented. Because you can't stop the falls – that's just the nature of my condition. But we can limit the number of falls.
AR	**Yeah.**
M	Like, I fall less when there are people around me. The chance of that … that's definitely been noted: that when there are people around for support, I can still fall, but it changes the fall. It's sometimes not as

	serious, sometimes I … um … the times with K, when I've fallen, and she's sort of guided me down … I haven't hit the floor so hard …when my mum's around, she wouldn't necessarily help me … sort of supervise … she wouldn't actually help me out of bed, but just make sure I was ok … walking from the bedroom to the bathroom, using the loo, and wait until I get back in bed. And then she goes back to bed. Like that. Under supervision, the falls do tend to be less frequent, and sort of less injuries, but that was hinted at in the report. Could it have been prevented? I could have fallen earlier, as in not in the bathroom, and … um …
AR	**I guess what I was … why I asked that … because it sounds like get support at that time …**
M	Yeah, yeah.
AR	**And there were all these barriers, and you didn't then have the support you were asking for, that you thought you needed, by your own judgement. And then you had the fall. It sounds like it was a really terrible experience, actually.**
M	Horrible, yeah.
AR	**Compounded by the terrible lack of support, really, that you got then, afterwards. It sounded very demoralising …**
M	Yeah.
AR	**You talk about a dark place as well. And I think it might be helpful if you tell me a little bit more about that dark place, because I think it might be important for people to understand the emotional impact of that experience on you. You know, the depth of it.**
M [after slight pause]	Yeah … um … I think you sort of hit the nail on the head. Because that whole 2015 was appealing, or waiting for appeals, or waiting for the outcomes of appeals. I broke my knee two or three days before the New Year, and … um … even then … I knew the offices had closed and I wasn't going to hear back from her until January, I was still in a sort of waiting period. And then when I broke my knee, the care package I was given, essentially reduced you to your bodily functions. I was nothing more than a: wake up call, a lunch call, a dinner call, a bed call. And at those calls, if you do not use the loo, you'll have to hold it to the next call. And that put me in very dangerous positions of me, in my cast, trying to get myself onto the commode, when no one was around. And risking falling again. And hurting my good leg. Or re-hurting the bad one.
AR	**Mmm.**
M	Because your body just doesn't work like that. It doesn't work to a routine. To a time slot. Ok, it's one o'clock, you need to go the toilet now. You're not going to be able to go again until four. So you'd better go. But … you can't control your body like that. And the care package I had

	literally reduced me to those four calls. I had that for two and half months. I *did* get depressed. You get incredibly depressed; because your body's not listening to you. I'd fractured my leg, which I'd never done before, I'd never felt this level of pain before, I'd never been this immobile before. Like, usually, in my mind, growing up, I'd thought my condition would do that to me not a factor, so – realising that there are other things that could go wrong with your body – is quite scary, when you've already got this condition that is already very debilitating. And then, also, not having my mum around at the time, was incredibly distressing. Poor reception, phone lines hardly work in [African country], unless you're in [African country], so her calling here, I'd only hear from her in the evening times, a couple of times a week. And trying not sound so depressed to her, made me feel more depressed. I didn't want to distress her, she was on a different continent. So, it was just, you know, very … I also don't think I've ever had to … when on top of that you have to tell all your friends, and think if they'd come and help. I'd never done that. I'd usually … [indistinct] … make things seem less than they are … like not making my condition seem so *apparent*, or seem so needy. And now … [indistinct] … I'm constantly calling people for help, or needing to tell them I need help in a certain way. Like, when I was in hospital, because of my condition, in a bed in a cast, I just looked like a young woman …
AR [softly]	**Yeah …**
M	You can't see my [progressive condition]. So a lot of them thought I was lazy; I wouldn't get out of bed; or couldn't roll; or that kind of stuff. It was only 'til one of my carers had a word with them, that: 1) closing a curtain doesn't mean the patient can't hear you, and: 2) it's not lazy, it's because she's got a condition, she can't raise her hand to wipe her face in the morning, or hold her arm to brush her teeth. Like, that's part of my condition …. [indistinct] tell other nurses to stop saying: the lazy one in the corner over there … yeah, it was such a demoralising period in my life. Um … yeah.
[redacted]	**The next section is redacted to safeguard the privacy of the interview participant.** [redacted]
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	[redacted]
AR	**Ok …**
M	So I can sort of … in my mind, I feel like … the way I experienced social services … they're sort of thrashing out at first, because clearly you didn't need us for two decades, why do you need us now, sort of thing. Before a kind of understanding that, actually, my mum saved you lot two decades of looking after me with no complaint. And now that she needs you lot to step in, because she's getting older and my needs are changing, that sort of took them a little bit of understanding. Because it doesn't fit the system, because the system needs you to have … the moment you become disabled is the moment they need to know about it, that is the start of the process. As opposed to someone who's got quite a complex condition appearing out of the blue, saying: hey, I need help, a lot of help. Because, ideally, the hours that I was asking for, or even stuff that I needed, I would only have got it had those hours accumulated over growing up. Maybe it started with only two hours a week, and by the time I'm 20 now, I would have had a care package that was between 40s and 60s in terms of hours per week. As opposed to coming up here and asking for a massive care package.
AR	**And you would see that different, then, would it be the same if someone had a car accident? For example. I mean, that's someone who hasn't access for a different reason, they didn't need it …?**
M	Yes, yes. I think, yeah. Because they could equate the accident … they wouldn't need social services until the accident. The accident has a date on it. As opposed to me just presenting myself when I'd just moved into my own flat, is more kind of, like, well, you didn't need us 20 years ago, why do you need us now, kind of thing … um … and the level of need as well.
AR	**Right.**
M	I think they just felt like sometimes as if it was … not that I was deceiving them, but that something wasn't quite right with that? I was 20/21 at the time. And I'm asking for quite a big care package. Well, at the beginning I wasn't. Because I played down my condition …stupidly! But then, I was asking for a lot more. But … isn't your mum around? Someone who could just help you? So, you don't have to pay, basically.
AR	**So, in a way, then, there's something about your own judgement and assessment of yourself … this idea of self-assessment didn't really work in the system. Because it was either that you were assessing yourself**

	based on the presumption or the thing that you could do stuff you wanted to do, and would try and do as much as you could for yourself …
M	Ye-es.
AR	**But you needed some support. So that, in that way, you were now potentially, looking back on it, minimising or playing it down, which doesn’t work in this system.**
M	Yeah, yeah.
AR	**Or … I had two strands of thought, what’s the other one?! I’ve lost my train of thought …!**
M	But I completely …
AR	**You see what I mean?**
M	But you do that. When you have a disability, there’s no way, even in school and in everyday life, I’d go around telling people what I can’t do. Or bigging that up, as well. I mean, one of the things I found working at the charity was that, when dealing with the system, it has to be separate from yourself.
AR	**Mmm.**
M	And you have to tell them your worst day. What are you like on your worst day. And if we’re talking in that respect, if I had known that going into assessment, we’re talking: can’t get out of bed, need help getting out of bed, need help using the loo, need help getting into the wheelchair, need help dressing, showering, need help making a meal, need help opening windows, opening the curtains, need help getting on the laptop, need help making a call. I would need help for *every single thing*. But I was going into self-assessment thinking, going in thinking I had to tell them that it’s actually ok most days, I’m alright, I have the odd bad day where I could fall, I have headaches so have to go and lie down … I was just sort of, like, I’m ok most days … yeah, focusing on the good days. I need support on those days. Completely neglecting the stuff from my really horrible days. They may not come around as often, but they do happen.
AR	**Yeah.**
M	And not understanding how that … not understand how that’s what the system wants to know … they want to know you at your worst.
AR	**Mmm.**
M	And if I thought like that every day, I could just never do anything. I would never leave the flat. And sadly, the system if very polar, in the sense where it’s either: you’re very able, you don’t need any help; or: you’re incredibly … you have so many needs, or have so many conditions, which means your needs are so many … you have a lot of needs. As opposed to both people, their disabilities move up and down that spectrum; from day

	to day, week to week, month to month. The system, it's not cut out for that – it's one or the other.
AR	**Uh-huh.**
M	They're quite extreme. Because you're either saying that I'm completely able-bodied, and fine, or that I'm on a breathing machine and have a pump that supports me, or something.
AR	**Mmm.**
M	Which may well be the case later on, when I'm much, much older, or when the condition progresses even, more, but that's not right now.
AR	**So, do you think the system was flexible and accommodating around you? That you were at the centre, or that you had to adapt – maybe still do, actually – to the requirements of the system?**
M	Yeah, I definitely have to adapt to the requirements of the system. Maybe … I'm just talking about Local Authority, I don't know if that's the case in other boroughs …
AR	**But it's *your* experience. Because Local Authority, like all local authorities, are signed up to this idea of personalisation … which I'd be interested if you've come across that word, actually, or that term?**
M	[Murmurs]
AR	**I guess it's the idea of the *people*'s services, and the way it works, the *person* should be at the centre of it, it should be *personalised* to them. And you could take that approach in relation to the whole journey: you know, the assessment, but then also the provision of services, as well. And I guess, a kind of theme that should run through the whole thing as well, is one of having choice, and being in control of your own care and support.**
M	I think there's that, in the sense when you've been given a care package, that comes into play. But not so much when at the beginning of the assessment, and stuff. Which is why I felt like I needed three people at the most recent assessment, because if you don't say it right, you don't get the hours. And I don't know the jargon, or the terminology … those golden nugget words which get you the support you need. Because if you don't say that, then they can kind of … it's very easy for Panel to then veto any sort of hours for social life. Like, in that 37, in that 37.5 I have now, of all the hours when …'cause you have to shape them into what they're for. So, this is for washing, this is for dressing, this is for changing catheter, whatever … they've only given me one hour a week for social, to go and hang out with friends. It takes an hour to get anywhere, basically …
AR	**Yeah, yeah.**
M	Let alone actually get to somewhere and what have you …

AR	**So you're taking about the 37 hours – has it been broken down …?**
M	It has.
AR	**In the support plan?**
M	Yes.
AR	**And did they give you a copy of that?**
M	Yes. I have it on my laptop somewhere, and a hard copy. That's what Panel thinks those hours are being used for. That's the only reason they'd give you those hours. Because they are … someone said: *social* services. Especially because of the cuts at the minute, it's not about the social, it's just about services.
AR	**Who said that to you?**
M	Who said that to me? [repeating question]
AR	**Was it someone in the system? Was it a social worker …?**
M	*Yes!* [emphatically] Yeah … I think it was the new lady. She was really open with me. She was great. With the cuts at the minute, they're not thinking about you going out to meet friends. Or even going to uni. It's just about: what do you need – sadly – to survive.
AR	**Ok.**
M	Which is bed … You know, they make sure that you get someone … so, like I need overnight support, which I don't get at the minute … I've said I'm taking a break before I go back into the real system. Because it takes so much out of you: time, energy, stress. And I'm not ready at the minute. I'll just enjoy the 37.5 I have at the minute. Even though I know it's not enough, I've got a really great support system, with people I can call upon to help me when I don't have enough hours for something.
AR	**This is all a Direct Payment, then …? The 37 hours.**
M	Yes.
AR	**But you were told that you need to use them according to the … is it a schedule, or is it breakdown, then, that you might be able to …?**
M	Yes. You've got a support plan, detailing … which is helpful to give to new carers who make not have had experience working with you, or working with your kind of condition. It's helpful to them, it's great, like: how many hours you need for such and such: for dressing, getting up in the morning, washing, making a meal. That's all great that they've scheduled that. The reason that I've got 37.5, if you divide it by 7, it should give you how many hours I have per day. And that's what Panel thinks I used it for, and how I use it.

	However, doing Direct Payments has given me more control. Because if I went to an agency, they'd want to see that support plan, and that's how they sort of send carers. But that's not how I live at all, and that's not how I want to live. So I went the other route, hiring people myself, with more flexibility about the times they can come, how long … we can save hours and use it … like, I remember when I went … surprisingly one of the first weeks that K was here, me and a friend and K went to Bath. Visited Bath for the day. And that was, like, 12 hours. But I'd *saved* hours for that trip. Which you wouldn't necessarily be able to do if you were with an agency. And because I hire people myself, I can shape … Sunday night, I'll look at the following week, and divide the hours between the activities I have. That's how *I* [emphasised] want to live. Not: Monday to Friday, every day, I do this in the afternoon, and at this time, I need this … I don't want to live like that. I *can't* live like that.
AR	**It sounds like Direct Payments has given you more choice and control.**
M	Absolutely. That's where it comes from. If you let the council do the work, the paperwork and the … using agency … it will be regimented. And they rarely divert from the regiments. You're not at the centre of it, you're have to adhere to it.
AR	**Which sounds like … wasn't a nice experience at all.**
M	No. No. It's only when I fractured my knee, that's what I was doing. Adhering to this lifestyle: I didn't even live like this before, why do I have to live like this now? Yeah.
AR	**Ok. So, can you tell me how many Direct Payments staff you employ?**
M	So, though Direct Payments, at the minute, just two. I am looking to expand, because when either of them is sick, or go on holiday, the other might not be able to cover. So I will need like a bank staff in the background, who can fill in, who don't mind … basically someone who is flexible, for part time work, and who lives locally, but that reduces the … because public transport is unreliable if someone comes very far, for a very part time job … So I am still looking to expand. But that's like a gradual thing. I've been following … I have friends who … and very new friends as well, who I met through the charity who have different forms of [progressive condition] … there's the twin sister's who've had … basically, who've never used agencies their whole life. They've got a much more severe condition than I do – probably why their care package is more – but they've never used agencies, they've always hired, over the span of, like, a decade, if not more … longer. They've been through many great carers, as well as many bad carers, but have, like, bank staff – 15 plus more people. Yes, they're employed to them, but they don't always all work the same month. Sort of a rotation of whoever's around: these are my main carers for these months, this week … if one of them leaves, moves, gets married, whatever their life changes,

	then there are these people in the background who don't mind stepping in. So that was in my plan, as well. Just to gradually build up a roster of people. So, at the minute, I've just got two. That's enough.
AR	**How did you actually find those people?**
M	So, one of them is from one of the agencies I used a couple of years ago. And we got on really well. And even though she's, like, she's got children my age, but she's got the right attitude. I think a lot the time with carers, it might not necessarily even be about whether they've got the right experience, because a lot of that can be learnt on the job … but that's where the personalisation comes from … when they learn how *you* like things to be done. So I met her though an agency, and asked her if she would be interested in working with me, one on one, and I'd be employing her. She said yes.
AR	**Uh-huh.**
M	And that's great, because we already had, like, two and half years behind us. And then K who you met … I put an ad in just before [local train] station under the bridge, there's a café, I put an in there, and she saw that. She just lives around the corner. And got in touch, did an interview, DBS, and again she was really honest and open that she didn't have any care experience, but she had the right attitude, and … we felt like we got on. In the ad, I mentioned some of my interests, so that anyone with similar interests, we've already got something in common.
AR	**Yeah.**
M	K's really interested in film and film production. I'm interested in the writing side of film, but we both enjoy watching films. Which has been great, and … so, like, she had a month's probation, which she passed, and it has been great. Just taking it each week, as it comes. If there are any sort of concerns, or issues, she can raise with me, and if she needs time off, she needs to give a week in advance, that's fine … and in the meantime, while I'm still building up the roster of carers, my mum, or [siblings], will step in from time to time to help out with things. But just not as much, which is great for them … they've got their … as I tell my mum: mum, You've got a [laughs, indistinct few words] if I haven't heard from her for a few days … you do know you've got four kids, right? I'm still here! Yeah, it just lessens the pressure on them, now that I've found two really great carers
AR	**And I think you said something which I thought was really quite interesting … that personalisation is more about the attitude. You talk**

	about: if they have the right attitude … could you say more about what, for you, what that right attitude is?
M	It’s a sort of openness, and … um … patience. Patience is key. Like, I’m patient with them, I’m not expecting them to know how I like everything done, I’m very much sort of … yeah, like, *mutual* patience. We’re going to both learn about how each other works, and we’re going to both make mistakes. And we’re both going to address them. And we’ll both move forward together, like it won’t be that I’m not very … um … I mean, the job itself is quite high … demanding … them supporting me in my daily living. That … that has to be understood from the get-go, that, actually as soon as … I might need help after making a meal, we might do a bit of light cleaning, or … so it’s like understanding that you’re working in my home. So there’s got to be a certain level of respect. You’ve got to treat this as seriously as any other job, turning up on time, informing me in good time if you’re going to be late, or you’re ill, or whatever. And I too will be respectful, and making sure you’re paid on time. And sort of just respectful of each other, because it is very personal, very intimate care. And they need the right attitude, I think someone who cares, to be honest. Somebody who is like … that’s not to say that its great money, it doesn’t pay as well as a bank job does, but if you kind of want to get to know people … and if you’re a people person, and care about someone whose life is limited by the infrastructure around them, and you want to support them into accessing that infrastructure, I think is the right attitude. Because it is about supporting and empowering, as well as the actual care itself. And I think one of the issues with agencies … agencies are businesses first. Even if they’re a care agency, they’re still a business. They are about making money. And for some of the staff, they don’t pay them well. Like, and these are just things I’ve heard, because they just talk …
AR	**In front of you …**
M	They *vent*!
AR	**To you?**
M	To me. Yeah. And in front of me, to each other. Or to me, about the difficulties of agencies – they’re in it to make profit, they’ve got to keep costs low … one of the ways of keeping costs low, is either by not paying them for their transport to work, or between jobs, by not giving them … the shifts they give them are, like, you can do 40 hours a week … but if they’re in 30:30 hours, you’re only getting paid half of what you get for a full hour. So morale is low in a lot of the agencies. A lot of people have been dispirited … less by the clients than the agencies themselves: not being paid on time, or not being paid properly, money being withheld for whatever reason …

	And that kind of seeps through into the level of care you get, you know. I had carers who were a bit physically too rough, heavy-handed, or one … clearly this job isn't for her … one carer did the top half of me, the other didn't want to do the bottom half. She just didn't do, couldn't clean in that area. But I couldn't just have a half-shower, like, I have to have a full shower, you have to clean there. So there's all these people who are doing it for the wrong reasons, who should really be … just shouldn't be in the job. The thing is, being a care worker, being a carer, you don't need qualifications. Which is fine, you don't. Because that's how you can personalise things to people. But you do need the right attitude, and if you don't have the right attitude, please give up the job. Don't make some poor person's life miserable. And I'm lucky, because I can communicate my needs really directly to carers. But elderly with dementia, or whatever kind of mental or learning disability, you can't, then you're at the mercy of this stranger. This person doesn't have time, or patience, or any mercy. It's horrible care that's being delivered. And actually no care is better than bad care, to be fair.
AR	**Mmm.**
M	Bad care can have really bad repercussions on the person you're caring for. As opposed to no care. Like, actually, It's better not to even have the memory of being in the company of those people.
AR	**Have you felt like that at times?**
M	Yeah.
AR	**Looking back at your experience …**
M	Yeah, when I was in it, I would have preferred to have no care, to be honest. Yeah, because some of them shouldn't be in care … shouldn't be around people, to be honest. Some of them. [Hollow laugh] Let alone people who are a bit more vulnerable. And I was thought, when people said you're not a vulnerable adult, a vulnerable person, but I think you are. When you're half naked in front of a stranger, they see you in un-dress, or they see you in dis-tress …they have to clean you up after you've, you know, spoiled yourself, or whatever. You *are* vulnerable, of course you are. So, you've got to have the right frame of mind, a certain level of sensitivity. And if you don't have that *naturally* in you, this isn't the job for you.
AR	**Mmm. That's quite powerful. Quite a powerful message, actually. And an important one.** **I wanted to ask you, if we can just shift gear a little bit … I'm just wondering about this notion of: independence. Which is around a lot in social care, and is one of the things that are associated with personalisation, as well.**

	So, I guess I'm just wondering, if you've come across that in your interactions with social services … were the social workers talking about independence … to you?
M	Ye-ah. In terms of, kind of, even, needing a care package. The idea that this care package would give you independence. And it's a bit of a … when I hear the word *independence*, it's a bit of a fallacy, to be honest. Because no one is really independent. And autonomous. One of the things I have learnt […] is, rather, inter-dependence: we all rely on people for various things; whether it is services, or living, or support. You know, the way a baby relies on its mother for food and changing and stuff; or an older person relies on someone to help them with their clothes, or to go out, or to remind them of things. We're all inter-dependent on one another. And what I think, especially in terms of social care, or social services, should be this idea that independence includes support. Like, it's not about going off and doing something on your own, but actually about you going off and doing something with the right support means you can do it.
AR	**And do you think you got that … that they understand … that they got the message? Do you think maybe they've got more of the fallacy …?**
M	I think they've got more of the fallacy. Because I think when – and it's just in terms of me – when the not-so-good social workers, when they spoke about independence, it was almost like this idea that if a carer gets me dressed in the morning, and all that stuff, then I can go out and do anything. When it's actually, no, I still need that care accompanying me out … whether it's to hold the door, help me get on a bus, or whatever. It's not the idea that: if the carer does one thing, then I'll be fine. Actually, sometimes, me and the carer have to do stuff together … so that I think is more the way I was spoken to about independence. A lot of it is what I can do by myself. Yeah, and it's, like, not very much … [laughs] … I can list the stuff I can do by myself, it's very small! But the list of what I can do with someone else, is bigger. That grows.
AR	**Yeah.**
M	And I think, especially with Panel, when they say: she's got a wheelchair, why can't she take public transport, or when she needs help in the library, go to a librarian, and it's like, if only the world were that simple! Like it's black and white, as opposed to actually: I need a carer to let the bus driver know what stop I'm getting off at, because even if I press the button, sometimes it doesn't stop, or deploy the ramp, he just drives to the next stop. But with a carer, you can knock on the window and say: we'd like to get off now, can you deploy the ramp? So that kind of thing, that … that's independence …
AR	**Mmm. Yeah.**

M	We're working together to do something. Not that I … if the carer does one thing, if I do one thing, then I can go do it on my own. Yeah. [chuckles]
AR	**Ok. That's really helpful.** **I'm just checking back over my notes … I think I may have asked everything, actually, for the moment. I mean, there's a lot that I've got fragments in my head, you've kind of given me a lot to think about. And also, I think in terms of the group, I think they'll be quite interested actually in your story.**
M [quietly]	Thank you.
AR	**And I'm sure that they'll have things that they'd like to know more about. And that's the process of reflection that I need to go through.** **I wonder, was there anything else you want to say at this time?**
M	[after a pause] Well, I guess it's less to do with social workers, something to do with the care agencies and stuff, I think. When it comes to training and stuff, the workers are given blanket care. And because I've used about three agencies now, and seen the blanket care training that they deliver, because they all do the same thing. It's so weird. And this is just a small note, but I feel like it's a metaphor for the big things. It's like, some carers from this agencies, after I've taken off my pyjamas, they'd fold it up, or they'd all want to do my bed, do up my bed, and make it look nice and stuff. And they fold my pyjamas up and put them under the pillow. Why do they do that? I'm only going to take them out again. Hang it on the hoist, so I can see it, without looking for it. Because one day I forgot where it was. Found it under a pillow when I was going to sleep! But this idea that they always want to do the bed. But, for me, and for the way my bed works, the only thing that can be on the bed is the pillows. Because that's how I get into the bed. And when I come out, you have to rip the blanket off me completely. So, when I get out, and you fold the blanket, you can leave it on the bed, or put it away. But they all made the bed the exact same way! And there was one time, when it was my time of the month, and I had a leakage, and there was clearly a stain on the bed, and the woman just made the bed over. Rather than change the bed sheet, she just made the bed.
AR	**And she would have seen it?**
M	She saw it. The bottom sheet … I use sliding sheets, so I have silky, satiny pyjamas on a silky, satiny bed, so that I can roll in the night, and I don't start developing pressure sores. So, I had a leakage, and it was as clear as day, red on white, and she just made the bed over. I just felt like that was a metaphor for a lot of agencies; where, regardless of your condition, or your situation – 70-year old dementia is very different from a 20-year old with [progressive condition], the care's the same. They deliver the care exactly the same, regardless. I was just like … come on … which is one of the things that probably turns me off using agencies. Because they all

	had, probably, the same training. That's when the personalisation is knocked out of the carer. They don't look at what they've got, or whatever condition … they all like their tea the same way, they all like their bed the same way, which isn't the case at all.
AR	**And it's those things, perhaps, that are actually very important. They're what define you. Or us. As individuals. You know, I have a particular way … I don't like sheets tucked in, or feeling constrained in a bed …**
M	I don't like milk in my tea, yet all of them would assume that I did. That kind of thing. That's where there's lack of personalisation in a lot of care agencies.
AR	**Mmm. And it sounds like that happened a lot.**
M	Yes.
AR	**It was the majority of your experience. Feeling quite impersonal. Or de-personalised.**
M	Yes. And with agencies, because as long as they know your key code to your key safe, so they can get the keys out, anyone can let themselves in. There's faces and names I don't remember, because it's just a revolving door of people, who wouldn't have been briefed on the kind of condition I had, and my level of mobility. And I would just be the four o'clock. I wouldn't even be M! You're the four o'clock, I was meant to be here at four, sorry I'm late.
AR	**They didn't even know your name? They didn't use your name?**
M	Yeah. You'd just be the one who's got half an hour: four to four thirty. Or the twelve to twelve thirty. Will you sign my timesheet? Or whatever.
AR	**So, you know, that's really fascinating actually, because I noted earlier that you were talking about the hours. And there was a real strong emphasis on the four hours, then it went up, slowly, through a massive struggle. But it was: hours, hours, hours. And that's the hours of support, less the social services administrative side of it, I guess. And then you've got carers from agencies coming in, concerned about … conceptualising you as: hours! Or more likely, minutes, because I imagine they were quite small calls, is that right?**
M	All of them, yeah.
AR	**What was the average call time?**
M	30 minutes.
AR	**Ok.**
M	It used to be 15. But apparently there was some sort of policy change, across all care. And it went up to 30 minutes. And most of them don't even spend ten minutes here, kind of thing. Just really quick. And also sometimes, because I wanted them to leave as quickly. If I needed

	something, I wouldn't ask them for it, because they'd stay longer … they were like a bad cloud … get out, get out!
AR	**For me, I'm not quite sure what … I think it's something of the impersonal, the de-personalised. Maybe it's something about the … and I think we can reflect a bit together … [both chuckle] … that may the hours, the numbers, is this something about the money, the cuts environment? Is it having an impact? Is it somehow filtering down as well?**
M	Absolutely. Especially if you are using agencies, and that person has maybe ten other people they've got to see that day, for various things, so if there's two people they'd always, like, talk to each other. Where are you going next? My one o'clock is … and then I've got to get to someone for one thirty. And the idea like they've got a space of about five minutes to get from one side of Local Authority to the other, to get to someone on time. And it just didn't work. It's very like the … the failings felt very systemic, in that it was every agency. They just wouldn't have enough time to get to the next person. That cuts into the time of that person; you're supposed to get 30 minutes, but you only get 15; or less. Or they'd stay the length of that time, but that makes them late for the next person. Their whole day is just blocked up. They don't get paid for lunch or anything, or travel, and they're chock-a-block with clients they've got to get to as soon as possible. So it always felt very rushed … and … yeah … very impersonal, without respect. And there's just this idea that I think, like, you know when I say it out loud sometimes, 37.5 hours a week, you know, of the *week*. There are, like, 24 hours in each day, I'm not expecting … some people do get 24-hour care, those I was told by the social worker who were terminally ill, or those with … high … high level of need in terms of mental disability. So not even learning … mental, in the sense that they're … they can be very violent, or something. Those sort of people got 24 hours care packages. I wouldn't. Because my level of need is not considered high enough.
AR	**Yeah, yeah.**
M	And, even hearing that, I was, like, wow … it means, if I was someone who didn't have the support network that I had, my life would only be 37.5 hours a week. Because there would be nothing outside of that. If I didn't have my family, didn't have my friends. If I didn't have carers who understood, who I actually explain how the system works to, they understood why they had to sometimes go away for lunch and come back later. I don't have enough hours for them to stay, kind of thing. And, yeah, it's so … it's just baffling, really. Yeah, because there are more than 37.5 hours in a week.
AR	**Yeah. So I wonder … I don't know if you can answer this, but if you could … are you able to say then in terms of the amount of support you might need now, ideally?**

M	*Ideally*, for all the things that I'm doing, I want to do, or I'm trying to do, I would need around … I could manage with … I could manage with, like, eight hours a day. Eight hours a day.
AR	**Every day?**
M	Every day. Yeah. I could do much more, and that's actually like a proper working hours for someone. Eight hours times seven is, like …
AR	**56.**
M	And divided by two people, three people, that's enough for a part time, almost full time job. I could … I could … that's what I really need. I would need overnight. But it would be sleeping nights, not waking nights. Because sometimes my [indistinct, ulcer = best guess] flares up, and sometimes it doesn't. But I need help, because I want to go to bed at any time I wanted, like, and for it not to be a problem. If I came back late from shows … like, I don't go to see shows that are a long way from home, because I won't be able to get back home in time. But if I could, like, go out late, and come home late, and know that a carer would be here to put me into bed, and they'd sleep, and we'd both get eight to nine hours sleep … because I could wake up late the next morning. Kind of thing. It's not 24 hour care, but it would just be substantially more than I have now. And include overnights, to take into account that, for whatever reason, sometimes I don't get home before ten, or after ten, or whatever. Whether it's traffic, or something ran over, if it's a workshop or show, or what have you. That's my … I mean, that's the life I want. And to be able to get it, I need certain things in place. Because shows sometimes start at nine and finish at eleven; and the idea for social services of going to the cinema or theatre is a hobby, and it's like for me, it's my career. It's my job. I go and see shows, I find out who made them, I contact those people if I want to work with them, I go and create those opportunities. To make work. Like, that's the industry I want to be in. And that's the way they work. It's not like a 9-5 like my [sibling], [they] work in a private [enterprise] … sometimes she has to be there at 8 a.m. And leave 6 p.m. Sometimes she works from home. But then she also travels; she travels sometimes for four weeks on end. I want the freedom to do that, to be able to work, but also work around … the way I work at the minute, I work around my condition – it's how much strength and energy I have day to day. And I need a flexible care package, that reflects that. At the minute, it's still very restrictive, but I'm trying to make the best of it. And the hope is … [indistinct few words] … that one day I might be in the position to hire somebody myself. And not even need Local Authority social services. That I'd …
AR	**Through paid work …?**
M	Yeah, through paid work, I'd be able to pay for someone myself. And whatever hours … yeah.

AR	**Mmm. Sounds good! [Both chuckle]**
M	Got to write that screenplay. That’ll sell to Spielberg for a million pounds!
AR	**Ok, well thank you very much.**
M	No worries!

Appendix 9: Cross-case thematic analysis themes

Themes	**Mandy**	**Ginnie**	**Roger**	**Michael /Karen**	**Nigel**	**Carol**	**John**
Austerity	**M**	**G**	**R**	**MK**	**N**	**C**	**J**
Austerity as a source of anxiety.	✓			✓		✓	✓
Anxiety associated with assessments/reviews. Fear support will be taken away.	✓		✓	✓			✓
Brexit as a source of anxiety.				✓	✓		
Fear of closure of centre based support.						✓	
‘Reablement’ used to try to deny ongoing support to people who need it.							✓
No trust in government.				✓		✓	
Feeling lucky to get a good service/enough money in the personal budget. Postcode lottery.							✓
Fighting the system to get the required support.	✓		✓	✓			✓
Assessment: Knowing how to best present one’s needs to social services to secure sufficient funding.	✓						✓
The need for advocacy.	✓						✓

Personal budgets: Panel rejecting requests for more hours/funding.	✓			✓			✓
No contact from adult social care – unresponsive system. Calls/emails not responded to.	✓		✓	✓			✓
Being reduced to ‘bodily functions’.	✓						
Experiences of impersonal and regimented care/support.	✓	✓	✓				✓
Relationships and interdependence	**M**	**G**	**R**	**MK**	**N**	**C**	**J**
Ongoing relationships with professional staff valued.	✓	✓	✓	✓	✓	✓	✓
Social Worker experienced as distant / remote.	✓	✓	✓	✓	✓		✓
Wanting Social Workers to be honest about how the ‘system works’ and the impact of austerity.	✓			✓			
The importance of emotional support being available.	✓	✓	✓		✓	✓	
Wanting the impact of a particular disability/condition to be understood by professionals.	✓	✓	✓	✓		✓	✓
Needing support to navigate the system – learning the jargon/terminology.	✓		✓	✓			✓
Impact of projecting a positive self-image of oneself (in assessment processes).	✓	✓	✓	✓	✓		
Not wanting to be defined by impairment/condition.	✓		✓	✓		✓	✓
The challenges of being ‘vulnerable’ and ‘needing to ask for help’.	✓	✓			✓		✓
The importance of having shared interests with PAs /support workers.	✓						

Centre-based support considered ‘family’.		✓			✓	✓	
Importance of family and informal support network.	✓	✓	✓	✓	✓		✓
Aspects of independence experienced as painful – experiences of separation and loss.	✓	✓		✓			
Transition to adulthood and separation (from family).	✓			✓			
The concept of independence challenged	✓						✓
Reciprocity	**M**	**G**	**R**	**MK**	**N**	**C**	**J**
Importance of reciprocity/‘giving back’ emphasised.	✓	✓	✓	✓	✓	✓	✓
Importance of peer support.	✓	✓			✓	✓	✓
Able to advocate for others/harder to stand up for oneself.	✓						✓
Strengths-based assessment experienced as being told ‘do it yourself’ or ‘can’t someone else do it?’	✓						✓
What’s possible/how one can achieve one’s potential with support.	✓	✓	✓	✓	✓	✓	✓
Choice and control	**M**	**G**	**R**	**MK**	**N**	**C**	**J**
The realities and limitations of ‘choice’.	✓	✓		✓	✓		
Direct payments valued	✓			✓	✓		✓
The term personalisation experienced as confusing / jargon.	✓	✓	✓	✓	✓	✓	

Confusion about the mechanics of personal budget.		✓			✓		
Proscribed support plans. Restrictions on usage of personal budgets.				✓			✓
Negative experiences with a Resource Allocation System (RAS).				✓			✓
Not ‘fitting’ the requirements or expectations of the system.	✓		✓				
Experiences of limited privacy.	✓	✓					
A focus on units of time – ‘hours’ (in relation to support plans).	✓	✓					
Notions of ‘choice and control’ valued.	✓		✓	✓	✓		✓
Not following prescriptive support plan experienced like breaking the rules.	✓						✓
Limitations of ‘personalisation’ in the home/family context.		✓			✓		
Encountering prejudice, assumptions and low expectations in society associated with disability.			✓			✓	
Culture and religion	**M**	**G**	**R**	**MK**	**N**	**C**	**J**
Disability and culture. A focus on being ‘cured’ and issues of how disability impacts on family honour.	✓		✓				
Religion – views on disability.			✓				

Appendix 10: Poster presentation, ISFW European Social Work conference, Reykjavik Iceland, 28th – 30th May 2017

The power of co-production in Adult Social Care
A case study in a London local authority

CONTACT
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Andrew Richardson, Independent Social Worker and Doctoral student, London United Kingdom.

Introduction

This project took place in a diverse inner London borough as part of a programme which was initiated to 'transform' services and make them more efficient and 'personalised' to the unique needs and preferences of people needing care and support. The approach of the project and subsequent research was based on principles of 'co-production'.

A parallel goal was to strengthen the voice of service users and carers. An opportunity was therefore created to pursue a rights based Social Work approach rooted in notions of empowerment and community development.

Emotional sensitivity and a focus on 'enabling' and respectful relationships was also key in an effort to build confidence, knowledge and skills among a group of disabled people who became known as 'Experts by Experience'.

Working as equal partners, the Experts by Experience exerted a strong influence on the project and the research. The project and subsequent research is a case study in the largely untapped yet considerable potential of disabled people and people who use social care services.

Source: new economics foundation

Background

The project took place in a context of financial austerity imposed by the Conservative government in the United Kingdom. £4.6bn has been cut from social care budgets between 2010 and 2015. The project was based in a local authority where central government had drastically cut funding for local services.

The research forms part of a Doctorate in Social Work. The research was undertaken after the conclusion of the project. Learning from the experience of the project has therefore informed the subsequent research project.

The approach

An approach to working together via a process of 'co-production' was adopted by the Project Manager and lead researcher.

The emphasis on sharing power more equally in decision making was informed by notions of 'the integrity of the process' – a community development principle about embodying the change you want to see in the world advanced by Jim Ife (2002).

The confidence and skills of the Experts by Experience were strengthened. They took part in a bespoke community leadership programme. This included modules on self-esteem, public speaking, participating in and chairing meetings, leadership and influencing skills.

Regular support meetings for the Experts by Experience provided emotional containment and strengthened the group cohesiveness.

The experts by experience were later asked to join a Reflective Learning Group which was part of the research project.

Project outcomes

The project achieved the following:

- Highlighted what can be achieved when service users and professionals work together as equals.
- Social Workers and other professionals associated with the programme highly valued the opportunity to work in a more equal and creative way with people using services.
- A comprehensive action plan was co-produced by the programme board and published locally and nationally. Many important actions were delivered including co-produced training for staff, new groups and forums, changing approaches to complaints, supporting peer support initiatives, reviewing and simplifying processes for 'personal budgets'.
- The 'voice' of service users and carers was strengthened, the profile of disabled people and their value, their rights and contributions to the community were re-asserted at a time of cuts and budgetary austerity.
- The economic case for co-production was evidenced by the programme. There were several instances where creative ideas and/or challenge by Experts by Experience resulted in much more cost effective and relevant services being developed.
- Some Experts by Experience have gone on to develop research expertise. This includes undertaking accredited training in Participatory Appraisal.

From practice to research

Following on from the project, a small scale qualitative research project was undertaken. The research focused on understanding 'personalisation' from a service user perspective.

The research aimed to answer the following research questions:

1. What are the range of meanings of personalisation that Adult Social Care service users ascribe to this concept when given an opportunity to explore their lived experience in depth?
2. What does a systematic analysis of literature relating to personalisation reveal in relation to ideological positions?
3. What might be the tensions and connections between the lived experience of Adult Social Care service users and personalisation policy?
4. What is the value of identifying and conceptualising unconscious forces at play in the development and practice of personalisation policy?

Research methods

A multi-method approach was adopted. This included undertaking in-depth interviews and establishing a 'reflective learning group'.

Free Association Narrative Interview method

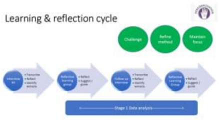
The principles that underpin the free-association narrative approach include the use of open ended questions, eliciting stories, avoiding why questions and using respondents ordering and phrasing.

The approach is guided by psychoanalytic principles. It considers that people being interviewed are likely to be 'defended subjects' – and we need to listen carefully and observe beyond what is being said.

Each participant was interviewed twice. There was an initial and follow up interview.

The reflective learning group included 6 Experts by Experience and was facilitated by an independent facilitator with the researcher in an 'observer' role.

Anonymised extracts of each interview were shared with the Reflective learning group. They group reflective on the material in a way that encouraged 'free association'. They also shared suggestions for follow up questions with the researcher. Featured below is a summary of the 'learning and reflections cycle' that informed the research.



Emerging themes

Preliminary analysis of the data suggests the following:

Meanings of personalisation

- Can means lots of different things or nothing to service users.
- The language of personalisation can obscure other important roles and functions.
- Relationships, including supportive and empathic relationships with professionals are valued by service users.
- There are aspects of independence which are painful – including separation and fear of isolation. What is gained from 'independence' can also mean something is lost.

Choice as a priority?

- Notions of 'choice' feature must less prominently in the interview data than in the literature and at a policy level.
- Personalisation associated more with community inclusion and family/social connectedness and less with 'choice and control'.
- Notions of reciprocity, 'giving back' is prominent in the data.

Personalisation in a context of cuts

- Cuts are causing huge anxiety. Struggle to keep and defend support and services. Fear of what has been given (personal budget) being cut or taken away.
- The challenges of being 'vulnerable' and 'needing to ask for help'. Assessment processes can and some services can be experienced as de-humanising.
- Social Services reviews and assessments are associated with DWP review and assessments. Service users may not perceive the differences between separate arms of government as clearly as professionals might.
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- The challenges of being 'vulnerable' and 'needing to ask for help'. Assessment processes can and some services can be experienced as de-humanising.
- Social Services reviews and assessments are associated with DWP review and assessments. Service users may not perceive the differences between separate arms of government as clearly as professionals might.
- There is a wide gulf between the rhetoric of 'choice' and 'flexibility' for example and the reality of restrictions on usage of personal budgets. It is confusing to service users and leaves some people thinking they are "breaking the roles quietly" if they deviate from their written support plan.
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Learning for Social Work

'Co-production' is an approach that appears to be congruent with core Social Work values. There is much to be gained for Social Workers who seek to integrate co-production into their practice. Grass roots organising and using Social Work skills to develop confidence and leadership skills among service users can be an effective way to influence policy and service development. The links between community development and rights based Social Work approaches and 'co-production' are not difficult to discern.

However, working with people who have experienced discrimination, marginalisation and who may have low confidence and may be in pain can be demanding and hard to bear for practitioners and researchers. Drawing on notions of 'containment' (Bion, 1958. 1962a,b) and related psychoanalytic concepts can provide useful tools alongside community development and rights based Social Work approaches.

Finally, while the research project outlined above is still in progress, it already seems evident that psychosocial and psychoanalytically informed research has utility in illuminating some complex challenges in contemporary Social Work.

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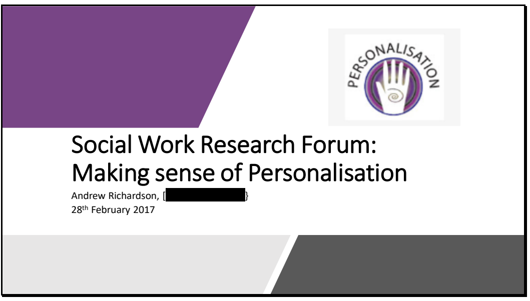
Appendix 11: Camden and Islington Social Work Research Forum slide pack, London, UK, 28th February 2017

Participatory research today

- Live research event today
- Contribute your views

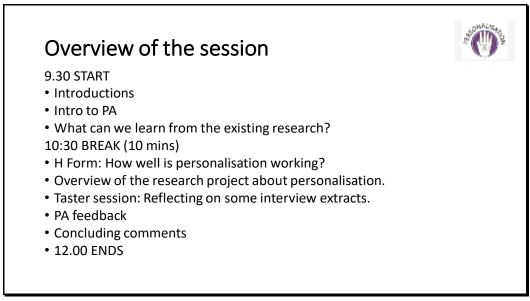
Questions:

- What does personalisation mean to you?
- How is it working in Camden & Islington?
- We hope you find it interesting and fun!
- Feedback at the end of the day



Social Work Research Forum: Making sense of Personalisation

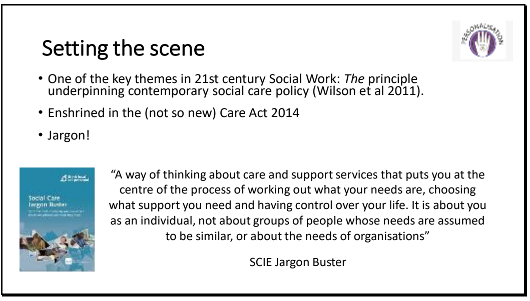
Andrew Richardson, [redacted]
28th February 2017



Overview of the session

9.30 START
- Introductions
- Intro to PA
- What can we learn from the existing research?

10:30 BREAK (10 mins)
- H Form: How well is personalisation working?
- Overview of the research project about personalisation.
- Taster session: Reflecting on some interview extracts.
- PA feedback
- Concluding comments
- 12.00 ENDS

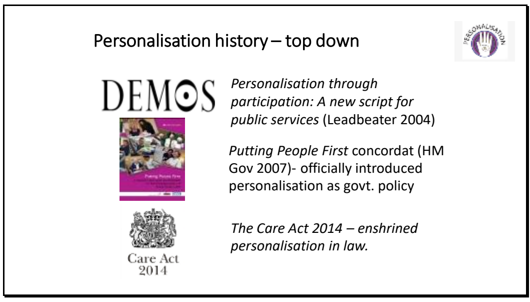


Setting the scene

- One of the key themes in 21st century Social Work: *The* principle underpinning contemporary social care policy (Wilson et al 2011).
- Enshrined in the (not so new) Care Act 2014
- Jargon!

"A way of thinking about care and support services that puts you at the centre of the process of working out what your needs are, choosing what support you need and having control over your life. It is about you as an individual, not about groups of people whose needs are assumed to be similar, or about the needs of organisations"

SCIE Jargon Buster



Personalisation history – top down

DEMOS

Personalisation through participation: A new script for public services (Leadbeater 2004)

Putting People First concordat (HM Gov 2007)- officially introduced personalisation as govt. policy

Care Act 2014

The Care Act 2014 – enshrined personalisation in law.

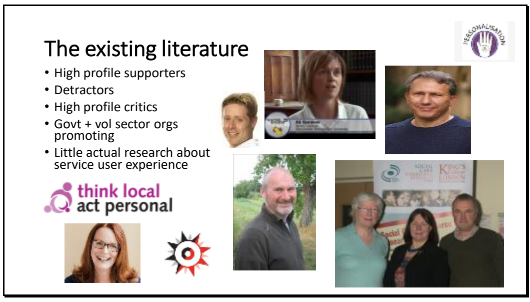
Personalisation history – bottom up

Disability activism

Links / (origins?) with movement for independent living

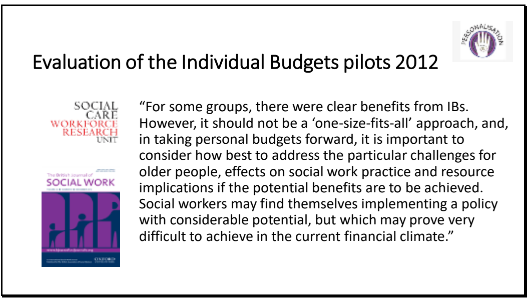
Links with the Social Model of disability

Direct payments as a precursor to Personal Budgets



The existing literature

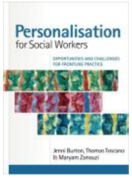
- High profile supporters
- Detractors
- High profile critics
- Govt + vol sector orgs promoting
- Little actual research about service user experience



Evaluation of the Individual Budgets pilots 2012

"For some groups, there were clear benefits from IBs. However, it should not be a 'one-size-fits-all' approach, and, in taking personal budgets forward, it is important to consider how best to address the particular challenges for older people, effects on social work practice and resource implications if the potential benefits are to be achieved. Social workers may find themselves implementing a policy with considerable potential, but which may prove very difficult to achieve in the current financial climate."

Personalisation… means different things to different people…



"Some people are supportive of… personalisation because they see it as part of a campaign for greater civil rights, choice and control for disabled people; others see it as an essentially market based mechanism for… rolling back the welfare state and as a form of privitisation by the back door"

(Glasby & Littlechild cited in Burton et al, 2012)

Powerful stories

- Needham (2011) discovered in her analysis of personalisation policy, that there are a set of stories being told about how personalisation has transformed the lives of service users.
- Personalisation used as a term that summarised all that was wrong and all that could be done to improve the system.
- Impossible to challenge

POET Survey

POET™
Personal Outcomes Evaluation Tool

- Focuses on Person, Process, Impact
- Third National PB Survey Oct 2014

"More than 80 per cent of people surveyed said that a personal budget had made things better or a lot better when it came to dignity in support and quality of life. At least two thirds also said their personal budget had made things better or a lot better when it came to independence, arranging support, mental health, control over their life, feeling safe, relationships with family and people paid to support them, friendships and self-esteem".

In-Control.

It's not working!

"Overall, there is no evidence that personal budgets necessarily improve outcomes. Indeed, on the contrary, there is evidence that they do not, along with the process being disliked by service users and practitioners alike"

Slasberg, Beresford

& Schofield, 2012

"Loss of faith in personalisation"

COMMUNITYcare.co.uk
For everyone in social care

"In 2009, 67% of you thought personal budgets would benefit service users, last year it was 51%, now it's 41% (26 May 2011)

"Training gap, cuts and paperwork damaging personalisation, warn social workers." (2013)

Denigrating dependency

- Unconscious denigration of dependency – manifests in Social Care policy
- Promoting 'independence' is frequently a stated objective of personalisation and personal budgets.
- Fear and hatred of dependency?
- Denial
- Unrealistic notions of independence at the heart of personalisation discourse?

2017 study – publication pending

"There's lot of places I'd like to go and things I'd like to do"

Aimed to explore the daily living experiences of adults with mild/moderate intellectual disabilities

Focus group discussions with s/users and support workers, were analysed thematically.

Two broad themes emerged (1) independence and agency AND (2) social capital and wellbeing.

While some participants echoed ideas central to the personalisation narrative, a number of contextual barriers to achieving greater independence and agency were discussed. **Moreover, greater independence was not a desired or realistic goal for all participants.**

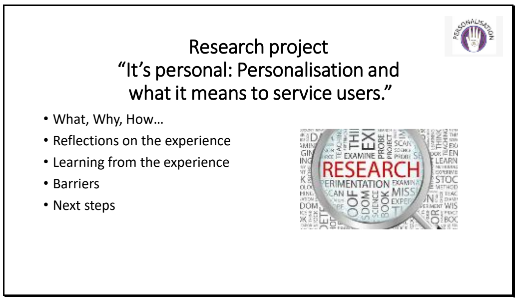
So…

- Meaning depends on ideological position.
- Positive outcomes are being attributed to personalisation.
- Personal Budgets and personalisation are often conflated
- If Personalisation = Personal Budget, does Personal Budget = Support from Social Services?
- A split seems evident in the literature: it works / doesn't work. It's all good / all bad.
- Proponents of personalisation attribute any actual or perceived failings to issues with process.
- We need to better understand what is happening at a practice level…

Gaps

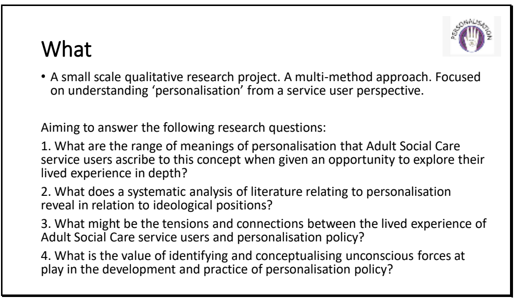
- More authentic stories from a s/user perspective.
- Unconscious factors.
- Is it just about process…?
- Bridging the splits. Does it have to be 'all good' or 'all bad'?
- Co-production?
- The place of relationship based practice.

Break – 10 minutes & PA reminder



Research project
“It’s personal: Personalisation and what it means to service users.”

- What, Why, How…
- Reflections on the experience
- Learning from the experience
- Barriers
- Next steps



What

- A small scale qualitative research project. A multi-method approach. Focused on understanding ‘personalisation’ from a service user perspective.

Aiming to answer the following research questions:

1. What are the range of meanings of personalisation that Adult Social Care service users ascribe to this concept when given an opportunity to explore their lived experience in depth?
2. What does a systematic analysis of literature relating to personalisation reveal in relation to ideological positions?
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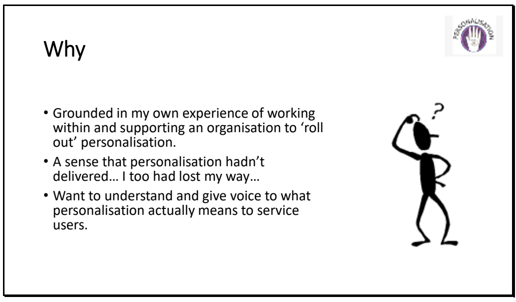
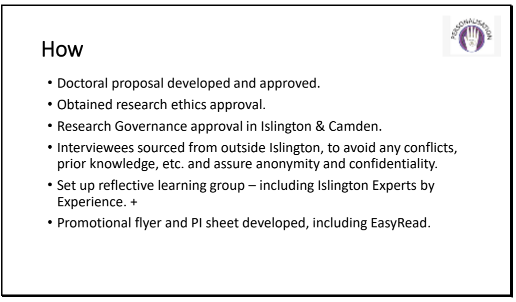


Why

- Grounded in my own experience of working within and supporting an organisation to ‘roll out’ personalisation.
- A sense that personalisation hadn’t delivered… I too had lost my way…
- Want to understand and give voice to what personalisation actually means to service users.



How

- Doctoral proposal developed and approved.
- Obtained research ethics approval.
- Research Governance approval in Islington & Camden.
- Interviewees sourced from outside Islington, to avoid any conflicts, prior knowledge, etc. and assure anonymity and confidentiality.
- Set up reflective learning group – including Islington Experts by Experience. +
- Promotional flyer and PI sheet developed, including EasyRead.

The data

14 interviews.
7 people x 2.

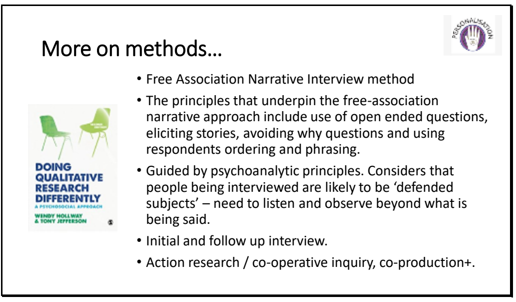
Approx 27 hours of recording

7 reflective learning group discussions

1626 minutes of recording.

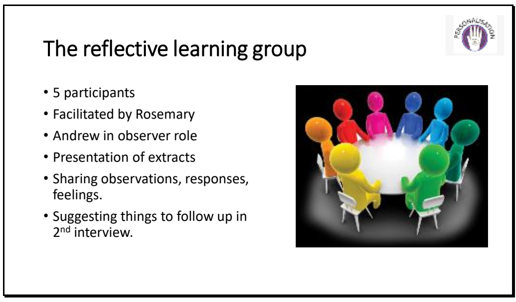
Literature review (discourse & narrative analysis)

Interviewees: Self selected, experience of Adult Social Care, outside Islington. x7 people from a variety of backgrounds and experience. +



More on methods…

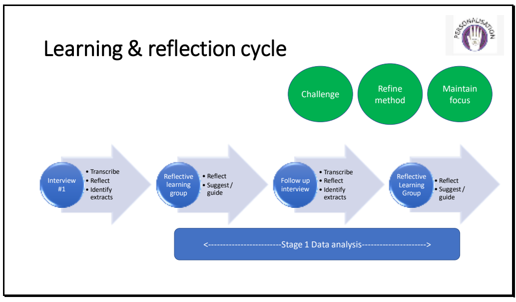
- Free Association Narrative Interview method
- The principles that underpin the free-association narrative approach include use of open ended questions, eliciting stories, avoiding why questions and using respondents ordering and phrasing.
- Guided by psychoanalytic principles. Considers that people being interviewed are likely to be ‘defended subjects’ – need to listen and observe beyond what is being said.
- Initial and follow up interview.
- Action research / co-operative inquiry, co-production+.



The reflective learning group

- 5 participants
- Facilitated by Rosemary
- Andrew in observer role
- Presentation of extracts
- Sharing observations, responses, feelings.
- Suggesting things to follow up in 2nd interview.

The experience of being involved



Learning & reflection cycle

Challenge

Refine method

Maintain focus

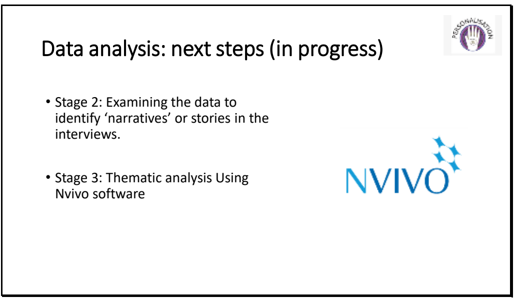
Interview #1
- Transcribe
- Reflect
- Identify extracts

Reflective learning group
- Reflect
- Suggest / guide

Follow up interview
- Transcribe
- Reflect
- Identify extracts

Reflective Learning Group
- Reflect
- Suggest / guide

<-----------------------Stage 1 Data analysis--------------------->



Data analysis: next steps (in progress)

- Stage 2: Examining the data to identify ‘narratives’ or stories in the interviews.
- Stage 3: Thematic analysis Using Nvivo software

Extracts reflection: Taster

- Extracts
- Discussion:
- What do we notice?
- What thoughts, feelings, associations come to mind?
- What might we learn from the extract about the person's experience of 'personalisation'?
- Feedback to larger group.

Emerging themes and stories (1)

Meanings of personalisation

- Can means lots of different things or nothing to service users.
- The language of personalisation can obscure other important roles, functions, experiences and approaches.
- Stories of struggle, resilience, narrative of 'progress under threat', fragmentation / connectedness, inclusion/exclusion.
- Relationships, including supportive and empathic relationships with professionals were valued by interviewees.+
- There are aspects of independence which are painful – including separation and fear of isolation.

Emerging themes (2)

Choice as a priority?

- Notions of 'choice' feature much less prominently in the interview data than in the literature and at a policy level.
- In the interviews personalisation seems to be associated more with community inclusion and family/social connectedness and less with 'choice and control'.
- Blurred lines between personal and professional systems. Services as 'family', PA's as friends.
- Notions of reciprocity, 'giving back' is a prominent feature in the interviews.

Emerging themes (3)

Duffy's Observations

Personalisation in a context of cuts

- Cuts were causing huge anxiety to interviewees.
- The challenges of being 'vulnerable' and 'needing to ask for help'.
- Social Services reviews and assessments were associated with DWP review and assessments by interviewees.
- There is a wide gulf between the rhetoric of 'choice' and 'flexibility' and the reality of restrictions on usage of personal budgets.
- Keen to be (or seen to be) open to scrutiny, accountable with public money. Distancing themselves from 'benefits scrounger' narrative.

Challenges

- Approvals and recruitment

- Limitations of the research approach

Generalisability and sample size
FANI approach

- Issues raised during fieldwork

Testing knowledge of meaning
Extracts vs full transcripts

Participatory research feedback

Questions?

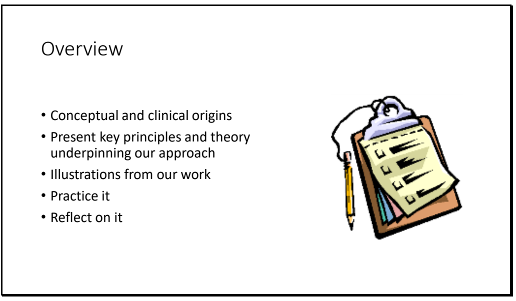
Thank you

Appendix 12: Presentation slide pack, SWSD Social Work conference, Dublin, Ireland, 4th – 7th July 2018

Working with unconscious processes in reflective practice groups for practice, education & research

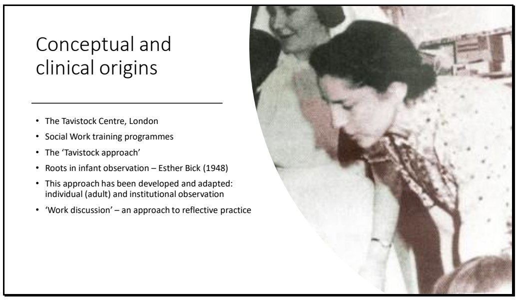
Clare Parkinson & Andrew J. Richardson

4th July, 2018



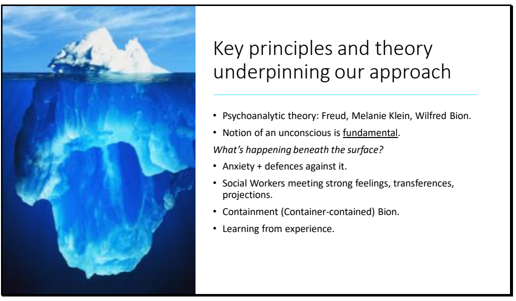
Overview

- Conceptual and clinical origins
- Present key principles and theory underpinning our approach
- Illustrations from our work
- Practice it
- Reflect on it



Conceptual and clinical origins

- The Tavistock Centre, London
- Social Work training programmes
- The ‘Tavistock approach’
- Roots in infant observation – Esther Bick (1948)
- This approach has been developed and adapted: individual (adult) and institutional observation
- ‘Work discussion’ – an approach to reflective practice

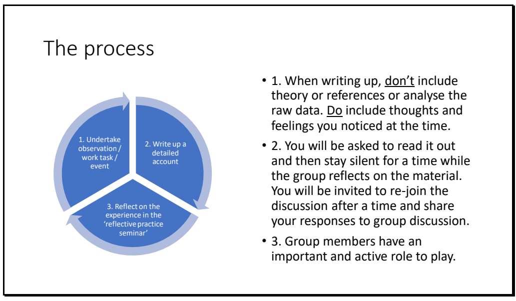


Key principles and theory underpinning our approach

- Psychoanalytic theory: Freud, Melanie Klein, Wilfred Bion.
- Notion of an unconscious is fundamental.

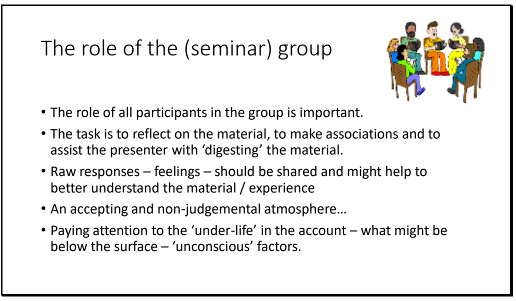
What’s happening beneath the surface?

- Anxiety + defences against it.
- Social Workers meeting strong feelings, transferences, projections.
- Containment (Container-contained) Bion.
- Learning from experience.



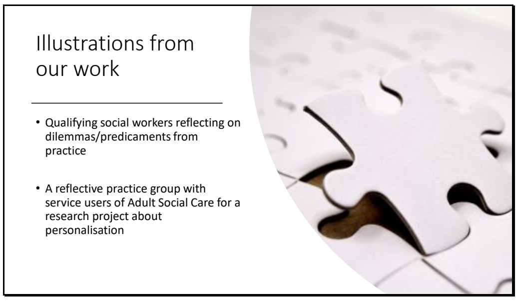
The process

- 1. When writing up, don’t include theory or references or analyse the raw data. Do include thoughts and feelings you noticed at the time.
- 2. You will be asked to read it out and then stay silent for a time while the group reflects on the material. You will be invited to re-join the discussion after a time and share your responses to group discussion.
- 3. Group members have an important and active role to play.



The role of the (seminar) group

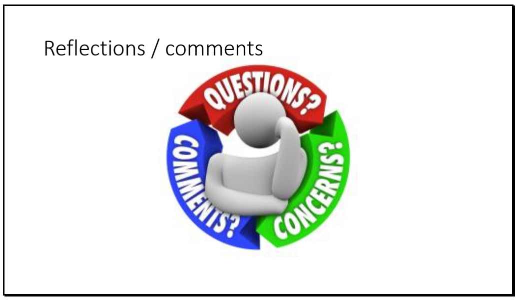
- The role of all participants in the group is important.
- The task is to reflect on the material, to make associations and to assist the presenter with ‘digesting’ the material.
- Raw responses – feelings – should be shared and might help to better understand the material / experience
- An accepting and non-judgemental atmosphere…
- Paying attention to the ‘under-life’ in the account – what might be below the surface – ‘unconscious’ factors.



Illustrations from our work

- Qualifying social workers reflecting on dilemmas/predicaments from practice
- A reflective practice group with service users of Adult Social Care for a research project about personalisation

Reflective practice group



Reflections / comments