

**Context Statement for PhD by Public Works,  
School of Health and Social Science, Middlesex University**

**Administration or transformation? An exploration of  
personalisation reforms, service user participation and diversity  
strategies in adult social care**

**Sarah Carr**

**October 2011**

**This is dedicated to the life and memory of**

**Nasa Begum**

**1963-2011**

**Sister, struggler, survivor**

**Inspiration and friend**

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**Abstract**

This PhD by Public Works demonstrates how three key topic areas with convergent themes emerge from a systematic analysis of 21 submitted public works. These are: The personalisation policy agenda in adult social care and mental health; Service user participation; and LGB (T) service user experience. The final synthesis brings together these three topics and core themes as a coherent critique of how the personalisation policy has been constructed and implemented. It examines the way in which this reflects some of the broader political, operational and systemic barriers to service user participation, the use of experiential knowledge and evidence and the recognition of the full diversity and complexity of people who use mental health and social care services (with particular reference to LGB (T) service user experience). The resultant exploration and argument is informed by my service user perspective and associated methodologies. This context statement shows how the knowledge for the PhD by Public Works was produced, how it makes a significant contribution to knowledge in the field and to the broader sphere of social care and mental health research methodology and service user epistemology.

**Introduction**

This PhD by Public Works presents a unified account of the new knowledge generated by 21 published works which focus on the personalisation policy agenda in adult social care (HM Government 2007), service user participation in mental health and social care and the experiences of lesbian, gay, bisexual (and in some cases transgender – see note on terminology p5) (LGB (T)) service users (with a focus on mental health). The key themes and ideas resulting from the 21 submitted works form a coherent critique of several aspects of recent policy and practice arising and inherited from New Labour's public service modernisation programme (see 2020 Public Services Trust 2009; Harris & White 2009; Newman et al 2008), which promoted the participation of service users in decision-making and choice and control over individual social care and support through the use of personal budgets and self directed support (Glasby & Littlechild 2009; Culter, Wayne & Brehony 2007; Beresford & Croft 2001). The modernisation reforms in social care also encompass the promotion of 'equality and diversity' strategies in local authorities which are intended to include LGB (T) people (Cocker & Hafford-Letchfield 2010; McNulty et al 2010) and were underpinned by a government strategy of using evidence for practice and policy (Wells 2007). I ask if and how these modernisation reforms for adult social care, aimed at transforming services so they are responsive to difference

and inclusive of diversity, are working. This resultant exploration is informed by my service user perspective (a note on terminology is included on p5).

The core arguments from the submitted works largely relate to the operation of (often hidden) power dynamics, value systems and processes in adult social care and mental health which can result in the marginalisation of certain service users, exemplified here by those who identify as LGB (T). This is evidenced for service user participation processes and diversity strategies as well as more broadly for how experiential knowledge is understood as evidence and valued by non-service users in policy implementation and, as I ultimately argue in the case of personalisation, for national social policy construction. A critique of the functioning of current administrative systems in mental health and adult social care emerges from the collected works. This informs the line of argument that processes and categories are restricting the potential of service user participation and personalisation to affect positive change in the lives of people who use services.

This 'perspectival' (Alvesson & Skoldberg 2009) investigation and critique is explicitly informed by my experience as a gay mental health service user. This influences the methodological approaches used and developed for many of the works and is the subject of detailed discussion the chapter on my personal development as a researcher.

## **Structure**

This context statement presents a unified account of the papers and reports submitted for the degree of PhD by Public Works to demonstrate their combined unique and significant contribution to knowledge in the field. It is constructed using the following chapters:

1. A brief critical, thematic and descriptive overview of the individual works using a suitable critical appraisal framework. Each account includes a short commentary on the methodologies used. The work is examined chronologically to demonstrate links between the works and to begin to show the development of the lines of investigation of predominant themes. These themes are then explored further in chapters 2 and 5.
2. A brief review of the relevant existing topic literature to contextualise the works and to demonstrate their unique contribution to knowledge in the field. This includes examples of citation to demonstrate the impact of selected works to knowledge in the field. This section is structured thematically using the themes identified as a result of the chronological critical analysis in chapter 1.
3. A critical account of the various methodologies used.
4. A critical review of my personal development as a researcher. This section is illustrated using a sub-group of works from the main submission which focus on the personal experience of mental distress and mental health service use and the impact of this on my identity as a researcher.

5. An examination of how the works relate to each other and the predominant themes and core arguments which emerge from the collected body of work. This section demonstrates the unique contribution to knowledge in the field and defines the authorial position on the topic.
6. A full reference list.
7. An appendix of submitted works.

### **The public works submitted: numerical list for reference in the text**

A total of 21 works are submitted. For ease of reference each piece has been assigned a number, as below, which will be used within the text when the corresponding work is mentioned or to indicate links between works:

1. Carr S (2003) Duty of care: employment, mental health and disability *Journal of mental health promotion* 2(1) pp.6-23.
2. Carr S (2004) *Social Care Institute for Excellence Position paper 3: Has service user participation made a difference to social care services?* London: SCIE/Policy Press
3. Carr S (2005) 'The sickness label infected everything we said': lesbian and gay perspectives on mental distress in Tew J (ed) *Social perspectives in mental health* London: Jessica Kingsley pp.168-183
4. Carr S (2007) Reflection: Sehnsucht cinema in Coyte M.E, Gilbert P & Nicholls V *Spirituality, values and mental health* London: Jessica Kingsley pp.97-102
5. Carr S (2007) Chapter 5: Through a glass darkly: looking for my own reflection in Coyte M E, Gilbert P & Nicholls V *Spirituality, values and mental health* London: Jessica Kingsley pp.84-88
6. Carr S (2007) Participation, power, conflict and change: theorising dynamics of service user participation in the social care system of England and Wales *Critical social policy* 27(2) pp.266-276
7. Carr S (2008) The sick and the well? In Sweeney A, Beresford P, Nettle M & Rose D (eds) *This is survivor research* Ross on Wye: PCCS Books pp.182-183
8. Carr S (2008) Sexuality and religion: a challenge for diversity strategies in UK social care service development and delivery *Diversity in health and social care* 5(2) pp.113-122
9. Carr S (2008) *Personalisation: a rough guide* London: SCIE (2<sup>nd</sup> revised edition, 2010)

10. Carr S & Robbins D (2009) *Social Care Institute for Excellence Research briefing 20: The implementation of individual budget schemes in adult social care* London: SCIE
11. Needham C & Carr S (2009) *Social Care Institute for Excellence Research briefing 31: Co-production: an emerging evidence base for adult social care transformation* London: SCIE
12. Carr S (2010) Personalisation: an introduction for mental health social workers in Gilbert P (ed) *The value of everything: social work and its importance in the field of mental health* (revised edition) London: Jessica Kingsley pp. 60-66
13. Bowlam S, Carr S & Gilbert P (2010) The Partnership Project: learning from experts by experience in mental health services; the Jersey Partnership perspective *International journal of leadership in public services* 6 (2) pp.54-67
14. Carr S (2010) Remote or related? A mental health service user's perspective on leadership *International journal of leadership in public services* 6 (2) pp.20-24
15. Brand D & Carr S (2010) Chapter 14: The person on the receiving end in Webber M & Nathan J (eds) *Reflective practice in mental health* London: Jessica Kingsley pp.244-254
16. Ross P D S & Carr S (2010) 'It shouldn't be down to luck': training for good practice with LGBT people – Social Care TV *Diversity in health and care* 7 (3) pp.211-216
17. Carr S (2010) Seldom heard or frequently ignored? Lesbian, gay and bisexual (LGB) perspectives on mental health services *Ethnicity and inequalities in health and social care* 3 (3) pp.14-25
18. Carr S (2010) *Social Care Institute for Excellence Report 36: Enabling risk, ensuring safety: self directed support and personal budgets* London: SCIE
19. Carr S (2010) *Social Care Institute for Excellence Report 37: Personalisation, productivity and efficiency* London: SCIE
20. Carr S (2011) Mental health and the sexual, religious and spiritual identities of lesbian, gay, bisexual and transgender (LGBT) people in Gilbert P (ed) *Spirituality and mental health* Brighton: Pavilion Publishing pp.335-352
21. Carr S (2011) 'A chance to cut is a chance to cure': self harm and self protection – a gay perspective in Hafford-Letchfield P & Dunk-West P (eds) *Sexual identities and sexuality in social work: research and reflections from women in the field* Farnham: Ashgate pp.31-45

## **Note on terminology**

This PhD by Public Works context statement uses terminology which is contested or problematic. In order to write on the topic of service user participation and lesbian, gay, bisexual and transgender – LGB (T) - perspectives and experiences, a decision on terminology needs to be made. It should also be noted that the use of terminology is additionally influenced by my own self-definition.

I use the terms 'service user' 'mental health service user' and 'survivor' and refer to the following pragmatic definitions from Beresford and from Lewis:

'The term "service users" is used in this discussion to describe people who receive or are eligible to receive social work and social care services...The term "service users" is problematic, because it conceives of people primarily in terms of their use of services, which may well not be how they would define themselves. However, there is no other umbrella term which can helpfully be used to include all these overlapping groups...Therefore the term "service user" is used as a shorthand to describe the subjects of social work and social care, without seeking to impose any other meanings or interpretations upon it or them' (Beresford 2000 p489)

'These terms indicate differing identities, with the term "survivor" used to denote survival of both distress/illness and service usage, and "mental health service user" being less political' (Lewis 2009 p271)

Terminology associated with sexual orientation or identity and gender identity is problematic for social care and mental health (Hicks 2008; Jones & Ward 2010). However, for the sake of pragmatism the term lesbian, gay and bisexual (LGB) is used and where the discussion broadly includes transgender issues, the term lesbian, gay bisexual and transgender – LGB(T) – is used. The 'T' appears in parentheses because while the topic discussion might include transgender perspectives, it may not give them equal weight for various reasons. This is further discussed in chapter 2.

# **Chapter 1: A critical, thematic and descriptive overview of the submitted works, including a brief introductory commentary on the methodologies used**

## **Introduction**

This section examines each of the works in chronological order starting with the earliest first, as this illustrates how the exploration of key themes and arguments has progressed and allows the thematic development to be outlined more clearly. However, a sub-group of works (Works 4, 5, 7 and 15) constitute a collection of personal 'recovery pieces' which articulate the experience of a severe mental health crisis and personal, non-psychiatric strategies for recovery and self-management. They also form a core reference point for the chapter that discusses my personal development as a researcher and will be dealt with separately in chapter 4.

In this chapter each work is briefly examined (except Works 4, 5, 7 and 15) and a descriptive and critical commentary on the topic, methodology and argument is provided. The critical appraisal methodology and analytical framework used for this chapter draws on the work of Hart (Hart, 2002) and Aveyard (Aveyard, 2007). However, there are notable limitations to using some of the critical analysis methods, such as that which determines research quality by methodology (Cochrane 1972), offered by Hart and Aveyard for this body of work. Firstly, the works submitted are very diverse in terms of methodology and publication type (they range from peer-reviewed journal papers to peer-reviewed reports and practice oriented book chapters); none of them are primary qualitative or quantitative research studies or systematic reviews. This means that they do not fit well within the conventional 'hierarchy of evidence', designed primarily to critically assess the quality of clinical research (Crombie 1997). Some of the research reviews submitted are influenced by the social care research review methodology developed for the Social Care Institute for Excellence (SCIE) and published in a volume entitled *Types and quality of knowledge in social care* (Pawson et al 2003), which details a critical appraisal framework designed specifically for the different types of knowledge and research methodologies used in social care, including that of service users and practitioners (for further details see chapter 3). For particular works I have developed my 'own hierarchy of evidence' (Aveyard 2007 p64) for the systematic analysis of research from a service user perspective. These reflect the 'increased recognition that systematic reviews should seek to incorporate the types of research most likely to answer the research question' (ibid p63), which can include user research (Pawson et al 2003).

In addition, when undertaking a critical examination of my own work, my approach is contrary to that of Hart, who directs researchers to focus on 'ideas, theories and arguments and not on the author of those arguments' (Hart, 2002 p176). Where appropriate I refer to the use of personal experience as part of the methodology or evidence. Likewise, the methodologies used in some papers (to be discussed further in chapter 3) mean that, as Aveyard notes 'some experts might become so engrossed in their subject that they are less able to provide an objective assessment of the topic area' (Aveyard 2007 p66). However, in such papers it is not my aim to achieve scientific objectivity and, in some cases, the intention is to challenge it. But, as Alvesson and Skoldberg argue, a reflexive methodological approach is important

to such an endeavour so that 'confessionalism' does not slip into 'self-absorption': 'reflexivity, in the research context means paying attention to these aspects without letting any one of them dominate. In other words, it is a question of avoiding empiricism, narcissism and different varieties of social and linguistic reductionism' (Alvesson & Skoldberg 2009 p269). Therefore, over the course of the examination for each piece I explore my standpoint and position as author and, where relevant discuss the extent to which I am explicit about the influence of my experience as a mental health service user/survivor on the argument and analysis as well my subjective association with the topic under discussion.

Although this initial approach is fragmented, the findings from the examination of each work later inform the broader demonstration of how the works relate to each other and the predominant themes and core arguments which emerge from the collected body of work. The identified themes form the thematic structuring of chapter 2. The findings also inform the wider methodological discussion (chapter 3), particularly when the methodologies relate to the generation of experiential knowledge and its application in research analysis and interpretation within the discipline of health and social science.

### **The submitted works**

1. Carr S (2003) Duty of care: employment, mental health and disability *Journal of mental health promotion* 2(1) pp.6-23.

This is the first work published in a peer-reviewed journal where I use a methodological approach which combines experiential knowledge and personal narrative with research review and policy analysis (discussed in detail in chapters 3 and 4). In the introduction I fully disclose the personal endeavor to understand and share experience using Wilkins' model of 'storytelling' as research (Wilkins, 2000). The purpose of this paper was to produce an 'encapsulating account' where I use my own experience of trying to stay in work while managing a mental health problem to inform analysis of relevant research, policy and legislation. This is in order to define a position of mental health and disability access in the workplace.

The work was written as a response to a period of mental distress triggered by workplace stressors which prompted this wider exploration of the relationship people with mental health problems can have to workplace environments. I make the argument that in terms of disability access, there are psychosocial barriers (including stress, discrimination and stigma) to the workplace for people with mental health problems. I also argue, using research evidence and legal precedent cases, that stress can cause 'psychiatric damage' should be recognised as a workplace hazard in line with health and safety regulations. The core concept of linking disability discrimination law (now subsumed into the Equality Act 2010) and employer duty of care regulations, via personal reflections and narrative, to argue for better practice for people with mental health problems in the workplace provided a new way of thinking about mental health and disability access. This work contributes to the exploration of my personal development as a researcher in chapter 4.

2. Carr S (2004) *Social Care Institute for Excellence Position paper 3: Has service user participation made a difference to social care services?* London: SCIE/Policy Press

This report is a 'review of reviews' designed to provide one of the first comprehensive sources of evidence on the overall impact of service user participation on social care service development, design and provision. It is a narrative synthesis (Green et al 2001) of four directly commissioned literature reviews (older people, children and young people, disabled people and people with learning disabilities) and two NHS Service Delivery Organisation (NHS SDO) programme literature reviews on mental health and user participation in change management (Rose et al 2002).

I commissioned and managed the production of the four SCIE reports, which required developing a methodology for service user participation in the commissioning process as well as with the teams conducting each research review – relatively new approaches in research commissioning and review. The extent of control users had in the production of each report differed, with only one of the four studies being user-controlled and authored. Inclusive commissioning, tendering and peer review processes were developed as part of this work and later set standards for research commissioning (particularly with INVOLVE, an NHS National Institute for Health Research organisation supporting public and patient involvement in health and social care research [see INVOLVE 2003]) as well as inclusive systematic or literature review methodology (see chapter 3). In this particular instance the report was given additional credibility by the explicit acknowledgement the service user status of the author.

The research synthesis reveals what will become a consistent theme within the body of work presented here – that participation strategies do not necessarily accommodate difference or can result in user-led change. Although organisational participation processes were monitored, the impact and outcome of participation was seldom evaluated and fed back to participants. There were strong indications about a lack of organisational responsiveness to issues identified by service users and a lack of commitment to change as a result of service user participation. The report findings on power and conflict, political commitment and control, process and system change are key concepts that will later resurface in work focusing on the implications of personalisation and the evidence concerning co-production and personal budgets. This work also provided findings which were later investigated further and in more detail in two follow up peer reviewed journal papers - Works 6 and 8 –and is a significant work because it provides evidence for subsequent arguments concerning power dynamics and value systems in service user participation.

3. Carr S (2005) 'The sickness label infected everything we said': lesbian and gay perspectives on mental distress in Tew J (ed) *Social perspectives in mental health* London: Jessica Kingsley pp.168-183

Originally a conference paper for a study day on social perspective in mental health (Start making sense...developing social models to understand and work with mental distress - notes from Social Perspectives Network [SPN] study day 11 November 2002 [Carr, 2003]), this chapter presents an auto/biographical (Stanley 1990) or

'auto-ethnographic' 'case study' of myself as a gay mental health service user (a methodology I use subsequently and explored in chapters 3 and 4). This work is recognised in the literature as an example of 'auto-ethnography' (Trotter et al 2006), and represents a unique account by an author who fully discloses their status and identity in the process of writing and as a part of the methodology (see chapter 3).

Again, the chief methodological approaches could be defined as standpoint epistemological (Harding 1993) and emancipatory (Barnes & Mercer 1997) (see chapter 3). I use qualitative, quantitative and case studies and research reviews to evidence and illustrate the social and cultural influences on the mental health of lesbian and gay people. Within this critique, the psychiatric system itself, I argue, can be damaging to lesbian and gay people, because of the influence of the personal prejudice of mental health practitioners and the history of the pathologisation of lesbian and gay people within psychiatric services (an argument which continues in Works 16, 17, 20 and 21).

The question 'who is taking control of my identity?' is implicit in the drawing together of explicit individual personal experience and narrative together with the accounts of other lesbian and gay people who have been through the mental health system or 'treated' for their 'homosexuality'. The historical investigation demonstrates that some lesbian and gay people who have mental health problems have been subject to the type of processing, classification and administration which can reduce the individual to a set of behaviours, symptoms and needs. This forms an example of the system which categorises and administers individuals (Finkelstein 1993), later criticised with particular reference to LGB (T) service user experience in Works 8, 16, 17, 20 and 21 which becomes a key thread of argument between significant works.

6. Carr S (2007) Participation, power, conflict and change: theorising dynamics of service user participation in the social care system of England and Wales *Critical social policy* 27(2) pp.266-276

This theoretical paper represents a further analysis of some key findings on the power dynamics inherent in service user participation from Work 2. It is a deeper analysis of the dynamics between social care organisations and service users who are participating in change. I use the political theories of Chantal Mouffe (Mouffe 2002) to examine the wider influence of the dominant liberal democratic culture on organisational behaviour in relation to user-led change. Mouffe's theory of the functioning of liberal democracy had not been previously used to analyse service user participation and power relations in adult social care and this paper represents the formation of new knowledge in this field. It is cited in subsequent works from UK and international sources (for example Storm et al 2010; Lewis 2009; Webb 2008; Bochel et al 2007).

The findings from Work 2 suggest that conflict has a role in service user participation strategies but the response of organisations has sometimes been to avoid conflict and resist change. This paper examines how organisational ideology, language, structure and mechanism can exclude service users who are perceived as 'too political' or 'too emotional', or where experience as expertise is not recognised. However, I argue that if service users' own understanding of participation is accounted for, it can be recognised as a political act rather than compliance with a

process (the theme of process compliance also appears in Work 11 on co-production).

I use the post-Marxist political theories of Chantal Mouffe to analyse findings from Work 2 and other research on user participation (e.g Hodge 2005a). Her argument that liberal democracy demands 'rational consensus' and 'regulates dissidence' is one which can be applied to social care organisations engaged in service user participation. Mouffe's assertion is that 'antagonism' or conflict is inevitable when there is a plurality of ideas and experience, some of which are expressed in more emotional ways. For the line of argument in this paper, this means service users challenging the rational professional consensus and doing so in ways which do not always fit with the dominant organisational language or process. The solution, I suggest, is not to resist or exclude people, but to change the process and terms of discourse so that different voices are heard and there is an opportunity to form what Mouffe calls 'collective forms of identification' (Mouffe 2002).

The conclusion of this largely analytical paper is that service users and frontline practitioners should be supported to find a continuity of common understanding, based on their experience at the frontline of adult social care delivery. I suggest that change informed by common understandings and experience between service users and frontline practitioners can occur as a result of open dialogue rather than artificial 'rational' consensus. The argument and conclusion of this paper anticipates later work on 'co-production' in adult social care, as presented in Works 11 and 13. It also forms a core contribution to this body of work and to the developing arguments on service user participation.

8. Carr S (2008) Sexuality and religion: a challenge for diversity strategies in UK social care service development and delivery *Diversity in health and social care* 5(2) pp.113-122

This work continues the inquiry into the structural, ideological and behavioural barriers to service user participation in social care organisations (originating with Works 2 and 6). I explore particular issues for diversity in mental health and social care and examines how local authorities and providers are responding to a mainstream, 'single equality approach' within which there is, I argue, potential areas of conflict. The investigation is informed explicitly by my own experiential knowledge and pursues the argument that balancing the interests of religious groups or individuals with those of lesbian, gay, bisexual and transgender (LGB(T)) people may result in marginalisation of the latter or conflict with the former. The work therefore employs a 'standpoint' epistemological approach (chapter 3), which in this case uses personal experience as a gay person (who uses mental health services) as the point of departure. I evidence my argument by reviewing the main UK literature on lesbian, gay, bisexual and transgender (LGB(T)) experiences of participating in local public service decision making processes and in adult social care as service users.

The research evidence examined indicates that there are tensions between the influence of religion and sexual orientation in determining public service and individual frontline practice. I argue that this tension can influence the way local authorities and social care organisations provide services to, and serve the interests

of, LGB(T) people. This is particularly highlighted for LGBT people from black and minority ethnic (BME) communities when the state administers funding and support through faith groups, thereby conflating race and faith identity for administrative purposes (as further explored in Work 17). I argue that, based on the evidence explored for public services and social care, liberal 'rational' consensus making (as explored in Work 6) which misunderstands the complexity of diversity can result in 'hierarchies of equality', which can marginalise LGBT people, particularly those from BME communities. The conclusion outlines the implications of the Equality Act 2010 and of personalisation reforms in adult social care. I argue that enhanced understandings of diversity and person-centred practice are needed. The argument and conclusion of this paper anticipates some of the themes and findings in Works 16, 17, 20 and 21, therefore it forms a core contribution to this collected body of work.

9. Carr S (2008) *Personalisation: a rough guide* London: SCIE (2<sup>nd</sup> revised edition, 2010)

This report was produced in response to a stakeholder priority consultation with 38 members of SCIE's Partners' Council (a stakeholder group of service users, carers, academics, practitioners and providers) which was designed to prioritise some of the key emerging priorities for personalisation and self directed support in adult social care and identify sources of knowledge (see: HM Government 2007) (SCIE 2008 [appended]). This was done through a series of talks, themed focus groups and stakeholder voting on which areas of personalisation where they thought SCIE could make the most impact. Participant voting was analysed using Max QDA software. The resultant SCIE Partners' Council discussion paper (Fleischmann & Carr, 2008 [included in the works submitted]) indicated the importance of mainstreaming radical and user-generated approaches to social care; frontline workforce issues and the need to understand whole system change. The consultation concluded that SCIE had an important role to play in supporting the development of personalisation and was in a position to provide independent leadership, information and direction. The organisation was also perceived to have a role in supporting the development of the user voice in relation to the policy.

The report *Personalisation: a rough guide* 'aims to tell the story so far about personalisation of adult social care services' (Carr 2008/2010). (It is important to note that because of the rapidity of policy and practice change and development between 2008 and 2010 the original 2008 edition was updated to include supplementary material in April 2010 [this later edition is submitted]). For the first 2008 edition it was too early to ascertain the impact of broader personalisation reforms in public services and adult social care through existing research and evaluation. Other approaches had not been subject to evaluation or research beyond the pilot personal budget or individual budget schemes (Glendinning et al 2008, Poll et al 2006). Therefore the evidence gathering for this report could not conform to SCIE's knowledge review methods (Pawson et al 2003). Instead the material identified and included is explicitly presented as a broad, coherent policy narrative intended to analyse and interpret the reforms for adult social care providers, practitioners and users, supplemented by practice evidence on the various implications of the personalisation agenda for key sector stakeholders.

The problems of providing a research evidence base for this report has been acknowledged as being a particular problem for personalisation in general (Cutler, Wayne & Brehony 2007; Beresford 2009a; Glasby & Littlechild 2009), particularly as the report explicitly aimed not to conflate adults social care personal budgets with broader personalisation reforms (an aim of the report was to address this confusion). However, the use of the types and quality of evidence framework established by SCIE (Pawson et al 2003; see also chapter 3), facilitated the assessment and inclusion of user, practitioner, policy and organisational knowledge, where research-based knowledge was scant. The articulation of the findings using a narrative framework and the 'borrowed' name of the report ('a rough guide') are an attempt to make the work accessible and inclusive of all those involved in implementation as well as ensuring a degree of transparency about the limitations of the evidence presented. The report acknowledges and examines some of the issues and themes, particularly those regarding practical implementation of the policy, which were under-discussed or absent in official government policy documents (HM Government 2007) and the early research and social policy reports which influenced the self directed support and personal budget policy agendas (Poll et al 2006; Leadbeater et al 2008). It also situates and explains personalisation as part of an historical reform continuum from institutionalisation to independent living, with explicit reference to wider public service reforms, residential care settings, 'co-production' (see Works 11 and 13) social work values and the role of collective activity like that of user-led organisations.

The report was the first national publication to independently analyse and synthesise fragmented central government policy discourse and the wide-ranging sources of knowledge on the topic (explored further in chapter 2), and to incorporate the contribution of the service user movement and the importance of social work practice into a coherent, historical narrative of personalisation in adult social care (for further discussion of the policy context, other accounts of personalisation and a critique of the influences on the construction of the New Labour personalisation policy agenda for adult social care, see chapters 2 and 5).

10. Carr S & Robbins D (2009) *Social Care Institute for Excellence Research briefing 20: The implementation of individual budget schemes in adult social care* London: SCIE

This SCIE research briefing, conducted using an established methodology (see: [www.scie.org.uk/publications/briefings/methodology.asp](http://www.scie.org.uk/publications/briefings/methodology.asp)), more akin to a broader narrative rather than a systematic review (see Aveyard 2007), examines some of the international research on personal budget schemes as well as providing a concise summary of recent influential UK research (including that on established Direct payments). It was produced in response to the need in the social care and health and social policy sectors for more evidence about the implications and potential outcomes of personal budget schemes, such as that being introduced into England as part of personalisation (NHS Confederation 2011; Boxall et al 2009; Beresford 2009a; Roulstone & Morgan 2009; Cutler, Wayne & Brehony 2007). Therefore this report incorporates research findings from international sources, as UK research was limited. It also draws on findings from existing evaluations of Direct payments.

The focus is on distilling key messages and lessons; examining drivers, barriers and facilitators and identifying gaps in the knowledge (including equality and diversity aspects). Although not explicitly stated, the examination of the international research implicitly revealed potential flaws in the construction and implementation of the particular adult social care personal budget scheme proposed for the UK as part of personalisation reforms. The findings revealed that different service users may have differing support needs or experiences and may be subject to certain practitioner assumptions during the assessment and planning processes – this was strongly highlighted for older people and people with mental health problems. The challenge of balancing adult safeguarding, duty of care and proportionate risk management with choice and control over care and support emerged as a major theme (this is expanded in detail in Work 18), as did the role of the independent support infrastructure, user-led organisations (like Centres for Independent Living), and strategic government leadership. Finally, despite claims about potential cost effectiveness (Poll et al 2006; Leadbeater et al 2008) reliable evidence on the long-term cost implications was not available, and at best personal budget schemes remained cost-neutral, with potentially better outcomes for service users and carers and savings to health (this is explored further in Work 19).

Because of the values and additional user standpoint I brought to the task (which is not explicitly stated in the briefing methodology; attendant methodological issues to be discussed further in chapters 3 and 4), the analysis retains a focus on the experience of and outcomes for different service users and carers; and what is required to ensure that personal budget schemes work positively to increase choice, control and independent living on their terms, rather than for local authority process or social policy reform agendas (for further discussion see chapters 2 and 5).

11. Needham C & Carr S (2009) *Social Care Institute for Excellence Research briefing 31: Co-production: an emerging evidence base for adult social care transformation* London: SCIE

This SCIE co-authored research briefing was again conducted using an established, essentially pragmatic (Trinder 2000), narrative review methodology (see: [www.scie.org.uk/publications/briefings/methodology.asp](http://www.scie.org.uk/publications/briefings/methodology.asp)) and examines some of the international research (later reflected in Work 13) to support a practice definition of 'co-production' for adult social care in the context of personalisation reforms. The *Putting people first* concordat announced that personalisation is 'the first public service reform programme which is co-produced, co-developed, co-evaluated and recognises that real change will only be achieved through the participation of users and carers at every stage' (HM Government 2007 p1).

The work was produced to clarify the origin of the term co-production and examines some of the international evidence to distill key lessons and establish some evidence-based working models specifically for adult social care. Many of the available accounts of co-production to date focused on wider public service renewal without detailed consideration of the meaning of the approach for adult social care (Boyle et al 2006; Bovaird 2007; Cummins & Miller 2007, Needham 2007; new economics foundation 2008, Stephens & Ryan-Collins 2008). However, the quantity and quality of evidence identified for this work was limited because co-production is

a new term for the sector and is not yet commonly used to describe participative approaches to service development and delivery.

The work reviews and analyses theory and research to establish a working model for understanding different forms of co-production that can operate in adult social care, with the aim of identifying a form of co-production that will result in user-led change in adult social care (within the context of personalisation reforms). The different levels of co-production identified from the research range from compliance with services, through to an intermediate level which acknowledges and encourages active participation but maintains service status quo and does not change the fundamental service design and delivery systems. Finally we argue, that the highest 'transformative' level of co-production should be implemented for adult social care. This level requires a redistribution of power and control between professionals and service users and recognition of frontline expertise and experiential knowledge as having equal value.

The concepts and arguments in this work are used for Work 13 where a case example of co-production in mental health service improvement is analysed. The work also establishes a model for understanding the ideal outcome what is essentially a form of service user participation which explicitly recognises and builds on 'assets and expertise'. This model feeds into the broader argument about how service user knowledge is understood and incorporated in social care practice development and policy making and can be used to critique some of the policy activities around co-production itself (see chapter 2).

12. Carr S (2010) Personalisation: an introduction for mental health social workers in Gilbert P (ed) *The value of everything: social work and its importance in the field of mental health* (revised edition) London: Jessica Kingsley

This work is a chapter in an edited book for mental health social work practitioners and students. It draws on, expands upon and reinstates some of the themes in Work 9, but introduces new material specifically relevant to mental health, and the influence of the mental health service user and survivor movements. The aim is to explain the concept and implications for practice of personalisation (particularly the aspects of service user 'choice and control') for mental health practitioners and to connect the policy rhetoric to social work and service user value-bases (such as independence, self-determination and rights-based approaches). The discussion also situates personalisation within a brief historical overview of the deinstitutionalisation of people with mental health problems (and learning disabilities) to emphasise the nature of standard, institutional provision before the 1990 NHS and Community Care Act.

The discussion aims to join up personalisation in adult social care and recovery in mental health (Care Services Improvement Partnership et al 2007), which appear as disparate government policy, but share the same basic goals. This account of personalisation for mental health includes the exploration of user-led and person-centred approaches in mental health that are compatible with personalisation, such as recovery, to demonstrate that they are not parallel initiatives but have shared values and aims. I explicitly and proportionately discuss the direct contribution of the

disability, service user and survivor movements alongside organisations which influenced personal budget and self directed support models. I also include a brief examination of the research findings about direct payments and people with mental health problems to inform practice for self directed support and personal budgets. Finally, I go beyond the confines of the policy analysis and interpretation imposed on Works 9 and 10, to provide a brief critique about some of the policy assumptions on 'voice and choice', power relations and the meaning of personalisation for individual and collective approaches. The chapter concludes by asking the readers to think about choice, control and the effects of disadvantage and discrimination for people with mental health problems. These questions inform themes in the wider argument presented for the PhD by Public Works on the limitations of personalisation and service user participation.

13. Bowlam S, Carr S & Gilbert P (2010) The Partnership Project: learning from experts by experience in mental health services; the Jersey Partnership perspective *International journal of leadership in public services* 6 (2) pp.54-67

This co-authored peer-reviewed journal paper provides an account and analysis of an example of 'co-production' in mental health service change in Jersey and reflects some of the themes explored in Works 2, 6 and 11. I was invited as a consultant to the project and my specific involvement included using my own personal narrative as part of an early workshop to facilitate others to share their own experiences. These direct user experiences, along with those of staff who were also present, then formed a collective body of local user knowledge and an overall critique of current mental health services provision to inform service reform.

My contribution to the paper focuses on the theory and practice of finding 'common ground' between service users and staff as part of 'co-producing' change. I analyse the Partnership Project according to the most radical, power sharing 'transformative' model of 'co-production' (as articulated in Work 11) where people are engaged in, and feel ownership of, the services they use or work in. The discussion includes questions about the practical application of this model, particularly how to facilitate human engagement and open dialogue between service users and staff, and draws on some research findings to explore possibilities. Shared feelings of disempowerment, common agendas, shared solutions to frontline problems and the issue of organisational responsiveness to change are key themes to come from the analysis of the project and evidence-base on co-production (many of which will be explored in chapters 2, 4 and 5).

14. Carr S (2010) Remote or related? A mental health service user's perspective on leadership *International journal of leadership in public services* 6 (2) pp.20-24

This work is a commentary on and critique of leadership in mental health services from a mental health service user perspective, and draws on academic material to support and explore some of the arguments made (see chapters 2, 3, 4 and 5). I am open about my standpoint and there is clear use of narrative and autobiographical material in the open paragraphs. This is used to demonstrate the impact of a particular leadership decision on the life of an individual in order to highlight some of

the problems in leadership behaviour within current power structures in adult mental health services. Because the paper was published in a special edition on spirituality, leadership and values, I adopted an interdisciplinary approach, drawing on philosophy and theology as well as personal experience, research and management theory. In particular I draw on the post-Holocaust theology of Reinhold Niebuhr (Niebuhr 1996 & 2005) and the philosophy of Emanuel Levinas (Peperzak & Levinas 1993) to interpret some of the negative effects of working in a large system which can result in losing sensitivity to the human impact of decisions.

The paper critiques top-down, remote and technical approaches to leadership in adult mental health services and explores the implications of radical power sharing and cultural change. The wider philosophical themes about humanity within systems are linked to current thinking in business management theory and research on leadership in voluntary sector governance and on disabled people in leadership positions. The idea of 'transformational' rather than 'transactional' leadership (characterised by process and hierarchy, see Burns 1978) is introduced as a preferable approach from a mental health service user point of view. My concluding argument is that service users should be in positions of leadership but that chronic underlying problems of stigma, perceptions of value, management culture and wider inequalities need to be recognised and addressed before direct user or frontline experience and emotional intelligence are seen as necessary for leadership in mental health services. This argument contributes to the critique of the construction of the personalisation adult social care and mental health policy in chapter 5.

16. Ross P D S & Carr S (2010) 'It shouldn't be down to luck': training for good practice with LGBT people – Social Care TV *Diversity in health and care* 7 (3) pp.211-216

This work discusses the context and content of an innovative online resource for social work and social care training on working with LGBT people. It is a collaboration between myself and an information specialist. We both bring an LGB and service user perspective to the work. The authorial standpoint is made clear at the outset and we are explicit that the paper is informed by lived experience (although autobiographical material is not used). We had both been production advisors for a Social Care TV series of films on working with LGBT people in adult social care. Social Care TV is an online training and education resource giving access to specially commissioned films on certain social care topics, which include interviews with service users, frontline practitioners and providers. We discuss the key user and frontline practitioner messages from the films and foreground this with an overview of some of the context which draws on an analysis of some of the research and policy on LGBT issues in social care training and practice. My contribution to the paper was to provide the latter.

The work presents research and policy evidence to make the case that, for people, social work and social care education, training and practice need to improve, especially as increasing personalisation demands responsiveness to service user diversity, greater levels of trust with practitioners and services and relationship-based working. The discussion contextualises the Social Care TV (SCTV) resource within a situation where, we argue, LGBT people and equality issues have often been marginalised; in effectiveness studies, in social care training and in the social

work curriculum (Fish 2006). Using user testimony from the SCTV films and research evidence, we argue that this, coupled with the fear of coming out in potentially discriminatory service contexts, can result in the invisibility of LGBT people as potential and present service users and carers. We explain why it was important to have LGBT service users and carers speaking directly about their experiences for a training and education resource.

The key messages from the research and policy evidence are linked to common themes from the analysis of the LGBT service user testimony and accounts from specialist practitioners from the SCTV films, to give an overall picture of priorities for training and good practice. This includes a strong focus on the personal and emotional elements of the individual service user or carer and practitioner relationship, as well as an awareness of people's unique, often multiple, identities which can determine their support preferences and chosen outcomes. This latter issue is explored in great detail in Works 17 and 20 and forms part of the wider thread of argument about the restrictive nature of administrative activity in social care and mental health services.

17. Carr S (2010) Seldom heard or frequently ignored? Lesbian, gay and bisexual (LGB) perspectives on mental health services *Ethnicity and Inequalities in health and social care* 3 (3) pp.14-25

This peer-reviewed paper builds on a workshop on a 2010 National Mental Health Development Unit (NMH DU) Equalities in mental health conference workshop entitled 'Seldom heard or frequently ignored? Lesbian, gay and bisexual (LGB) perspectives on mental health services'. The publication of this paper in a special edition of a journal with a primary focus on race and ethnicity represents the gradual broadening out of discussion on race, ethnicity and racism to include consideration of multiple identity and sexual orientation. No autobiographical material or authorial user experience is included, but at the outset I disclose that the discussion is partly informed by experience, so that readers can judge if this constitutes bias or strengthens the argument. In addition, the paper does not include transgender perspectives because the psychiatric interventions in the gender transitioning process are distinct from those experienced by LGB people.

The paper aims to map out an under-explored aspect of LGB mental health. This encompasses the mental health experience, needs and individual (as well as collective) histories of black and minority ethnic LGB people or LGB people who are refugees or seeking asylum. I piece together fragmented research and policy to provide a new articulation of the issues based on a social justice and person-centred approach, rather than one which is defined by practitioner, service or clinical perspectives. I surface and evidence key problems which need to be addressed but are unknown or ignored because those affected by them do not have a direct voice within research, policy and practice (a key general theme from works) or remain overlooked and unchampioned in general mainstream initiatives and activities.

My intention is also to raise awareness of the existence a LGB people who are from black and minority ethnic groups or who are refugees or seeking asylum and to draw attention to their particular mental health issues. Their absence in mainstream initiatives is evidenced by a brief analysis of reports claiming to provide a

representative picture of the conditions and needs of a particular minority group and reform initiatives focusing on improving the mental health of populations defined only by one characteristic. The paper concludes with a discussion on 'super-diversity' and 'intersectionality' (see Fanshawe & Sriskandarajah 2010 & Fish 2007) and the challenge of person-centred working with people who appear to be causing social policy, research and administration a problem because of their multiple identities and preferred self-definition. I argue that this problem can lead to a mixture of (often unintentional but unrecognised) institutional discrimination and administrative reductionism in mental health services which needs to be addressed so that individuals can be treated holistically. This argument is further extrapolated in chapters 2 and 5 where this work is used as evidence.

18. Carr S (2010) *Social Care Institute for Excellence Report 36: Enabling risk, ensuring safety: self directed support and personal budgets* London: SCIE

This work is one of the first systematically conducted evidence overviews on risk enablement and safeguarding in the context of self directed support and personal budgets to be published in England. It is an analysis and synthesis of findings from recent UK and international literature (research and policy) as well as emerging directions from practice. The focus is on facilitating evidence-informed policy making, person-centred frontline practice and the promotion of choice, control and independent living for people using services. The research identified covers older people, people with physical or sensory disabilities, people with learning disabilities and people with mental health problems. The report addresses some of the findings from *SCIE Research briefing 20: The implementation of individual budget schemes in adult social care* (Work 12) which showed that 'perceptions of risk, legitimate use of public funds and concerns about safeguarding and duty of care need to be debated as research is showing that these are potential barriers to implementation'. The work makes an evidence-based argument which contributes to this national debate. It was peer reviewed by several topic experts and the core methodology was that used in Works 10 and 11 (as detailed in chapter 3).

The work looks at some of the research findings and emerging policy, principles and practice concerning risk enablement in the self directed support and personal budget process, while recognising the wider context of adult safeguarding in social care. While the primary focus is on self directed support and personal budgets, the report examines how the concepts and practice of adult safeguarding and personalisation relate. The aim is to build an evidence base drawn from both research and practice to indicate what could work to promote risk enablement, independence and control, while at the same time ensuring safety. The key research findings, evidence-based recommendations and practice points presented give an indication of new and potentially efficient and effective ways of working that are person-centred and consistent with the principles of personalisation and adult safeguarding.

There are several themes and findings from this research and emerging practice review which link to the significant themes being identified for this PhD by Public Works (to be defined and discussed further in chapters 2 and 5). The practice of self directed support and adult safeguarding has the potential to be far more user-led, but organisational strategic, operational and administrative cultures often determine that these aspects of adult social care should be subject to greater degrees of 'process',

because of perceptions of risk. The body of evidence analysed for this report shows the tension between technical or administrative approaches to risk management in both self directed support and person-centred working which facilitates the service user to take control with the support of practitioners who are skilled and confident in relationship-based working, sharing power and communicating. Crucially, the evidence examined for the report suggested that user perceptions of risk and the user voice was absent or minimal in research and practice, although concerns about safety, risk perception and management are identified as significant barriers to implementing self directed support and personal budgets. This work contributes evidence for the emerging argument from the body of works about the limitations of administrative processes for facilitating personalisation and relationship-based working at the frontline.

19. Carr S (2010) *Social Care Institute for Excellence Report 37: Personalisation, productivity and efficiency* London: SCIE

This report was commissioned from SCIE by the Department of Health to examine evidence of whether recent personalisation reforms (particularly direct payments, personal budgets and self directed support) in adult social care have resulted in increased 'productivity and efficiency' in line with the Coalition demands for cost effective and productive adult social care services (DH 2010b). Therefore the task had a political dimension which required thorough, independent examination of the evidence (methodology outlined in chapter 3) and a careful articulation of the findings so that the focus remained on best outcomes for the people using services rather than on direct monetary cost savings. The short timescale and lack of robust evidence (a general issue for personalisation as noted for Work 9 and chapter 2) on costs and outcomes for England meant that the work had limitations, which were clearly indicated from the outset. Therefore the report is not a research review, but rather an overview of emerging evidence, which may be seen as a limitation (NHS Confederation 2011).

I established a definition of efficiency for personalisation to centralise the importance of user outcomes and to assert that any attempt at cost reduction must be linked to its impact on outcomes for the individuals using the service. The majority of the evidence came from sources such as the Care Services Efficiency Delivery (CSED) programme, the Audit Commission and the voluntary sector, with only a few research studies, many of which were about direct payments which preceded the personalisation agenda. The material on personal budgets and self directed support highlighted the issue of gap between what was predicted in policy (that cost savings would occur) and what was happening in practice (that costs were at best the same but with the potential for better outcomes and value). The analysis of the evidence revealed that personal budgets were one of the options for personalisation that were most susceptible to high resource procedure and administration, while wider inter-related dimensions to personalisation such as integrated working, prevention, effective use of social work skills at the frontline, strategic commissioning, the role of user-led organisations and small voluntary and community services could result in greater efficiency and productivity in the longer term.

20. Carr S (2011) Mental health and the sexual, religious and spiritual identities of lesbian, gay, bisexual and transgender (LGBT) people in Gilbert P (ed) *Spirituality and mental health* Brighton: Pavilion Publishing pp.335-352

This work returns to and further explores some key themes on LGBT people, mental health and religion from Works 8 and 17. It provides a further account of LGBT people's experiences of mental distress and mental health services, discussing the effects of discrimination, identity and pathologisation, grounded in both research and personal testimonies. However, this work introduces in an additional dimension of religion and spirituality and draws together research evidence, policy and personal testimony to provide a clear, illustrated position on the sometimes complex or contentious issue of spirituality and faith, gender identity, sexuality and mental health. As with other works on this topic, it is written from a service user perspective and is intended to ensure that the voices and perspectives of LGBT people become part of the wider mental health knowledge base (see chapter 3 for methodology). My view is that this is particularly important in relation to the topic of spirituality and religion, which is rarely recognised as important to the identity and mental health of LGBT people. It is also written to promote an understanding of the complexities for accommodating difference and diversity, a key theme for a core selection of the submitted works (see chapters 2 and 5).

Because the work appears in a book for mental health practitioners, I acknowledge that discussion of LGBT issues in social care or mental health training may sometimes be problematic or contested, particularly if social care students or practitioners have certain moral or faith-based beliefs about LGBT people (Work 8; Hafford-Letchfield 2010; Cocker & Hafford-Letchfield 2010; Cocker & Brown 2011; Foreman & Quinlan 2008). I therefore combine an evidence based approach, drawing on an analysis of data, research, legislation and policy, with personal narratives or testimony from four people from the LGBT community who come from different faith backgrounds. I draw on the methodological approach established for Work 3 and further discussed in chapter 3 designed to construct an 'encapsulating account' (Wilkins 2000) based on service user narrative, testimony or experiential knowledge combined with an analysis of research and policy. I argue that, in the context of personalisation, mental health practitioners should be able to work with LGBT individuals holistically, which may mean reflecting on their assumptions, or their own morals and beliefs. Again, the limitations of psychiatric or social categorisation and administrative approaches to adult social care and mental health are explored.

21. Carr S (2011) 'A chance to cut is a chance to cure': self harm and self protection – a gay perspective in Hafford-Letchfield P & Dunk-West P (eds.) *Sexual identities and sexuality in social work: research and reflections from women in the field* Farnham: Ashgate pp.31-45

This work demonstrates the culmination of the auto/biographical (Stanley 1990) or 'auto-ethnographic' (Trotter et al 2006) methodology in which I use myself as a 'case study' that was first used for Work 3 and further detailed in chapter 3. I combine a number of sources, including experiential knowledge and personal narrative, to explore the use of self harm as a way of managing mental distress, particularly

among LGB people (who are evidenced as being at higher risk of using self harm in King et al 2008). I offer a different paradigm for understanding self harm, based on experiential perspective and knowledge rather than clinical pathology. I argue that pathologisation is inadequate for comprehending self harm and working with LGB people who harm themselves as a way to manage mental distress. Drawing on the work of a mental health survivor activist who pioneered the discussion of self harm from a survivor perspective, I explore how self harm can mean autonomy and self-determination in a mental health system which seeks to control the behaviour and classify those who do it as deviant.

I argue that psychiatric or clinical perspectives, research and data without service user perspectives and testimonies cannot constitute a complete body of knowledge on self harm. This, I contend, results in restrictive diagnoses and imposed or inappropriate therapeutic regimes or behaviour modification techniques. Focusing specifically on the LGB experience and perspective I use my own personal testimony as the point of departure for an investigation into the social factors that impact on LGB mental health, including the psychiatric system itself. I use the Goffman's theory of 'spoiled identity' (Goffman 1990) to explore self harming behaviour in LGB people and provide historical evidence on the practice of therapeutic 'bloodletting' in early psychiatry to argue that there is a clinical precedent for cutting and bloodletting. The conclusion of this work reinforces the argument built up for the submitted body of works – that simplistic categorisation or limited clinical diagnoses will not promote person-centred working which should encourage people to make choices and take control. I argue that by self harming to manage extreme mental distress, LGB people can be understood as taking control.

## **Chapter 2: A review of the relevant existing topic literature to contextualise the works and to demonstrate their contribution to knowledge in the field**

### **Introduction**

This chapter is thematically structured using themes identified as a result of the chronological critical analysis of the submitted works in chapter 1. The themes have emerged from the analysis of the topics, discussion and arguments from the 21 works submitted. The arguments, themes and concepts from particularly significant works such as 2, 3, 6, 8, 9, 10, 11, 17, 18 and 21 contribute to the flow of ideas on personalisation, service user participation and LGB (T) service user experience. Core arguments about the capacity of certain approaches to service user participation, the personalisation reforms and diversity strategies to accommodate complexity, conflict and difference emerge from this flow of ideas. The critique of mental health services from an LGB (T) perspective (from Works 3, 16, 17, 20 and 21) provides a specific example for this key argument.

Chapter 1 framed the development of particular themes and arguments over time and mapped the relationship of particular works to others. Chapter 2 presents a brief overview of the UK literature on each particular theme in order to contextualise the relevant works and to demonstrate their unique contribution to their respective fields. Three main themes have emerged as a result of the analysis in chapter 1:

**Personalisation policy in adult social care and mental health:** The personalisation reforms in adult social care and mental health in England, with particular reference to the ‘choice and control’ and ‘empowerment’ agendas; self-directed support and personal budgets. Works 9, 10, 12, 18, 19.

**Service user participation:** The impact and problems of the participation of adult social care and mental health service users in organisational change and policy development, with special reference to power dynamics in participation strategies and the exercise of ‘co-production’ as a way to determine, develop and deliver social care and support. Works 1, 2, 6, 11, 13, 14.

**LGB(T) service user experience:** The recognition and experiences of LGB(T) people as users of adult social care and mental health services, with special reference to potential areas of tension for developing person-centred practice for this group, including that relating to religion and belief. Works 3, 8, 16, 17, 20, 21.

### **Personalisation policy in adult social care and mental health**

Works included:

9. Carr S (2008) *Personalisation: a rough guide* London: SCIE (2<sup>nd</sup> revised edition, 2010)

10. Carr S & Robbins D (2009) *Social Care Institute for Excellence Research briefing 20: The implementation of individual budget schemes in adult social care* London: SCIE

12. Carr S (2010) Personalisation: an introduction for mental health social workers in Gilbert P (ed) *The value of everything: social work and its importance in the field of mental health* (revised edition) London: Jessica Kingsley pp. 60-66

18. Carr S (2010) *Social Care Institute for Excellence Report 36: Enabling risk, ensuring safety: self directed support and personal budgets* London: SCIE

19. Carr S (2010) *Social Care Institute for Excellence Report 37: Personalisation, productivity and efficiency* London: SCIE

This section provides an overview of the main literature on personalisation in adult social care (mainly from between 2006 and 2008), in which to contextualise the contribution of the submitted works covering this theme. An overview of the literature from before the first work (Work 9) in this theme was published should demonstrate how this initially made a new contribution to the knowledge about personalisation. It will also show how subsequent works fit with other literature on personalisation. As outlined in chapter 1, these works include evidence (research and practice) and policy overview reports and research review briefings, all of which are peer reviewed.

The New Labour government personalisation reform programme in adult social care was formally introduced in December 2007, with the publication of the cross-sector concordat *Putting people first: a shared vision and commitment to the transformation of adult social care* (HM Government 2007) and the subsequent *Local authority circular 1 (DH 2008): Transforming social care* which detailed the plan for transformation in order to develop 'a personalised approach to the delivery of adult social care' and introduced a ring-fenced Social Care Reform Grant of £520m (DH 2008a p1). The personalisation agenda is recognised as being part of the wider Blairite public sector modernisation programme (Cutler, Wayne & Brehony 2007) and was prefigured in the 2005 social care *Green paper: Independence, well-being and choice* (DH 2005); and the *White paper: Our health, our care, our say: a new direction for community services* (DH 2006). They were also strongly influenced by the policy direction set out in *Improving the life chances of disabled people* (Prime Minister's Strategy Unit 2005) and the local government *White paper: Strong and prosperous communities* (Department for Communities and Local Government 2006). The 2008 *Local authority circular* (LAC) set out some of the defining principles and approaches for personalisation, the main ones for the context and direction of the submitted works on personalisation being:

- 'Personalisation is about whole system change, not just change at the margins...[it] reaches beyond the confines of adult social care. It is essentially about a significant cultural shift and management of change for the wider social care and local government sectors' (DH 2008a p5-6).
- 'Importantly, the ability to make choices about how people live their lives should not be restricted to those who live in their own homes. It is about better support, more tailored to individual choices and preferences in all care settings' (ibid p5).
- 'For the past ten years, direct payments have successfully given some people the ability to design the services they want but their impact has been limited...Evidence shows major variations in take up across the country, with

success determined less by the characteristics of people who use services or the features of direct payments themselves, than by local leadership, professional culture and the availability of support' (ibid p5).

- 'The role of social workers will be focused on advocacy and brokerage, rather than assessment and gate-keeping' (ibid p4).
- 'With self directed support, people are able to design the support or care arrangements that best suit their needs. It puts people in the centre of the planning process, and recognises that they care best placed to understand their own needs and how to meet them' (ibid p4-5).
- 'Councils will...need to talk directly to disabled people and their organisations'
- 'If effectively delivered personalised support can be a route to efficient use of resources, offering people to identify their own priorities, and co-design and focus the support they need' (ibid p7).

The submitted works in this sub-section are written in response to these key policy claims and proposals, and aim to address the sector need for independent interpretation and evidence on the personalisation reforms in adult social care. It needs to be noted that the first edition of Work 9 (the 2010 updated revised edition has been submitted) was published in 2008. Therefore it is in itself the overview of the main literature on personalisation available at the time and was then the only publication of its type. Works 9 and 10 are cited (as SCIE) in the second edition of *Direct payments and personal budgets: putting personalisation into practice* (Glasby & Littlechild 2009), which is a core academic text on the subject; Work 9 is cited in Needham's critical exploration of personalisation as a public service narrative (Needham 2011). According to Google Scholar (accessed 03/10/11) Work 9 has been cited 30 times in UK and international academic works and Work 10 has been cited 10 times in academic papers. Below is a concise overview of the immediately preceding and contemporaneous literature that defined the policy and proposed practice of personalisation in adult social care, and to which works in the personalisation sub-section form a unique contribution. Works 18 and 19 were produced after the second *Local authority circular 1 (DH 2009): Transforming adult social care* (DH 2009a) and make a significant contribution to the evidence base on risk management and on efficiency. This brief overview of the key contextual documents and concepts is neither exhaustive nor definitive, and, as clarified above, the main body of literature is from the period 2006 to 2008.

Personalisation was initially explained by a number of different agencies and sources with different perspectives and interests, each providing a partial view of the policy or evidence. The agenda had already formed part of the policy for education reform and was being championed by the policy think tank Demos, particularly through the work of Charles Leadbeater (for an extensive critique see: Pykett 2009). Leadbeater and Demos also directly influenced the personalisation agenda for adult social care, with Demos publishing *Making it personal* (Leadbeater et al 2008), a largely theoretical outline for radical reform, two months after the 2008 LAC. This report focused on self directed support and personal budgets. Demos positioned the 'new operating system' of the In Control programme (discussed below) as the model for adult social care reform, using evidence from the small scale evaluation of the first pilot phase in seven local authorities and highlighting particular individual stories to illustrate the positive impact of the 'radical' new approach. The report also claimed that self directed support and personal budgets could result in cost savings for local

authorities, based on evaluations of very small samples (some single figures) of personal budget users, almost exclusively people with learning disabilities. The report cover featured the following quote: 'Personal budgets and self directed services mobilise the intelligence of thousands of people to get better outcomes for themselves and more value for public money' (ibid, front cover).

Leadbeater et al argue that 'personal budgets promote choice and will expand the competitive market for social care services, from which budget holders can choose' (ibid p47). He goes on to claim that 'in self directed services people have real choice over the services they get but they are not just consumers' (ibid p81), but citizens with rights and entitlements who make choices about their lives, and have a collective dimension beyond individual purchasing activity. This model of 'citizen-consumer' was developed by Leadbeater in a series of articles on public sector reform published in *Marxism today* in the late 1980s and early 1990s, where he conceives of 'progressive individualism' (Leadbeater 1988) and sets out a 'manifesto for the public sector' (Leadbeater 1991). The theories from these early works, such as 'individually-based collectivism' and 'a decentralisation and democratisation of the state' (Leadbeater 1988 p18) and citizen-led services appear in the policy construction of personalisation in his Demos policy manifesto-style reports *Personalisation through participation: A new script for public services* (Leadbeater 2004) and *Personalisation and participation: The future of social care in Scotland* (Leadbeater & Lownsbrough 2005) and finally in *Making it personal*. However, this model of citizenship does not always fit with the citizen identities and experiences of people who use social care and mental health services (Beresford 2009a; Ferguson 2007; Rummery 2006), rendering implementation of the policy influenced by Leadbeater's thinking potentially problematic (see next section in this chapter and chapter 5).

References to the origins of direct payments, the social model of disability, the goal of independent living, the mental health service user/survivor perspective, the effects of social and economic deprivation and the role of social work do not feature in Leadbeater's policy concepts (see also chapter 5). This has led some social work academics to be very critical of his conceptualisation of personalisation early on, with Ferguson (2007) in particular noting that for reasons of inequality and deprivation, many people who use social care services will not fit the model of active citizenship required to benefit from Leadbeater's conception of personal budgets: 'The central issue for Leadbeater is lifestyle change, with health and economic inequalities barely discussed...the failure to engage with the structural inequalities also vitiates Leadbeater's conception of people who use services' (Ferguson 2007 p395). Critics of personalisation point to the lack of service user involvement and evidence in the construction of policy, the particular model of citizenship used, its internal ideological conflicts, the claims about cost savings and the speed of its implementation (Boxall et al 2009; Beresford 2009b). The public sector union, UNISON, later voiced workforce concerns about social care funding, pay and conditions and the increased marketisation associated with personalisation (Land & Himmelweit 2010).

The 'potentially revolutionary' influence of the In Control model of self directed support and personal budgets was anticipated by Glasby, Glendinning and Littlechild in their chapter on the future of direct payments in the book *Developments in direct payments* (Leece & Bornat 2006). They also saw the In Control approach as offering

a potential solution to some of the operational issues which had impeded the uptake of direct payments, particularly for people with learning disabilities. This citizenship and rights-based approach was initially designed to improve the direct payments process for people with learning disabilities, and In Control was set up as a professionally-led partnership between the Department of Health Valuing People support team, Mencap and participating local authorities. In short, 'the seven steps that form the central line through the system (Set personalised budget, Plan support, Agree the plan, Manage personalised budget, Organise support, Live life, Review and learn) imply many changes to surrounding functions and services' (Poll et al 2006 p11). One of these changes is the introduction of a Resource Allocation System (RAS), the original purpose of which was to be 'a system which could build on this vested interest [of individuals wanting best value for their support money]. The RAS needed to offer the maximum control at the earliest possible stage. The system was designed to offer openly, publicly and fairly an allocation of funding that was affordable within current authority budgets' (ibid p64). Then, as a result it is assumed that, as Glasby et al argue, 'with clear entitlements to specified levels of funding service users would no longer be passive recipients of professionally defined and controlled services, but active citizens with rights to specified levels of support' (Glasby et al 2006 p273). This reflects some of Leadbeater's theories about the outcomes of progressive individualism, as discussed above, and fits with the Blairite public services modernisation agenda (Cutler, Waine & Brehony 2007; Farnsworth 2006), as discussed further in the next theme section: service user participation.

Much of the criticism about personalisation, and personal budgets in particular, stems from the fact that evidence, particularly that relating to broader and long-term impact and cost effectiveness, is lacking (Cutler, Waine & Brehony 2007; Beresford 2009b; Roulstone & Morgan 2009; Audit Commission 2010; NHS Confederation 2011). An evidence base on, and critical analysis of, direct payments and implementation issues (particularly for people with mental health problems) had been previously established (Davey et al 2007; Barnes et al 2006; Leece & Bornat 2006; Spandler & Vick 2006; Spandler & Vick 2005; Spandler 2004; Ellis 2007; Rummery 2006; Morris 2004); literature reviews on person-centred planning in social care were available (Dowling et al 2006); service users had provided experiential evidence on transforming social care (Beresford & Hasler 2009; Glynn et al 2008) and later Mind published a review of evidence and service user views on personalisation in mental health (Mind 2009a; Mind 2009b [this cites Works 9 and 10]). However, the new English model of self directed support and personal budgets had not been subject to independent evaluation. Instead In Control evaluated its own work, positively demonstrating the impact the new model had on a relatively small number individual recipients, the majority of whom had learning disabilities (Poll et al 2006; Hatton et al 2008). The third phase evaluation report describes issues of system change and discusses the implications of self directed support for all service user groups (Tyson et al 2010). Much of In Control's evaluation of self directed support and personal budgets could be critiqued in line with Scourfield's criticism of early research on direct payments where 'on the whole...the discussion in the UK largely focused on 'narratives of achievement'' (Scourfield 2007 p13); it also reflects the positive and optimistic interpretation of personalisation as being an intrinsic and self-evident 'good thing' (Duffy 2010).

In parallel to the In Control evaluation was the IBSEN project - *National evaluation of the individual budgets pilot projects* by the Social Policy Research Unit at York University (Glendinning et al 2008). Individual budgets (IBs) were piloted as a new way of providing support for older and disabled adults and people with mental health problems eligible for publicly funded social care. The Department of Health set up IB pilot projects in 13 English local authorities, running from November 2005 to December 2007, and commissioned a national evaluation. The evaluation was the first robust (randomised controlled trial) UK study of the implementation and impact in social care of individual budget approaches which aimed to streamline several funding streams, including non-social care money (from welfare benefits sources), into one coherent budget. The study found that because of regulatory and administrative systems originating in central government, the set of funding streams from different sources could not be integrated. This and later research on social care personal budgets in English local authorities points to issues relating to risk and safeguarding, cost efficiency, culture and system rather than mechanism change as well as the importance of frontline relationships between users and staff (NHS Confederation 2009; Audit Commission 2010).

Having examined the major policy documents and pilot evaluations which contributes to the literature on personalisation between 2006 and 2008 it is possible to discern that explanations and accounts of the reform policy were fragmented and/or partisan. There was therefore a risk of the adult social care sector itself not having access to an independent, consistent, broad account of personalisation and an exploration of implementation issues. The focus for the majority of the defining documents and evaluations was on direct payments and personal budgets as the main mechanism for delivering personalisation, which had gained impetus from existing practice and recent pilots. There were already indications from the SCIE consultation which informed Work 9 that the focus for personalisation appeared to be on introducing personal budgets, rather than addressing the wider reforms, as outlined in the 2008 *Local authority circular* (see chapter 1). Added to this was the uncertainty among practitioners and users as to the difference between a direct payment, a personal budget and an individual budget. Works 9 and 12 aimed to address this gap in the literature during the early implementation period by providing a comprehensive overview of the origins and implications of personalisation in adult social care, which includes the perspectives and contributions of all actors in adult social care. They addressed the need for an explanation of how a 'transformative' policy concept, with limited evidence, could translate into practice. The works provide a broader picture of personalisation and emphasise that personal budgets are a part of the reforms, but that the reforms are wider than the introduction of this new mechanism. The 2008 edition of Work 9 preceded and anticipated some of the clarifications about the breadth of the reform policy published in the second *Local authority circular 1 2009: Transforming adult social care* (DH 2009a). Work 12 is aimed at mental health social work students and practitioners and is focused on interpreting personalisation for mental health. Few accounts on personalisation existed for mental health (see Mind 2009a) at the time this book chapter was written. The approach taken to explaining the origins and meanings of personalisation for mental health was similar to that taken for Work 3. Both include historical perspectives and Work 12 presents the personalisation agenda as part of an historical reform continuum, with an emphasis on deinstitutionalisation, the core contribution of the disability, service user and mental health survivor movements and the subsequent importance of choice, control

and co-production for people who use mental health services. As noted, this history does not always feature in official or influential policy narratives of personalisation, such as those constructed by Leadbeater. Work 12 also demonstrates the strong similarities between the original intentions of the 'recovery' approach in mental health and the values of personalisation, both of which determine that the service user should have choice about their support and control over their lives, with services and support having the capacity and flexibility to enable this, at least in theory.

The second significant gap in the literature on personalisation has been the lack of specific research reviews and evidence overviews which incorporate findings from studies on direct payments as well as personal budgets and individual budgets, particularly those which maintain a focus on frontline practice and the impact on service users and carers. Work 10 provides one of the first systematically conducted international English language research reviews on the operation and impact of personal budget schemes. The review findings contribute new evidence to the knowledge base and indeed debate about the critical factors for successful implementation of the personal budget scheme in England. Several of the findings challenge the policy construction of personal budgets as a mechanism to support decentralisation. They reveal shortcomings in policy assumptions about equity, the transferability of models developed in different national welfare systems and the leadership role of central government in ensuring policy and practice coherence. The review findings also show that, despite policy claims about cost effectiveness, in practice the international and UK research was inconclusive. The personalisation and cost effectiveness topic is investigated further for the England in Work 19, which is one of the first comprehensive overviews of the evidence on personalisation, productivity and efficiency. This peer-reviewed report indicated several implementation issues that were later to become critical concerns for those responsible for progressing personalisation in adult social care, particularly in the context of unprecedented local authority funding cuts announced by the Conservative dominated Coalition Government in 2010 (HM Treasury 2010). The evidence shows that 'the potential for efficiency gains through increased choice and control can only begin to be realised if the changes are supported by improved information, market development and choice in care and support provision' (Work 19 p viii) and that if 'the personalisation agenda is stimulating review and change in business processes...this appears to have reliable potential to generate efficiency savings and improve productivity' (ibid p vi). Furthermore, an examination of the available evidence in England established an outcomes-oriented, person-centred benchmark definition for efficiency in the context of personalisation: 'the term "efficiency" encompasses issues of cost reduction, cost neutrality and waste reduction ("efficiency gains" are achieved where costs are reduced and outcomes maintained or improved). A service can be described as offering "value for money" where there is an optimum balance between three factors – relatively low cost, high productivity and successful outcomes' (ibid p v). By maintaining that efficiency should link directly to the service user (and carer) outcomes as a goal for services and as part of the report's evidence assessment methodology, this report represents a unique contribution to the personalisation evidence base.

As noted, risk management, practitioner concerns about 'duty of care' and safeguarding are identified as potential challenges for implementing personal budgets along with questions about longer term cost efficiency and effectiveness.

The Department of Health released a response to the IBSEN study, outlining these and several other key areas that needed further investigation and evidence (DH 2008b). Previously, risk management had not been fully discussed in the influential practice and policy documents (see for example Poll et al 2006; Leadbeater et al 2008). Works 18 and 19 are the first evidence-based, peer-reviewed reports published in the UK to address their particular topics, and as such are in themselves a review of the relevant contextual literature. Work 18 focuses on the question of risk enablement and safeguarding for adults using self directed support and personal budgets. It forms a unique contribution to the knowledge because it examines international evidence on how one of the perceived barriers to achieving choice and control has been constructed and operates in policy and practice and looks at research and practice on how people using personal budgets can be supported to take risks and stay safe. Building on the findings of the IBSEN study (Glendinning et al 2008), the report offers new insights into the problem of risk perception, risk enablement and, to a certain extent, adult safeguarding for personalisation. The chief insights relate to the lack of service user voice in the research and in practice (where the individual is at risk of being 'lost' in a technical or 'mechanistic' process of either self directed support or safeguarding), perceptions of risk and practitioner dilemmas about duty of care and empowerment. It is particularly notable that, despite a specific search strategy designed to identify user-led or user-focused studies on risk perception and risk management, none could be located. The report also highlights the importance of traditional social work and building consistent trusted relationships with practitioners who know the individual and their circumstances. This finding poses a challenge to early conceptions of self directed support and self assessment as being activities which did not require the support of qualified practitioners (see Poll et al 2006; Leadbeater et al 2008; Leece 2010). Moreover, the research analysis revealed the possibility that organisational risk management strategies mean that frontline practitioners can be concerned with protecting organisations from fraud or reputational risk when administering personal budgets, and particularly direct payments to people with mental health problems. The research showed that this then reduces their capacity to work with people who are using self directed support and personal budgets to enable risk and identify and manage safeguarding issues. Along with the IBSEN study (Glendinning et al 2008), emerging policy on adult safeguarding (DH 2009b) and adult safeguarding practice guidelines (Williams 2010), the report provides a new contribution to the evidence and debate about person-centred risk management in adult social care.

### **Service user participation**

Works included:

1. Carr S (2003) Duty of care: employment, mental health and disability *Journal of Mental Health Promotion* 2(1) pp.6-23.
2. Carr S (2004) *Social Care Institute for Excellence Position Paper 3: Has service user participation made a difference to social care services?* London: SCIE/Policy Press

6. Carr S (2007) Participation, power, conflict and change: theorising dynamics of service user participation in the social care system of England and Wales *Critical social policy* 27(2) pp.266-276

11. Needham C & Carr S (2009) *Social Care Institute for Excellence Research briefing 31: Co-production: an emerging evidence base for adult social care transformation* London: SCIE

13. Bowlam S, Carr S & Gilbert P (2010) The Partnership Project: learning from experts by experience in mental health services; the Jersey Partnership perspective *International journal of leadership in public services* 6 (2) pp.54-67

14. Carr S (2010) Remote or related? A mental health service user's perspective on leadership *International journal of leadership in public services* 6 (2) pp.20-24

As noted above, the works in this section focus on the impact and challenges of the participation of adult social care and mental health service users in organisational change and policy development, with special reference to power dynamics and the concept of 'co-production' as a way to determine, develop and deliver adult social care and mental health services. The works in this and the previous section were written during the time of New Labour's public sector modernisation programme, the nature of which generated considerable debate within adult social care (see for example: Harris & White 2009; Newman et al 2008; Scourfield 2007; Farnsworth 2006; Beresford & Croft 2001). Personalisation and the increase in choice and control notionally accorded to the service user can be seen in the overall context of this public sector 'third way' modernisation programme, which had several underpinning and, some would argue sometimes ideologically or practically conflicting drivers (2020 Public Services Trust 2009; Bochel et al 2007), two of which will be discussed here. The first aim was to increase the participation and influence of users to shape services from below: 'modernisation has...required that the relationship between state and citizen be reconstructed' (Scourfield 2007 p107) and for adult social care, 'participation or...user involvement, has come to be seen as a cornerstone of social care and social work policy and philosophy...arrangements for participation now permeate public policy' (Beresford & Croft 2001 p295-296). The second was an increase in market mechanisms and the involvement of business, in the belief that this would not only boost consumer choice, but also improve quality and efficiency through competition (see for example Leadbeater et al 2008). However some policy analysts have noted that those with business interests had greater degrees of influence and involvement in social policy than other stakeholders, such as the 'consumers' or service users (Farnsworth 2006). Others have argued that the New Labour government's 'inclusive' policy making strategy involved a range of stakeholders, so service users were competing with political officials, special advisers and professionals (Bochel et al 2007).

Scourfield (2007) contests that the combination of user empowerment, citizenship and consumerism does not necessarily result in a fundamental shift in power or rights, but the reconstruction of the 'role' of the service user as a particular sort of citizen to operate in the adult social care system: 'This transformation is not simply about the reconstruction of citizens as consumers but the transformation of citizens into both managers and entrepreneurs. New Labour's perspective on citizenship

appears to focus less on what the citizen should expect from the state in terms of social rights, and more on how the citizen *should be* – in this case, active, responsible and enterprising’ (Scourfield 2007 p112). In understanding the citizenship of people who use adult social care services, others argue that there is an inherent incompatibility between the service user understanding of citizenship and empowerment and that of the state and service system: ‘for service user movements, getting involved has meant the redistribution of power, democratisation and achieving change in line with their rights and needs. For the state and service system there has more often been a managerialist/consumerist model, framed in market terms’ (Beresford, 2009 p4). For Rummery the problem is also about power, ‘the consumerist model of user empowerment in community care policy has failed largely because disabled people themselves are not the consumers with powers of voice, choice and exit’ (Rummery 2006 p640). This situation can be further understood through Scourfield’s observation that the ‘dominant [policy] discourse...stresses independence, individual choice and responsibility. The desirability of funded, collective and mutually supportive networks to make them work is seldom articulated as strongly, at least not by government’ (Scourfield 2007 p117). It is these networks, arising from the collective nature of the disability and service user movements and the broader aim of creating a more inclusive democracy that are important for the realisation of participation and change, but as Barnes et al observe, ‘while disadvantaged groups might achieve improvements to their material circumstances, this is not necessarily accompanied by improvements in access to, or control over, decision making processes’ (Barnes et al 2007 p48). Similarly, Beresford and Croft have argued that ‘the welfare system has shown remarkable capacity to resist the demands of its users as expressed through consultation and conventional schemes for involvement’ (Beresford & Croft 2001 p297). The key problem they identify is that ‘while the aim may be to make change, control remains with the service system’ (ibid p296). This is one of the main problems under investigation in the works in this section, with works 1 and 14 being uniquely informed by my own autobiographical accounts of service use (For methodology see: chapter 3; section 3).

As suggested in chapter 1, Works 2 and 6 (also 8 which is concerned with the participation of LGB(T) people and is discussed in the final section below) are related in that Work 8 is a further investigation of some of the findings from Work 2, namely that although health and social care organisations have service user participation strategies and initiatives, often very little change happens as a result of participation. According to Google Scholar (accessed 03/10/11), Work 2 has been cited 60 times in UK and international academic works, Work 6 has 27 academic citations (including in Bochel et al 2007, Webb 2008 and Lewis 2009, as referenced here) and Work 11 has been cited 18 times in UK and international academic papers. While the work in this section fits within the wider field of literature on service user participation, it also contributes to a specific area of study into the structural, communication and emotional power dynamics of service user participation. This section presents a brief UK literature review of some of the main theoretical pieces on the power dynamics and discourses in service user participation in adult mental health and social care to situate the submitted works for this section in the field and to demonstrate their contribution. The review does not include specific literature on the principles and practice of service user participation, the design of participation initiatives or the

outcomes of service user debates or findings from user research on welfare and service reform (see for example Turner et al 2003; Beresford et al 2011).

A tendency towards organisational and professional resistance to implementing change generated by service user participation is evidenced in Work 2, a research synthesis report which includes a literature review on user and carer involvement in a mental health context (Rose et al 2002). The literature review concludes that for promoting democracy, representation and cultural change, 'resistant organisational or professional cultures and embedded power differentials are seen as primary obstacles to user involvement in formal representative structures' (ibid p9). The report authors identify the problem of incompatible understandings of 'the service user' as discussed above – that is the tension between the models of 'consumer' and 'citizen' – as being influential here, defining the problem as follows:

'A central framework for analysing the stakeholder relation in mental health services turns on the distinction between users and carers as consumers and citizens. The aims of user movements, however, are not always consonant with or limited to consumerist interests...Service users may have a dual identity as consumers of services, and as citizens to whom such services are accountable...The user movement calls for a more robust range of citizenship rights than those found in the customer relation' (ibid p12).

The report also identifies two issues which are relevant for the discussion of the theoretical analyses which follow: understandings of democratic process and ambivalence about service user involvement and the 'hidden' obstacles posed by structural and power differentials in the participation forum. The literature generating theories deriving from analyses of case studies and other research into user participation in adult social care and mental health, identified for this section, has three main themes: understandings of representative democracy; user voice, experience, expression and identity; and power differentials, discourse and rules. These themes and the associated theories and findings are now examined.

The central political tension, between the policy construction of the service user as a consumer and the service user movement's recognition of the broader citizenship of people who use social and mental health services, has already been acknowledged here as a tension for the adult social care personalisation policy agenda. However, this tension also relates to wider issues of political agency and more general understandings and expectations of different democratic processes, of which service user participation is one. In their literature review, Rose et al reveal a problem that service users often encounter in the participation process, and which was surfaced in Work 2:

'It appears to be a particular problem that users and carers are asked to be more 'representative' than any other group of stakeholders in the change management process. Articulate users may be criticised as unrepresentative because 'ordinary' users are often not seen as articulate. Other stakeholder groups, in contrast, will not be subject to such challenges – articulate and assertive professionals and managers, for instance, are not likely to be questioned as 'unrepresentative' (Rose et al 2002 p14).

For those whom citizenship can be complex, conditional or contingent (Rummery 2006; Flint 2009) and who ally themselves with 'new social movements' such as the disability or mental health survivor movement, participation can be a difficult process in spaces determined by services and professionals. As Hodge has argued, 'the inadequacies of service-led attempts to give service users a voice in the policy-making process are contrasted with the activities of user-controlled organisations, both in developing their own alternatives to mainstream provision and in campaigning for change within mainstream services on their own terms' (Hodge 2005a p165). The notion of service user 'representativeness', as Rose et al evidence, is often used to resist participation and change (see also Bochel et al 2007). Barnes et al's definition of 'representative' and 'deliberative' models of democracy and democratic engagement aims to draw an important distinction between the understanding of how representative democracy should function in general governance and how a form of deliberative democracy should characterise the activity of specialist participatory decision-making forums (Barnes et al 2007). Service user participation in the decision making process about services very rarely fits with the elected representative model, and yet the expectation is that service user participants be representative when they may perceive participation as an opportunity to exercise their right to be critical citizens: 'Such initiatives require [professionals] to share their power with others who they may think ill-informed, lacking legitimacy and scarcely representative of the communities they claim to speak for' (Rao quoted in Barnes et al 2007 pp.41-42). While recognising its limitations, deliberative democracy, Barnes et al surmise, can offer a participative form of governance and decision making which is more useful for understanding service user participation:

'advocates argue it can generate a stronger democracy with citizens empowered in relation to both politicians and public officials. The practice of deliberative democracy is intended to open knowledge previously restricted to specific scientific or other communities to lay scrutiny, as well as open up political arenas to more direct processes of citizen involvement... Underlying such initiatives is the belief that technical or expert knowledge alone is inadequate to the resolution of policy problems, since the issues such problems raise are also political and ethical' (ibid p35-36).

However, the chief limitation of deliberative democracy for understanding service user participation, Barnes argues, is the fact that the conditions of social parity, equality of access, capacity and opportunity and the type of power sharing required for it to function properly do not exist in reality. Instead she argues that 'we need a practice of deliberation which explicitly recognises and encompasses inequalities of power and diversity of experience and expression, rather than assuming that such inequality and diversity will be accommodated within processes governed by universalist notions of fairness and competence' (Barnes 2002 p324).

Referencing Work 2 to demonstrate the lack of evaluation of the impact of service user participation in adult social care, Webb argues that the 'concept has been consistently under-theorised in both research and policy remits' (Webb 2008 p271). He also discusses the political dimension of participation in terms of 'representational and participatory democracy'. However, he asserts that such understandings of service user participation are too simplified and he is critical of the way 'social care

research has engaged in too general discussions of participation such that they cannot be operationalised' (ibid p269). Instead, Webb offers a social network analytic model for evaluating the extent and impact of service user participation in service development and change, arguing that 'traditional approaches to participation based on outcome evaluation have failed to capture the impact and qualitative nature of relationships of participation' (ibid p284). However, Bochel et al's observation that organisations evaluating the impact of service user participation have tended to focus on 'output' (process) rather than 'outcome' (impact and change) suggests that outcome of service user participation are not always evaluated (Bochel et al 2007), echoing the findings of Rose et al and those of Work 2. Lewis' analysis of how power relations function in participation processes draws on human rights perspectives, and she argues that 'recognition is not just socio-political but also personal, with a strong moral dimension to the issue' (Lewis 2009 p 259). Her analysis focuses on some of the themes that emerge in Works 2 and 8, and in chapter 4 about the effects of the non-recognition of mental health user and survivor perspectives and knowledge which is 'undermining of [their] personhood and humanity [and] can work to have a deleterious effect on interpersonal and therefore self-respect' (ibid p267). She argues that 'psychiatrising', or the pathologising of service user and survivor contributions, is a form of this 'misrecognition' which perpetuates and even deepens the injustice that participation initiatives in mental health seek to address, and points to the need to challenge 'institutionalised patterns of cultural values which impeded participation' (ibid p270).

Analysis of case studies in the participation of mental health service users shows how the user voice and experience can be marginalised or downplayed. This is not always by conscious strategy of exclusion, but rather as the consequence of the interplay of power and identity in participatory processes and decision making forums that are professional spaces into which service users are 'invited'. From the perspective of the 'critical professional', Batsleer and Humphries have located this difficulty in the construction of welfare discourse more generally: 'the discourses of welfare mark social division, inclusion and exclusion: mark 'us' and 'them' in changing and shifting ways' (Batsleer & Humphries 2000 p2). Hodge's examination of the workings of a mental health service user forum centres on the analysis of power dynamics and discourse (Hodge 2005a). She shows how 'power is exercised discursively in various, apparently trivial, ways, ensuring that the forum's discourse remains within established normative boundaries and serving, ultimately, to reinforce existing institutionally defined power relations' (ibid p164). Her research leads her to decide that certain negative experiences of treatment (such as electroconvulsive therapy or ECT), suggestions for service change, alternative understandings of mental distress and practitioner personal agreement 'if not off-limits, are incapable of being incorporated into the forum's discourse in any meaningful sense. They clearly all outside the discursive boundaries that have been set' (ibid p170). She concludes that by examining linguistic interaction 'it is possible to demonstrate precisely how power is used to exclude certain voices, to give legitimacy to the status quo and...to reinforce existing structural power inequalities between service users and officials' (ibid p165).

Barnes and colleagues progress this theme of the operation of power and discourse in service user participation by examining the responses to the emotional expression and experience of mental health service users in professionally or bureaucratically

determined participation forums (Barnes 2008; Barnes et al 2006; Barnes 2002). She explicitly discusses what was implied by Hodge's conclusions about certain topics and modes of expression being 'off limits' in terms of often unacknowledged 'rules of engagement' as defined by the services or professionals which can exclude or delegitimise the types of 'contested knowledges' brought by service users. Such rules, according to Barnes, should not exclude 'the bearers of such knowledges' and if they 'are to be included within processes previously determined by rules governing dialogue on the basis of scientific evidence, bureaucratic procedures and/or party political debate, then this may require rethinking those rules in order to accommodate them' (Barnes 2002 p323). Barnes perceives that rules of the game do not only work to exclude 'contested knowledges', but also mitigate against emotional expression. Again, using evidence from case studies, Barnes argues that:

'public officials find any emotion – whether it be anger, pain or despair, difficult to handle in the context of deliberation directed at issues of policy or service delivery. The onus on managing emotions thus rests with the service users or citizens taking part, officials can invoke institutional rules and norms to define what is acceptable in contexts they control' (Barnes 2008 p472).

The difficulties of the exercise of power and influence by service users in spaces created and controlled by professionals and their services have also been reflected in the construction of policy terminology used to describe a certain sort of service user participation. Co-production is a policy term that first appeared as an official government strategy for service user participation in the 2007 *Putting people first* concordat for adult social care reform in England:

'the first public service reform programme which is co-produced, co-developed, co-evaluated and recognises that real change will only be achieved through the participation of users and carers at every stage' (HM Government 2007 p1)

Although co-production is a concept originally associated with the generation of social capital (Whitaker 1980; Cahn 2001, Cummins & Miller 2007), the term later became more embedded in policy language as a way of describing an approach to service user participation in the reform, development and delivery of adult social care services as part of the broader personalisation transformation agenda. Cummins and Miller's brief definition is useful as a starting point for understanding co-production: 'basically, services have to learn how to *work with* rather than *do unto* service users' (Cummins & Miller 2007 p7). In addition, 'Service users should be regarded as an asset encouraged to work alongside professionals as partners in the delivery of services' (Boyle and Harris, 2009, p 15). Co-production was explored by Barnes and colleagues as a way to manage community care services and user participation in 1999 (Barnes et al 1999) and resurfaced after the theoretical approach was conceived as part of personalisation. Again, the work of Charles Leadbeater is most evident in the construction of the policy concept of co-production as a way of describing 'deep' personalisation in the Demos report *Personalisation through participation* (Leadbeater 2004) which outlined his potential 'new script' for public services. Leadbeater emphasises the direct participation of the people who use services: 'By putting users at the heart of services, by enabling them to become participants in the design and delivery, services will be more effective by mobilising

millions of people as co-producers of the public goods they value' (Leadbeater, 2004 p19). Leadbeater's co-production appears to be a concept posited as a coherent policy solution, then adopted as a part of the New Labour reform package of adult social care services, of which personalisation was the central driving force.

Hunter and Ritchie explore the implications of co-production and personalisation for changing relationships in social care and provision of welfare services, giving examples of existing practice (Hunter and Ritchie 2007). They describe co-production as 'a particular approach to partnership between people who rely on services and the people and agencies providing those services' (ibid p9), which moves from organisational partnership in strategy and governance to the service users and practitioners at the frontline. Notably, Hunter and Ritchie argue that a key problem in social care services is located in the nature of human relationships, which a co-production approach could address: 'Many people are underserved by the human service system. Some of this results from the orientation and focus of services, with people's important needs not being addressed at all, or with services actually compounding people's problems' (ibid p13). They refer to the place of co-production as 're-engineering' approaches to the design and delivery of social care and support following the 'philosophical reorientation' by the disability and independent living movements and by policy developments in consumerism. They argue that the collaborative relationship between the practitioner and service user and the bringing together of their expertise has the potential to solve particular (and often 'site specific') problems in social care service design and delivery.

In response to the emerging developments in government policy, a series of practice explorations, political position papers and further conceptual work focusing on co-production appeared (Boyle et al 2006; Bovaird 2007; Cummins & Miller 2007, Needham 2007; new economics foundation 2008, Stephens & Ryan-Collins 2008). Some argued at a political 'macro level' for a new understanding of market economy, social capital and the value of people's 'assets' (knowledge, experience, ideas) (new economics foundation 2008, Stephens & Ryan-Collins 2008) while others evaluate practical implementation issues and highlight good practice points (i.e. Boyle et al 2006). Most authors conclude, along with Hunter and Ritchie, that a re-evaluation, new understanding and re-figuring of frontline relationships and relative expertise and assets are vital. However, co-production as a way to reform wider public services has been the focus of a 'public sector innovation lab' work programme and a series of reports from the National Endowment for Society and the Arts (NESTA) in partnership with the new economics foundation (nef) (see Boyle, Coote et al 2010; Boyle, Slay & Stephens 2010; Boyle & Harris 2009). While this work aims to define co-production for public service reform and identify and evaluate practice, the project activity is essentially at the level of 'policy makers...those who have the political, organisational or professional power to determine the overall philosophy or strategic direction of the policy process' (Bochel et al 2007 p202). It does not appear to include those identified in theory and research as key players in co-production, service users, carers and frontline practitioners, in strategic discussions about policy development and implementation. This in itself exemplifies some of the challenges for service user participation in policy making and organisational change identified by those analysing the operation of service user participation and how user knowledge and expertise is valued and conceptualised (Beresford 2003).

Work 11 represents a significant contribution to the literature on co-production as it reviews existing research and conceptual work in order to form an evidence base and definition for practice in adult social care service design and delivery. It has been cited in 17 UK and international academic papers according to Google Scholar (accessed 03/10/11). It also formed part of the literature used in the Department of Health technical working paper on co-production and delivering *Putting people first* (DH 2010c) and thereafter used by the Department of Health to define co-production for social care and service user participation (Ramsden 2011). The research review navigates the discussion on co-production and creates a workable definition of the concept for adult social care 'transformation' and identifies practical examples. The work is partly in response to the appearance of the term and concept in the policy concordat, *Putting people first* (HM Government 2007). As with much of the personalisation policy proposals and objectives, further examination of the evidence was needed and Work 11 provides a new way of understanding the different operating levels of co-production in adult social care, the most 'transformative' being the level where 'the people who use services can be involved in shaping the ethos of care and in empowering frontline staff as well as themselves' (Work 11 p9). This specific research review on co-production also underpins the findings in Work 2 on resistance to change as part of service user participation. It also reflects the findings and arguments formulated in Works 2 and 6 and in Works 8 (discussed further in the next theme section on LGB(T) service user experience), 9 and 12 (discussed in the previous theme section on personalisation) about the need to remain mindful of the fact that 'some people are already able to be active citizens and take advantage of the opportunities that co-productive approaches will offer, whereas others are disadvantaged, both socially and personally' (Work 11 p9). Work 13 is a particular case example on a co-productive project in mental health service reform, which draws on the co-production literature to analyse the process, with an emphasis on learning from experts by experience.

As suggested, there are distinct findings, ideas and concepts linking together the works in this theme, and for the next theme concerning LGB (T) service user experience. Importantly, all these works are directly or indirectly informed by a service user standpoint perspective (see chapters 3 and 4 for extensive discussion). Work 2 represents one of the first reports to analyse research on service user participation across all service user groups in social care (including children and young people) and uses a methodology which ensured that users participated throughout the research process (see chapters 1 and 3). At time of publication (2004) it provided new knowledge for adult social care and for the service user movement, particularly as it provides an evidence base on particular challenges about power dynamics in the participation process, organisational resistance to change and evidences more broadly some of the complex issues on marginalisation, legitimacy and acceptability as discussed by Barnes and others in relation to mental health user participation strategies (Hodge 2005a & 2005b; Barnes 2002 & 2008; Lewis 2009). Work 6 is a more detailed analysis of findings in Work 2 on power relations and resistance to change, in particular the conceptualisation of participation as political by service users and organisational responses to conflict in participation forums. These findings from Work 2 are analysed using the political philosophy and theories of Chantal Mouffe (Mouffe 2002). Although service user participation as a form of democracy had been analysed using political and social theorists such as Habermas (Habermas 1984: see Barnes 2008 & Hodge 2005b) or Foucault

(Foucault 1980: see Tew 2007), Mouffe's critique of how liberal democracy seeks to enforce a rational consensus at the expense of 'passions' as a driving force for political action had not been used to examine service user participation before. In this way, Work 6 offers new thinking about service user participation using political theory. Some of the conclusions in Works 2 and 6 anticipate certain difficulties with personalisation, particularly the tensions between the differing constructions and understandings of consumerism and citizenship between policy makers and service user activists, as previously discussed. They also inform the analysis in the key works on LGB(T) service user experience and participation, particular for Works 8 and 17.

### **LGB(T) service user experience** (see note on terminology p5)

Works included:

3. Carr S (2005) 'The sickness label infected everything we said': lesbian and gay perspectives on mental distress in Tew J (ed) *Social perspectives in mental health* London: Jessica Kingsley pp.168-183

8. Carr S (2008) Sexuality and religion: a challenge for diversity strategies in UK social care service development and delivery *Diversity in health and social care* 5(2) pp.113-122

16. Ross P D S & Carr S (2010) 'It shouldn't be down to luck': training for good practice with LGBT people – Social Care TV *Diversity in health and care* 7 (3) pp.211-216

17. Carr S (2010) Seldom heard or frequently ignored? Lesbian, gay and bisexual (LGB) perspectives on mental health services *Ethnicity and inequalities in health and social care* 3 (3) pp.14-25

20. Carr S (2011) Mental health and the sexual, religious and spiritual identities of lesbian, gay, bisexual and transgender (LGBT) people in Gilbert P (ed) *Spirituality and mental health* Brighton: Pavilion Publishing pp.335-352

21. Carr S (2011) 'A chance to cut is a chance to cure': self harm and self protection – a gay perspective in Hafford-Letchfield P & Dunk-West P (eds) *Sexual identities and sexuality in social work: research and reflections from women in the field* Farnham: Ashgate pp.31-45

This section gives a brief overview of the main UK literature on LGB service user experience from the past ten years, relating particularly to service user participation, the recognition of service user knowledge and how the mental health experience of LGB people has been reported and discussed. To date, there has been very little UK literature on the participation of LGB service users in social care and mental health generally, so this section will also provide a brief, indicative overview of the broader discussion from the past ten years on the type of LGB issues that have been explored for the sector. It also briefly considers methodological issues relating to use of personal experience. This enables the works included in this section to be

discussed within the context of the main literature, so that their significant contribution is clarified.

There is an additional issue for the submitted works focusing on this theme, and for the literature in general, which needs to be acknowledged at this stage (see also note on terminology p5). Most papers purport to include the interests and perspectives of transgender/transsexual people because they use the term 'LGBT', but in reality the main focus is on sexual orientation rather than gender identity and the inclusion of 'T' can be tokenistic. This is a shortcoming of the submitted works which come under this theme (this is influenced by the fact that the author does not identify as transgendered/transsexual and so cannot bring this perspective to works informed by experiential knowledge, standpoint or reflexive methodologies), hence the use of brackets in the title of this section. There are some common experiences that LGB *and* T people share in relation to access to mental health and social care services and discrimination which can be derived from the works, but the specific issues for transgender/transsexual people are under-researched (Browne et al 2007) and gender identity merits a separate course of investigation (for example see Alleyne & Jones 2010). This brief literature review therefore focuses predominantly on material which looks at LGB people, although this in itself is additionally problematised by the fact that bisexual people can be subsumed into this category without full consideration of their unique standpoints and experiences (Jones 2010).

Findings and concepts from the preceding sections of personalisation and service user participation feed into some of the ideas explored in the submitted works themselves (indeed Works 6 and 8 were inspired and informed by various findings from both these fields of investigation) and within the wider literature. Of particular relevance to the work on LGB service user participation and experience of mental health services is that personalisation means care and support should be person-centred and shaped by and for the individual. In principle, this would be regardless of any protected characteristic this individual has under the Equality Act 2010 (HM Government 2010), including a sexual orientation that is lesbian, gay or bisexual. So personalisation is of particular relevance to social care and mental health practice with LGB people, something which is discussed in Works 8, 16 and 17 in particular, and which had not previously been fully acknowledged or explored for LGB service users in the UK literature before 2010 (Brown & Cocker 2011). There are several relevant themes from the specific observations and arguments about service user participation explored for this PhD by Public Works. The main ones focus on the effects of mainstream, service-determined participation strategies which result in certain discussions, knowledge and experiences being 'contested' or 'off limits', as described by Hodge and Barnes (Hodge 2005a & 2005b; Barnes 2002 & 2008) and the challenges of balancing the interests of different stakeholders (Bochel et al 2007). Barnes asks about the possibility of 'bringing difference into deliberation' for disabled people and users and survivors of mental health services and Bochel et al ask about 'marginalised or enabled voices' in user participation strategies in policy and practice, while Hodge argues that 'our capacity to speak is constrained by our sense of who we are, and how we relate to those with whom we are speaking' (Hodge 2005b p167). In addition, Beresford and colleagues have argued that knowledge gained through experience of using services should be valued alongside other types of social care and health knowledge and research and can be used to improve services (Beresford & Croft 2001; Beresford 2003): 'Disabled people's and

service users' organisations have developed their own knowledges, theories and models, based on their on their first-hand experience' (Beresford & Croft 2001 p295). These questions and arguments, developed primarily with disabled people, are of direct relevance to theory building about people who identify as lesbian, gay or bisexual who either use social care and mental health services or participate in their delivery and development. They are explored accordingly in the submitted works in this section, which are uniquely written from an explicit LGB service user perspective (with distinct methodologies as discussed in chapter 3 and personal motivations as discussed in chapter 4) and therefore draw on and present the type of epistemological approach and experiential knowledge use described by Beresford (2003).

The main UK academic literature focusing on LGB issues in social care and mental health from the past ten years falls into several categories: works discussing or investigating general adult social work education, discourse, training and practice (CSCI 2009; Brown 2008a; Bywater & Jones 2007; Hicks 2007; Fish 2006); mental health (Bartlett et al 2009; King et al 2008; Smith et al 2004); care and support for older LGB people (Pugh 2005; Knockor 2006; Ward et al 2010); education, practice and training in children and families' services (most specifically about adoption and fostering) (Cocker & Brown 2010; Brown & Cocker 2008; Hicks 2006 & 2005). Such work often has core themes and arguments about identity construction, accessing services, understanding diversity, achieving equality and examining anti-oppressive/discriminatory practice. In addition to the body of work in social care and mental health, very recently, and possibly prompted by the implications of the Equality Act and the preceding anti-discrimination legislation (Cocker & Hafford-Letchfield 2009), researchers have begun to examine the engagement and participation of LGB people in wider local democratic decision making processes and service improvement initiatives (McNulty et al 2010; Ryrie et al 2010) and the problems associated with data collection (NatCen 2009; Price 2011). However, the UK literature on LGB service user participation in and experience of social care and mental health services specifically remains sparse (Fish 2009), as does literature exploring the operation of 'heteronormativity' and the construction and administration of LGB identities in social care and health (Fish 2006; Fish 2007; Hicks 2008; Fanshawe & Sriskandarajah 2010). Further, tentative explorations of how to approach the problematic or complex management of the potentially conflicting interests of LGB people and those with certain religious beliefs which classify same-sex relationships as sinful or punishable, when both are protected under the Equality Act 2010, are beginning to appear in the literature (Dinham & Shaw 2009; Aymer & Patni 2011; Brown & Cocker 2011; Macaulay 2011).

For the vast majority of the academic books, research and theory papers referenced here, the sexual orientation and/or service experience of the author could be assumed or implied by the subject matter under discussion and the concluding arguments; or the authors may simply have an interest in examining anti-discriminatory practice and exploring the health and social care experiences of a minority group. None of the papers contain information which locates personal narrative in the evidence base or uses personal experience to critique certain bodies of research and dominant concepts (such as the historical pathologisation of sexuality in psychiatric practice or the effects of the construction of non-heterosexual orientation as disease). Nor do they appear to include explicit disclosure of identity

as lesbian, gay or bisexual, thereby using variants of standpoint or reflexive methodologies (as explored in chapter 3) for their investigations or service user experience and knowledge in construction of theories. However, a UK health and social care policy and practice edited book published in 2010, *LGBT issues: looking beyond categories*, contains details of each contributor's sexual or gender identity alongside their professional affiliations, thereby revealing the additional perspective they bring to their interpretation and analysis. The book is specifically about how sexual and gender identity is used in health and social care practice, both by practitioners and by service users and draws on the 'deconstructive' approaches to gender identity categories and gendered behaviour from 'queer theory' (see for example, Butler 1990). Notably, chapter five of the book which looks at trans identities in health and social care settings 'draws on both academic literature and personal experience' (Alleyn & Jones 2010 p56). The discussion includes an explicit personal narrative about a gender transition process, surgery and the re-construction of an identity where the person eventually identifies as neither male nor female. This methodology is very similar to that employed for some of the works submitted here (most significantly for Works 3 and 21) and, as discussed in chapter 3, it not only aims to generate new knowledge (rather than a fixed truth) (Alvesson & Skoldberg 2009) but is political in the sense that it allows people who have often been characterised or rendered as 'invisible' (Fish 2009) to speak for themselves (see also chapters 3 and 4).

It is here where Works 3 and 21 in particular make a unique contribution to the literature on LGB experiences of mental health and social care services, because of their methodology as well as the subject matter. The author's standpoint and identity is disclosed, personal (and political) motivation is explicit and service user experience is used to construct the type of new knowledge based on reflexive approaches discussed by Alvesson and Skoldberg (2009) (see chapters 3 and 4 for extensive discussion). LGB mental health service user standpoint and experience is very seldom seen in the UK literature, perhaps with the exception of Staddon (2005) and acknowledging the work of disability campaigner and founder of REGARD, the LGBT disabled people's organisation, Gillespie-Sells (Shakespeare, Gillespie-Sells & Davies 1994). Smith, Bartlett & King (2004) provide groundbreaking insights into LGB experiences of psychiatric treatment in England since the 1950s through oral history methods. Although this is a very important study which gives voice to LGB psychiatric system survivors and resulted in influential findings (for mental health in general and for Works 17 and 21 here), it was not user-led or explicitly informed by LGB standpoint perspectives. As noted in category 3 in chapter 3, Work 3 has been recognised as an example of the use of 'auto-ethnography, reflexive and personal narrative methodologies' for 'researching, learning and writing about lesbian and gay issues' (Trotter et al 2006 p373). Work 21 not only uses the distinctive methodologies already discussed in chapter 3, but employs direct experience of self harm to challenge dominant clinical theories, disorder constructions and research, as well as giving what appears to be a newly-constructed theory, based on experience, research and historical investigation, on why LGB people are at higher risk of using self harm as a way to manage mental distress.

Work 8 is a further exploration of combined themes and findings from Works 2 and 6, while being explicitly informed by Work 3, which draws on literature and personal experience (see also chapters 3 and 4). It is an exploration building on a fusion of

personal experience of discrimination based on religious belief and the research findings from Works 2 and 6 on how certain groups with contested status or knowledge (including LGB people) can be marginalised from mainstream service user participation initiatives. Work 8 also took into consideration the context of the then new anti-discrimination legislation which addressed sexual orientation alongside religion and belief (Work 8 was published in 2008 before the Equality Act 2010) and argues that an unintended consequence of this development could be the creation of equality hierarchies that do not favour LGB people. The work analyses research and policy evidence and outlines some of the complexities and potential problems relating to balancing these interests in the development and delivery of social care services and in user or citizen participation strategies. The conclusion posits the argument that the personalisation agenda in adult social care could offer some solutions to the difficulty of balancing what appear as competing interests or tensions within a single equalities approach. Work 8 has subsequently been cited in Brown & Cocker (2011) and in Hafford-Letchfield (2010). It represents new knowledge for social care and mental health practitioners as well academics and activists concerned with the complexities of achieving LGB equality and initiated a discussion early on about potential conflicts of interest between LGB equality and the interests of religious groups within the new UK legal 'single equalities' framework (as realised in the Equality Act 2010) .

Works 16, 17 and 20 follow up some of the concepts and arguments from the earlier works in the LGB theme and continue to be produced using a standpoint methodology, to a greater or lesser extent. In particular Works 17 and 20 have some focus on faith or spirituality and use research findings and in the case of work 20, personal testimony, to clarify a position on LGB people, mental health and faith. This use of research in these works could be criticised as playing the 'evidence-game'. In the context of social work practice around sexuality, identity and adoption and fostering, Hicks argues that 'corrective points are important sources of knowledge, but they also work as evidence game examples because they do not raise moral or epistemological questions' (Hicks 2008 p70). However, the methodological and epistemological underpinning for these works (as described in chapter 3) is designed precisely to raise such questions, particularly when the underlying critique of psychiatry focuses on its moral control function and the social perspectives of mental health (Tew et al 2006) or the work analyses the negative effects of administration and categorisation in mental health and social care. As with Work 8, Works 16, 17 and 20 argue that approaches to working with individuals (such as self directed support planning and co-production) as promoted by the personalisation agenda in mental health and adult social care, should be explored by trainers and practitioners –something that had not hitherto appeared in the UK mental health literature on practice with LGB people. Although these works do not interrogate or fully critique anti-discriminatory training and practice (see Hicks 2008; Brown and Cocker 2011), the consistent argument, based in evidence, concerns the importance of person-centred support and the need to understand the individual, which can be challenging in a mental health and social care system characterised by administrative processes and categorisation. Work 17 discusses the complexities relating to the mental health and treatment of LGB people from black and minority ethnic communities and/or who are refugees or asylum seekers. The work argues that the administrative structures of the present mental health system seem unable to accommodate people with 'multiple identities' who are expected to behave or identify 'correctly' in order to be

administered. This, it is noted poses a particular problem for the personalisation of mental health and adult social care where 'tailoring' is expected to supercede 'targeting'.

## Chapter 3: A critical account of the various methodologies used

### Introduction

This section discusses the main methodologies used for the submitted works and the epistemological traditions which have influenced the authorial approach and choice of methodology. Broadly, the works split into four categories:

1. Works associated with SCIE using the organisation's epistemological and methodological frameworks (Pawson et al 2003; Coren & Fisher 2006). These mainly consist of research and practice reviews and evidence overviews. The main topic areas for these pieces of work are service user participation; personalisation of adult social care; personal budgets and self directed support and co-production. These works (except Work 2, as noted in chapter 1) do not include the explicit disclosure of the author's status, identity or experience. This category includes Works 2, 9, 10, 11, 12, 18 and 19.
2. Works independently produced for journals and books which are critical analyses of research and policy evidence, which integrate self-disclosure or self-reflection relating to standpoint and experience. These works focus mainly on the dynamics of service user participation and the recognition of LGB(T) people in mental health or in adult social care user participation and training. This category includes Works 6, 8, 13, 16 and 17.
3. Works independently produced for journals and books which are primarily driven by author standpoint and personal experience. These use autobiographical or narrative accounts alongside both research and policy analysis to create an 'encapsulating account' or argument grounded in evidence and experience. This category includes Works 1, 3, 14, 20 and 21.
4. The sub-group of works published in edited volumes intended to directly convey the experience of a severe mental health crisis and its treatment as well as personal, non-psychiatric strategies for recovery and self-management (to be further explored in chapter 4, as noted in chapter 1). This category includes Works 6, 7, 9 and 15.

These categories form the structure for this chapter and the methodologies will now be discussed for each.

### Category 1: SCIE associated works on service user participation and personalisation

Works included:

2. Carr S (2004) *Social Care Institute for Excellence Position paper 3: Has service user participation made a difference to social care services?* London: SCIE/Policy Press
9. Carr S (2008) *Personalisation: a rough guide* London: SCIE (2<sup>nd</sup> revised edition, 2010)

10. Carr S & Robbins D (2009) *Social Care Institute for Excellence Research briefing 20: The implementation of individual budget schemes in adult social care* London: SCIE

11. Needham C & Carr S (2009) *Social Care Institute for Excellence Research briefing 31: Co-production: an emerging evidence base for adult social care transformation* London: SCIE

18. Carr S (2010) *Social Care Institute for Excellence Report 36: Enabling risk, ensuring safety: self directed support and personal budgets* London: SCIE

19. Carr S (2010) *Social Care Institute for Excellence Report 37: Personalisation, productivity and efficiency* London: SCIE

The methodologies used for works in category 1 reflect the wider project of the definition, construction and use of social care knowledge. At its inception one of the first tasks for SCIE was establishing a more inclusive, but transparent and robust, methodology for developing the evidence base for social care (Edwards 2002). This was partly because of the limitations for social care of the models determined by the 'positivist' research and critical traditions of medicine and health, which traditionally privilege one source of knowledge over another (usually based on methodology) (Trinder & Reynolds 2000; Humphries 2000; Long et al 2006). This involved determining an epistemological value base; defining the types and quality of knowledge in social care; and establishing a suitable critical assessment framework (Pawson et al 2003; Long et al 2006). This offers an alternative to the clinical hierarchy of evidence which prioritises scientific research methods such as randomised controlled trials and quantitative research (Cochrane 1972; Crombie 1997), the universal suitability of which is contested for social care research investigations (Trinder & Reynolds 2000; Aveyard 2007), but has also been adapted for social care research (MacDonald 2003; Sheldon & Chilvers 2000). Following on from this work, the possibility of an appropriate systematic literature review methodology for social care was explored and it was acknowledged that such research reviews could be improved by the participation of service users, carers and practitioners (MacDonald 2003, Coren & Fisher 2006).

As noted in chapter 1, for various reasons given, not all the works in this category can conform completely to the SCIE social care systematic review methodology (Coren & Fisher 2006). Some are closer to narrative reviews or narrative overviews, which also discuss theory and context (Green et al 2001). However, the works abide by some of the key epistemological and methodological principles established by SCIE and take a 'pragmatist' approach to constructing and using a social care evidence base, as described by Trinder: 'Grand science and grand experimental designs are cut down to size within a realist epistemological framework' (Trinder 2000 p143).

Firstly, the research question determines the type of literature included in the works, in line with Aveyard's assertion that 'the type of literature you need to address your research question depends on your question' (Aveyard 2007 p66). My approach to setting and answering the questions or tasks for the works in this category has

incorporated a service user perspective (Fisher 2002), which then influenced the pragmatic establishment of my 'own hierarchy of evidence' (Aveyard 2007 p64) appropriate for addressing the question. The guiding principle for the investigations has been the consistent focus on frontline impact and how the policy or practice will affect the lives of service users: 'The aim is to improve outcomes, always keeping in mind that the 'moment of truth' lies in the quality of the user's experience of the service' (Edwards 2002 p13). Therefore if the investigation focuses on service user experience or outcomes or includes a user perspective, as these works do, then service user research and knowledge is included in the evidence hierarchy and literature search strategy. However, this type of inclusive or collaborative approach to literature reviewing (even though the researcher and author has user experience – a 'dual identity' issue to be discussed further in chapter 4) in SCIE does not constitute user-controlled or user-led research, partly because it was not carried out by a user organisation or solely by user-researchers (Turner & Beresford 2005).

Secondly, explicitness and transparency are noted as being vital for reporting social care literature reviews (MacDonald 2003; Coren & Fisher 2006), and the limitations of the evidence are clearly stated in the works submitted for this category. This means being transparent about the searching and the nature of the evidence as well as the methodology used and type of product resulting. For example, because of significant acknowledged limitations, Work 19 needed to be presented as an 'evidence overview' rather than a 'literature review'.

Finally, the overall approach to the works in category 1 conformed to the epistemological framework and core domains of social care knowledge established for SCIE and the generic appraisal standards for these (Pawson et al 2003; also Long et al 2006). As Long et al observe:

'Social care policy and practice are informed and influenced by multiple sources of knowledge. These range from the tacit, experiential knowledge arising from everyday practice, to the knowledge embodied in rules and regulations, to the formal, codified knowledge arising from research into social work issues' (Long et al 2006 p208).

The publication, *Types and quality of knowledge in social care* (Pawson et al 2003) details the classification of different sources of social care knowledge and the framework of generic standards (or set of questions) designed to critically appraise the artefacts from those sources, gives the underpinning structure to the methodologies and materials used for works in category 1 and also for certain works in categories 2 and 3. The non-hierarchical social care knowledge domains or 'the main forms of research, experience and wisdom' (ibid p vii) are given as:

- organisational knowledge
- practitioner knowledge
- user knowledge
- research knowledge
- policy community knowledge

For the purposes of social care evidence and knowledge, the 'classification's first task is to help direct users [not meaning service users in this instance] to appropriate

knowledge to support each different social care function and information need' (ibid p3), rather than to establish a hierarchy.

Works in category 1 and in many instances in category 2 and 3 used the following 'TAPUPAS', generic standards framework for critical appraisal, that 'illustrate the anchor points for judgments and prompt critical reflection' (ibid p43) :

Transparency – is it open to scrutiny?

Accuracy – is it well grounded?

Purposivity – is it fit for purpose?

Utility – is it fit for use?

Propriety – is it legal and ethical?

Accessibility – is it intelligible?

Specificity – does it meet source-specific standards? (ibid p3)

This framework was established to address the need for a generic critical appraisal schema suitable for social care research, but it has some constraints associated with the fact that it has not yet been widely tested and utilised by those undertaking systematic reviews in social care (Long et al 2006; Sharland & Taylor 2006). However, during testing the developers found that 'use of the TAPUPAS schema forced consideration of the strengths and weaknesses of each document and broadened the common notion of quality and quality assessment to sources beyond the traditional research domain' (Long et al 2006 p 207). This means that the framework gives space and weighting to research and knowledge generated by service users and carers (as noted for social research in mental health in Tew et al 2006), and as such was appropriate for use for works included in category 1 and category 2.

### **Category 2: Independent works on service user participation and LGB(T) perspectives on social care and mental health – critical analyses informed by service user experience**

Works included:

6. Carr S (2007) Participation, power, conflict and change: theorising dynamics of service user participation in the social care system of England and Wales *Critical social policy* 27(2) pp.266-276

8. Carr S (2008) Sexuality and religion: a challenge for diversity strategies in UK social care service development and delivery *Diversity in health and social Care* 5(2) pp.113-122

13. Bowlam S, Carr S & Gilbert P (2010) The Partnership Project: learning from experts by experience in mental health services; the Jersey Partnership perspective *International journal of leadership in public services* 6 (2) pp.54-67

16. Ross P D S & Carr S (2010) 'It shouldn't be down to luck': training for good practice with LGBT people – Social Care TV *Diversity in health and care* 7 (3) pp.211-216

17. Carr S (2010) Seldom heard or frequently ignored? Lesbian, gay and bisexual (LGB) perspectives on mental health services *Ethnicity and inequalities in health and social care* 3 (3) pp.14-25

The works in this category draw on the 'TAPUPAS' social care knowledge appraisal framework (Pawson et al 2003) and use a range of sources from the social care knowledge domains established by Pawson et al, as discussed above. However, additional attention is paid to adhering to standards for user and carer knowledge, which should be able to demonstrate:

- 'Use of a 'social model': all knowledge should adhere to an explanatory model, focusing on the institutional, economic, environmental and cultural barriers – and their social and psychological consequences – for disadvantaged groups and individuals.
- Clarity of ideological standpoint: as all knowledge is coloured by the political complexion of its producers, there should be a clear declaration of loyalties.
- Empowerment: all knowledge should be judged on whether it has meaningful and practical outcomes for users, rather than simply being assessed on paper' (ibid p62).

As well as being guided by the standards set out by Pawson et al, these works are also informed by feminist standpoint approaches which recognise 'situated knowledge' (Harding 1993) and empowerment and emancipation agendas in service user research, which demand a degree of self-reflection and self-disclosure (Humphries, Mertens & Truman 2000; Rose 2004). As Tew and colleagues have explained:

'Put simply, standpoint epistemology asserts that life experience of subordination or exclusion (as a woman, a black person, a mental health service user, etc) can give people greater knowledge about certain realities that those in positions of relative power and privilege cannot easily know about in the same way, because they lack that life experience. This can be knowledge of 'what is' and also knowledge of 'what is important': both of which may be crucial to harness within the research process' (Tew et al 2006 p8).

In addition, the methodologies used for these works are influenced by the type of reflexive approaches which seek to balance 'theory and fact' and acknowledge the politics of doing research, as described by Alvesson and Skoldberg (2009). They define such 'reflexivity' as being aware of your own perspective as a researcher who theorises and interprets: 'we always lay a perspective into what we say, and not only that, but seeing is inseparable from the perspective, it is *perspectival*' (Alvesson & Skoldberg 2009 p6 [author's italics]). In the case of these works, where multiple perspectives (and paradigms) are influential in developing theories and interpreting data, Alvesson and Skoldberg's description of the reflexivity in research is particularly illuminating: 'various paradigms, perspectives and concepts, as well as research and other political interests all bring out certain types of interpretation possibilities' (ibid p263).

The intention for these works is also to produce knowledge which service users, particularly those who use mental health services and/or who are members of the LGB(T) community, can use for empowerment, defined as ‘the liberational model [which] offers the opportunity to focus on broader issues relating to citizenship rights and preferred status within society, possibly via collective action by service user groups’ (Starkey 2003 p281). As Oliver asserts: ‘The key issue is not how to empower people, but once people have decided to empower themselves, [to decide] precisely what research can do to facilitate this process’ (Oliver 1990 p13). For the purposes of mental health service user/survivor research, Rose has clarified the argument for standpoint epistemology: ‘There is no ‘universal knowledge’ but only particular or situated knowledge produced through different standpoints. Different standpoints produce ‘different truths’” (Rose 2004 p28). As already noted, the works in this category (and in category 3) are explicitly influenced and motivated by my particular perspectives, knowledge and standpoints and my aim therefore is to use methodologies that are consistent with the aims of standpoint practices, as described by Harding:

‘Standpoint practices are overtly politically engaged in their conscious, intentional critical focus on power relations that oppress women and other economically and politically vulnerable groups’

‘Such research announces its accountability, its responsibility to ‘the facts’ of nature and social relations and to ending the oppression and exploitation that have been maintained in part through suppressing or neglecting to notice such ‘facts’ (Harding 2006 pp.83-84).

Given the focus of the works in this category is on power dynamics, inequality and the inclusion of service users and LGB(T) people in social care and mental health research, policy and practice (ultimately the extent to which are able to exercise ‘citizenship’ – to be explored further in chapter 5), it is important to note they can be categorised as contributions to the collective knowledge of ‘new social movements’ (such as the survivor, disability or gay movements) (see: Beresford 2002; Campbell & Oliver, 1996; Lister 2003; Truman 2000). The research orientation of such movements ‘has sought to make visible those experiences which are misrepresented or ignored by official statistics and by methodological assumptions which result in normative ideas about family life and household structure’ (Humphries 2000 p10). Barnes has argued that ‘social movements which give expression to the experience of oppression among marginalised social groups also offer a critique of the rational scientific basis of knowledge production’ (Barnes 2002 p322). For the works in category 2, and to some extent in category 3, I use the various types of social care evidence to explore and explain certain perceived trends or phenomena (such as certain aspects of the relationship LGB(T) people have with mental health and social care services) of which I am aware because of my standpoint and experience. This approach could be termed ‘standpoint analysis and interpretation’ because the works are not primary research studies, but are the analysis and interpretation of existing research and policy in the light of lived experience - as Morgan asserts: ‘document analysis is as much bound up in political and ideological disputes as is all social research’ (Morgan 2000 p120). This is similar to the points about reflexivity, perspective and interpretation made by Alvesson and Skoldberg (2009) as previously discussed. Despite this distinction, the works reflect Truman’s

observations that: 'Participatory approaches to emancipatory research recognise and are centred upon the transformative potential of the social research process...new social movements may use research to influence the thinking and to alter the knowledge bases of others – particularly those in powerful positions' (Truman 2000 p24). The generation and collection of service user knowledge can then facilitate a dialogue between service user knowledge and practitioner knowledge which has the potential to offer more inclusive and robust forms of organisational knowledge, as described by Toikko (Toikko 2011). For works in categories 2 and 3, the intention is precisely to expand the mental health and social care knowledge base by creating and inserting absent or marginal knowledge through publication in mainstream peer-reviewed journals and academic books (see also chapter 4).

### **Category 3: Independent works on mental health and LGB(T) perspectives on mental health – explicit service user perspective**

Works included:

1. Carr S (2003) Duty of care: employment, mental health and disability *Journal of Mental health promotion* 2(1) pp.6-23.
3. Carr S (2005) 'The sickness label infected everything we said': lesbian and gay perspectives on mental distress in Tew J (ed) *Social perspectives in mental health* London: Jessica Kingsley pp.168-183
14. Carr S (2010) Remote or related? A mental health service user's perspective on leadership *International journal of leadership in public services* 6 (2) pp.20-24
20. Carr S (2011) Mental health and the sexual, religious and spiritual identities of lesbian, gay, bisexual and transgender (LGBT) people in Gilbert P (ed) *Spirituality and mental health* Brighton: Pavilion Publishing pp.335-352
21. Carr S (2011) 'A chance to cut is a chance to cure': self harm and self protection – a gay perspective in Hafford-Letchfield P & Dunk-West P (eds.) *Sexual identities and sexuality in social work: research and reflections from women in the field* Farnham: Ashgate pp.31-45

The works in category 3 share the methodologies of category 2 works, but go further in that they contain autobiographical material, personal narrative or accounts of lived experience. Work 3 has been recognised as an example of the use of 'auto-ethnography, reflexive and personal narrative methodologies' for 'researching, learning and writing about lesbian and gay issues' (Trotter et al 2006 p373), and has the potential to contribute to the emerging body of 'queer methodologies' (Browne & Nash 2010). Because of the 'lived experience' dimension they could come within the broad category of 'mental health user/survivor research' (see: Sweeney et al 2009; Rose 2004; Beresford & Wallcraft 1997), albeit one which does not involve the production of primary research studies but rather attempts to undertake a 'storytelling research process' which Wilkins describes as:

'the recasting of personal stories in the light of...pre-existing stories (which may include anecdotes or the literature) and the production of an encapsulating account' (Wilkins 2000 p147).

Part of the endeavour is to begin to make 'collective sense of individual stories' (ibid p147), in this case my own stories and those I gather from the literature, thereby combining research review methodology with reflections on personal experience, and partially addressing the problem of 'personal experience versus the scientific method' in some emancipatory research (Humphries 2000). Again, to refer to the reflexivity theories of Alvesson and Skoldberg, they advocate maintaining a personal awareness of perspective and interpretation rather than polarising into opposing methodological approaches which seek to establish truths. Further, they note how maintaining reflexivity in the research process means that:

'serious attention is paid to the way different kinds of linguistic, social, political and theoretical elements are woven together in the process of knowledge development, during which empirical material is constructed, interpreted and written...this...can provide an important basis for a generation of knowledge that opens up rather than closes, and furnishes opportunities for understanding, rather than establishes truths' (Alvesson & Skoldberg 2009 p9).

Although Barnes has been critical of the use of biographical accounts in emancipatory disability research, citing the risk of sentimentality, medicalisation and potential for only weak political impact (Barnes 2003), establishing new perspectives through the use of individual narrative has been highlighted as having a potential contribution to make to evidence-based practice in mental health (Roberts 2000; Greenhalgh & Hurwitz 1998), because 'the subjective, personal, patient story and the interpretative, scientific, medical story are not translations of each other but independently co-existing narratives' (Hunter 1991, quoted in Roberts 2000 p434). Further to this, Roberts describes the importance of narrative processes for understanding mental distress, and his observation about the effect of 'toxic stories' on mental health is particularly relevant to the works in category 3 (perhaps most effectively demonstrated by Works 3 and 21) and in category 4, in the context of their emancipatory intention:

'Some grow up with life-denying meanings and are hostage to toxic stories that adversely define and constrain their identity and self-image. They are caught in a story, and the task is first to understand this and then to find ways of modifying (re-authoring) these myths-people-live-by to promote a more constructive, effective and adaptive context for living' (Roberts 2000 p435).

While the methodology for works in category 3 can be situated within certain paradigms, my overall approach for these particular works has been similar to that of the disability sociologist Shakespeare in that my use of methodology is pluralist and pragmatic: 'I am a pluralist and would rather follow my own intellectual and ethical standards, rather than trying to conform to an orthodoxy' (Shakespeare 1996 p118). For the majority of the works in the category, my particular standpoint and methods of knowledge production can be partly explained with reference to the work of Frye (Frye 1983), as described in Stanley: 'a lesbian feminist epistemology... brought into

existence out of an explicit consciousness of oppression, out of silences, intrusions, misnamings' (Stanley 1990 p.33). Again, I am guided by emancipatory research principles, here defined by disability activist researchers, as 'openness, participation, accountability' (Barnes 1992 p121) and 'empowerment and reciprocity' (Oliver 1996 p30). Moreover for works in category 3, as Stone and Priestley have asserted, it is important that emancipatory research has 'the ability to give voice to the personal [and] to legitimise previously marginalised voices' (Stone & Priestley 1996 p706) while others emphasise the importance of reflexivity: 'Emancipatory research is about the empowerment of disabled people through the transformation of material and social relations of research production' (Barnes 2003 quoted in Wright [no date] p1). Therefore the works in category 3 are emancipatory in their endeavour and are guided by the appropriate principles, particularly the 'social model of madness and distress', as defined by mental health service users and survivors (Beresford & Wallcraft 1997). Broadly the topics and investigations for the works in categories 3 and 4 fit with the research investigations suggested by survivor researchers as being important for further understanding this 'social model of madness and distress' (Beresford et al 2010) and social perspectives on mental health:

'Social causes of madness and distress; medicalisation of our experience and distress; the destructive and discriminatory response from both psychiatry and broader society; the need for a social response to the distress and disablement which survivors experience, addressing the social origins and relations of their distress, instead of being restricted to people's individual difficulties' (Beresford & Wallcraft 1997 p83).

However, to return to the use of self, autobiography and personal narrative in the works, it needs to be noted that the majority of thinking about the use of reflexivity and biography in the research process concerns addressing the relationship between the researcher and the researched (Finlay & Gough 2003; Chamberlayne et al 2000; Merrill & West 2009; Alvesson & Skoldberg 2009). Self-disclosure and self-awareness in the social research process are ways of addressing the need for other-awareness of the research 'subjects' (Shakespeare, Atkinson & French 1993). Similarly the model of feminist 'praxis' and 'Auto/biography' focuses on researcher/subject relations (Stanley 1993 & 1990). However, the works in category 3 review existing literature (in which I appear as the research subject or conceptual 'problem') through the application of experiential knowledge and personal biography in order to reposition knowledge, reframe the 'self' (which includes experience and behaviour), to add to the collective knowledge of a marginalised group (LGB(T) people with mental health problems) and to offer a new perspective which others who identify with my story can use for their own empowerment. Despite this, the principles and methodology of reflexivity and auto/biography are also relevant for this endeavour. In some cases I am interpreting and understanding my own experience through research and policy analysis to construct counter knowledge from the margins (see hooks 1990a): 'The auto/biographical 'I' is an inquiring analytic sociological agent who is concerned in constructing rather than 'discovering' social reality and social knowledge' (Stanley 1993 p49).

Humphries has warned that, 'as researchers, commitment to self-reflexivity is fundamental, although this can deteriorate into self-indulgence which places the researcher as the norm' (Humphries 2000b p188). As already mentioned in chapter

1, Alvesson and Skoldberg argue that a reflexive methodological approach is important so that 'confessionalism' does not slip into 'self-absorption' and 'self-reflective isolationism': 'reflexivity, in the research context means paying attention to these aspects without letting any one of them dominate. In other words, it is a question of avoiding empiricism, narcissism and different varieties of social and linguistic reductionism' (Alvesson & Skoldberg 2009 p269). It could be that some of the works in category 3 (and particularly category 4) could be dismissed as 'self-indulgent' by some readers, but part of my intention in self-disclosure is to make visible what has been invisible in research and policy – that is, the personal stories and direct, unmediated experiences of people with mental health problems and/or LGB(T) people *in their own voice*. Where possible, I position my experience within a historical continuum (especially the history of psychiatry) and alongside that of others and do not to claim that my personal narrative is representative or universal. Rather I suggest that some of my experiences may be shared by others and can contribute to collective service user knowledge (Beresford 2003). Thereby I aim to offer an example of my own life account produced by myself which challenges the accounts about me or 'my kind' as determined by others, as Goodley and Clough have argued: 'expert discourses are being challenged by exposing their narrative construction...[and] grand political and cultural narratives are under attack by personalised and localised narratives' (Goodley & Clough 2004 p336). The works in category 3 have been produced in response to my own critical question as a research *subject* about 'who benefits from the research'? (Truman 2000). In my position as the *'other'* the works are produced from what bell hooks [sic] describes as 'marginality as site of resistance' (hooks 1990a) and one in which I reclaim the position of 'author and authority' (hooks 1990b). Finally, bell hooks provides the best accounts of the conditions in which most of the works in category 3 were produced and why they were produced:

'I am waiting for them to stop talking about the 'other', to stop even describing how important it is to be able to speak about difference...Often this speech about the 'other' is also a mask, an oppressive talk hiding gaps, absences, that space where our words would be if we were speaking, if there was a silence, if we were there...This 'we' is that 'us' in the margins, that 'we' who inhabit marginal space that is not a site of domination, but a place of resistance...Often this speech about the 'other' annihilates, erases: 'no need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice...I want to know your story. And then I will tell it back to you in a new way...I am still author, authority' (hooks 1990b p151-152).

'This marginality [is] a central location for the production of a counter-hegemonic discourse that is not just found in words but in habits of being and the way one lives. As such, I was not speaking of a marginality one wishes to lose...but rather of a site one stays in...because it nourishes one's capacity to resist. It offers to one the possibility of radical perspective from which to see and create, to imagine alternatives, new worlds' (hooks 1990 quoted in Harvey 1996 p103).

## **Conclusion**

The submitted works draw on a range of methodologies, which are largely characterised by the standpoint, reflexive and emancipatory approaches. While works in category 1 conform to a formal, systematic methodology established by SCIE, the critical framework for quality assessment accords value to service user research and experiential knowledge. This reflects one of the unifying characteristics of the methodologies used in the submitted works – that service user and experiential knowledge needs to be included in social care and mental health evidence because it contributes particular perspectives, potentially new discourses or interpretations and ‘opportunities for understanding’ (Alvesson & Skoldberg 2009). The methodologies are largely reflexive in nature and as such determine that the submitted works transparently offer particular perspectives, interpretations or new knowledge constructions, rather than establishing ‘truths’ or ‘facts’. The submitted works containing narrative or auto/biographical accounts, positioned in dialogue with evidence and other perspectives, and in which standpoint and experience is used to interpret research and policy, are examples of this.

## **Chapter 4: A critical review of my personal development as a researcher**

### **Introduction**

This chapter is an account of my personal development as a researcher. While chapter 3 discusses some of the methodological developments for the submitted works and how these are influenced by various approaches relating to the use of self, standpoint, reflexivity and user experience and knowledge, this chapter focuses on inter-relationship of various other personal and experiential factors on my identity and personal development as a researcher. Because these factors include experience of mental distress, ideas of disability and the effects of stigma, it is illustrated using a sub-group of works from the main submission (Works 4, 5, 7, and 15) which focus on the personal lived experience of mental health problems and mental health services and the impact of this on personal and professional identity. They constitute a small collection of personal 'recovery pieces' which articulate the experience of a severe mental health crisis and personal, non-psychiatric strategies for recovery and self-management. They also form a reference point for this section which presents a critical review of my personal development as a researcher. The discussion of my development refers to the work of mental health service user/survivor researchers and includes an account of how my research work and identity has an 'activist' or political dimension. I also track some of the emotional and psychosocial motivators which include conceiving myself as part of a collective of service users and people with experience of marginalisation who use writing and research as ways to interpret their individual experiences which can then contribute to collective knowledge (Beresford 2003).

While this chapter aims to outline developmental progress, recounting a linear history is not necessarily straightforward as my working life in research has been punctuated with episodes of mental distress of varying severity followed by periods of recovery. These, as I will explore, have had an effect on my work and on my development, outlook and identity as a researcher. Therefore, I propose a thematic rather than chronological structure for this chapter, as I feel this approach allows me to better frame and articulate the discussion. I have used Beresford's cue: 'how we think about ourselves, other people and our experience, can also affect how we interpret direct experience and distance us from it' (Beresford 2003 p43). Bearing this in mind and having reflected on my history and work to date, I have identified some key themes which usefully describe elements of my personal development and motivation: the notion of *capacity*; the construction of *identity*; the search for *solidarity*. These themes form the structure for the rest of this chapter and the discussion for each includes some reference to thinking and ideas I have found helpful for my development.

### **Overview of submitted works referred to in chapter 4**

Firstly, below is a brief overview of Works 4, 5, 7 and 15.

4. Carr S (2007) Reflection: Sehnsucht cinema in Coyte M.E, Gilbert P & Nicholls V *Spirituality, Values and mental health* London: Jessica Kingsley pp.97-102

This short work appears in an edited collection of work deriving from different perspectives on the issues of mental health and spirituality. The book is a resource for mental health practitioners and draws on service user experiential knowledge. This work is written from a purely personal perspective and describes how I have used cinema, and one film in particular, to understand and interpret a severe episode of mental distress.

5. Carr S (2007) Chapter 5: Through a glass darkly: looking for my own reflection in Coyte M.E, Gilbert P & Nicholls V *Spirituality, values and mental health* London: Jessica Kingsley pp.84-88

This work appears in the edited book described above. It describes and interprets an experience of severe mental distress and hospitalisation, and uses the mirror in both a literal and metaphorical way to 'translate' the impact of the hospital environment and the mental distress itself.

7. Carr S (2008) The sick and the well? In Sweeney A, Beresford P, Nettle M & Rose D (eds.) *This is survivor research* Ross on Wye: PCCS Books pp.182-183

This work is a brief personal reflection on 'being a survivor researcher' which appears in a book on survivor research entirely written and edited by mental health service user or survivor researchers.

15. Brand D & Carr S (2010) Chapter 14: The person on the receiving end in Webber M & Nathan J (eds.) *Reflective practice in mental health* London: Jessica Kingsley pp. 244-254

This work was co-written with another mental health service user and forms part of an edited book on reflective practice in mental health. The work draws on the personal experiences, both positive and negative, of mental distress and the mental health system. My contribution concerns the importance of humanity in mental health practice and self-determination for those who use mental health services.

## **Theme 1: Capacity**

This theme on capacity explores my relationship to research activity and challenges to my professional identity resulting from my experiences of managing mental distress and associated stigma and in relation to my self-defined status as a service user researcher. I use the term capacity because it can be applied to this discussion in several ways:

- a) My own intellectual capacity – my self-perception and what I fear others perceive about my intellectual capacity.
- b) The capacity of certain knowledge arenas to accept and value certain types of knowledge and its expression.

c) The capacity of publications to include user research, experience-based knowledge and direct narrative accounts (or storytelling) of mental distress and mental health service use.

I now discuss each of these sub-categories one by one.

*My own intellectual capacity – my self-perception and what I fear others perceive about my intellectual capacity*

In their paper entitled 'Human agency and social suffering', Frost and Hoggett (2008) make an observation about how the 'welfare subject' (or service user) has been constructed in Western liberal democracies:

'The notion of the "liberal subject" as addressed by much welfare policy...mean(s) a person with autonomy, a unified consistent coherent identity, rationality and agency. Against this version of humanity, the welfare subject is invariably construed within a deficit model, as lacking enlightenment traits: a dependent, unpredictable, unable to act in their own best interests, lacking agency' (Frost & Hoggett 2008 p439).

My personal experience as this type of constructed 'welfare subject' has been influential for my development as researcher. My experience as a 'welfare subject' is a particular one as I also have a psychiatric diagnosis, thereby adding an extra, perhaps intense dimension to my perception of my intellectual capacity and fear about what others believe it to be. It is partly what survivor researcher Straughan describes as 'researching with an eye on others' perceptions' (Straughan 2009 p108). Because of my long-term mental health condition and episodes of acute distress I sometimes feel that I occupy the Enlightenment's realm of 'unreason' (Foucault 1967), while at other times I interpret my distress as a response to being 'sane in insane places' (Rosenhan 1973). During my most acute episode of mental distress, I believed that my brain was broken and that it would never work properly again. Now I have effective medication to stabilise my mental health, I still hold an underlying belief that the medication gives me the capacity to function well and to research and write efficiently, even though 'rational' understanding would determine this to be untrue. Often my endeavours can be in response to being trapped in 'a false, distorted and reduced mode of being' (Taylor 1995 p225 quoted in Frost & Hoggett 2008 p444) and I can succumb to an internalised form of what Lindow calls 'psychiatric disqualification' (Lindow 1991). Lewis' observation about the broader internal contradictions in rights-based mental health service user and survivor participation strategies is also relevant to my personal situation: 'from a human rights perspective, it also poignantly illustrates how the normative principle of being viewed as having 'rational insight' and a 'reasonable moral agent' which underpins our understandings of humanity, and therefore moral and legal legitimacy and the ascription of rights, is undermined when people are deemed "mad"' (Lewis 2009 p267).

Reflecting the points made about rationality and the deficits of the 'welfare subject' or those who inhabit the realms of 'unreason', Rose, a leading senior UK survivor researcher (writing in the *British medical journal*) describes well the type of challenge I have faced, both internally and from external sources: 'One's user status may be

used to undermine one's opinions, as it is held that a person cannot be both logical and mad. It is a difficult balance to strike...' (Rose 2003 p1131). So, the notion of the need to understand and exercise my individual intellectual capacity comes into play for my development, as it challenges and builds my resilience to the sort of internalised thinking partly described by Rose. Stigma, therefore plays a part in my self-concept as a capable researcher: 'the stigmatised individual may find that he feels unsure of how...normals will identify him [sic] and receive him...in the stigmatised arises the sense of not knowing what the others present are 'really' thinking about him' (Goffman 1990 p24-25). My feelings could also be recognised as a form of mental health stigmatisation as described in 'social attribution theory' (Corrigan 2000). In Work 1 I explore a lot of the difficulties with trying to manage a mental health problems and stigma which can result in negative self-concept and remain active in my paid research work. If you experience severe depression I say that 'it seems natural to regard yourself as a failure...and hard to believe that your employer (or anyone else for that matter) sees you as a capable person, even if they are unaware of your mental health problem' (Work 1 p18). Overall, in undertaking the research, analysis and writing that a project or paper demands, I am often attempting to demonstrate to myself and others that, despite my mental health problems and history, I have the capacity to access and exercise the sort of rationality and agency that the 'normal', functioning 'liberal subject' can.

Many people who identify as mental health service user or survivor researchers will say that their research activity can be a haven from the distress emanating around the rest of their brain. As Sweeney attests, when she describes her retreat into her studies at a time of crisis:

'For months I hid in my room. I lost all concentration, yet somehow I could immerse myself in the research project, even though I could not face anything else...I was uncovering a love of research and discovery' (Sweeney 2009 p165).

Here, certain research activity as 'meaningful occupation' can be seen as a 'strategy for living' (Mental Health Foundation 2000), or in other words a self-chosen intervention or occupation that helps an individual with the management of mental health and stigma. It might be true to say that the degree of control and determination, along with the discovery element, has made research and writing therapeutic at times. As Webb writes: 'Research – 'disciplined enquiry' – is a wonderful and privileged opportunity to pursue the spirit of ruthless enquiry, on which my personal sense of well-being depends' (Webb 2009 p170). Researching as an intellectual exercise as well as a voyage of discovery can be a reminder that my brain has the capacity to function well, even if I am experiencing mental distress or trying to manage and understand difficult emotions. In a way it could be seen as a self-reflexive demonstration of my intellectual capacity. Papers such as Work 1, which looks at my own experience and more broadly at employment, mental health and disability, or Work 21, where I discuss self harm, were written in part as a response to loss of agency or as an exercise in taking control. Work 1 possibly demonstrates the beginning of my conscious development as a mental health service user/survivor researcher, or at least in my development as someone who is becoming aware of how her mental health and employment relate to each other. My perception of my intellectual capacity and resultant research results in a dynamic

similar to that described by Straughan: ‘...you aim to drive through change in an environment that may seek to question every move you make and decision you take, and whose behaviours you naturally question in turn’ (Straughan 2009 p119).

*The capacity of certain knowledge arenas to accept and value certain types of knowledge*

My formal training as a working researcher was as a research reviewer in mental health and later in social care. When I worked at an NHS Trust reviewing research for evidence based mental health I was trained on the NHS Critical Appraisal Skills Programme (CASP). This taught me the type of critical appraisal skills which place a high value on clinical research and ‘positivist’ scientific research methodologies such as Randomised Controlled Trials (RCTs), systematic reviews and meta analyses (Cochrane 1972). However, I also worked for a consultant community psychiatrist whose approach was biopsychosocial (Engel 1977), meaning that she recognised that there are multiple factors that impact on a person’s mental health – biological, psychological and social. Alongside my research reviewing for clinicians, I also had the opportunity to undertake a review of literature relating to alternatives to psychiatric medication for a local user group she worked with. They wanted to know about the effectiveness of treatment like St John’s Wort, acupuncture and how nutrition may play a part in mental health. According to the CASP hierarchy of research (Crombie 1997), nothing I found on these topics could be included because of the types of methodology the studies used did not meet the approved criteria. However, I couldn’t return to the service user group telling them I had found nothing because none of the research I had evaluated was admissible as good quality according to the critical appraisal framework I was using. Instead I told them what I had found, how I had evaluated it and let them know what the findings were while being transparent about the limitations of the review.

It was carrying out this literature review for a user group, focusing on subjects which were important to them, that first made me fully aware of the relationship of mental health service users and research (at the time I hadn’t yet identified as a service user researcher). The problem it seemed was something to do with the epistemological capacity of psychiatry to include the perspectives of service users in the production of knowledge. In this case it wasn’t user or survivor research, it was research on topics that were of importance to people experiencing mental distress who wanted to know about other ways of managing their mental health. However, the research topics were of little interest to clinicians whose primary interventions were psychiatric medication, and therefore, I guessed, did not attract the type of research budget that could fund an expensive RCT. I was exposed to a real dilemma about the different values being placed on research: some knowledge is dismissed by using simple, positivist evaluation techniques by practitioners, but that dismissed knowledge can be valued by service users because it gives an insight into matters of direct importance to their understanding or management of mental health. In short this early experience heightened my awareness of the politics of knowledge production.

When I moved from a research and information environment that had a culture based more on social work and social care rather than a clinical milieu, I became increasingly aware of the shortcomings of the CASP evaluation model for the type of social care research I was coming across. The introductory paragraphs in chapter

one and the first section of chapter 3 outline some of the relevant methodologies I worked with in social care research reviewing. However, most importantly, I was in a position to learn more about service user research and knowledge. I had first been introduced to the idea of service user research and knowledge through the work of Diana Rose and the User Focused Monitoring programme at the Sainsbury Centre for Mental Health (Rose et al 1998). Then when I worked at the National Institute for Social Work it was supporting Peter Beresford and colleagues to establish the Shaping Our Lives service user network (Shaping Our Lives 2003). Later at SCIE I joined INVOLVE, the national advisory group, funded by the Department of Health, which aims to promote and support active public involvement in NHS, public health and social care research.

Becoming aware of, and later involved in, work which explored and promoted service user knowledge gave me a greater understanding of how social care and social policy should develop the capacity to include that knowledge in evidence and decision making. After the experiences which lead me to write Work 1 and having been exposed to service user activism, the conceptualisation of user experience as valuable knowledge and forums in which the objectivity of certain types of clinical or positivist research was being debated, I began to identify as a service user researcher. I was prompted to reflect deeply on my professional experiences at the NHS Trust, my personal experiences of using mental health services and medication and how the types of research and knowledge influencing services and interventions are constructed and operating. At the same time, my employer, SCIE was exploring and developing a position on social care epistemology and evidence classification that created a working environment and culture which valued service user experience and knowledge. Knowledge for social care was seen as 'fit for purpose' if it included 'user knowledge gained from experience of service use' (Grayson et al 2004). Accordingly, I began to see my working role as a research analyst and research commissioner in a different way: to enhance the capacity of social care and health research and knowledge to include service users and their perspectives, including my own. My next challenge was to publish work that was explicit about my own experiences, promoted service user knowledge or promoted the interests of service users. The former at least has been described as the 'grey zone' of research (Straughan 2009).

*The capacity of publications to include user research, experience based knowledge and direct narrative accounts (or storytelling) of mental distress and mental health service use*

During my development as a researcher and writer I have become aware of the practice and politics of publication. Any academic or practice material appearing in print will have gone through some sort of editorial selection or peer review process operating according to quality and inclusion and exclusion criteria. For high ranking health and social care journals, these criteria often include research methodology, subject, style, potential impact and authorial academic status. It is these higher ranking peer reviewed journals that are abstracted for the databases used for literature searches which can then determine citation levels. Therefore, where papers and articles are published influences the perception of their value, their dissemination and impact. However, this makes identifying material and assembling the broadest possible evidence-base very difficult because much service user

research, studies which investigate user experience and direct experiential accounts of mental health service use or mental distress do not qualify for publication in this knowledge strata, but are often classified as 'grey literature'; the majority of which is not included in the major social care and health databases. This situation will be influenced by Beresford's argument about the value placed on service user experiential knowledge: 'because you will be seen as 'close to the problem'...you cannot claim that you are neutral, objective or distant to it...you are likely to be seen as a less reliable source of knowledge' (Beresford 2003 p13). I recognise that Works 1 and 14 appear in reviewed journals which are abstracted for some databases, while Works 3, 4, 5, 7, 15 and 21, which include strong narrative or descriptive elements and appear as book chapters, may count as 'grey literature'.

Outside the normal remit of my professional research work, I have attempted to articulate direct accounts of mental distress, treatment in the psychiatric system and alternatives for managing mental distress for publication. However, this knowledge appears in more marginal places, perhaps because of the type of user participation dynamic described by both Barnes and Hodge (Hodge 2005a & 2005b; Barnes 2002 & 2008), which can marginalise or devalue or even erase certain types of knowledge and their expression. In his exploration of how experiences of extreme trauma can be articulated and understood in biographical methods and professional practice, Bar-On argues that 'a lack of distinction between the indescribable and the undiscussable [are] two impediments to human discourse' (Bar-On 2004 p102). Further he stresses that 'undiscussability, represents the disappearance of certain facts, silenced by society, including the helping professions' (ibid p102). Bar-On's theory is useful for exploring my experience of how the publication process can marginalise knowledge and how only certain types of publication have the capacity to include discussion of mental distress that would otherwise be considered 'undiscussable'. It is also helpful for me as I explore my efforts to articulate mental distress which has been 'indescribable' by the use of metaphor and proxy, particularly with reference to cinema.

Regarding the notion that rules operate to govern different types of publication, the levels of disclosure and stories a person who has experienced mental distress and the psychiatric system (and in my case who also has a stigmatised sexual orientation and identity) are limited to certain publications. Because I have come to understand that research and writing can have an activist dimension, I have been motivated to add my stories to the knowledge about mental distress and mental health. I have done this despite the fact that some accounts are of things that could be considered 'undiscussable' in Bar-On's terms and can be marginalised from the mainstream health and social care journal publication and knowledge production process, as described above. But if I had not sought publication somewhere, I feel I would have colluded in the hidden dynamic of stigmatisation and isolation of the user voice and experience which, in some respects, reflects the wider impact of prejudice against people with mental health problems (Thornicroft 2007). For example in Work 21 I attempt to discuss the 'undiscussable' when I describe my relationship to self harm, sexual identity and managing mental distress within the context of the history of psychiatric practice. Similarly, in Work 3 I speak directly about my experience of how a therapist attempted to change my sexual orientation and use it as a springboard for my investigation. In Works 14 and 15 I openly describe the process of being admitted to psychiatric hospital and using community mental health services in order

to highlight the importance of relationships and humanity in mental health systems and practice, again something which is often 'undiscussable' in certain published contexts, especially if the discussion is led by a service user or survivor researcher. So, Works 3, 14, 15, 21 and even 20 are attempts to address topics and experiences which some publications do not have the capacity to discuss. Their appearance as chapters in edited books attests to the importance of having supportive academic allies or senior user researcher mentors who can provide opportunities to publish subject matter that might be 'undiscussable' in other arenas. I have found the support of academics who champion such work and value the contribution of service user perspectives to mental health education, practice and policy vital for my development as a researcher and writer who is confident to speak out and use my own experiences to form a critique of research and practice.

Bar-On's 'undiscussable' relates to his 'indescribable' for people trying to write about direct experience of mental distress, psychiatric treatment, trauma and recovery, but as he argues, they remain distinct. As described above, my written attempts to discuss the 'undiscussable' have been published as book chapters or journal articles commissioned by academic allies and would not have appeared as papers in the type of high ranking peer reviewed journals that influence mainstream evidence and practice in psychiatry. Added to these are the works in which I struggle with the 'indescribable' nature of madness and recovery. If I reflect on how my own understanding of what could be called 'epistemologies of madness' has developed, I can see where Bar-On's theory about 'impediments to human discourse' has influenced my struggle as a self-reflexive researcher informed by direct experience. In this discourse how do we determine who decides what is 'indescribable'? I believe that some experiences cannot be described by people who have not had that experience, no matter their expertise in research or theory. Someone who has experienced extreme mental states and subsequent recovery should be seen as a source of unique insight into emotional distress and altered states because they are closest to the event or experience which is deemed to be 'indescribable'. As Beresford argues: 'Experience is about being as well as happening' (Beresford 2003 p27) and people with mental health problems have internal, uniquely isolating experiences of distress as well as experiences of external conditions and situations relating to their mental health (such as the psychiatric system and its treatments or the associated stigma). This may then make us: 'Subjects whose inner worlds cannot be understood without knowledge of their experiences in the world, and whose experiences of the world cannot be understood without knowledge of the way in which their inner worlds allow them to experience the outer world' (Hollway & Jefferson 2004 quoted in Frost & Hoggett 2008 p440). When confronting the task of describing the ineffable I felt as though I was coming up against the limits of the expression of knowledge provided by conventional research or academic arenas. Having gone through the psychiatric system I had had the 'indescribable' functionally interpreted for me by doctors using clinical symptom descriptors and diagnostic classification. Beresford and Wallcraft have argued that this psychiatric framework can limit people's ability and opportunity to describe and understand their experiences on their own terms, arguing that the psychiatric system 'is...likely to be the only analytical framework with which they are familiar for understanding their situation, feelings and perceptions' (Beresford & Wallcraft 1997 p72). As part of my later recovery I used research and writing from outside this framework to try to

describe some of the ineffable ('indescribable') experiences of madness, the psychiatric system and recovery.

Initially, I had to use the non-verbal film image and music to interpret my experiences as part of my recovery before I could attempt to describe them in words. I have described one such act of translation in Work 4, where I discuss how a certain film helped me come to terms with some of the more existential aspects of the acute episode of mental distress I was recovering from. I translate these feelings by referring to scenes in the film, some of the dialogue and draw on my background in theology to help with interpreting what happens in the film alongside what has happened to me. By exploring a narrative, images and ideas with which I identify, I make an attempt to tackle 'indescribable' internal states. Similarly, Work 5 is an effort to describe the effect of the external environment of a locked psychiatric ward on my self-perception. Based on my discovery that there were no reflective surfaces on my ward, I use the mirror as a literal and metaphorical device to piece together a personal account of incarceration, fragmentation and dissociation, an experience which I found 'indescribable' in words during the early stages of my recovery. In these two works I use my analytical skills to understand, interpret and eventually describe some personal experiences of extreme mental states. The investigation of my own trauma has been the most challenging research project I have undertaken. There was no pre-determined methodology and I had to look beyond conventional written forms to find adequate reference points. But the task was also therapeutic in the way Sweeney describes above (Sweeney 2009), including the idea that research is discovery – in this particular instance, self-discovery. These two works are published in an edited book which had the capacity to contain such accounts, which were not deemed 'indiscussable', but were seen by the editors as insights into living through and recovering from severe mental distress. However, their power to address Bar-On's 'impediments to discourse' remains limited. This is because such attempts by people with mental health problems to articulate the 'indescribable' are often seen as 'undiscussable' in mainstream publications influential to psychiatric practice and approaches to the treatment and management of mental health problems. As a critical user of mental health services and a researcher I sometimes perceive myself as not only having a 'double identity' (Rose 2003) but almost a double life in print determined by the capacity of publications to include service user voices and insights.

## **Theme 2: Identity**

As suggested above, there is a sub section of works that do not appear on my official, professional research CV. Their value as 'legitimate' knowledge about mental health and service use is contested by mainstream research and clinical evidence makers and their processes. However, these works when positioned alongside or combined with the 'formally approved' research (i.e. that published in peer-reviewed journals and official reports) I have done, demonstrate an additional dimension to the development of my practice and identity as a researcher. It could be said that as a researcher I have an official published self and a hidden published self as well as a 'double identity' at work. Therefore, self and identity as partly determined by experience is important to the discussion of my personal development as a researcher. Research plays an important role in the construction, exploration and articulation of this identity. Under this theme I discuss how my multiple identities

have influenced my research practice and investigations well as the development of my identity as a researcher. This entails brief explorations of stigma, mental health and sexual orientation and how these have impacted on my knowledge production activity.

Firstly, I have used research and writing as a way of exploring and managing the various aspects of social stigma which relate to my mental health and sexual orientation. The relationship between social stigma, the construction of personal identity and how stigmatised people operate in the world was comprehensively explored by Irving Goffman in his book '*Stigma: Notes on the Management of Spoiled Identity*' (Goffman 1990). Although I recognise that there are other theories on identity formation from the disciplines of social psychology and anthropology (Mead 1967, Tajfel 2010, Turner 1988), Goffman's sociological work has had a great influence on my understanding and development as a person and as a researcher because his arguments on, and case examples of, stigmatisation make sense to me. Goffman's theories have helped me to theorise and understand my own identity and behaviour. For example, I use his theories in Works 3 and 21 when I discuss the inter-relationship between having both a stigmatised sexual orientation and psychiatric status. Frost and Hoggett (2008) sum up Goffman's theories of the subjective experience of social hurt and its impact on personal identity in this way:

'the experience of the individual who cannot produce the "normal" social identity required, and is aware that they do not come up to standard, is that of being discredited, of a personal failure to pass. Because the opinion formed by those making judgments does not stop at presentation, but makes moral judgements and imputes certain characteristics, the discrediting of the person impinges on the whole identity' (Frost & Hoggett 2008 p445).

This analysis of Goffman allows a link back to some other aspects of my personal development and identity as a researcher already discussed: perceptions of capacity, legitimacy and marginalisation. Partly because of the effects of stigma, I live with an unstable perception of my own intellectual capacity and professional worth. But to some degree, all my research activity is a response and challenge to this perception of a 'personal failure to pass' and the 'spoiled identity' that results. Here, another element of Goffman's theory of how a person manages stigma relates to information control and personal identity has been useful for my thinking. Regarding my view that as a researcher I lead a double life in print, with a commitment to discussing and interpreting hidden or marginalised knowledge and experience, I have found Goffman's thoughts on information management and the 'discredited and discreditable' enlightening for my development: 'Norms regarding the *personal* identity, however, pertain not to ranges of permissible combinations of social attributes but rather to the kind of information control the individual can appropriately exert. For the individual to have had what is called a shady past is an issue regarding his social identity; the way he handles information about this past is a question of personal identification' (Goffman 1990 p82). During my personal development as a researcher, where appropriate I have disclosed my standpoint or experience, thereby taking positive control of the management of information about me or 'my kind'. My eventual identification as a mental health service user/survivor researcher can be partly explained by this idea of personal identification and information control.

What is research if not some kind of information control? Survivor researcher Russo describes her understanding of research as empowering activity, where she controls information: 'Working as a researcher ideally means taking observation, measurement and interpretation into my own hands' (Russo 2009 p174). Works 1 and 3 could be seen as the public 'coming out' stage of my research life. In Work 1 I disclose my mental health problems and their impact on my professional life alongside exploring what disability means for me and could do for others with mental health problems. In Work 3 I openly disclose my sexual orientation and mental health status in order to explore some of the wider issues facing lesbian, gay and bisexual people who have mental health problems. It has been argued that 'people can also be distanced from their experience by being encouraged to fear and reject it. For many years this is what has happened to gay men, lesbians and bisexuals' (Beresford 2003 p44) and Work 3 was written as a personal response to my experience of being present at discussions about equality and diversity where no one ever mentioned sexual orientation as an issue (Work 8 is a further and wider investigation of this observation). I felt that I was in a unique position to address this situation and the experience acted as a catalyst for my acceptance of my own personal experience, particularly as knowledge that has potential value. This example also shows how some of my research activity is about challenging stigma (internal and external), becoming visible and controlling information.

In Works 1, 3, 8, 14, 15, 20 and 21, using my personal experience blended with theory, research, historical and other personal accounts, I have tried to challenge or reclaim and reinterpret some of the decisions that have been made about people with mental health problems and/or people who are lesbian, gay or bisexual by those who do not share our identity, stigma or experiences. Here my personal development as a researcher becomes complex because of the other relationships I have to research: personally as a research subject; as someone with an orientation and behaviour which has historically been the subject of 'objective' research investigations and discourse; and as someone whose treatment by society and by social care and mental health services has been historically determined influenced by either the legacy of that research or unexamined myths and prejudices. In short, I got fed up with other people saying who, why and how I am without a right to reply. From researching psychiatric history I also knew how damaging this could be. As Russo maintains, 'like individual psychiatrists, clinical researchers ask the wrong questions that lead them to wrong, irrelevant or damaging conclusions. They are often incapable of reaching the realities of their subjects' (Russo 2009 p173). So I decided to use my research and analysis skills to provide myself and others with alternative perspectives and possibly new knowledge. The supposedly objective 'who are you?' research questions of others became the essentially subjective 'who am I?' questions for me to investigate. After all, I saw myself as 'living the hypothesis' (Straughan 2009 p 108). So, I have also come to understand research as being about personal empowerment as well as academic advancement. Research for papers and chapters like Works 1, 3 and 21 gave me greater degrees of insight into my own situation and the chance to explore alternative ways of understanding and managing it.

Like other service mental health service user/survivor researchers, for me discovery is an important part of the research process; this isn't just about the objective

discovery of new 'facts' but the discovery of new knowledge, which in my case included historical knowledge about how LGB(T) people have been treated in the psychiatric system (as demonstrated in Works 3 and 21). Such research activity has been important for the development of both my research and personal identity. Essien, a black woman mental health survivor researcher, recalls how one of the black women she is interviewing identifies with her: 'we are from the same place, the same blood' (Essien 2009 p66). If, like me, you are gay or have mental health problems or are gay with mental health problems, you do not necessarily enjoy this depth of immediate physical or ancestral association with others to help form or protect your identity (as I argue in Works 3, 17, 20 and 21). We do not have blood and place ancestry and we cannot trace our origins to a race, country or continent, but what we can do, along with black people, disabled people and other marginalised peoples, is build 'a dynamic and developing source of experiential knowledge' (Beresford 2003 p39) to share. For example, LGB people have been subject to social myth and psychiatric experiment, but we can also 'come out' to challenge those myths and have a history of the use of self as counter evidence in our civil and health rights campaigning: 'User controlled research has an important role to play here, pulling together 'user knowledge' in a systematic way. In this way, groups can develop their own discourses, to set next to, and sometimes challenge, prevailing views and understandings' (Beresford 2003 p39).

### **Theme 3: Solidarity**

Essien writes that: 'Identity is important for mental health, as it bestows upon the bearer a sense of belonging with others who share similar experiences' (Essien 2009 p63). Under this theme of 'solidarity' I explore how identifying with researchers, theorists and activists has helped my development as a researcher, how an understanding of collaboration and collective approaches to knowledge building have influenced my research identity and activity and my feelings of responsibility affect my research work. In chapter 3 I discuss some of the methodologies I have used which are influenced by emancipatory and feminist approaches and explore how my work relates to the collective knowledge production activity of new social movements. Because of my identity, association and understanding that research can be 'activism', I have made pragmatic use of some of the interpretive methods and theories of the disability, psychiatric survivor, service user and LGB(T) rights or 'new social' movements.

In Work 7 I say that: 'I did not start out identifying as a survivor researcher, but through my work I have met with many remarkable survivors who have enlightened and inspired me. I have been very fortunate in this respect. One of the things I feel strongly about psychiatry, and indeed academe, is that they strive to keep us from each other'. I now have a research identity and access to knowledge and methodologies I didn't know I could have until I met with people who identified as service user or survivor researchers. Through their example and ideas I have come to an understanding of research as activism and the know importance of collective knowledge. I realise I share with others a political, personal and emotional drive to interpret and communicate experience. This brings an extra dimension to our motivation as researchers because our investigations are often about 'being rather than observing'. In this way I would argue that I am not just a subject expert or part of a group of people with a special research interest (this argument has been used

as a challenge to my research activity on LGB issues) – but with people who have similar identities or experiences who discuss the ‘undiscussable’ and who may have experienced the ‘indescribable’. For me as a researcher identifying with and being part of a group of people who share similar experiences and values has helped me feel less isolated in my own position and has allowed me to recognise mental health service user and survivor research activity as the means of transitioning knowledge from the individual to the collective. Research and writing can be individual and solitary but when it is published or disseminated it can become part of collective knowledge for others to draw on and add to. In this way it can make a small social contribution to the alleviation of isolation and a feeling of solidarity, as perhaps demonstrated by an email I received in response to Work 8, in which the correspondent wrote: ‘I read your paper on sexuality and religion a couple of years ago, and I must say parts of it really had me nodding as if I’d contributed to it myself. It affirmed so much of my own experience as a social work student, as a past service user, and I suppose as a citizen’ (Tom, personal correspondence, 2011). As Beresford has argued:

‘...it is possible to move from individual to collective knowledge. We can share our experience with others and relate our different interpretations and understandings of experience to each other. In this way, it becomes possible to develop knowledge which synthesises people’s understandings and perspectives on their common (and varied) experience’ (Beresford 2003 p39).

I was fortunate to have begun my research career at a time when service user and survivor research was gaining a profile. I found myself in professional situations where I encountered researchers who became influential role models who shaped my research identity and activity. They also deepened my awareness of participation, methodology, epistemology and power dynamics in research. Of particular importance to me were mental health service user and survivor researchers who enabled me to rethink my perception of my intellectual capacity and realise that my experiential knowledge could have some value for the mental health and social care evidence-base. Referring back to my reflections on the effects of my construction as a ‘welfare subject’ as well as a researcher, Frost and Hoggett emphasise that ‘the new social movements...offer a fundamental critique of the human subject of classical liberalism’ (Frost & Hoggett 2008 p439). My exposure to the social model of disability (UPIAS 1975) was significant for my development as a researcher, as it gave me an entirely new way to understand my own situation as well as an empowering research paradigm, elements of which are transferable to the situation of other marginalised people. For example, in Work 1 I use the social model of disability as a framework for analysing my personal experience and research and policy on understanding mental health as disability for the workplace. Later through the work of Beresford and Wallcraft I learned about the ‘social model of madness and distress’ located ‘within the framework of the social model of disability’ (Beresford & Wallcraft 1997; Beresford et al 2010), which I used to analyse LGB experiences of mental health and psychiatric services, particularly the construction of ‘homosexuality’ as pathology. In doing so, my historical research led me to discover and draw together disparate knowledge about LGB experiences of the psychiatric system (particularly in Works 3 and 21). Through this research I discovered that my experience in the psychiatric system was part of an historical continuum; I felt solidarity with those who had gone before me (a 2004 study by Smith, Bartlett and

King entitled *Treatments of homosexuality in Britain since the 1950s—an oral history: the experience of patients* as well as a later 2009 study by the same authors called *The response of mental health professionals to clients seeking help to change or redirect same-sex sexual orientation*, were very influential here) and recognised the need to use my research, writing and publication activity to try and effect change. This appears to be important to a lot of researchers who have had experience of mental distress and/or the psychiatric system: ‘In these pioneering days of researching from a service user standpoint, a standpoint that is theoretically at the heart of mental health services, those who have the skills and tools and the lived experience, as well as insight into the meaning and value attached to that lived experience, have the chance to engender real change’ (Straughan 2009 p118).

Finally, I see my individual development as a researcher in a broader context of my activity within what could be termed a ‘movement’ or at least as something which has a distinct value-base and purpose – to reiterate a quote used in chapter 3: ‘always keeping in mind that the ‘moment of truth’ lies in the quality of the user’s experience of the service’ (Edwards 2002 p13). My standpoint position has influenced the research work I have done for SCIE, particularly the research and policy analysis I have undertaken on service user participation and the personalisation reforms in adult social care and mental health. With my ‘dual identity’, I am in a particular position from which to provide a critical overview of personalisation reforms. My standpoint and the effect of my solidarity with service users could bias my work, but the work published by SCIE undergoes a peer review and quality assurance process and the organisation has a commitment to supporting user perspectives and improving user experiences of services. My investigations for Works 18 and 19 maintained a focus on the service user’s experience and outcomes, not only in line with my own personal and research values, but in accordance of the stated aims of the personalisation reform policy. Recalling my early experiences of clinical research reviewing and realisation that questions which are important to service users are not often the ones that are asked, for Works such as 18 and 19 I included and examined evidence to answer questions that users were asking and used knowledge sources that service users would value or have produced themselves.

## **Conclusion**

During my development as a researcher, my personal experiences and identity have influenced my standpoint epistemology, the types of methodology I use and many of the topics and ideas investigated as part of my extra-curricular research activity. The discussion under the three themes which structure this chapter suggest the body of knowledge I have built up in the public domain as published works has both an individual (personal) and collective function. I have used research to interpret my own experiences and understand how they relate to the experience of others and to research evidence. By developing this approach I have also formed a standpoint from which to critique or inform social care and mental health policy and research.

As discussed in chapter 3, reflexivity, emancipation and the use of disclosure and personal narrative are central to my methodological approach. This choice of methodology is strongly influenced by the innate reflexivity I have developed as part of managing my identity, self-concept and stigma in everyday life, including work. I

am conscious that this type of reflexivity and emancipatory purpose is inherent in my research processes, particularly in interpretation and analysis.

Having a dual identity (as a researcher and a mental health service user/survivor) impacts both on my self-concept as a researcher and on my experiences within the research community and mental health and social care system. This results in a tension because how I am treated in the mental health and social care system interacts or even conflicts with my knowledge and status as a researcher. I am aware that my knowledge, both 'professional' research and experiential, have no currency when I become a 'service user' or 'research subject', both of which involve significant loss of power and agency. This tension is present in my professional psychological construct and inevitably influences my work as a researcher. I feel that my own situation is reflected in Lewis' description of the institutional and psychological complexities associated with mental health service user and survivor participation:

'There was a struggle for recognition of power operating within ostensibly benign, helping relations and institutions and of the effects of this for the service users involved, a form of political resistance dependent on moral insight into injustice and of 'imaginative agency' which afforded self-respect and self-esteem' (Lewis 2009 p266).

## **Chapter 5: Final synthesis and contribution to the field of social care and mental health**

### **Introduction**

In this concluding chapter, I present the core arguments that unify the themes and concepts arising from the submitted works and the synthesis which makes them a coherent, unique body of work. In order to further illustrate the distinctive contribution, I briefly outline how the submitted works use particular approaches to evidence assessment, knowledge production and epistemology. This includes a summary of the key points in chapters 3 and 4 about the use of particular epistemological perspectives and research methodologies. Therefore this chapter also shows how the knowledge for this PhD by Public Works was produced and how it makes a contribution to the broader sphere of social care and mental health research methodology and service user epistemology.

### **The contribution of the methodological and epistemological approaches**

This PhD by Public Works context statement gives an account of the methodologies used and an examination of my development as a researcher which includes reflections on my epistemological standpoint as someone who identifies as a mental health service user/survivor researcher (chapters 3 and 4, respectively). Chapter 3 explains a particular value-based methodological design I have used for reviewing research and policy which I call 'standpoint analysis and interpretation'. This fuses my own personal experience and narrative with wider research and practice accounts and I situate this approach within the 'emancipatory' research paradigm (Barnes & Mercer 1997). Chapter 4 reviews my research development and details my particular epistemological stance arising from the way I interpret and manage my research career and identity, mental health and self-concept. It presents the main ways in which I have sought to understand and navigate environments where I have found myself marginalised or silenced, and explores how I have articulated and interpreted this experience using research and critical analysis. Much of this understanding and articulation is gained through the reflective writing and research investigations included in the submitted works, which then add to collective service user knowledge (Beresford 2003).

My standpoint and experiential (or 'situated') knowledge means that I am able to examine and interpret social care and mental health policy from a service user perspective. As noted in the introductory section, my exploration and critique is 'perspectival' and therefore I cannot make 'positivistic' claims to objectivity and truth for my work, but rather produce a 'composite position' using experiential knowledge to analyse research and policy (Alvesson & Skoldberg 2009). Specifically, my perspective is that of a person who has additional experience of particular social stigma relating to sexual orientation and mental health status. From this position, I argue that it is not just the personalisation policy or its implementation that need examining, but the very way in which it has been constructed should be called into question. My critique of mental health and social care administrative systems and processes is based on research evidence, but it is also informed by the fact the I have been personally subject to these systems, which gives me a particular critical perspective and an awareness of the politics of knowledge production. Similarly, my

experience as a research subject has influenced the reflexive approach I take in my own research work. I would therefore argue that this PhD by Public Works constitutes new knowledge for social care and mental health because of the way the knowledge has been produced, specifically the LGB standpoint exploration of psychiatry and mental health and the critiques of service user participation and the personalisation policy in adult social care and mental health. For many of the submitted works the explicit authorial standpoint and perspective brings new insights and contributes to different ways of analysing research, policy and practice.

### **Final synthesis: core arguments from the collected body of work**

This PhD by Public Works has demonstrated that three key topic areas with particular themes emerge from a systematic analysis of the submitted works. Chapter 2 details the topics and themes as: The personalisation policy agenda in adult social care and mental health; Service user participation; and LGB (T) service user experience. This final synthesis brings together these three topics and associated themes as a coherent critique of how the personalisation policy has been constructed and implemented. It examines the way in which this reflects some of the broader political, operational and systemic barriers to service user participation, the use of experiential knowledge and evidence and the recognition of the full diversity and complexity of people who use mental health and social care services. My argument is also supported by reference to several selected theories and evidence sources.

#### *Power, politics and participation*

In order to place the relevant submitted works in the wider literature, chapter 2 has already defined some of the origins and referenced some key critiques of the personalisation agenda for adult social care. I contend that personalisation in adult social care and mental health is a policy constructed within the 'rational' professional consensus making paradigm, as explored in Work 6. The subjugation of difference and dissent ('politics and passions') in the interests of creating a rational consensus without engaging in tensions and complexities, is a theory originating with Mouffe (Mouffe 2002) and applied in the analysis of service user participation strategies in adult social care in Work 6 which in turn drew on evidence from Work 2. Here I argue that participation forums designed by professionals and services require service users to behave and contribute in certain ways, which often exclude the discussion of certain topics or de-legitimise the politicised understandings, emotional expression and personal experience of service users. This tendency can be viewed as a form of conflict avoidance for the purposes of professionally-determined rational consensus making and, as Works 2 and 8 argue, this limits the capacity of participation and diversity strategies to accommodate complexity and difference. As a consequence they can restrict the impact service users have on change. As detailed in chapter 2, this argument is supported by the wider literature, confirmed by authors coming from different perspectives and using different theoretical analyses. Work 8 extrapolates this concept further to analyse some of the emerging dynamics within social care and local authority diversity strategies which appear to be marginalising the voices and interests of people from LGB(T) communities in the interests of creating a 'consensus' which could accommodate the perspectives of so-called 'faith communities'. It is in this work that the critique of the construction of central

government policy (in the case of Work 8 it is the proposed 'single equalities' agenda) and its implementation through local authority, adult social care and mental health service organisational structures and administrative processes begins to cohere.

*Diversity, humanity and administrative reductionism*

A core argument across the works in all three themes and in the literature reviewed for chapter 2 on both service user participation and LGB (T) service user experiences concerns how organisational structures and administrative processes in adult social care and mental health can mitigate against the type of relationship-based working, person-centred support and self-determination valued by service users and evidenced as effective for personalisation. My argument is supported by Finkelstein's theories about intervention and his 'administrative model of disability:

'In my view administrative approaches dominate all forms of helping services for disabled people in the UK, whether these are provided by statutory agencies or voluntary bodies, or demanded by pressure group organisations. The cure or care forms of intervention are administered within the rehabilitation and personal-care services respectively' (Finkelstein 1993 p.37)

My concept of 'administrative reductionism' is demonstrated in Works 16, 17 and 18 for people from LGB (T) communities who use social care and mental health services, and who are subject to forms of categorisation which do not reflect their full complexity (or 'multiple identities') and often require them to behave or identify 'correctly' in order to be administered (for example in psychiatric or needs assessments or in self directed support planning). In-depth analyses of how the psychiatric system can work in this way are presented in Works 3 and 21, which are a fusion of personal experiential and research knowledge. My arguments in Work 8 focus on how participation processes and equality strategies have worked in a way that create hierarchies and competitive situations between religion and belief and sexual orientation. In Work 8 I use evidence to argue that an administrative (and forced rational professional consensus) approach to equality and participation has served to provoke further tensions between those with strong religious beliefs about homosexuality and sin and LGB (T) people in the context of implementing a 'single equalities' framework for social care and mental health. My view is that technical administrative systems which operate to over-simplify complexity and suppress difference or dissent (either in service user participation strategies or in individual care planning) are inherently incapable of producing the conditions in which people who use services can collectively participate or define their individual needs and determine their own support. Again, as Finkelstein has argued in the case of disabled people: 'what is important is not *which* profession is dominant but that disabled people are marginalised in their own affairs as *others* administer to their needs on their behalf because, one way or another, disabled people are regarded as incapable of doing this comprehensively for themselves' (Finkelstein 1996 p9). This therefore poses a potential problem for the practical realisation of some of the theoretical ideals of the personalisation policy agenda, such as co-production, person-centred support and self-direction.

A key criticism of personalisation, particularly the principal mechanism of personal budgets, was that for a policy requiring fundamental change, it lacks a robust evidence base (Cutler, Waine & Brehony 2007; Beresford 2009a; Glasby & Littlechild 2009). Practitioners are concerned about how to balance empowerment with duty of care and the general risk implications of personal budgets and self directed support, something which had not been considered in detail at policy level. Works 10, 11, 18 and 19 provide some of this research and practice evidence, much of which further elucidates the need to move away from a concentration on administrative process to a renewed focus on the quality of the service user and practitioner relationships at the front line (this is particularly evidenced for risk management, safeguarding and self directed support in Work 18). The evidence examined for the research reviews and evidence overviews which form part of the submitted body of work suggest the need to attend to the human dimension as well as the technical processes of adult social care and mental health, such as communication, trusted relationships and practitioners who are capable of respectful understanding of an individual's life history, circumstances and preferences. These findings already reflect what service users have indicated is most important to and effective for them (Shaping Our Lives 2003; Turner et al 2003; Beresford et al 2008; Glynn et al 2008; Beresford & Hasler 2009; Beresford et al 2011). The findings also relate back to the arguments in Works 8, 16, 17 and 20 about the restrictive or oppressive nature of categorisation and administrative processes for people using social care and mental health services. In addition, the evidence provided by these works supports my argument about the need to recognise difference and work with complexity, with LGB (T) people being the particular example. Such administrative reductionism may then challenge some of the discernable ideal aims of the personalisation agenda.

### *Personalisation, participation and policy construction*

When it first appeared, the adult social care personalisation policy seemed to assume that there was a universal understanding of the policy terminology, meaning and aims, which included a rhetorical commitment to 'empowerment', 'co-production' and 'choice and control' (HM Government 2007). Critics and observers now largely agree that as a policy discourse, personalisation is imprecise, ambiguous and contains certain internal inconsistencies and tensions (Cutler, Wayne & Brehony 2007; Beresford 2009b; Needham 2011), particularly as regards the conceptualisation, design and operation of the personal budget scheme in England (Boxall et al 2009; Audit Commission 2010; National Audit Office 2011). As suggested in chapter 2, the policy implications initially required independent analysis and clarification for adult social care stakeholders, something that Work 9 provides. This work also sought to provide a coherent policy narrative which included some of the perspectives that were absent from the dominant discourse, led by Charles Leadbeater, the think tank Demos and the provider charity In Control (as outlined in chapter 2). Work 9 (and Work 12) therefore reinstated the contribution of the service user and Independent Living movements (where direct payments originated), and examined some of the implications for social work practice and user-led organisations.

Personalisation was announced as being the main concept for driving the 'transformation' of adult social care services. The Putting People First concordat was clear that this would happen by putting 'citizens at the heart of a reformed system'

(HM Government 2007 p1) and argued that 'real change will only be achieved through the participation of users and carers at every stage' (ibid p2). However, I would argue that one of the problems for implementing personalisation in adult social care stems from the fact that the policy and underpinning theories themselves were constructed precisely *without* the participation of service users and carers. It appears that service users did not make a direct contribution to the original policy problem formulation and so could not influence the proposed solutions, but were instead asked to participate in the implementation of those solutions, the main one being personal budgets (Beresford 2009a & 2009b; Boxall et al 2009). Instead, those defining how the personalisation policy should work for adult social care borrowed direct payments from the service user movement, but the origins were unacknowledged and direct payments were removed from their value-base (the social model of disability and independent living [UPIAS 1975]) and political context to become a universal personalisation mechanism in the form of personal budgets (Beresford 2009b; Boxall et al 2009). Service user experiential knowledge, evidence and theories did not appear to inform Leadbeater's original conceptualisation of the free, active and enterprising 'consumer-citizen' whose purchasing power would eventually have a positive effect of public service provision in a 'bottom-up' approach to adult social care 'transformation' in the context of decentralisation and marketisation (Leadbeater 1988; 1991 & 2004; Ferguson 2007; Scourfield 2007; Leadbeater et al 2008; See also chapter 2). Leadbeater's original personalisation model also implies that central government does not need to play a central role in ensuring equity and policy coherence (evidenced as being important for personal budget schemes in Work 10), as discussed in chapter 2, it also resulted in some internal contradictions for the personalisation policy in terms of consumerism and citizenship.

Some service user experiences of restrictive or oppressive adult social care and mental health systems and administrative processes (such as assessment) would stand in direct contradiction to Leadbeater's assertion that through personalisation the '[consumer ] engagement with a public service should deepen a sense of civic attachment and underpin a sense of citizenship' (Leadbeater 2004 p54). It is questionable whether this generalised idea of what a public service is easily applies to adult social care. Many service users argue that current system configurations, eligibility criteria and processes can actively prevent them from exercising their 'citizenship' and do not accord them the consumer power of 'voice and exit' (Morris 2004; Morris 2005; Rummery 2006; Flint 2009). Nor do they easily provide the conditions for collective (citizen) as well as individual (consumer) action (Scourfield 2007), again a critical dimension for user-led organisations responsible for providing support for direct payment holders (DH 2008a, Davey et al 2007; Ipsos MORI 2011). Finally, Finkelstein's theories about 'restricted citizenship' can be used to expose a disablist conceptualisation of citizenship in the original proposals for public service personalisation:

'The 'restricted citizen' model starts with the positive view that disabled people have no intrinsic impediment to their independent rights. In this model disabled people's citizenship rights are restricted by the environmental and social barriers that have evolved over the centuries as people with abilities moulded and adapted the world according to their own idealised *normal* attributes... *Interventions*, then, are aimed at controlling the way disabled

people enter or conform to the needs of the market created by people with abilities' (Finkelstein 1996 p11).

I would therefore argue that, despite personalisation policy claims to 'transform' adult social care, administrative structures and procedures are being maintained because their history and impact has not been properly understood by policy makers. Such understanding comes from using or working at the frontline of adult social care and mental health services and I suggest that this understanding constitutes the experiential knowledge about humanity, relationships, difference and complexity that becomes marginalised. As Barnes and Mercer have argued, disability research from a social model perspective can undermine 'the notion of a homogenous category of "privileged" knowers [non-disabled professionals] and turn[s] the spotlight on competing discourses, voices and experiences within the disabled population' (Barnes & Mercer 2006 p55). This raises familiar questions about how and when experiential knowledge is valued and how power dynamics and the desire for 'rational consensus' can determine the way in which service user participation strategies operate and impact.

## **Conclusion**

From the analysis of the adult social care and mental health personalisation policy and associated evidence presented here, my view is that central government social policy making arenas are not permitted spaces for service users to bring their experiential expertise, even when the policies directly borrow from their movement and will have consequences for their lives. Even in his most radical conception of personalisation, Leadbeater preserves the power of the professional in making macro-scale decisions about public service reform: 'the professionals are designing environments, networks and platforms through which people can together devise their own solutions' (Leadbeater 2004 p24). So it appears that the original personalisation policy concept explicitly maintains established systemic power relations and excludes service users from participating at the highest strategic level.

In chapter 2 I outline how the concept of co-production has been paradoxically determined by policy think tanks without the involvement of people who use services – and yet it is those very people who are recast in co-production discourse as experts. It is my view that in policy making processes resulting in the adult social care and mental health personalisation agenda, the value of service user experiential knowledge has been contested, marginalised or ignored in the same way as it has historically been in health and social care research and service development. I would even argue that beliefs about the legitimacy of certain types of knowledge in research also exist for policy making: experience is subjective, emotional and unreliable, while theory is objective, rational and reliable (even if, in the case of personalisation, it has not been subject to robust testing or underpinned by a compelling evidence base). As Lewis notes in her study on mental health service user participation from a human rights perspective: 'the accounts of statutory sector service providers tended to infantilise and patronise service users, constructing them in dialectical opposition to their own more 'mature' and 'reasonable' stance' (Lewis 2009 p 265). Work 14, a discussion of leadership in mental health from a service user perspective, explores the consequences of maintaining this dichotomy for human relations in service systems. I argue that 'leaders in services should have

human and emotional skills because their decisions have human and emotional consequences...User experience is [therefore] valuable for leadership' (Work 14, p20). But, as Cook has argued in a paper on engaging users and communities in the policy process: 'while government does indeed "talk the talk" on consultation, it has yet to "walk the walk". If the objects of social policy – service users, the poor, powerless and disaffected – were to find their voice, the talk itself may become unpalatable' (Cook 2002 p529). This brings my argument back to the original idea that service user participation strategies and discourses determined by professionals or their organisations rarely have the capacity to accommodate complexity and difference and as a consequence marginalise those who are conceived as 'difficult' (such as people with mental health problems and/or LGB (T) people) for the purposes of forcing 'rational' consensus. This then limits the impact service users and experiential knowledge can have on change, at the level of national policy, at the frontline and, most crucially, in their own lives.

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