

2013

# Personal Budgets for all? An Action Research Study on Implementing Self-Directed Support in Mental Health Services

Hitchen, Sherrie

<http://hdl.handle.net/10026.1/1529>

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<http://dx.doi.org/10.24382/3742>

University of Plymouth

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**PERSONAL BUDGETS FOR ALL? AN ACTION RESEARCH  
STUDY ON IMPLEMENTING SELF- DIRECTED SUPPORT IN  
MENTAL HEALTH SERVICES**

**by**

**SHERRIE HITCHEN**

A thesis submitted to the University of Plymouth in partial fulfilment  
for the degree of

**DOCTOR OF PHILOSOPHY**

Faculty of Health, Education and Society

**OCTOBER 2012**

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## Abstract

# Personal budgets for all? An action research study on implementing Self-Directed Support in mental health services

Sherrie Hitchen

### Background

The recent political agenda for health and social care requires more client-centred, personalised services. Self-Directed Support, encompassing Direct Payments and Personal Budgets, is designed to provide people with more choice and control over how their needs and outcomes are met. Personal budgets are available for eligible people however take-up is low in mental health services.

### Research Aims

The study was set in an NHS Health and Social care Trust covering a large predominantly rural area. The aims of this study were: (1) to develop Self-Directed Support within one mental health Trust and; (2) understand more fully service user and carer involvement in the process.

### Methods

This study used action research incorporating: a spiral methodological framework; a project steering group; and service user and carer co-researchers. Data collection took place between 2007 and 2011, and the project ran in three sequential spirals using qualitative methods to triangulate the findings and identify any divergence in data.

### Findings

Findings showed that organisational language, structures and power relations provide barriers to effective involvement of service users and carers. Action research is very relevant for researching projects involving transformational change in health and social care, and including service user and carer co-researchers adds rich and authentic data.

Findings concerning Self-Directed Support concluded that it afforded people more choice, flexibility and control than previous policy, and an improved quality of life. Concerns about bureaucratic processes, lack of information and knowledge of Self-Directed Support were found. Workforce concerns about safety of service users under Self-Directed Support and cultural shifts to more democratic methods of working were reported.

### Conclusions

This study's results correspond closely with national studies: staff attitudes and culture need changing to empower people to take up Self-directed Support. Concerns about quality assurance and safety are prevalent. Mental health services pose additional obstacles in their structures and reliance on the medical model. Social care knowledge cannot be assumed for all mental health Trust practitioners.

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## **List of abbreviations used in this thesis**

AR      Action research

DH      Department of Health

## **Authors Note**

The term Personal Budget is used throughout this thesis to refer to Personal Budgets including Direct Payments. References to Direct Payments apply to Direct Payments only, excluding wider reference to Personal Budgets.

## **ACKNOWLEDGEMENTS**

I would like to sincerely thank and acknowledge my appreciation of the enormous support of Professor Mary Watkins and Dr Graham Williamson without whom I would not have completed this thesis. As a part-time student with many competing priorities their enduring encouragement and perseverant approach enabled me to make the journey to completion. Mary Smith, my Trust Librarian has also been invaluable with her patient help in obtaining books and articles for this study. I would also like to thank Graeme Barnell and Ralph Hayward, my former Trust managers, for enabling me to begin this project and their interest and encouragement in my research. Further thanks and gratitude are extended to my co-researchers who enlivened this action research study with their enthusiastic approach and sharing of perceptions and feelings at all stages of the project. I would also like to acknowledge and thank all of those people who contributed to the steering group and the focus groups and took the trouble to be part of this study. Finally I would like to thank all the members of my Trust social care team who have been supportive throughout the four years of this study and whom I can rely on unreservedly for encouragement and positive feedback.



**DECLARATION**

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Graduate Committee.

Devon Partnership NHS Trust financed this study.

During the course of this study relevant postgraduate courses were attended to gain research and transferable skills and I was awarded the Postgraduate Certificate in Clinical Research from the University of Plymouth. Relevant conferences and seminars were attended at which this work was presented at various stages of development. These are reported in the Peninsula Postgraduate Health Institute (PPHI), Annual Research Events Abstracts books.

Signed.....

Dated.....

Word Count of the main body of thesis: 89,096

## **CHAPTER ONE: INTRODUCTION**

### **1.1 Setting the scene**

In this introductory chapter the national and local context of the research is discussed including my personal motivation to undertake this study using an action research (AR) methodology. The study's aim, design, methodology, methods of data collection and analysis is explained. Finally the thesis structure to be found in the following chapters is outlined.

This AR study investigates the implementation of Self-Directed Support in one mental health Trust. My work role focussed on implementing Self-Directed Support in order to provide people with mental health problems needing social care resources, with personalised care and support in the form of Personal Budgets. I was very interested in finding out whether this approach would enable people needing social care support to gain better outcomes than in previous policy. This study tells the story from 2007-2011, of a continuing implementation and journey towards a different approach, whereby people needing social care support could access and experience this in a more empowering and personalised form.

#### **1.1.2 Definitions**

The term Self-Directed Support is often used interchangeably with personalisation. Both refer to the provision of individualised social care services. The term Individual Budget was used from 2003 and referred to a Personal Budget including other funding streams such as Independent Living Fund monies, Disability Living Allowance and other grants. More recently Individual Budgets are not referred to and the term Personal Budget is used to describe providing a person with a

personalised fund using only Local Authority social care monies. In this study Personal Budget refers to a managed Personal Budget where the monies are made explicit but held and managed by the Local Authority or a Direct Payment where the person receives the cash to direct their own services.

## **1.2 Self-Directed Support and social care commissioning**

Self-Directed Support has been defined as:

*“.....a term that describes the ways in which individuals and families can have an informed choice about the way that support is provided to them. It includes a range of options for exercising those choices through a co-production approach to agreeing individual outcomes, options are considered for ways in which available resources can be used so that people can have greater levels of control over how their support needs are met, and by whom”.*

(Scottish Government, 2010: 12)

Self-Directed Support is rooted in the Disability Rights and Independent Living Movement which has at its centre the social model of disability (Williams and Tyson, 2010; Jacobs *et al.*, 2011). This argues that people with impairments are disabled by society; therefore disabled people are an oppressed group (Shakespeare, 2010) and that disability is created by barriers that are either environmental, attitudinal or organisational (Office for Disability Issues, 2010). Self-Directed Support and Personal Budgets reflect international moves towards service personalisation and the increased pressure to give greater control to service users over social care resources used in their care and support (Timonen *et al.*, 2006; Da Roit and Le Bihan, 2010; Jacobs *et al.*, 2011; Netten *et al.*, 2011).

The 1996 Community Care (Direct Payment) Act gave Local Authorities the power to give 'willing and able' adults a Direct Payment: cash instead of a service. Uptake for Direct Payments was slow and in mental health remained relatively low (Newbigging and Lowe, 2005; Taylor, 2008). Direct Payments became a mandatory requirement in 2001 in the context of the Department of Health's (DH) commitment to independence and choice. In contrast, the earlier 1990 National Health and Community Care Act introduced care managers as commissioners of social care resources on behalf of service users and carers requiring needs assessments to be conducted (Office of Public Sector Information, 1990; Thornicroft, 1994). This Act's powers remain however emphasis has changed and in 2003 the challenge of reforming the way in which social care resources were allocated was taken on by 'In Control'<sup>1</sup>. Six Local Authorities worked with 'In Control' to increase service users' choice and control over the social care services they received.

Following learning from the 'In Control' project, in 2005 the Cabinet Office introduced Individual Budgets in the paper 'Improving the Life Chances of Disabled People' (Cabinet Office, 2005). Further government papers: 'Opportunity Age' (Department of Works and Pensions, 2005) and 'Independence, Wellbeing and Choice' (DH, 2005) followed. These papers and the complementary health white paper 'Our health, Our Care, Our Say' (DH, 2006a) set the scene for the more wholesale personalisation agenda. 'Our health, our care, our say' stated that eligible people would have a single transparent sum based on need allocated to

---

<sup>1</sup> 'In Control' is a multi-agency programme supported by a wide range of partners including Care Services Improvement Partnership, DH and Mencap. It now works with over 80 Local Authorities on Self-Directed Support.

them or held on their behalf, that they could choose to use in the form of a direct payment in cash, or as a mixture of both cash and services up to the limit of their budget. It also promoted a national network to share findings from the 'In Control' project.

The underpinning belief was that Individual Budgets would empower people to design their own support packages and decide the nature of that support. Individuals could add to the money allocated by pooling any available additional income. The government clarified that no new monies towards Individual Budget implementation were forthcoming; therefore Local Authorities had to afford this within existing resources. The underlying argument was that Self-Directed Support should be more cost effective; individuals could get support that suits them using no extra resources, if those around them can be involved in designing something suitable (Social Care Institute for Excellence, 2007a). Internationally however similar schemes in the European Union had suffered considerable financial problems (Timonen *et al.*, 2006) suggesting that cost containment needed to be built in from the outset to ensure affordability. Contextually, increasing numbers of people, especially older people, required social care resources (Social Care Institute for Excellence, 2007a).

In 2010, 86 Local Authorities returned surveys using the Personal Budget Outcome Evaluation Tool (POET) evolved by 'In Control' and Lancaster University. This surveyed Personal Budget holder's experience providing one of the largest service evaluations, including people with mental health problems. 76 (20%) of those surveyed self-reported having mental health needs with 75% of those receiving a Direct Payment. Findings suggested mental health recipients were likely to receive a smaller sum (£1-200 weekly) than in learning or physical

disability services (£501+ weekly). Over half of respondents with mental health needs reported difficulties in obtaining advice and information; planning, getting, managing or changing support; choosing services; or complaining. However over 70% found their Personal Budget had supported them with dignity, put them in control, increased their independence and improved their mental well-being. Carers, across all disabilities, reported good outcomes from Direct Payments but stressed that support planning is critical. Carers who felt included in the planning were most likely to report good outcomes (Hatton and Waters, 2011).

### **1.2.1 Local context**

This study is set in a large mental health Trust with integrated health and social care provision. Services include: acute and inpatient care; wellbeing and access to mainstream services; recovery and independent living services for people with long term conditions; and services for specialist needs.

Local Authority social care monies are assigned to the Trust for the purchase of independent, voluntary, and third sector organisation services for clients. The Local Authority provides contracting and finance support for the management of these monies. From these funds Personal Budgets are offered to eligible people as an alternative to contracted services: budgetary safeguards are applied requiring community packages of support to cost no more than residential care costs, averaging £500 per week locally, though this can be waived.

I am Head of Contracting and Provider Partnerships. I manage a team undertaking projects to bring new services into the Trust; work alongside partnership agencies providing housing, community and social services; lead on carers and commissioning social care services: residential and nursing care; and

community based services. My role is modernising services to reduce residential care reliance; encourage development of community services to enable recovery and independence; and ensure that service users can access the support they need within budgetary limits. My remit covers adults with mental health problems who have affective and psychotic disorders. This includes older adults of any age but not people diagnosed with any form of dementia.

The Trust was formed in 2001 and covers a county with a population of 880,600 people. It employs 2,000 staff, of which one in thirty are social workers or social care by background. There are reporting mechanisms in place concerning accountability, governance and contract monitoring relating to assigned Local Authority staff and monies.

The Trust has a strong ethos of research with an active research department linked to two universities, promoting the interconnection of research and practice within its culture. The research department helped me explore my initial ideas giving encouragement and advice concerning next steps. The overall direction of the Trust supported and shared the values and objectives of Self-Directed Support as a means of developing choice and contestability within mental health services. This was endorsed in the Trust business plan and strategy and provided a positive influence on the work of the steering group.

However, whilst this was the espoused direction of the Trust, the culture lagged behind and in practice many staff still retained a strong paternalistic approach. This is supported by the literature concerning user involvement: 'Many professionals really believe they know what is best for their patients' (Bertram, 2002: 5). Over 70% of Trust staff are over the age of 40 suggesting they may incline towards a

protective professional approach reflected in their training (Cole and Perides, 1995). Very few people are employed in developing external relationships with service providers to increase choices and senior managers recognised that more investment in social care knowledge, skills and approaches was needed in the Recovery Coordinator role.

### **1.2.2 Personal motivation**

I was interested in how effective Self-Directed Support could be in providing positive outcomes for people with mental health problems, and what the best way to develop this service would be. Self-Directed Support presented a dichotomy of possibly providing better patient care whilst at the same time containing costs. I was interested in understanding whether this could be achieved. Using an AR spiral methodology was a method by which implementation could develop and respond to the local context and involvement of stakeholders including people using services. Being a full time manager in an NHS Trust, with an ever broadening agenda, this also provided an opportunity to complete a research study and I registered for a PhD. Self-Directed Support incorporated aims of transparent systems, more choice and control for people and an empowering approach; this was a direction of travel that I strongly identified with and suggested a collaborative approach with service users and carers as co-researchers which the Trust was willing to endorse.

### **1.2.3 Selecting action research**

AR was selected as it combines both action and research and is closely aligned to my preferred method of working when developing projects: agreeing action; acting; reviewing; and revising actions, undertaken democratically and based on a continual improvement cycle. AR also provided a means of improving my



knowledge about the implementation process and my own practice through reflection. In AR the research story unfolds to explain the processes of the action and what is learned at different stages, making explicit what and why certain actions were taken and how data was gathered and evidenced. For me this enabled the project to be undertaken and researched contemporaneously providing personal and organisational learning. The democratic nature of AR also personally appealed, providing a method of involving service users and carers in a participative research process.

### **1.3 Study aim, design, methodology, methods of data collection and analysis**

The aims of this study were to better understand and develop Self-Directed Support within mental health services, and learn from service user and carer involvement in the change process. This study used AR methodology, in particular a participatory AR approach. The research study follows an AR cycle where a degree of uncertainty is incorporated into the AR spiral methodology of planning, taking action, reflecting and taking action again. This project incorporated a steering group, comprising a range of involved professionals and other stakeholders including service user and carer co-researchers, and provided the central method by which the collaborative process of the inquiry was conducted.

Data was collected using qualitative methods of focus groups, training meetings, steering group meetings, documents and my reflective diary entries. Findings were triangulated to offer different interpretations and improve rigour in data interpretations. Data from focus groups, co-researcher interviews and steering groups were analysed using coding schemes, adopting intra-coding reliability (Miles and Huberman, 1994) and sharing of draft analysis with respondents (Reason and Rowan, 1981; Silverman, 2001; Denscombe, 2007). Diary and

document analysis was based on text entirety using a holistic method rather than using textual analysis methods (Sarantakos, 2005).

#### **1.4 Thesis structure**

Following this introductory chapter, Chapter Two provides a literature search to set the study in the national context including analysis and discussion of the results of Self-Directed Support implementation. Self-Directed Support outcomes in mental health appear encouraging but vary and depend on relationships with staff and good processes for success. Longitudinal studies into Self-Directed Support in mental health are scarce and there are lower Personal Budget numbers in mental health than other disability areas. At the point when this study began little knowledge about Personal Budgets in mental health services was available; and considerable confusion and ignorance about Self-Directed Support existed suggesting the benefits of a longitudinal AR study such as this one.

Chapter Three discusses action research methodology. The early origins and development of AR to demonstrate AR as an appropriate and robust methodology is examined. AR is considered in relation to: health and social care research; service user involvement; validity and quality; insider research; political and ethical considerations and AR's relevance as a methodology for this study.

Chapter Four, 'Methods of data collection and analysis', discusses: the aims and design of this study; co-researcher recruitment and training; methods of data collection including focus groups, steering group meetings, training sessions, diary extracts and documents; and data analysis. Consideration of how validity and ethical research is demonstrated. Triangulation of findings to improve rigour is discussed.

Chapter Five fully examines the data collected and findings of this study. This chapter comprises three sections for each of the AR spirals concerning each Self-Directed Support implementation phase, with findings from the methods employed reported in order of their analysis in the study.

Chapter Six discusses separately the findings relating to using AR and to Personal Budget implementation. The chapter covers: the impact and rationale of using AR including the AR spiral methodology; steering group collaboration; political and ethical issues; contributions to new knowledge; rigour and reflexivity in this study and quality and transferability of the findings. The benefits and the barriers of Personal Budgets found in this study are then discussed and contrasted to national research findings.

In the final chapter conclusions from this study are drawn in relation to Self-Directed Support, service user and carer involvement, AR and data collection methods. Recommendations are suggested relating to AR, service user and carer involvement, Self-Directed Support, the Trust, and for future research.

## **CHAPTER TWO: SELF DIRECTED SUPPORT IN MENTAL HEALTH LITERATURE REVIEW**

### **2.1 Introduction**

This review aims to provide comprehensive understanding of research in mental health services on Self-Directed Support implementation including Personal Budgets and Direct Payments. The review considers existing research including: the landmark studies; research methodology; key findings, limitations and areas for further research. All references to Personal Budgets are inclusive of Direct Payments.

A literature review includes effectively evaluating available documents relating to the research being proposed, in order to fulfil certain aims, or express certain views on the research topic's nature and how it is to be investigated (Hart, 1998). This literature review's objectives were to: provide a context and rationale for this study; use quality criteria to determine studies worthy of inclusion; and examine findings and knowledge gaps to enable comparison and contrast with this study.

### **2.2 METHODS**

#### **2.2.1 Searching the literature**

Using the search terms Personal Budget\* or Individual Budget\* or Self-Directed Support or Direct Payment\* and mental health and research, I searched the free text of the on-line bibliographical databases for papers published between January 2000 and 2008 to inform my study design and, throughout the period of data collection, and second and third AR spirals until 2012. This was to ensure the findings of the project could be discussed and reviewed in relation to contemporary published work.

Direct Payments grew slowly in mental health services. Individual Budgets were initially reported on in 2006 therefore research prior to 2000 was unlikely to provide relevant findings to this study. Initially SCIE, CINAHL, EMBASE and MEDLINE were searched, however for completeness HEALTH BUSINESS ELITE and PsycINFO were added yielding three further papers (Table 2.1).

Databases	Number of articles retrieved	Included	Excluded	Number after duplicates removed
Social Care Online (SCIE)	326	42	284	42
CINAHL	177	19	158	11
EMBASE	20	0	20	0
MEDLINE	14	0	14	0
HEALTH BUSINESS ELITE	1425	4	1421	2
PsycINFO	29	1	28	1
TOTAL	1991	66	1925	56

*Table 2.1: Literature search strategy*

### **2.2.2 Review strategy**

My review strategy was to focus on research articles excluding papers that were: opinion or viewpoints; policy documents; non-UK; grey literature; book reviews or other educational resources. Only research in mental health or broad studies, including findings related to mental health, was included.

Systematic online reading of abstracts enabled identification of relevant papers that were printed for detailed reading. This resulted in 56 research papers. 35 viewpoint articles were additionally printed for potential contribution to discussion in chapter six.

### **2.2.3 Existing literature reviews**

Four related literature reviews were retrieved. These were:

- Sainsbury Centre for Mental Health (SCMH)/ Kings Fund review on choice and mental health literature (Warner, 2006)
- Social Care Institute for Excellence (SCIE)/ New Economics Foundation review on personalisation (Slay, 2011)
- Norah Fry Research Centre's review in mental health for Mind (Heslop *et al.*, 2009)
- Scottish Government Social Research review of the barriers and facilitators in SDS (Manthorpe *et al.*, 2011).

Literature reviews were used for: checking reference lists for further relevant studies; and reflection with this review's synthesis of findings; but were not included in this review.

#### **2.2.4 Quality assessment**

Following more detailed scrutiny eleven further papers were excluded for not meeting inclusion criteria. Checking reference lists from studies and literature reviews provided four further relevant papers to make a total of 49 papers. All papers were then ranked in study end-date order to allow examination and provide a research chronology. Much of the research was qualitative and interlinked: large-scale evaluations produced several research papers on different aspects of each study and/or produced a report and a journal article. In these cases the papers were reviewed together rather than separately.

Using the 'Standard Quality Assessment Criteria for Evaluating Primary Research' paper each of the 49 papers was scored using the authors' qualitative and/or quantitative checklists. The scoring grids and resulting scores, ranging between 0 and 1 for each study are shown in Appendix 1 (Kmet *et al.*, 2004). A cut-off point of 0.75 was selected for inclusion in this review in order to ensure that the

research was well designed and relevant. This reduced the total to 38 papers. The qualitative scoring exercise excluded the 'In Control' papers and the early Individual Budget evaluations (Poll *et al.*, 2006; Sanderson *et al.*, 2006; Henwood and Hudson, 2007, 2008; Hatton *et al.*, 2008; Tyson *et al.*, 2010): these studies were used for context at 2.5.1 and 2.5.2.

Of the 38 included studies, 13 used findings from the generic Individual Budgets Evaluation (IBSEN) (Glendinning *et al.*, 2007, 2008, 2009; Manthorpe *et al.*, 2008, 2009, 2009a, 2010, 2010a; Rabiee *et al.*, 2009; Jacobs *et al.*, 2011; Moran *et al.*, 2011; Netten *et al.*, 2011; Stevens *et al.*, 2011). The generic IBSEN studies all scored very highly in the quality assessment and were landmark studies; however in most mental health comprised the smallest disability group with very small sample sizes. I thought it important therefore to have sufficient mental health specific research to contrast and compare to the cross-cutting studies. Following thorough reading of the studies I concluded that the generic studies' results shared similar findings to those specific to mental health, however mental health Personal Budget implementation appeared more difficult. This concurred with my experience that mental health provides additional limiting factors: complicated funding arrangements; poor social care assessment and care management processes; which together with the unpredictable and debilitating impact of mental illness on people may all accentuate barriers to Personal Budget take-up.

The remaining 25 papers comprised 18 studies (Maglajlic *et al.*, 2000; Witcher *et al.*, 2000; Ridley and Jones, 2002, 2003; Spandler and Vick, 2004, 2005, 2006; Tobin and Vick, 2004; Riddell *et al.*, 2005, 2006; Davey *et al.*, 2007; Fernandez *et al.*, 2007; Homer and Gilder, 2008; Daly *et al.*, 2008; Mind, 2009; Jones and Netten, 2010; Campbell *et al.*, 2011; Coyle, 2011; Leece and Leece, 2011;

Manthorpe *et al.*, 2011; Ridley *et al.*, 2011; NHS Confederation, 2011, 2011(a), 2011(b); Newbronner *et al.*, 2011). These had little consistency in: research method; sample population, or analysis. All 38 studies used qualitative methods except four (Spandler and Vick, 2004; Riddell *et al.*, 2005, 2006; Glendinning *et al.*, 2007, 2008; Manthorpe *et al.*, 2008; Jacobs *et al.*, 2011) that used mixed methods and one was a quantitative study (Fernandez *et al.*, 2007).

There were nine specific mental health studies comprising 11 papers. Five mental health studies scored highly: two early studies on Direct Payments (Ridley and Jones, 2002, 2003; Spandler and Vick, 2006) and three later studies on Personal Budgets (Coyle, 2011; Newbronner *et al.*, 2011; NHS Confederation, 2011, 2011a,). Due to the low number of mental health specific studies I decided to include the Mind (2009) study scoring .5, as an exception: service user focus groups matched my study; and the sample corresponded to the profile of people using my Trust's services.



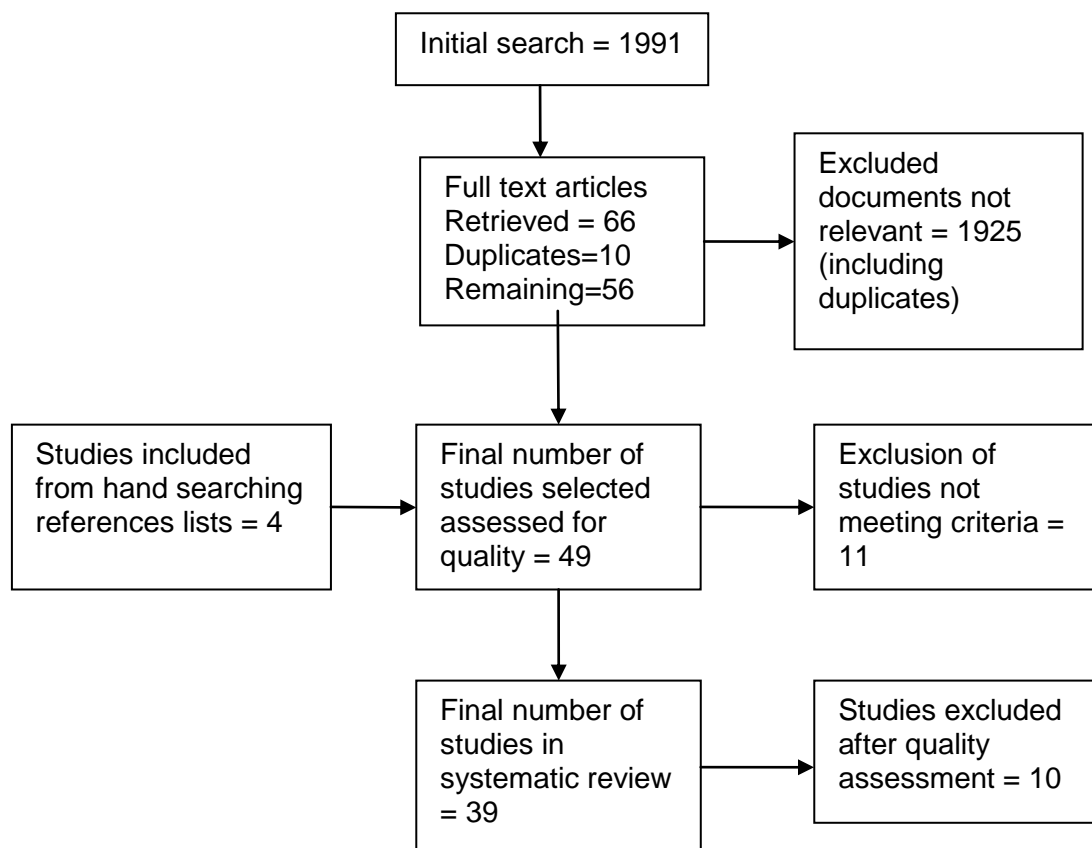


Figure 2.1 Process of searching and reducing records for the literature review (adapted from Eick et al., 2012).

Preliminary reading was designed to highlight common themes from each paper's findings which were systematically collected in order to report the results thematically. This is one means of analysis for integrative reviews. This review is not intended to meet that definition however the method provides a helpful means to compare and contrast a large amount of studies and consequent findings (Dixon-Woods et al., 2005).

Firstly studies researching Direct Payments, up to 2006, when Self-Directed Support research started to emerge, were examined. Although Self-Directed Support includes Direct Payment implementation I considered that early findings, before the advent of the Government's personalisation agenda, would be better

reported separately. This differentiates the review into two stages, producing initial themes that could be compared and contrasted with those following. These are considered below with reference to the emerging themes.

## **2.3 THEMES FROM THE LITERATURE: DIRECT PAYMENTS**

### **2.3.1 Low take-up of Direct Payments in mental health**

Low take up of Direct Payments in mental health services is identified as concerning in several studies (Maglajlic *et al.*, 2000; Ridley and Jones 2003; Spandler and Vick, 2004). By the end of the national mental health pilot in 2001-3 to promote Direct Payments in five Local Authorities, 58 people took up Direct Payments (Spandler and Vick, 2004). Recipients with mental health problems comprised a very small proportion of United Kingdom (UK) Direct Payment numbers in 2003; 229 out of 12,585 overall (Commission for Social Care Inspection, 2004). Spandler and Vick (2004) considered the variety of policy initiatives and continual local reconfigurations hindered mental health workers from giving Direct Payments priority. Health and social care funding divisions and the 1983 Mental Health Act, now superceded by the Mental Health Act (2007), focussing on risk assessment, were other factors considered as constraints on increasing take-up.

The Health and Social Care Advisory Service (HASCAS) undertook a content analysis of Direct Payment policies whereby all LAs ( $n=150$ ) were written to, requesting a copy of their Direct Payment policies. Ninety six policies were returned (response rate = 66%) and assessed against a DH-developed coding framework informed by national legislation and policy. The percentage where mental health was specifically mentioned (57%) suggested less encouragement or guidance is provided for the uptake of Direct Payments in mental health, given

the very low numbers. The recommendations suggested that Local Authorities need to define the range of eligibility with reference to under-represented groups (Tobin & Vick, 2004).

Research used focus groups to engage with service users and professionals to raise awareness about Direct Payments and their potential in mental health. Data generated was used in a national event co-facilitated by people with mental health problems trained in facilitation skills. Key stakeholders appeared represented however sample sizes were unspecified. Findings provided key messages: easy assessment processes were needed; staff access to information; provision of advocacy and support; and paperwork to be simplified and aligned to the Care Programme Approach (Newbigging and Lowe, 2005).

A comparison 'four-country' UK study was undertaken (Riddell *et al.*, 2005, 2006) using multi-method and multi-stakeholder analysis aiming to compare implementation of national Direct Payment policy and explain regional variation. The findings describe implementation as a multi-factored phenomenon and that local variation is not directly attributable to local factors. This all-disability study found there were fewer Direct Payments in mental health than other disability areas. Innovative practice did not appear linked to above-average take-up of Direct Payments or any long-standing connection with the Independent Living Movement. During 2003-4 English authorities spent 0.4% of their community care budget on Direct Payments in mental health compared to 15.5% in physical disability, 0.8% for older people and 1.1% in learning disability. In mental health Direct Payment average intensity was also less: less than half of recipients had more than ten hours weekly support. This study was particularly

informative providing a broad view of Direct Payment implementation across the UK using a mixed method approach.

The London School of Economics and Personal Social Services Research Unit studied the uneven uptake of UK Direct Payments by survey. Survey content reflected the earlier 'four-country' data analysis resulting from stakeholder interviews (Riddell *et al.*, 2006; Fernandez *et al.*, 2007). The survey, based on a multi-method, multi-site, multi-tiered study including statistical analysis of existing data, aimed to examine differences in implementation and support structures. Interviews, a phone survey ( $n = 102$ ) with staff managing Direct Payments, postal questionnaires to UK Local Authorities and all organisations supporting Direct Payment recipients were used. Issues hampering progress were identified as: service users' and carers' concerns about their capacity to manage Direct Payments; staff resistance; and market issues like shortages of personal assistants. Statutory requirements to offer Direct Payments in mental health made no substantial difference to the level of provision. The report identified 400 people with mental health problems receiving Direct Payments in March 2005, with one third of Local Authorities providing no Direct Payments to people in this category. Two Local Authorities however provided Direct Payments to 53 and 63 people respectively in the group suggesting that access to Direct Payment in lieu of a mental health service can be improved (Davey *et al.*, 2007).

### **2.3.2 Benefits and uses of Direct Payments**

Direct Payment researchers in three Scottish Local Authorities conducted four focus groups and 23 interviews, including nine with mental health service users. Results reported service users and carers identifying greater control and flexibility over support and life decisions as advantageous; with carers further highlighting

Direct Payments providing more normality and inclusion (Ridley & Jones, 2003). However nobody with mental health problems in Scotland then received a Direct Payment, suggesting limited knowledge amongst a small participant sample, or a lack of will for change.

An evaluation of the national mental health Direct Payment pilot scheme from 2001-3 aimed to identify the range and variable use of Direct Payments. Implementation approaches were compared across five pilot sites using interviews with Direct Payment recipients, focus groups and questionnaires; exploring process, impact, benefits and problems; analysing findings in local and national contexts. The small sample of Direct Payment recipients ( $n = 27$ ) reported Direct Payments as: improving their quality of life; providing better access to social, educational and leisure activities; increasing their feelings of independence, self-worth, motivation, hope, and positive impact on their mental health. Less impact was reported on social and personal relationships however anecdotal indications suggested Direct Payments may reduce hospitalisation (Spandler and Vick (2004).

Using more detailed analysis of the same research study opportunities were considered for independent living using Direct Payments.

‘The flexibility of being able to organise support around one’s own life rather than having to adapt one’s life around support is central to the independent living philosophy’ (Spandler and Vick, 2004:112).

They also reported specific benefits such as social inclusion, already identified by Witcher *et al* (2000), and opportunities for mental health recovery: having assistance to be able to pursue one’s own self-defined aims and goals was cited as crucial to recovery.

National Direct Payment pilot (2001-3) take-up analysis in mental health indicated many packages ( $n = 58$ ) were very small: the majority (83%) used for ongoing support, and half used to employ personal assistants (Spandler and Vick, 2005). The HASCAS evaluation of five pilot sites reported mental health Direct Payments being used for: social, therapeutic, practical or domestic support; personal care; transport; education; arts; leisure; respite; childcare; and night sits (Spandler and Vick, 2004).

### **2.3.3 Barriers to taking up Direct Payments**

Maglajlic *et al* (2000) studied Direct Payment recipients with mental health problems, learning or physical disabilities by interviewing staff; and carers in a London borough. Direct Payment knowledge was limited and poor experience of services impacted on views of Direct Payments. The need for advocacy and support was identified. Mental health users wanted training, rights-information and most wanted Direct Payments for household tasks, to combat isolation and access community opportunities (Maglajlic *et al.*, 2000).

Ridley and Jones (2003) identified inhibitors reducing Direct Payment take up in mental health service users as: lack of publicity, knowledge and understanding including judgemental staff attitudes in not passing on information; the service-led nature of community care assessments; lack of client-centrality; lack of awareness of the impact of mental illness; eligibility uncertainty due to the need to be willing and able to manage a Direct Payment; overly bureaucratic processes; anxieties about people's capacity to manage Direct Payments; fears by staff of the impact on their workloads; lack of independent support services for Direct Payments; and the need for advance planning for contingencies such as becoming unwell. Having to handle payments and financial arrangements were seen as a primary

disadvantage by all research participants including concerns about misappropriation of payments (Ridley and Jones, 2003). The crucial role of care coordinators in enabling people to access Direct Payments was agreed by Spandler and Vick (2005) who noted that a radical re-appraisal of their roles and practices was required in order to increase take-up. Additionally they reported care coordinator's cautiousness leading to selectiveness and discretionary behaviour that was highly significant in either enabling or stalling Direct Payments (Spandler and Vick, 2005, 2006).

Risk aversion and protective behaviour including: conflict between risk taking and safeguarding; concerns about lack of resources; service led assessments; and people being willing and able to manage a Direct Payment were found to be widespread barriers in mental health services as well as other disability groups (Spandler and Vick, 2005; Fernandez *et al.*,2007).

Other barriers have also been identified including: lack of awareness and confusion about access to Direct Payments; lack of streamlined assessments; service user scepticism due to previous poor mental health services experience; treatment focussed organisational culture not fitting with Direct Payments; staff assessing people as incapacitated and Direct Payments not thought to be core business. Equally staff had anxieties about implications of Direct Payments; training needs; organisational barriers due to non-availability of Direct Payments for health needs and having no systematic approach to the introduction of Direct Payments (Newbigging and Lowe, 2005).

Concerns of overly bureaucratic processes and people's lack of knowledge, from Newbigging and Lowe's (2005) research, suggested the need for a cultural shift to

allow service users' self-determination and increased choice of support. Additionally Spandler and Vick (2004) reported unsatisfactory opinions of Care Trust staff viewing people with mental health needs being ineligible for Direct Payments: people were either deemed not ill enough to have care needs or too mentally ill to manage a Direct Payment. Specific barriers in mental health services included difficulties in determining health from social care needs; eligibility where conditions are unstable; and risks concerning people's capability in managing their own support (Ridley and Jones, 2002; Spandler and Vick, 2004).

## **2.4 SUMMARY: DIRECT PAYMENTS RESEARCH**

### **2.4.1 Key themes**

Thirteen research articles (Maglajlic *et al.*, 2000; Witcher *et al.*, 2000; Ridley and Jones, 2002, 2003; Spandler and Vick, 2004, 2005, 2006; Tobin and Vick, 2004; Newbigging and Lowe, 2005; Riddell *et al.*, 2005, 2006; Davey *et al.*, 2007; Fernandez *et al.*, 2007) including three (Spandler and Vick, 2004, 2005, 2006) reporting the national mental health Direct Payment evaluation, were thoroughly reviewed.

Samples, using participants with mental health problems receiving Direct Payments, are small in all studies. The key themes from the literature on Direct Payments in mental health identified are shown in Table 2.2 below:



Theme	Cited studies
<i>Direct Payments:</i> Low take-up of Direct Payments in mental health compared to other disabilities	Maglajlic <i>et al.</i> , 2000; Ridley and Jones 2003; Spandler and Vick, 2004 Commission for Social Care Inspection, 2004; Tobin & Vick, 2004; Newbigging and Lowe, 2005; Riddell <i>et al.</i> , 2005, 2006; Davey <i>et al.</i> , 2007; Fernandez <i>et al.</i> , 2007.
Benefits and uses of Direct Payments	Witcher <i>et al.</i> , 2000; Ridley & Jones, 2003; Spandler and Vick, 2004 2005.
Barriers to taking up Direct Payments: staff attitudes; bureaucratic assessment and application processes; lack of information; lack of advocacy and support; funding and lack of suitable services	Maglajlic <i>et al.</i> , 2000; Ridley and Jones, 2002, 2003; Spandler and Vick, 2005, 2006; Newbigging and Lowe, 2005; Fernandez <i>et al.</i> , 2007.
<b>KEY:</b> Mixed methods studies highlighted yellow, quantitative studies highlighted pink	

*Table 2.2: Thematic summary: literature review of Direct Payments.*

Benefits from Direct Payments relate to: independence; flexibility; choice; and links to recovery (Witcher *et al.*, 2000; Ridley and Jones, 2003; Spandler and Vick, 2004, 2005); but where Direct Payments are received, packages appear smaller than for other disabilities (Maglajlic *et al.*, 2000; Ridley and Jones 2003; Spandler and Vick, 2004 Commission for Social Care Inspection, 2004; Tobin & Vick, 2004; Newbigging and Lowe, 2005; Riddell *et al.*, 2005, 2006; Davey *et al.*, 2007; Fernandez *et al.*, 2007).

Barriers to taking up Direct Payments address:

- a) Staff attitudes: risk aversion; putting services not people first; increased work-load fears (Ridley and Jones, 2003; Newbigging and Lowe, 2005, Spandler and Vick, 2005, 2006);
- b) Bureaucratic assessment and application processes (Ridley and Jones, 2003; Newbigging and Lowe, 2005);
- c) Lack of information on Direct Payments for all stakeholders (Maglajlic *et al.*; Ridley and Jones, 2003; Newbigging and Lowe, 2005);

- d) Lack of advocacy and support for Direct Payment recipients (Maglajlic *et al.*; Ridley and Jones, 2003; Newbigging and Lowe, 2005);
- e) Funding; and lack of suitable services to access (Spandler and Vick, 2005).

It is noteworthy that two studies (Ridley and Jones, 2002; Spandler and Vick, 2004) suggested barriers may be greater in mental health services due to complicated health and social care interface-working and concerns about providing Direct Payments to people with unstable needs.

#### **2.4.2 Direct Payments: Areas for further research**

Further research at this stage suggests the reasons why mental health was so far behind other service sectors in implementing Direct Payments. Questions about: institutional barriers; complicated social care funding arrangements; lack of leadership to implement schemes and training; and care managers acting as unofficial resource gate-keepers; were raised by research findings.

### **2.5 SELF DIRECTED SUPPORT: INTRODUCING INDIVIDUAL AND PERSONAL BUDGETS**

#### **2.5.1 'In Control'**

'In Control' led pilot projects in six Local Authorities implementing Self-Directed Support during 2003-5, developing its own implementation manuals and programmes. Fifteen recipients with a non specified disability took up Individual Budgets in each site and 31 people completed a pre/post Individual Budget questionnaire to measure changes in domains of: self determination; support; home; direction; cost; and community life. Interviews with recipients were also reported (Poll *et al.*, 2006; Sanderson *et al.*, 2006). The report suggested significant improvements in all domains however findings were based on small

samples, lack of longitudinal follow-up, limited explanatory detail and reflect 'In Control's role as a crusading organisation with a questionably in-built bias to reporting favourable findings.

'In Control's second phase (2005-7) report is in two parts: firstly, an evaluation of 196 interviews with PB recipients in 17 English Local Authorities; secondly, reflections on Self-Directed Support including: support; planning; economics; brokerage; community; commissioning and the role of 'In Control' (Hatton *et al.*, 2008). Interviews used a standard questionnaire to report on differences Personal Budgets had made to people's lives, which was then statistically analysed. Fifty eight percent of the sample comprised people with learning disabilities, with six people identified with mental health problems. Authors state that the evaluation was not comprehensive but an example of low impact monitoring that Local Authorities could implement themselves. The findings suggest: very few people reported a worsening of their situation since taking up Self-Directed Support; 77% reported improvements in their quality of life; 64% improved community participation and 72% improved choice and control over their lives. More people reported no change rather than improvements in: their general health and wellbeing; economic well-being; and safety and security. The evaluation is acknowledged as being non-representative with Self-Directed Support development still at an early stage. Given the limitations of the research an independent evaluation was commissioned by the DH, reported below in 2.5.2.

'In Control' used a revised questionnaire for their third phase evaluation (2008-9) surveying 1,114 PB recipients, carers and staff. The service user survey utilises 14 domains to track changes in people's quality of life entailed by the move to Personal Budgets. Positive findings are reported in: getting the support needed;

being supported with dignity; being in control of support; and being as independent as you want. Little impact was found in: ability to choose where and with whom you live; volunteering and community help. No impact was reported on getting and keeping a job. Data concerning take-up of Personal Budgets was also reported showing that from 60 people in 2006 having a Personal Budget, there were 30,000, in late 2009, across 75 Local Authorities (Tyson *et al.*, 2010).

### **2.5.2 Individual Budget programme**

A national multi-disability Individual Budget programme gathered data in 13 sites during 2006, including 14% mental health representation. Only four sites planned to offer Individual Budgets in mental health but more sites included mental health as the project developed. The programme built on the 'In Control' projects and Direct Payment experience to offer: more flexible and personalised social care; increased opportunities for self determination; and flexible funding with an emphasis on transparency and support planning (Netten *et al.*, 2007).

In 2007 the DH commissioned two research studies: firstly a progress-review in 10 Local Authorities of Self-Directed Support implementation; and secondly in-depth case-studies in three Local Authorities. The first evaluation (Browning, 2007), an interim multi-disability progress report, concluded that the Self-Directed Support model, adapted from learning disability services: created tensions and difficulties in other disability areas; Resource Allocation System introduction was hugely challenging and very time consuming; mental health presented the greatest challenge but nonetheless benefitted from Self-Directed Support.

The second in-depth study reported no findings for mental health but recognised the huge cultural change at local levels required, dependent on staff and their

managers; and the difficulties in Self-Directed Support implementation alongside established social care systems. Change was seen as needed in areas of: the specific 'giving and doing' tradition; loss of collectivism; conflation of needs and wants; and the mistrust of service users who will try to get out of the system what they can (Henwood and Hudson, 2007). It found that support for Individual Benefits did not necessarily translate into action: integration of funding streams to form an Individual Budget was problematic; existing funding guidelines remained static undermining attempts to use funding flexibly. At this point brokerage and support planning services were under-developed with the main focus being on developing budgets and a Resource Allocation System (Henwood and Hudson, 2008).

The DH decided to move ahead with Self-Directed Support ahead of the evaluation's findings attracting widespread criticism amongst research and social service departments. It is following the national Individual Budget pilot that research specifically includes people with mental health problems. This research is now considered thematically.

## **2.6 THEMES FROM THE LITERATURE: SELF-DIRECTED SUPPORT**

### **2.6.1 Mental health Personal Budgets: Differences to other disability areas**

The theme of Self-Directed Support being more problematic to implement in mental health services is popular in the literature. Early findings from the Individual Budgets Evaluation (IBSEN) indicated delivering Individual Budgets in mental health took longer, were seen as more complicated and NHS workers were more cautious about the approach (Glendinning *et al.*, 2007). The final IBSEN used a robust research design of randomised control trial. Drawbacks remained including short data collection time, and possible effects of extra

attention and benefits due to pilot status that may not be evident in any subsequent roll-out. In the final IBSEN difficulties in the Local Authority-NHS interface were reported; differentiating health and social care needs was seen as problematic; and disaggregating the social care costs for Individual Budgets was thought to lead to Local Authority liability for previously jointly funded support. Difficulties also arose, where lead Individual Budget officers did not manage front line NHS staff, in effecting culture change promoting personalisation. Additionally the final IBSEN found that people with mental health problems had a smaller budget overall to use for home, personal or day activities: mean weekly value of £150 compared to £360 in learning disabilities (Glendinning *et al.*, 2008).

### **2.6.2 Quality of life and satisfaction with support**

Peoples' quality of life is consistently used as an impact measurement in Self-Directed Support research findings. The final IBSEN summary reported findings that mental health service users receiving an Individual Benefit reported 'significantly higher quality of life than those in the comparison group'. The sample comprised 959 people: 510 in the Individual Benefit group and 449 in the comparison group. 14% of the sample used mental health services (Glendinning *et al.*, 2008). After personal and home support the use of funding for leisure activities was cited by 66% of mental health users. The IBSEN used a mixed methods approach, based on a Randomised Control Trial, with the aim of examining outcomes and cost effectiveness of Individual Budgets. Two internationally recognised tools for measuring health outcomes were employed: General Health Questionnaire (Goldberg, 1992) and reporting self-perceived health (Robine *et al.*, 2003), as well as social care outcomes and quality of life measuring tools. The evaluation suggested that Individual Budgets offered a greater range and flexibility in support arrangements. The small numbers and lack

of details on personal characteristics of the respondents however prevented any recommendations about which groups of people with mental health needs are likely to benefit from Individual Budgets. For people who use mental health services, Individual Budgets appeared to be more cost effective than standard arrangements on both social care and psychological well-being outcome measures however conclusions suggested their *potential* for cost effectiveness (Glendinning *et al.*, 2008). A further caution in respect of the final IBSEN research was that people with mental health problems receiving services from integrated health and social care teams, were excluded from the research, limiting results to a particular subgroup (Netten *et al.*, 2011). Finally, quality of life evaluations that do not involve 'before and after' measurements may be subject to bias due to people being unable to compare accurately how they felt before. 'Before and after' measurements may help to reduce this problem.

A 2008 review of Self-Directed Support in Scotland undertook 38 interviews: 24 face to face interviews with Self-Directed Support recipients and carers including some ( $n = 2$ ) with mental health problems; and 14 with Local Authority staff. The report stated that finding people with mental health problems in receipt of Self-Directed Support was a significant challenge. The study found that the overwhelming majority of people were extremely positive about the difference that Self-Directed Support had made to their lives reporting increased flexibility, control, choice and independence as benefits. Self-Directed Support allowed them to live their lives largely as they wished, retain their sense of self-identity and self-worth. This included the two people with mental health problems who were 'absolutely clear that Self-Directed Support was enabling them to live a much fuller life' (p.55) (Homer and Gilder, 2008).

A study using focus groups with 26 people with mental health problems, found Personal Budgets can contribute to creative ideas to enhance people's quality of life including use for travel, social activities, living independently, holidays and keeping physically fit (Mind, 2009). Social Care Institute for Excellence (SCIE) reported on the experiences of people with mental health problems and older people across five study sites including two mental health trusts. Sixty nine Personal Budget holders and carers, 40 practitioners and 12 provider organisations contributed using methods of semi-structured face to face and telephone interviews and focus groups. The SCIE study echoed Mind's (2009) findings whereby Personal Budgets were used in creative and innovative ways. Given appropriate information, flexibility, advice, support and creativity in support planning, findings suggested that Personal Budgets can work very well for people with mental health problems (Newbronner *et al.*, 2011).

An Individual Budget pilot site study evaluated people receiving a Personal Budget based on an AR approach using individual and group-based data collection methods with 22 participants including one participant with mental health problems. The evaluation findings do not distinguish any disability group but report that all saw Personal Budgets as a positive development with increased choice and autonomy in assessment and support packages resulting in more flexible approaches and timings of services provided. This afforded more reports of feeling integrated into the community and greater independence. Challenges reported poor information, communication difficulties and recruiting support staff (Daly *et al.*, 2008).

It is noteworthy that many quality of life measurement tools vary in their make-up and level of depth leaving the term 'quality of life' open to definition though the



IBSEN uses a seven-point life satisfaction scale more commonly used to measure life satisfaction.

### **2.6.3 Health and well-being**

The IBSEN measures of well-being outcomes showed a general improvement across all disabilities except older people (Glendinning *et al.*, 2008).

IBSEN used universal measures of well-being and the general health questionnaire (GHQ) including self reported health outcomes.

A small study using semi-structured interviews with fourteen Individual Budget recipients including people with mental health problems ( $n = 3$ ), in four of the 13 early Individual Budget implementation sites, found that people with fluctuating conditions considered the flexibility of support-timing fundamental to their well-being enabling them to pursue personal goals (Rabiee *et al.*, 2009).

A study of three mental health early intervention teams found that Personal Budgets enhanced recovery for service users. The study used several methods including seven interviews, two focus groups and document examination. Service users reported experience of Personal Budgets included: hope towards recovery; moving from dependence towards positive self-direction; and co-creation of person centred plans from previously being assessed (Coyle, 2011).

### **2.6.4 Choice and control outcomes**

The outcome of increased choice and control is highlighted throughout the literature. Individual Budget recipients in the 2005-7 National Individual Budget Pilot found that flexibility over what their Individual Budget could be spent on, and when, as one of the most positive aspects, enabling greater socialisation, freedom

and independence (Rabiee *et al.*, 2009). The final IBSEN interview data was re-examined using choice in relation to: power relations; equity; and the public nature of decisions as organising themes. The study found that giving people a greater role in assessing their own needs and making choices regarding services was a challenge to existing power relationships with professionals, though professionals still kept their resource gate-keeping roles. Individual Budget recipients reported increased choice and control but that making effective choices needed accessible information: without this inequity could result. Findings suggested that choice was limited by workers' views on legitimacy of different types of resource, with choice constrained by the normative policy framework operating. Additionally some uses of IBs may be considered luxury items or a waste of public money, such as a computer or a 'holiday'. Choice was therefore promoted yet many workers focussed on helping people identify the kinds of support they needed, demonstrating ongoing power relationships in decision-making (Stevens *et al.*, 2011).

Confusion and misunderstanding surrounding Personal Budgets resulting in people feeling less confident about exerting their right to choice and control, essentially around planning their own support was found in the Mind (2009) study. Where a person took up a Direct Payment greater choices were reported providing: incentives for people with mental health problems and their carers; increased confidence; greater sense of responsibility; and more personalised support (Mind, 2009).

### **2.6.5 Carers**

Research specifically concerning carers and Self-Directed Support is scant however the SCIE study indicated that carers can have a central role in enabling

people with mental health problems to take up and manage their PB (Newbrunner *et al.*, 2011). A study into the impact of Individual Budgets on carers was built into the main IBSEN using structured and semi-structured interviews and telephone interviews with carers' leads. A Randomised Control Trial approach was used, including 9% ( $n = 46$ ) of the sample comprising carers of people with mental health problems, though the study focussed primarily on carers of people with learning disability and older people. Findings concluded that the principle support for carers is through the services and support provided to the service user and that Individual Budgets were associated with a positive outcome for carers in quality of life. Outcome gains, primarily resulting from increased choice and control over how carers spent their time, were achieved with no higher resource costs suggesting cost effectiveness. Additionally if the service user reported improved outcomes then the carer too acknowledged increased satisfaction. The study acknowledged limitations in its scope and cautioned about drawing conclusions regarding comparative costs to both carers and public funds; and an under-representation of carers of people with mental health problems. Nonetheless it reported that carers' satisfaction with care planning processes is important and that this varies according to the different disability groups. Nothing was reported specifically relating to mental health. More evidence of practice variations across different user groups was recommended for future research (Glendinning *et al.*, 2009; Moran *et al.*, 2011).

#### **2.6.6 Risks to Personal Budget recipients**

There are many references in the literature to workers' anxiety that Self-Directed Support will potentially put more people at risk of abuse or exploitation and increased stress and anxiety due to managing the new processes (Ridley and

Jones, 2003; Spandler and Vick, 2005; Davey *et al.*, 2007; Glendinning *et al.*, 2008; Manthorpe *et al.*, 2008; Mind, 2009).

The IBSEN reported that safeguarding issues had not been considered in many pilots, which was of concern to care managers (Manthorpe *et al.*, 2008).

Safeguarding was studied in the 13 Individual Budget pilot sites during 2006 using semi-structured telephone interviews with lead safeguarding officers. Links between safeguarding and Individual Budgets were either in early stages or not yet set up. Key concerns found were: financial abuse of Individual Budget recipients; and how to safeguard people through training, processes and policies. Concerns that Personal Budget recipients may commit fraud more easily were also voiced (Manthorpe *et al.*, 2009a).

A follow-up round of telephone interviews was held in the 13 sites during 2008. Concerns about potential for abuse and exploitation continued to dominate participants' thoughts: Direct Payments were generally acknowledged as carrying more risks than contracted services. Legislation and checks on personal assistants' suitability were either unavailable or not applied. This study was limited as it was based on a safeguarding lead's views rather than analysis of safeguarding instances; however it clarified that safeguarding knowledge was not built into Individual Budget implementation at this stage (Manthorpe *et al.*, 2010a).

With respect to self reporting of risk during assessment the SCIE (2011) study reported confusion about risk inclusion in self-assessment questionnaires, particularly if different agencies were involved in the Personal Budget process. Different interpretations of what was meant by 'risk' were applied (Newbrunner, *et al.*, 2011).

### **2.6.7 Resource Allocation Systems, assessment and support processes**

Process issues, inherent in assessment and support systems, are an important theme in the literature. The IBSEN reported cynicism amongst staff on the Resource Allocation System process and its ability to provide indicative budgets (Manthorpe *et al.*, 2008). Some found the approach too simplistic with inappropriate questions whilst others liked the clear and equitable process (Glendinning *et al.*, 2008). Ambiguities in self-assessment forms, difficulties in completion for people with fluctuating conditions and concerns whether the Resource Allocation System is appropriate for people with very high or specialist support needs were also found (Rabiee *et al.*, 2009). A later quantitative study involving 12 Local Authorities in the national Individual Budget pilot study, reported Local Authorities with most Self-Directed Support experience, highlighted Resource Allocation System development as one of the highest costs in the personalisation change management process (Jones and Netten, 2010).

Bureaucratic and sluggish processes with dependency on gatekeepers and depersonalised experiences of access to support services prevailed (Mind, 2009). Lengthy approval processes and concerns about people coping with paperwork and administration were also reported. Additionally Resource Allocation System processes asked questions unrelated to their needs: people wanted more individually tailored questions (Newbrunner *et al.*, 2011). Concerns were expressed about too many people involved in assessment processes in Trusts without integrated health and social care. One consistent person, using an outcome-focussed assessment was voiced (Mind, 2009). Improving the supply of services was also highlighted by Newbrunner *et al* (2011) as vital to keep up with changing needs and Personal Budget recipients' preferences.

The evaluation of Scottish Self-Directed Support test sites using interviews with individuals, carers, and care managers in three Local Authorities, found: current assessment processes were an obstacle to Personal Budget take-up; increase knowledge about Self-Directed Support was needed; and provision of multi-pronged training to drive culture change. Four of the sample group ( $n = 132$ ) were people with mental health problems (Ridley *et al.*, 2011).

However the SCIE study suggested that most mental health Personal Budget recipients were: able to manage Personal Budgets with little or no support, though many used their allocated worker or family members. Additionally, mental health recipients were less likely to use support from provider organisations but considered them a safety net if their ability to self-manage reduced (Newbrunner *et al.*, 2011).

The absence of an independent support service is seen to be an obstacle to Self-Directed Support development (Witcher *et al.*, 2000; Ridley and Jones, 2002; Davey *et al.*, 2007). Support planning and brokerage was researched in three sites funded by the Office for Disability Issues. The study considered how resources could be transferred from Local Authority assessment and care management systems to user-led support and brokerage. It comprised a change management support programme including qualitative and quantitative data analysis programmes. 80 service users, 41 of whom had support plans facilitated by user led organisations, were interviewed twice: once at onset of support plan and then six months later for comparison. Five people had mental health needs. Most reported poor care planning experiences and Direct Payment information leaving them feeling disempowered. Two receiving user led organisational support and advice were happy with this. All participants who received user led

organisational support planning were very satisfied with the choice and control in their lives (Campbell *et al.*, 2011).

### **2.6.8 Training and information**

Training and information requirements were consistently highlighted in research findings as a priority need. Having a lead Direct Payments officer and associated training increased Direct Payment take-up (Riddell *et al.*, 2006). Training is a factor to aide or hinder Direct Payment implementation (Maglajlic *et al.*, 2000; Ridley and Jones, 2003; Davey *et al.*, 2007) as is accessible information (Newbigging and Lowe, 2005). The IBSEN reported the need for more and better training across the areas of support planning and Personal Budget processes (Glendinning *et al.*, 2008). As part of the IBSEN telephone interviews with 11 training leads and six Individual Budget lead officers were conducted. Training for stakeholders including service users was considered appropriate, reflecting the need for a considerable culture shift and staff concerns about risk (Manthorpe *et al.*, 2009). Training for managers was recognised by eight respondents as an important activity. Overall training was seen as a way to influence the wider organisation's culture however the effects of Self-Directed Support on social workers' roles was acknowledged as yet to be fully identified (Manthorpe *et al.*, 2009).

Follow-up research was conducted during 2007-8 with nine of the original sample using an amended interview schedule. This was a limited small scale study, acknowledging potential bias of interviewees wanting to provide favourable reports. Findings suggested that all interviewees now reported Personal Budgets being part of their remit, with huge strategic implications for workforce development likened to the roll out of 'community care' in the 1990's. Training was

seen to need to cover partner organisations, independent and third sectors and people using services and carers (Manthorpe *et al.*, 2010).

The need for better training was echoed by Mind (2009) suggesting training and education for people receiving services was needed and Newbrunner *et al* (2011) suggesting all stakeholders in the process were seen to need training and provision of clear written information.

### **2.6.9 Impact on work-force**

Staff concerns about roles and jobs are reported resulting from Self-Directed Support implementation: losing these if services close; loss of professional control; skills lack; extra administrative complexity and general resistance to change (Witcher *et al.*, 2000; Manthorpe *et al.*, 2009; Mind, 2009). The IBSEN reported a mixed view of what Personal Budget implementation might mean for social workers: some seeing this as eroding skills and fragmenting the care management process; others as a reinvigoration of social work values (Glendinning *et al.*, 2008). Incorporated into the IBSEN was a study into the impact on care coordinators work activity pattern. Diaries were kept by 249 care coordinators, additionally 48 care coordinators and 43 managers were interviewed. 30% of staff worked in mental health services. This study found that care coordinators working with at least one Individual Budget recipient spent significantly more time care planning and arranging services for that person, suggesting that the increased time spent completing a support plan is universal. Interview results suggested an increased use of social work skills in evaluating care and support activities and indications of increased role of assessment. Study limitations include small sample size, with low numbers of people on caseloads receiving Individual Budgets due to the early stage of Individual Budget



implementation. This may suggest different results to future evaluations when SDS is more established (Jacobs *et al.*, 2011).

Research across all disability groups used an internet forum to access views on personalisation to collect data. A 'thread' was posted on 18 forums to generate discussion about the future role of social work within personalisation. 153 responses from 66 individuals were analysed. The sample was necessarily limited to those using computers and appeared to reach more service users than carers. The authors believed it enabled the view of 'hard-to-reach' groups, including those with mental health needs, to be heard. Over half of respondents questioned the usefulness of social workers, the powerful position that professionals occupy and most were overwhelmingly in favour of using independent brokers for Self-Directed Support. Statutory organisations' power in setting guidelines, bureaucratic procedures and eligibility criteria for services was seen as a negative effect on the person's ability to control their own support and the ability of social workers to exercise discretion. The study sample size however was small, neither random nor representative and may be biased (Leece and Leece, 2011).

#### **2.6.10 Staff culture change**

This theme links with training, and impacts on workforce, however is evident as a theme in its own right throughout the literature. The IBSEN suggested major shifts in culture, roles and responsibilities were required as front line staff were crucial to introducing Individual Budgets. This was linked to training and communication activities (Glendinning *et al.*, 2008; Manthorpe *et al.*, 2009) with staff attitudes found to be crucial to enabling Personal Budgets. Staff with traditional notions of social care and 'appropriate' uses of Personal Budgets, constrained their usage

and reduced conversations about individual options (Spandler and Vick, 2004, 2005; Newbigging and Lowe, 2005; Newbronner *et al.*, 2011).

Providing a rights-based service rather than a 'gift-model' challenges professionals who need to move services out of their professional silos of clinical responsibility, and see developing a plan and harnessing support as helping a person towards recovery, not as inequity or a threat (Coyle, 2011).

### **2.6.11 Personal health budgets**

Personal health budgets are a late theme in the literature from 2009 onwards. The perspective of mental health service users and carers to Personal Health Budgets was collected in a study using focus groups ( $n=60$ ) and survey ( $n=100$ ). Findings described frustration with the lack of involvement; over-medicalisation; and poor coordination. Almost all participants said they would choose to change some aspect of their care if they were in control. Some said they would take up a Personal Health Budgets but most were worried about taking on the autonomy without adequate support (NHS Confederation, 2011). Additionally 40 health and social care leaders were interviewed. Results found: a general consensus about engaging with and training the workforce to develop Personal Health Budgets; using story telling to reinforce positive results; harnessing the third sector for brokerage and positive influences on the process; working in partnership across health and social care organisations; and trying Personal Health Budgets out on an evolutionary basis (NHS Confederation, 2011b). A further study evaluated views of mental health professionals using a survey ( $n=645$ ) followed up by 60 telephone interviews. Understanding and awareness about Personal Health Budgets was low, with most responses based on knowledge of Personal Budgets in social care. Professionals were unconvinced, with significant concerns from

GPs, psychologists and psychiatrists, that Personal Health Budgets would benefit service users. They believed that they already offer choice and there is no evidence that Personal Health Budgets lead to better outcomes. There was a limited enthusiasm for Personal Health Budgets with concerns over poor choices being made by service users and professional unwillingness to relinquish control over the choice process. Factors cited were: people choosing what they liked rather than what would produce the best outcomes; and choices causing people undue anxiety. Other concerns were: capacity issues; risks; increasing bureaucracy; and changing roles (NHS Confederation, 2011a).

## **2.7 SUMMARY: PERSONAL BUDGET RESEARCH**

### **2.7.1 Research literature**

Twenty six papers were utilised in this part of the review. Fourteen studies reported on data collected from the IBSEN (Glendinning *et al.*, 2007, 2008, 2009; Manthorpe *et al.*, 2008, 2009, 2009a, 2010, 2010a; Rabiee *et al.*, 2009; Jacobs *et al.*, 2011; Jones and Netten, 2010; Moran *et al.*, 2011; Netten *et al.*, 2011; Stevens *et al.*, 2011). Three studies reported on Self-Directed Support development in Scotland (Homer and Gilder, 2008; Manthorpe *et al.*, 2011; Ridley *et al.*, 2011), with nine 'independent' research studies (Daly *et al.*, 2008; Mind, 2009; Campbell *et al.*, 2011; Coyle, 2011; Leece and Leece, 2011; NHS Confederation, 2011, 2011(a), 2011(b); Newbrunner *et al.*, 2011). Six papers were mental health specific (Mind, 2009; Coyle, 2011; NHS Confederation, 2011, 2011a, 2011b; Newbrunner *et al.*, 2011).

## 2.7.2. Key themes and critique of research design

Theme	Cited Studies
Mental health Personal Budgets: Differences to other disability areas	Glendinning <i>et al.</i> , 2007, 2008.
Quality of life and satisfaction with support	Glendinning <i>et al.</i> , 2008; Daly <i>et al.</i> , 2008; Homer and Gilder, 2008; Mind, 2009; Netten <i>et al.</i> , 2011; Newbronner <i>et al.</i> , 2011.
Health and well-being	Glendinning <i>et al.</i> , 2008; Rabiee <i>et al.</i> , 2009; Coyle, 2011.
Choice and control outcomes	Rabiee <i>et al.</i> , 2009; Mind, 2009; Stevens <i>et al.</i> , (2011).
Carers	Glendinning <i>et al.</i> , 2009; Moran <i>et al.</i> , 2011; Newbronner <i>et al.</i> , 2011.
Risks to Personal Budget recipients	Ridley and Jones, 2003; Spandler and Vick, 2005; Davey <i>et al.</i> , 2007; Glendinning <i>et al.</i> , 2008; Manthorpe <i>et al.</i> , 2008, 2009a, 2010a; Newbronner <i>et al.</i> , 2011.
Resource Allocation Systems, assessment and support processes	Witcher <i>et al.</i> , 2000; Ridley <i>et al.</i> , 2002; Davey <i>et al.</i> , 2007; Manthorpe <i>et al.</i> , 2008; Glendinning <i>et al.</i> , 2008; Rabiee <i>et al.</i> , 2009; Mind, 2009; Jones and Netten, 2010; Newbronner <i>et al.</i> , 2011; Ridley <i>et al.</i> , 2011; Campbell <i>et al.</i> , 2011.
Training and Information	Maglajlic <i>et al.</i> , 2000; Ridley and Jones 2003; Newbigging and Lowe, 2005; Riddell <i>et al.</i> , 2006; Davey <i>et al.</i> , 2007; Glendinning <i>et al.</i> , 2008; Mind, 2009; Manthorpe <i>et al.</i> , 2009, 2010; Newbronner <i>et al.</i> , 2011.
Impact on workforce	Witcher <i>et al.</i> , 2000; Glendinning <i>et al.</i> , 2008; Manthorpe <i>et al.</i> , 2009; Mind, 2009; Jacobs <i>et al.</i> , 2011; Leece and Leece, 2011.
Staff Culture Change	Spandler and Vick, 2004, 2005; Newbigging and Lowe, 2005; Glendinning <i>et al.</i> , 2008; Manthorpe <i>et al.</i> , 2009; Newbronner <i>et al.</i> , 2011; Coyle, 2011.
Personal Health Budgets	NHS Confederation, 2011, 2011a, 2011b.
<b>Key:</b> Mixed methods studies are highlighted yellow	

Table 2.3: Thematic summary: literature review of Personal Budgets

The key themes from the reported research on Self-Directed Support following the 'In Control' early pilots concern the outcomes of Personal Budgets in the areas

of: choice and control; quality of life and satisfaction with support; health and wellbeing; and risks; as shown in Table 2.3 above. Findings are reported using different outcome frameworks and indicators making comparisons difficult. These qualitative research studies use small sample sizes in comparison with health research using Randomised Control Trials. Randomised Control Trials however would not be an appropriate research method where the aim of the studies is to capture people's views, emotions and understandings, and where dialogue needs to be used to capture the subtleties and richness of participant perspectives. In particular, mental health participant sample sizes are extremely small, with little reference to their assessed needs level, or in some cases whether their mental health problem is dementia or an affective disorder (Glendinning *et al.*, 2008; Homer and Gilder, 2008; Daly *et al.*, 2008; Rabiee *et al.*, 2009; Newbronner *et al.*, 2011; Moran *et al.*, 2011). Little quantitative research or mixed methods research has been undertaken in order to afford a wider understanding of the impact of Personal Budgets (See Table 2.3).

Measurements of change did not include 'before and after' comparisons and different interpretations of concepts such as health and well-being may suggest cautious interpretation of results. The outcomes for people with mental health problems is varied and appears significantly different from other groups with decreased choice and control and lower psychological well-being (Newbronner *et al.*, 2011) however other research suggests that Self-Directed Support appears to produce good outcomes in mental health (Glendinning *et al.*, 2008) but the processes and relationships with staff supporting these processes are critical to success. Having access to information, and various means of support to discuss options are important (Mind, 2009; Ridley *et al.*, 2011; Newbronner *et al.*, 2011).

Additionally the health and social care interface with separate funding budgets and competing priorities, as experienced in many mental health Trusts, appear as potential barriers (Glendinning *et al.*, 2007, 2008). Workforce impact including concerns about future roles, training needs and cultures that are averse to increasing service user empowerment are also clearly evidenced as constraints to Self Directed Support implementation (Glendinning *et al.*, 2008; Manthorpe *et al.*, 2009; Mind, 2009).

Self-Directed Support is relatively new in development, particularly in mental health services. The literature reflects this with many studies' findings espousing the benefits of a personalised approach; however a lack of long-term reflective analysis should suggest cautious interpretations. Most studies focus on the outcomes and barriers to providing and holding Personal Budgets rather than on processes of supporting people in a different, more individualised way. The exception is the IBSEN evaluation (Glendinning *et al.*, 2007, 2008) which does include care planning processes and measurements over time. The research design was detailed and robust however follow up after only six months may, for many people be too early, particularly those changing their lives more radically using Personal Budgets: a longer follow-up may have provided different outcomes (Glendinning *et al.*, 2008). SCIE's research (Newbronner *et al.*, 2011), demonstrates that in mental health the right support is as important as the outcome. The process is a variable directly affecting the person's outcome, warranting research in its own right as a measure of whether Self-Directed Support is successful or not.

Many of the earlier findings in Direct Payment mental health research are similar to findings nearly a decade later: lower Direct Payment numbers than other

disability areas and concerns expressed by professionals about risks, increased workload and limited knowledge. Multiple advantages from Personal Budgets are described by recipients however processes are poor and slow take-up.

### **2.7.3 Areas for further research**

It is evident there is a lack of longitudinal and independent research with large samples regarding Self-Directed Support and people with mental health problems particularly using 'before and after' measurement tools to evaluate changes in outcomes. A substantial amount of research across disabilities has been based on the IBSEN (Glendinning *et al.*, 2007, 2008) using the same sample groups and in some studies the same data re-analysed to look at different aspects of Self-Directed Support implementation with very low numbers of people with mental health problems.

Comparisons between take-up in mental health services with different organisational structures and relationships with their partner Local Authorities may help to understand why mental health is lagging behind other disability groups in Self-Directed Support implementation and whether there are particular structural, cultural or practice impediments. Considering the poor knowledge and enthusiasm expressed by mental health professionals in the NHS Confederation (2011a) it would be interesting to research whether different Trust structures are better suited to overcoming these barriers.

As numbers of mental health specific studies were limited, links with the recovery approach are noticeably missing. This suggests opportunities for studies linking both areas: researching the impact of combined approaches of empowering people through recovery and Self-Directed Support.

Carers is another area where little is known particularly those receiving Direct Payments in their own right and whether Direct Payments have made any difference to their roles and well-being.

## **2.8 DISCUSSION**

### **2.8.1 Research prior to my study**

At the commencement of this study starting in early 2007 there was little knowledge about the impact of Personal Budgets in mental health and considerable complexity and confusion about the differences between Direct Payments, Individual Budgets and Personal Budgets (Henwood and Hudson, 2007; Mind, 2009; Carr and Dittrich, 2010; Reid Howie Associates, 2010). The term personalisation was used interchangeably with Self-Directed Support (Mind, 2009) and promoted by governmental policies aimed to increase choice for people using social care services. Individual Budgets were first mentioned in *Improving the Life Chances of Disabled People* (Cabinet Office, 2005) with a commitment to pilot the approach made in the green paper, *Independence, Well-being and Choice* (DH, 2005). These papers specified: the central role of individuals in assessing their needs and identifying their outcomes; the principle of the person being informed of the budget allocated to support them and; being offered a variety of means to increase their control over the money spent on them for those unwilling/unable to take up Direct Payments (Stevens *et al.*, 2011).

Direct Payments were being taken up by people with mental health needs but they were the least likely group to use them (Fernandez *et al.*, 2007) with papers expressing concerns about the low numbers (Maglajlic *et al.*, 2000; Ridley and Jones 2003; Spandler and Vick, 2004). Direct Payment take-up was extremely



slow and variable across the country (Henwood and Hudson, 2008). The specific mental health research on Direct Payments reported key themes, outlined in 2.4.1 above, however most of these studies were carried out with small sample sizes (Coyle, 2009; Mind, 2009; Newbrunner *et al.*, 2011) and using participants many of whom had limited knowledge of Direct Payments (NHS Confederation, 2011, 2011a, 2011b). Spandler and Vick's (2004) national evaluation of Direct Payments however did report on positive outcomes for mental health Direct Payment recipients: improved confidence; greater independence; increased access to mainstream activities. The sample group may have been more positive about Direct Payments than non-participants however which may have skewed findings.

Individual Budgets were being piloted nationally in 13 Local Authorities with the 'In Control' model being promoted (Duffy, 2006, 2007) including a low representation (14%) of people with mental health problems. Whilst 'In Control' was espousing positive results from their early Individual Budget implementation, findings from any independent research projects were yet to be published.

### **2.8.2 Rationale for this study**

Based on the limitations of knowledge in 2007 in relation to Self-Directed Support and particularly within mental health services I concluded that using AR would enable learning about the process, benefits and obstacles of implementing Personal Budgets in an integrated mental health Trust. There are few studies focussing on both implementation and changing practice therefore an AR study was justified. This provided an inquiry over time whilst executing a change intervention aimed at improvement and involvement (Waterman *et al.*, 2001).

Existing literature clearly showed that blocks existed in relation to Self-Directed Support particularly in mental health services and that an approach to understand

and overcome these whilst effecting change would meet my dual needs; as a manager to implement Personal Budgets as a project and as a researcher to study the process and outcomes producing organisational and self-learning, whilst allowing the newly emerging literature to inform best practice..

The HASCAS mental health specific report (Spandler and Vick, 2004) provided recommendations that were influential in this study's design: steering group development; access and usage of Direct Payments; practice development of teams and embedding related organisational processes. The resulting study is reported in the following chapters intended to extend knowledge of Personal Budgets in mental health services using an AR approach and qualitative data collection methods. In the next chapter I will discuss AR, its origins and key features in relation to my study.

## **CHAPTER 3: SELECTING ACTION RESEARCH METHODOLOGY AS AN APPROACH FOR THIS STUDY**

### **3.1 Introduction**

This chapter considers action research (AR) in all aspects in relation to the study and is divided into seven sections. Section one discusses social research and quantitative and qualitative research paradigms. The origins of AR are discussed in the second section. This includes the use of AR as both: a strategy for inquiry and development; and a form of social research linking learning to practice and being undertaken by practitioners and service users (Winter and Munn-Giddings, 2001).

Section three considers the relevance of AR in health and social care settings, and service user involvement in research. Section four discusses how to assess quality in an AR project and considers validity, rigour and generalisability. In section five researching your own organisation as an 'insider' researcher is examined. Section six examines the political and ethical considerations of AR. Section seven discusses the methodological implications and rationale for using AR in this study. Finally, specific suggestions for assessing the quality of this study, using the work of two AR authors, are discussed.

### **3.2 Section One: Research paradigms and action research**

#### **3.2.1 Social research**

This section considers how AR relates to other conceptions of research. There are two key forms of social research: quantitative and qualitative research, which are frequently contrasted with each other. A quantitative researcher attempts to fragment and delimit phenomena into measurable or common categories that can

be applied to all of the subjects or wider and similar situations (Winter, 2000). Methods include standardised measures so that various perspectives and experiences can be fitted into a limited number of pre-determined categories to which numbers are assigned. Standardised instruments are used to demonstrate validity and replicable results (Patton, 2002).

Qualitative research uses a naturalistic approach seeking to examine data context-specific, producing findings arrived from real-world settings where the 'phenomenon of interest unfold naturally' (Patton, 2002: 39).

Qualitative research produces a different type of knowledge than quantitative inquiries: focusing on understanding and illumination rather than the quantitative concerns with facts and causes of behaviour. This means that methods, such as interviews and observation, are predominant in the naturalistic (interpretative) paradigm and supplementary in the quantitative, (positivist) paradigm (Golafshani, 2003).

The value of any research method should be gauged in relation to what is being considered. Certain kinds of quantitative measures may also be appropriate in qualitative research. However a dependence purely on quantitative methods may neglect the social and cultural variables that quantitative research seeks to correlate (Silverman, 2001).

Epistemology (grounds for knowledge) and ontology (the nature of the world) can be assessed along a scale from objectivist to subjectivist perspective depending upon the researcher's epistemological and ontological viewpoint (Coghlan and Brannick, 2010). The epistemological concerns of the qualitative, interpretative paradigm are to interpret and understand individual and group experiences

whereas in quantitative, positivist research the testing of hypotheses would be used (Williamson, 2012). Reliability by replicability is significant in quantitative research (Golafshani, 2003) requiring methods that can measure and analyse causal relationships between variables (Denzin and Lincoln, 1998), for example, RCT. Interviews and observations are methods dominant in the qualitative paradigm and qualitative researchers embrace their role and involvement within the research (Winter, 2000). There is no implication that an interpretive approach is superior or preferable to a functionalist one rather, it is about maintaining an effective research approach (Ragsdell, 2009). Essentially it is the research question that drives the choice of paradigm and subsequent methods (Williamson, 2012).

### **3.2.2 The contrast of action research**

Objectivity and deduction favoured research in the quantitative paradigm can be contrasted to the 'real-life' exploration of qualitative research. Quantitative research is described by Winter and Munn-Giddings (2001) as a form of social power, people as countable objects, not definers of meaning. They critique quantitative social research as influenced by the researchers' motives, ideologies, values and purposes for the research therefore non-objective, suggesting researcher bias needs to be considered, and arguing against its scientific detachment in practice. They further argue it conceals individual differences of meaning and how those meanings relate to actual people in their social context. They suggest that quantitative research does not provide an adequate understanding of human experience; limits data interpretation and makes assumptions that complex systems of social reality can be understood as a series of abstracted fragments reducing complex behaviours or situations to component parts (Winter and Munn-Giddings, 2001).

Both objectivist and interpretative paradigms aim to separate participants from the research by collecting and analysing data with detachment in order to lessen any unplanned influence on the research process. In AR however the purpose is to work towards change: the process constructively acknowledges that people will respond in some way to the research, and that action researchers need to investigate their own practice as well as the practice of others, involving all participants in self-analysis and self-evaluation (Winter and Munn-Giddings, 2001). Self-involvement of the researcher is deliberate and active in the investigation (Avison *et al.*, 2001; McKay and Marshall, 2001). Reason (1988) defined this collaborative research or inquiry as new paradigm research: seen as research with or for people rather than on them; and not a neutral, value free process but a supporting and questioning initiative. AR can be defined as:

A participatory democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview. (Reason and Bradbury, 2008:1)

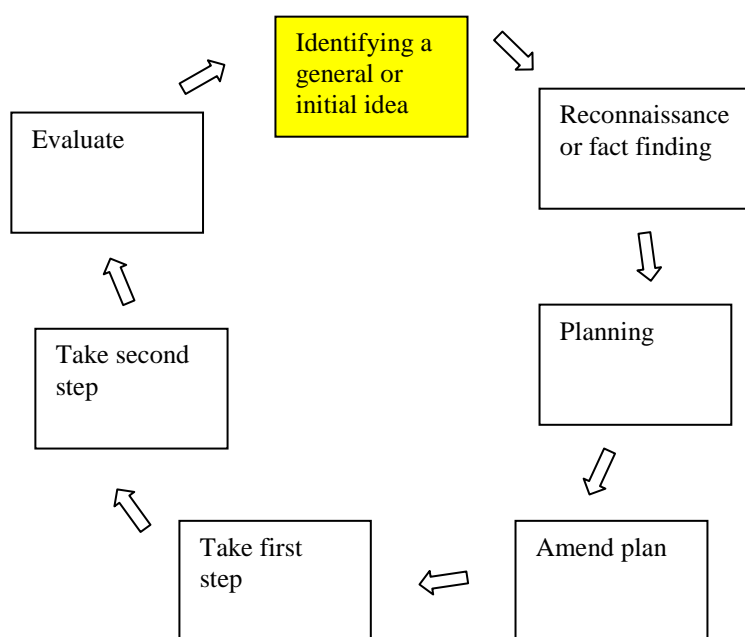
It is clear there are many forms of AR operating. Eikeland (2007) differentiates two separate practical approaches: AR as collaboration between researchers and work practitioners; and AR primarily practitioner led, within professions such as teachers, nurses or managers. In the second group AR may be radical reflection on their own practice. She suggests the latter will become the dominant form as workers perform increasingly knowledge intensive work.

### **3.3 Section Two: Origins of action research**

#### **3.3.1 The work of Kurt Lewin (1890- 1947)**

AR involves researching real problems in social systems using an iterative process of identifying the problem, planning, acting and evaluating. Kurt Lewin, a

social psychologist, is generally recognised as the founder of AR (Hart and Bond, 1995; Eikeland, 2007; Coghlan and Brannick, 2010). He asserted that research was needed to enable people and groups to change organisational and social lives for themselves (Lewin, 1946). His approach involved a spiral of steps, each a cycle of planning, action and fact finding about the result of the action. This basic cycle is represented below.



Key: Yellow indicates starting point

*Figure 3.1: Lewin's initial action research cycle adapted from Smith (2007)*

Most action researchers have tended to adopt some version of Lewin's (1946) formulation of AR, with the key concept of combining scientific inquiry with action, designed to change patterns of thinking within social or organisational settings (Winter and Munn-Giddings, 2001). His four stage framework of planning, acting, observing and reflecting is considered the basis for many of the more modern definitions of AR (Meyer, 1993). Lewin's (1946) concept of AR involved:

change experiments on real problems; iterative cycles of identifying a problem, planning, acting and evaluating; re-education of norms and values through participation in the AR cycle by rooting knowledge in experiential learning; challenge to the status quo congruent with effective re-education requirements; simultaneous contributions to social science knowledge and to social action alongside high standards in the development of theory in relation to practice (Argyris *et al.*, 1985).

### **3.3.2 Action research and change**

When it was introduced AR was heralded as an important contribution to social science inquiry. Subsequently people have built and developed Lewin's ideas however criticism of AR's methodology is that it does not apply the general principles of scientific method. Instead it offers a diverse means of researching and changing workplace practice (Winter and Munn-Giddings, 2001). AR can be used in many different forms; action enquiry; participatory action research; co-operative enquiry; action learning; appreciative enquiry; however most share common themes that often overlap. There is therefore no one model of AR but a number of connected ways of researching using action, reflection and change cycles. All presume collaboration between researcher(s) and clients: (Gronhaug and Olson, 1999; Winter and Munn-Giddings, 2001; Shani *et al.*, 2008; Coghlan and Brannick, 2010; Bellman and Webster, 2012) and some authors make the distinction between AR and participative AR, emphasising the potential emancipatory force within AR focussing on those without power in the AR cycle (Rahman, 2008; Coghlan and Brannick, 2010; Williamson, 2012). AR is described by Dick (2002) as a family of research methodologies pursuing action through change: an iterative process of emergence which changes and develops as understanding is increased.



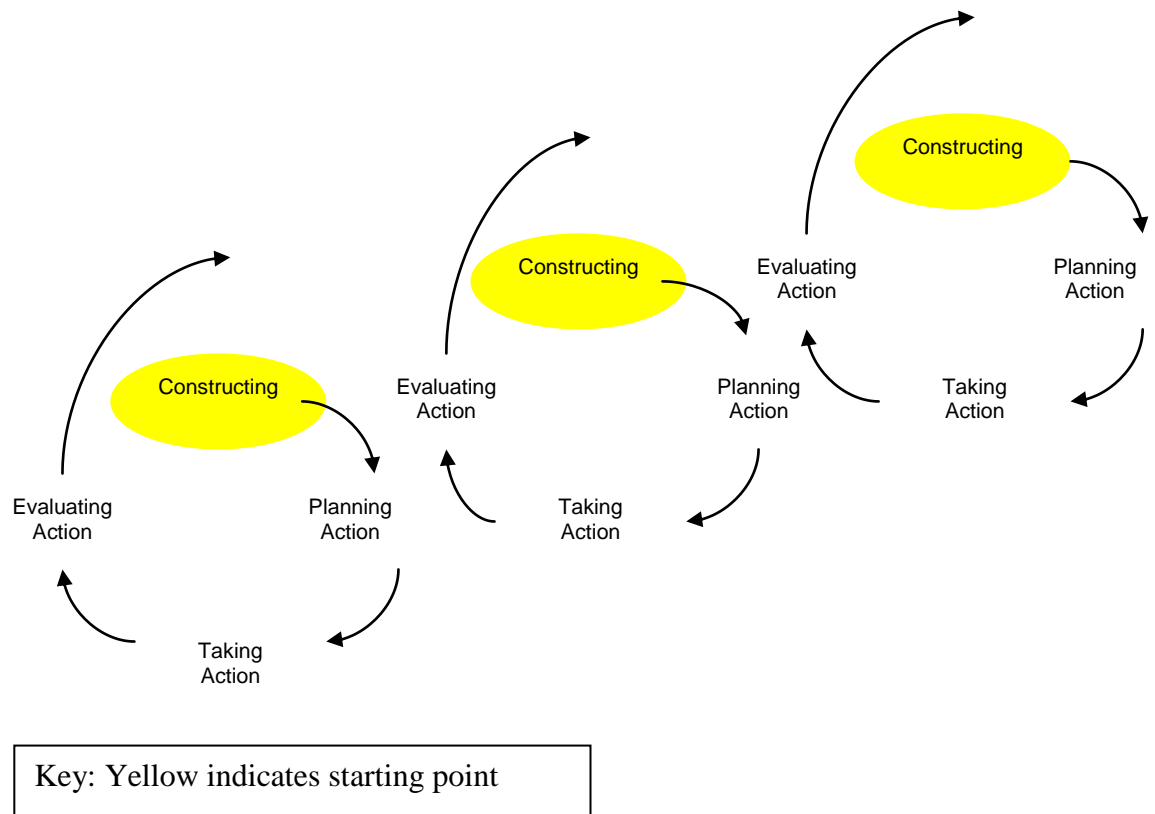
Change and learning are central to AR (Coghlan and Brannick, 2010) with action researchers asking what they can do and how they can do it (McNiff *et al.*, 2010). McNiff and Whitehead (2002) see AR as a commitment to collective social change, located within individual lives, as people aim to integrate theory and practice. AR is also a way to demonstrate how a change in your practice can mutually benefit a group of practitioners or social system (Reason and Bradbury, 2008; McNiff, 2002). Moves towards continually changing and updating practice has made AR increasingly appropriate in health and social care organisations and the emphasis on collaboration reinforces organisational commitment to partnership working with all stakeholders. It is relevant to those who want to change practice through reflection, and work in collaboration to influence change in social systems (Marshall, 2011).

In health services clinical audit is a tool that is regularly used to provide a continuous quality improvement cycle (Dixon and Pearce, 2011). Clinical audit involves improving the quality of patient care by looking at current practice and modifying this where necessary (Clinical Audit Support Centre, 2012) and is synonymous with quality improvement as a concept. Both AR and clinical audit aim to improve practice and outcomes using a cyclical process: clinical audit does so by measuring clinical practice to compare with evidence-based benchmarks and measure the impact of improvements until the intended improvement is achieved (Dixon and Pearce, 2011). This process shares some features with AR in that it is cyclical with the aim of driving changes and improvements in practice. However it does not link research, action and evaluation through a reflexive cyclical process and lacks a collaborative and democratic impulse. Clinical audit demands obligatory improvement from top-down often to meet external

requirements, not from individual practitioners wanting to grow and learn through personal and group reflection and dialogue.

### **3.3.3 The action research cycle**

Lewin (1946) was the first to describe the AR process as cyclical (Waterman *et al.*, 2001) comprising a pre-step and three activities of planning, action and fact-finding (see Figure 3.1). This model of AR has been interpreted in different forms: there is no one correct model however I have selected Coghlan and Brannick's (2010) interpretation. This starts with understanding the context of the project and the desired future state, including establishing the collaborative relationships needed to achieve this. Next is activity in which the stakeholders construct what the issues are: the practical and theoretical foundations of the action to be taken; planning action collaboratively followed by taking action; and finally evaluating the outcomes of the action before the cycle is repeated (Coghlan and Brannick, 2010). (Figure 3.2)



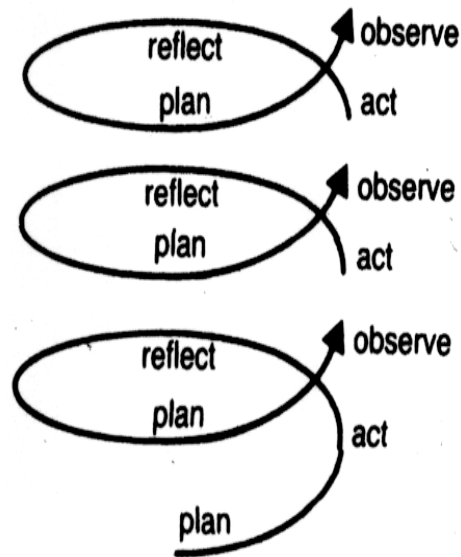
*Figure 3.2: Spiral of action research cycles: reproduced from Coghlan and Brannick (2010:10)*

The simplicity of this AR cycle representation is criticised by Winter and Munn-Giddings (2001) who argue it suggests: that the overall process is fixed and does not allow for shifts of understanding of situations deepening over time; secondly, that the overall process with its emphasis on repeated cycles will take a long time to sustain, which may prove difficult in many work settings. Finally the emphasis on plan, act, observe reflect and re-plan may be too general and could apply to any moderately complex activity.

The difficulties inherent in the assumptions of propositional models that practice can be portrayed as linear and sequential when real life situations are rarely like this, are agreed by McNiff and Whitehead (2002). As action generally does not proceed in a nice orderly fashion AR needs to be able to recount stories, including

complexities and confusions, whilst allowing the reader to be aware of the process steps in a coherent manner.

Figure 3.3 shows an early pattern of AR spiral of planning, acting, reflecting, planning again and observing for change. However AR is a transformational evolutionary process, therefore unexpected added cycles, within the main AR cycle that was planned, as a result of new evidence, events, perceptions, external or internal organisational pressures, may occur. Uncertainty is inherent in AR projects with many issues from diverse sources due to the nature of organisational life. Practitioners need to see these models as guidelines which enable planning with some aims in mind. The authors see the imposition of models on practice as turning AR into a technology and that this could be an oppressive means of stifling creativity (McNiff and Whitehead, 2002).



*Figure 3.3: Early conceptualisation of action research spiral methodology: reproduced from McNiff & Whitehead (2002:57)*

The idea of dual AR cycles has also been proposed (McKay and Marshall, 2001; Coghlan and Brannick, 2010). This describes AR cycles operating in parallel: the first cycle being one of diagnosing, planning, taking action and evaluation; and the second being a reflection cycle reflecting on the AR cycle that provides continual enquiry into all the main steps. The dynamic of the reflection cycle is that it incorporates learning about the process of the AR cycle and allows the process to be more than everyday problem solving. Reflection is not confined to the lead action researcher but to all of the participants and groups in the process. Their experience that manifests in, for example, struggles, conflicts and satisfaction is crucial to learning, problem solving and decision making throughout the life of the project (Coghlan and Brannick, 2010).

McKay and Marshall (2001) argue that their model, emphasising the dual imperatives of research and action, enables researchers to be more explicit about the reflection and learning cycles with their conceptualisation providing more credibility to AR as a research method. This approach will be discussed in

Chapter Six as applied to this study demonstrating the research and action at various stages of the AR cycle and the interaction between the two dynamics.

Other authors consider the parallel of the thesis inquiry into the organisational project. In this case it is the thesis that is submitted for examination which may reflect an unsuccessful outcome for the project but nonetheless the researcher's enquiry and academic award may be successful (Perry and Zuber-Skerritt, 1992), with the focus on data exploration, useful and interesting learning on the practice-based research (Waterman, 1998) and the contribution that the study has made to knowledge and how the findings have influenced practice (Koshy *et al.*, 2011).

### **3.3.4 Reducing the theory-practice gap**

The core basis to AR is that it is a research process focussing on simultaneous action and research in a participative manner. AR attempts to link theory with practice combining practical concerns with the goals of social science (Ragsdell, 2009) or theoretical insights with practical effects (Styhre and Sundgren, 2005). It focuses on the relationship and interaction between knowledge and action (Eikeland, 2007). AR assumes a participatory approach where the research subjects are also researchers or democratically involved, that the research is an agent for change and that data used in the research approach is systematically collected and comes from the experience of the research participants. This includes the use of quantitative and qualitative data according to different situations (Coghlan and Brannick, 2010).

McNiff and Whitehead (2002) highlight the debate about the methodological and epistemological bases of AR. They state that some regard AR as a methodology that can be applied to practice, others as a methodology that has developed

within practice to try to understand how values are lived in practice with resultant debate about the purposes of AR. They see AR as a form of researching one's learning, with an aim to improve their work and their understanding of how to improve social situations including personal and collective relationships. This implies that working with others is an educative process. They are concerned that AR is not turned into a set of techniques that would deny the humanitarian and egalitarian roots of AR:

'I came to see action research not as a step of concrete steps but as a process of learning from experience, a dialectical interplay between practice, reflection and learning', (McNiff and Whitehead, 2002:13).

The view of AR as enabling 'ordinary' people to think and act for themselves and respecting their individuality and experience is espoused by McNiff and Whitehead (2002). They see action researchers as generating a living form of theory by researching their own practice and improving the quality of educational experience within workplaces for personal and organisational improvement: this allows researchers to step outside of oppressive conceptual models of theory to exercise spontaneity and creativity by raising awkward questions and tensions. The challenge of combining both action and research can lead to difficulties of control in AR projects, compounded by the highly situational aspect of AR. The initiation of the project, determination of authority for action and the degree of formalisation of the project, such as structures and membership, are considered to be difficult areas to control and beyond the power of the individual action researcher (Avison *et al.*, 2001). Projects such as this one may have faltered if, for example, a new government drew back from implementing Self-Directed Support. The problem of being able to control the environment and research processes when researching in real life settings is also acknowledged by Styhre and

Sundgren (2005) and emphasises the differences in the paradigm from that of functionalist research using repeatable highly structured experiments.

AR is concerned with the apparent divide between: the academic community and practitioners; theory and practice. All AR approaches share the premise that knowledge needs to be closely connected to practical competence with variants of the AR cycle of action, reflection, implementation, action, reflection and so on, common to most approaches (Eikeland, 2007).

### **3.4 Section Three: Action research in health and social care contexts**

#### **3.4.1 The relevance of action research to health and social care**

AR is widely recognised as having a valuable application in health and social care contexts (Hart and Bond, 1995; Meyer, 2000; Waterman *et al.*, 2001; Reed, 2004; Stringer, 2007; Williamson *et al.*, 2012). A systematic review of AR in healthcare settings concluded that AR is suited to developing innovative practices over a wide range of healthcare situations, and can generate and develop creative ideas and changes in practice. Furthermore that it has the potential to play a role in achieving the NHS goals of: improving healthcare; developing knowledge; understanding and innovation in practitioners; and involvement in users and staff (Waterman *et al.*, 2001).

AR enjoys a growing reputation in health care research suggesting this may be due to the difference in its paradigm from traditional research (Bridges *et al.*, 2001; Coghlan and Casey, 2001). This reflects a growing awareness that a different type of approach may be needed to influence changing practice in complex health and social care settings (Hart and Bond, 1995; Meyer and Batchup, 1997) and enable practitioners to develop practices, processes and



skills to work more effectively. AR provides a useful approach for clinicians and managers developing services where quality, improvement, innovation, performance and productivity is focussed on (Williamson *et al.*, 2012). It demonstrates a non-hierarchical approach that is advocated in health and social care settings today, reinforcing the patient as expert, and removing professional barriers to people being involved in developing services they use. In order to provide services that reflect service user's views on what is required, organisations need to consider how to make best use of their workforce and reflect the more task-driven, problem-solving organisation advocated by Zuber-Skerritt (1996). Action research therefore with its emphasis on improving workplace practice, helping managers to develop professionally and implement change successfully is justified as the methodology of choice (Sankaran and Tay, 2003).

### **3.4.2 Service user involvement in health and social care settings**

Service user involvement in mental health services reveals four areas of concern: capacity to participate; lack of participation skills; need for positive organisational culture; and arenas for participation (McDaid, 2009). The difference that service users and carers make to service planning is recognised in governmental policy however there is very little monitoring of what difference that involvement makes (Carr, 2004).

Government policy first placed an emphasis on service user consultation in the 1970 NHS and Community Care Act, then increasingly on involvement with the modernisation agenda of New Labour and latterly with the personalisation of social care services however barriers to involvement exist that need to be considered. Principles such as: clarity of the aim of the involvement; honesty

about the potential for change; training for front line staff about the usefulness of involvement; extra time and support, sensitivity and clear communication are needed. Ensuring organisational commitment and agreeing how outcomes are fed back to service users must also be considered (Crawford *et al.*, 2003; Rose *et al.*, 2003). Some studies show that user involvement brings mixed blessings with increasing opportunities for involvement but many improvements needed to bring equality to the role that is more about decision making about scarce resources than service development (Wallcraft *et al.*, 2003).

For service users undertaking research over the past decade there has been growing emphasis by the DH on patient-centred services. This is reflected in various governmental guidance: Involving patients and the public (DH, 2001); Creating a patient led NHS: Delivering the NHS Improvement Plan (DH, 2005b); Research Governance Framework for Health and Social Care (DH, 2005a); and the Best Research for Best Health: NHS R&D Strategy (2006). There is also a growing body of literature on the principles of involving service users in research (Telford and Faulkner, 2004; Faulkner, 2004; SURGE, 2005). Whilst there is a growing awareness of usefulness of service user involvement in both research and service development there is little systematic evidence to evaluate its effectiveness and impact (Carr, 2004, Minogue *et al.*, 2005; Buckland, 2007). The need to ensure that staff routinely involve users and carers, are trained to do so, and importantly feedback on the experience of being involved and the outcomes of the research is argued by Minogue *et al* (2005). They consider this as part of the process that makes services relevant to the consumer involvement meaningful.

Telford and Faulkner (2004) describe mental health service users being involved in all or any stages of research and note that service user and researcher are not necessarily discreet categories, commonly there are overlapping roles. They also observe the distinction between user led or controlled research and user involvement in research often referred to as collaborative research. However fundamental ideological differences in approach may be a barrier to successful service user involvement in research though many organisations are overcoming these and demonstrating the value of involvement at all levels of research (Telford and Faulkner 2004).

Studies can demonstrate the competence and value that involving service users brings. One AR study involved people using mental health services to assess the competence of professionals undertaking professional training. Conclusions were that they were able to provide constructive meaningful feedback on professional's assessed work and during the course of the project their mental health improved, evidenced using a range of outcome measures, improving their overall situation (Bailey, 2005). Another example included patients with renal failure recruited as part of a participatory AR project to develop patient-centred care in Sweden which resulted in a number of planned changes to improve services (Blomqvist *et al.*, 2010).

A Health Technology Assessment into involving consumers in research and development agenda setting for the NHS concluded that productive methods for involving consumers require appropriate resources, skills and time to develop. Empowering consumers with information, support and resources to consult with their peers and prioritise topics; engaging consumer groups directly and repeatedly; and enabling consumer groups to influence research agendas; were

recommended. Further research to identify training methods, information and other support methods was also suggested and that consumers were well placed to reflect on their experience of research agenda setting and build on the evidence of their priorities and methods for involving them (Oliver *et al.*, 2004).

It is clear that service user involvement or controlled research needs a systematic evaluation of its strengths, weaknesses and impact in order to safeguard its future (Beresford, 2012) The role of experiential knowledge contributed by people with lived experience and its contribution to research currently appears to have less credibility than professional's knowledge and therefore more work to evaluate this area of knowledge management is required.

### **3.5 Section Four: Assessing quality in AR**

#### **3.5.1 Research validity, rigour and quality**

Questions of validity need to be considered within any AR study in order to ensure accurate data collection and transparency regarding interpretations of findings.

Questions include the validity of the data to examine the accuracy of what is collected and how researchers have affected the project in order to understand the process and outcomes of the study (Koshy *et al.*, 2011). This requires a reflexive account to be provided so that researcher's perspectives, background and experience are revealed as these may affect how data is interpreted. Biases and beliefs therefore must be revealed and addressed to establish internal validity (Williamson, 2012).

Waterman (1998) proposes three categories of validity regarding AR: dialectical; critical and reflexive. Dialectical has been discussed previously in section 3.3.4 as the AR movement between theory, action and research. Critical validity concerns

the attempt to improve people's lives by demonstrating the ethical implications and consequences of actions and theories through the emancipatory elements of AR. Lastly, the reflexive approach whereby biases or prejudices are analysed, attention is given to how interpretations are arrived at, and how the course of the research was influenced, also helps to rationalize threats to validity.

Data triangulation whereby different sources of data are collected and contrasted with one another, and feeding back information to participants provide other means of establishing validity and quality of research (Waterman *et al.*, 2001; Coghlan and Brannick, 2010; Williamson, 2012).

Reliability in AR, considering whether if the measure was repeated one would obtain the same result, needs also to be considered (Koshy *et al.*, 2011). This requires sufficient detail to be able to judge the extent to which the project could be replicated including the resources and local context (Koch and Kralik, 2006). Transferability is therefore possible if enough information is provided to assess whether findings would apply to similar contexts.

Conducting AR in your own organisation is opportunistic: the issue for research is happening anyway, whether or not you choose to research it. The actions of the project; the quality of the inquiry into how that inquiry progresses; and what knowledge can be extrapolated; needs to be differentiated. Research is then evaluated on the quality and rigour of the enquiry, rather than the success or not of the project where the insider researcher is responsible to the organisation (Coghlan and Brannick, 2010). Differentiation is therefore made between the researcher and the system in or on which the research is taking place similarly to the separation between the research quality and the success of the project as

proposed by Perry and Zuber-Skerritt (1992). In this way the focus of the researcher and the system can vary.

Winter and Munn-Giddings (2001) suggest that the debate about the validity of social enquiry needs to move from the dichotomy of objective truth and total relativism, with its own subjective or culturally determined truth criteria, to a continuum. Thus different types of statements are placed at different points on the continuum differentiated by the processes required to agree the conditions needed to verify them. In this way the authors argue that the value and purpose of AR's local narratives are not dependent on the theory of multiple realities and that truth is contextually relative. Instead AR inquiries promote good practice requiring a strong link between the rationale for the inquiry process and a reality that is fully shared between all participants. In this way AR reports describe the local process where consensus is reached concerning the generally shared truth criteria implicit in the outcomes. Thus AR does not claim absolute objectivity for its results however does accept the existence of an external reality that provides a final constraint upon interpretation (Winter and Munn-Giddings, 2001). Coughlan and Coughlan (2002) argue that action researchers need to combine advocacy with inquiry and to present all opinions, viewpoints and inferences as open to testing and critique so that with directly observable data this makes the reasoning explicit and testable.

As a key measure of quality in any research project is validity it is important to assess for validity in this AR project. Reason and Bradbury (2008) interpret validity to capture both rigour and quality and suggest that the following points need to be considered:

- Have appropriate research methods been chosen?

- Is theoretical integrity demonstrated?
- Do new working practices and processes emerge from the research?
- Is the AR reflexive and guided by practical outcomes?
- Does the AR project develop the practice of participation?
- Is the research significant?

Similarly Koch and Kralik (2006) pose questions based on Guba and Lincoln's (1989) work that defined validity as the means to assess trustworthiness of a project and as influential in interpretative inquiry:

- What is the world view?  
In AR participants validate findings in cycles of reflection and action and participation in the entire process ensures the findings are relevant.
- Is the inquiry credible?  
This is reinforced in AR when co-researchers are key producers and consumers of the research report.
- Is the inquiry transferable?  
Group actions are not transferable but theoretical notions can be transferred and understandings built on.
- Is the study dependable?  
Systematic research processes denote rigorous research. How data is generated, analysed and described is one aspect of that record.
- Is the study believable? The entire research process needs to be reflexive and visible to all involved people.
- What are the values and interests researchers bring to the inquiry?  
Continual self-critique and appraisal should characterize the reflective account which needs to be incorporated into the inquiry report.

- Is the work accessible? Participants contribute and should have access to all of the data and writings arising from the inquiry. Cycles of feedback are part of the process.

Winter and Munn-Giddings (2001) describe creating a culture of enquiry in practice settings where staff-members need to learn from and about their work in order to change and where criticism is seen as a part of the learning process. Evaluation is seen to be, above all, self evaluation, based in mutual support and involving client responses where the evaluation leads directly to action. They see that in health and social care organisations, service user movements are influencing practitioners and managers at all levels, leading to an increased emphasis on service users defining good practice. The authors suggest that the apparent conflict of interest is surmountable due to all having a vested interest in evaluating and developing services. However they do acknowledge that what goes on in organisations often falls short of the expectations that they outline (Winter and Munn-Giddings, 2001). This suggests that health and social organisations are increasingly receptive to the democratic approach of collaborative AR by insider manager and practitioner researchers. Whilst the growing involvement of service users and carers in developing services is acknowledged, other writers (Beresford and Turner, 2001) see it as falling short of the potential for involvement to make a real difference.

### **3.5.2 Generalisability and action research**

AR does not aim to produce generalisable results whereby the findings are applicable to a wide variety of contexts, as a means of establishing validity (Williamson *et al.*, 2012). Traditional standards of validity are inappropriate for AR (Waterman, 1995).



As AR projects are mainly located within the practitioner researcher's work site this does not provide a good prospect for representativeness of the data.

Research is not generally spread across a range of examples and is vulnerable to criticisms that the findings are not generalisable beyond the one case study.

Conclusions with universal applications are therefore not expected: it is the rigour of the project upon which it should be judged (Denscombe, 2007). However findings could be disseminated to others undertaking research in similar contexts who may wish to replicate the study (Koshy *et al.*, 2011)

### **3.6 Section Five: Researching your own organisation**

#### **3.6.1 'Insider' Research**

Coghlan and Brannick (2010) suggest three issues that action researching your own organisation produce:

*Role Duality:* The organisational role that you hold influences the degree of role confusion experienced as an inside researcher. If your sole role is an internal change agent then they suggest you are already an insider researcher. However if your role is that of a manager then you will have to manage dual roles with a high potential for role confusion and conflict. An example is needing to be totally involved and committed in your organisational role while the research role may require a more detached, theoretic and neutral observational position. Conflict between the two roles initially results in alignment with your organisational role however your involvement with the research role may set you apart from colleagues in your organisation. You may have to write a report with findings that are unpalatable to the organisation therefore it is essential to document evidence to inform difficult results. Managing organisational politics will be crucial to the insider researcher wishing to progress in their organisation.

*Secondary Access:* Primary access is the ability to be allowed to undertake research in an organisation which the insider researcher will have. Secondary access is access to the specific parts of the organisation relevant to your research which could be functional or hierarchical areas, and includes documents, data, people and meetings. Some insider researchers will find that particular avenues are closed to them because of their organisational position. Having high organisational status may mean access to more networks but exclude access to informal networks. Researchers who aim to publish need to be aware of the organisation's sensitivity to information being publicly available.

*Pre-understanding:* This refers to people's knowledge, insights and experience before they engage in the research programme. For the insider researcher this applies to theoretical understanding of organisational dynamics as well as lived experience of the organisation. Advantages of pre-understanding include having knowledge of organisational culture and informal structures with experience of what the organisation espouses and what its member's experience. However being part of this culture may make it difficult to stand back, observe and critique it. Researchers will therefore be close to the data but may make assumptions and probe less, or may be less inclined to ask questions than an external researcher. Insider researchers may have to work more explicitly at the process of enquiry being very close to the issues and may be less open to seeing this from other perspectives.

Coghlan and Brannick (2010) conclude that doing AR in your own organisation involves clarifying the project in terms of both your own and the systems commitment to learning in action and managing the issues of role and secondary access. The action researcher also needs to manage the potential for bias for

example in the design of the research, which may increase in potentiality the more senior the role the action researcher holds in the organisation. In relation to this study the question of bias will be considered in Chapter Four where the research design is discussed.

Williamson and Prosser (2002) suggest three main areas of dissonance for insider researchers. These are; being perceived as a threat to the status quo due to asking how to do things differently; challenging existing power relations as AR tests the commitment of the organisation to develop its learning from practice and thirdly, conflict with existing power relations when having uncovered areas needing change those more powerful tell them they have no authority to change this for yourself. This can expose 'insider' action researchers rather than traditional researchers. Generally however the literature implies that insider research is likely to be more successful (Coghlan and Brannick, 2010). Also that it is increasingly being practiced within the changing context of research with universities now making considerable contributions to practice (Perry and Zuber-Skerritt, 1992; Coghlan, 2001; Coghlan, 2007, Coghlan and Brannick, 2010).

Issues of organisational concern such as change projects, systems improvement and organisational learning are suitable for practitioner action research as they are real events to be managed, provide opportunity for action and learning, and may contribute to the theory of what really goes on in organisations (Coghlan, 2007).

Certain projects may however be best undertaken by external researchers, just as there are ones better suited to insider researchers. Sometimes the issue is confounded by roles and relationships changing during the course of a project

whereby insider researchers may become defined as an outsider and an outsider may move into an insider role (Hart and Bond, 1995). With the growth of partnership working particularly in health and social care the issue of insider/outsider becomes more blurred with assigned and seconded staff from other organisations that may be undertaking research. Additionally consideration of the organisation's readiness for an AR inquiry during the planning of an AR project is advocated by Zuber-Skerritt (1996). She also suggests that a move from traditional hierarchical organisations to problem-solving task driven learning organisation is required for revitalisation and is more conducive to AR.

### **3.7 Section Six: Political and ethical considerations of action research**

#### **3.7.1 Political Considerations**

All research of whatever kind has political dynamics involving internal and external stakeholders. Coghlan and Brannick (2010) argue that doing AR in your own organisation is particularly political. Examining, listening, questioning and democratic participation, as emphasised by AR, may be threatening to organisational norms. They suggest that you need to be politically astute to engage in AR; prepared to work the political system; and balance the organisation's justification of your project with your personal justification, whilst maintaining your credibility as a change agent and political player. This means assessing stakeholders for their power and interests in relation to the project. Ten key power relationships are suggested to manage the power-political processes of ensuring legitimacy of your project, with the authors concluding that attention to all ten is required to build support and involve key people. I have compared these key power relationships to this project, shown in Table 3.1 below:

Description of Power Relationship	How this affects this AR project
1. Relationship with your sponsor- Either immediate superior or elsewhere in the organisation. This relationship must be maintained to ensure continuation of the AR	<i>The project sponsor is the Lead Researcher's manager. The project is part of her work plan to be achieved.</i>
2. Your credibility and access may depend on your sponsor's organisational standing and their power relationship in the organisation which may be critical to the research being accepted from higher management	<i>The sponsor is a Trust Director.</i>
3. The power dynamics between departments may be relevant to promoting or blocking the research. This is particularly significant for insider researchers as exercising control will be difficult	<i>This is relevant to ensuring that the project is recognised as important across all Trust Directorates</i>
4. Relationships between researcher and significant others need to be established in order to maintain profile and the project.	<i>Project dissemination is part of the AR cycle in order to maintain its profile within the Trust and other involved organisations</i>
5. Senior management may undermine the research or withdraw consent which may be difficult to influence if you do not know them	<i>This is unlikely. The Trust is committed to research and to the envisaged outcomes of the project on which it will be externally performance rated.</i>
6. Relationships between managers and workers is important so the organisation accepts the research	<i>My integrity and that of the other managers involved in the study is vital in order that the research is accepted</i>
7. Some departments may have more power than others, which may work for or against a particular research project.	<i>I work strategically and operationally with good access to areas that may not recognise the project as important</i>
8. The relationship between researcher and their subordinates, whom they rely on for information, is key. Honest feedback being dependent on behaviour/management style	<i>Clarity of purpose, and a style of approach welcoming criticism and suggestions is vital</i>
9. Relationships with clients who may be the ultimate beneficiary of the research may raise political complexities around raised expectations of service provision	<i>This is an extremely valid observation relevant to this research project which will need to be considered in the data analysis</i>
10. Relationships between the researcher and their peers are particularly sensitive especially if they are the subject of observation and comment. Being wary of bias, due to close relationships, needs to be considered	<i>All comments and observations will be shared to ensure there is an agreed interpretation of events and viewpoints</i>

*Table 3.1: Key power relationships adapted from Coghlan and Brannick (2010:129-130)*

The theme of conflict and consensus is described by McNiff and Whitehead (2002) when action researchers espouse people's rights and democracy but conversely rule people out of the decision making process. The contradictions exist in the continuation of a power relationship that positions the researcher external to the situation, making judgements about other people. For some, the

authors suggest democratic models are applied rather than lived, seen as 'convenient discrimination rather than moral commitment' (McNiff and Whitehead, 2002; 33).

Politics is highly visible in AR because of its fundamental aim to influence people to change their situation (McNiff and Whitehead, 2002). Thus the theme of empowerment is fundamental and may cause political disagreements if, for example, an AR project results in a huge demand for a new service but no budget to afford it. AR as a form of social change with political dynamics within an organisational work context needs to be recognised (McNiff and Whitehead, 2002; Coghlan, 2001, 2007) and organisational and political conflicts planned for and managed (Williamson *et al.*, 2012). AR involves questioning organisational and individual practices and thus requires a degree of political acumen to succeed (Williamson and Prosser, 2002). In this study the ethics of personalisation implied a power shift from professional to service user and therefore involved work of a political nature to change attitudes and former professional practice to reflect an altered state of power relations affording more equality in professional – service user relationships.

Politically influential knowledge conventionally takes the form of statistically or theoretically based generalisations established by experts and promoted through organisational power hierarchies. In contrast AR attempts to create non hierarchical relationships as key to the inquiry process, and knowledge in the form of personal narratives giving voice to those who are silenced by conventional structures. Whilst in the NHS patients being experts by experience is espoused this may not be practiced in actuality. Thus practitioners' knowledge not academics, and service users' knowledge not professionals, is emphasised. As

such, AR risks being marginalised or rejected by senior managers as lacking reliability and validity of conventional research. Reservations from those with political influence has to be taken seriously for practical reasons and AR projects must be sound and convincing as the best process of inquiry (Winter and Munn-Giddings, 2001). Working in partnership forces students to appreciate and confront power differentials within therapeutic relationships and take more account of service user preferences which enhances student learning (Tee *et al.*, 2007)

Koch and Kralik (2006) describe some participatory AR prioritising working with oppressed groups of people, where exploitation, sexism, racism, marginalisation and inaccessibility are apparent. The authors note that this is inherently political when the aim is to restore to oppressed people knowledge to enable empowerment. Further that some research in this area is with the aim of actively revealing the ways that the establishment controls the use of knowledge, in order to expose power relations. The authors suggest that how power relations are mediated is a central concept in participatory AR. They recommend that the researcher and participants develop strategies for the inquiry to be used as a platform for voices of those involved to be heard and that personal experience and values of the researcher are an important component in this. Collaboration and equality are encouraged to create interactive dialogue and the mutual creation of data.

Reason (1998) discusses power relations on three levels. The first, being able to directly influence events, such as a person being directly involved in decisions about their care. Secondly, allowing participants to influence the health agenda, for example, deciding they want alternative therapies that were previously

excluded. Thirdly, recognising power relations and questioning authority. Where other's perspectives are recognised and valued this leads to a democratic attitude and participative behaviour but only thrives in a supportive environment. Reason (1998) sees capacity building with people as inevitably leading to confronting authority, with patients questioning authority being treated with suspicion or hostility and suggests that participants need to learn to sustain such confrontational environments. This is pertinent to AR within health and social care settings where a participative approach is taken with the aim of empowering participants involved in projects.

Coghlan and Brannick (2010) suggest researchers often think they have little power because they are dependent on others in the research process however others may see the researcher as powerful because they are knowledgeable, select who to involve, and their view of reality is publicly visible. This raises ethical issues which need examining.

### **3.7.2 Ethical considerations**

Attention to ethics is required in every research project and irrespective of the difference between AR and conventional research many of the ethical principles that guide social research are important and relevant to AR. These would include informed consent, protection from harm, honesty, confidentiality, and withdrawing from the project (Bellman, 2011a). In AR however the participative process suggests ethical considerations extend to more than not breaching confidentiality, not doing harm and not distorting data.

Authentic collaborative relationships involving open decision-making between researcher and participants need to be considered and resolved (Coghlan and



Brannick, 2010). Hall (1996) describes this in relation to emancipatory AR as researchers having ethical and political obligations to be reflexive in their research methods. The concept of reflexivity can be variously interpreted including being aware of our own perceptual biases. Winter, (1996) and Hall, (1996) describe it as monitoring and reflecting on the research including acting responsively on the methods employed and being self conscious about how one's doing of the research, as well as what one brings to it, can shape the way the data is interpreted and treated. Hall (1996) refers to this as constitutiveness and states it is complete when this awareness is incorporated into the research report.

Williamson and Prosser (2002) however refer to the political dissonance and ethical ambiguity as a consequence of collaborative working, as the closeness may generate new knowledge and change, but is also problematic. The authors suggest clarifying these areas before the research project begins.

The ethical code for health practitioners is subsumed within the ethical code for AR sharing a guiding impulse to improve people's situations involving a practical responsibility for others' well being. Winter and Munn-Giddings (2001) suggest all aspects of an AR project are meant to be directly beneficial for the participants themselves. They argue that the initial ethical principle include those of the professional relationship itself with underlying principles of the duty of care; respect for the individual irrespective of race, gender, age or disability; respect for cultural diversity; respect for individual dignity and protection from harm. Coghlan and Brannick (2010) list the following ethical issues in AR:

- Negotiating access with participants and authorities.
- Confidentiality in all aspects.
- Ensuring participant's rights not to participate.

- Keeping relevant others informed.
- Obtaining permission to use documents owned by others.
- Maintaining your own intellectual property rights.
- Being trustworthy and checking with others around misunderstandings.
- Negotiating with others about publishing their work and points of view.

Winter's (1996) principles for AR echo these issues adding the need to ensure the work remains visible and open to suggestions and influence from others and that the principles guiding the work are accepted by all in advance. He stipulates that action researchers need to follow a vigorous intellectual discipline ensuring the conclusions are broadly based, balanced and grounded in the perceptions of a variety of others. He argues that this results in objective and truthful outcomes in that the understanding of meaning is obtained by achieving consensus if possible amongst the actors.

The project itself can be considered as an ethical consideration since the researcher is asking people to devote their time to it. Whilst in principle it is for improvement and understanding of practice and should benefit all participants the danger may be that there are underlying motives of obtaining a qualification or enhancing career prospects for the researcher. They suggest the project should be planned so that its value for all participants should be obvious and immediate (Winter and Munn-Giddings, 2001).

There are additional factors to consider in participative AR where participants may be considered vulnerable. Tee and Lathlean (2004) in their study of mental health participative research involving service user co-researchers look at the guidance

for safe practice in involvement of users. They suggest that the lead researcher should constantly assess the co-researchers competence to continue, including risk assessments in relation to the emotional demands awakening past experiences. The lead researcher was seen to be pivotal to ensuring, through observation, interview and supportive sessions, the co-researcher's well being throughout the research period. They found that no studies had used any form of tool to monitor competence. Furthermore they found that the guidance for safe research did not give a definition of vulnerability but that the lead researcher needs to be able to use their knowledge of the research process, communicate fully the role of the co-researcher, and continually review their ability to make informed choices. It is noted that a lead researcher with previous clinical experience can make use of this to support, debrief and enable co researchers to participate as fully as possible.

Ethical principles of respect for individual dignity, diversity, the duty of care and protection from harm are particularly relevant in this study. Service user and carer co-researchers are integral to the steering group together with professionals, where ground rules for conduct and communication will need to be observed. Debriefing and feedback sessions are built into the research design as a means of supporting the co-researchers involvement and ensuring that any issues around conduct or communication are openly discussed and addressed.

### **3.8 Section Seven: Using action research in this study**

This section examines the model of AR chosen for this study, the rationale for that and the implications that being an insider researcher will have on the study.

### **3.8.1 The action research approach used in this study**

This chapter describes many different types and interpretations of AR. These include the simple spiral of diagnosing, planning, taking and evaluating action as described by Coghlan and Brannick (2010) (Figure 3.2) and similarly by McNiff and Whitehead (2002) in a spiral of reflecting, planning, acting and observing (Figure 3.3). Both authors then modify their descriptions to add layers of complexity with Coghlan and Brannick (2010) incorporating organisational dynamics into the cycle (Figure 3.4) and McNiff and Whitehead (2002) refining their concepts to more represent unexpected cycles. I have considered my study in relation to both of these authors and their models of AR in acknowledgment that both contributed a helpful approach for me in undertaking and writing up this project. The other approach that I have found useful to consider is that of McKay and Marshall's (2001) construction of dual cycles of action and reflection on action. These approaches were helpful to me as a guide in this project and illustrative of the various stages relating to action and research in this study. Other authors prefer to describe AR in terms of its principles rather than a model (Stanton, 1989; Zuber-Skerrit, 1996; Winter, 1996; Koch and Kralik, 2006) with Hart and Bond (1993) distinguishing AR through typologies. As AR is a flexible methodology that is ideal in a constantly changing clinical environment it is a suitable choice for this project. It also has an immediate relevance as variables are acknowledged and considered rather than controlled (Koch and Kralik, 2006).

This AR study is one where I was researching my own organisation whilst leading on a project implementing large scale change in systems, professional practice and outcomes for people needing social care resources in mental health services. It is important therefore to consider the issues inherent in researching your own organisation. The issue of senior people initiating change at grass roots level as

described in section four by Hart and Bond (1995) may be seen as applying to this AR project, as whilst it is partly about systems change it also seeks change at grassroots practitioner and service user and carer level. The ideology of reform and improvement in health and social care services points in the direction of AR at individual practitioner level and within organisational structures and processes (Hart and Bond, 1995; Bridges and Meyer, 2007; Koshy *et al.*, 2011; Williamson *et al.*, 2012). This is echoed in this study: participants are familiar with ongoing evaluation built into projects which incorporates reflection on previous actions; consultations with those affected by the change; and modifying actions as the next stage.

Winter and Munn-Giddings (2001) argue that AR is a model of research that arises naturally out of our practical experience of work, which presents opportunities for critical, constructive reflection. This resonates with the context of constant innovation and change in mental health services and the ethos of continuous evaluation and improvement as an underlying premise. Mental Health Trusts have job roles specifically around gathering patient and service user's views. Participation and feedback on services is built into manager's job descriptions and planning systems are designed to incorporate views from those using services and reflect practitioner experience.

The aim of any AR program is to bring about practical improvement, innovation or development of social practice, and for practitioners, improved understanding of their practices (Zuber-Skerritt, 1996; Coghlan and Brannick, 2010; Koshy *et al.*, 2011). This project incorporates all these aspects as overall aims with an emphasis on innovation and practical improvement for those receiving the services under change. It depends on individual practitioners accepting the

premise underlying the innovation: that of service user's self-assessment and ability to choose and arrange their own social care services, as to whether they would agree this constitutes improvement of their practice. Success of the project may not just depend on the implementation of individual budgets for people requiring services, but how these are offered by workers, as this will have an impact upon take up of opportunities.

The implementation of Self-Directed Support as a project inquires into both changes in professional practice through altered professional roles, where service users have more autonomy and control, and how that change is perceived by people receiving mental health services. This change is one promoted by the government based on the premise that people using social care services should have more power and control over the process. It has yet to be fully tested in mental health services therefore an AR approach to its implementation would appear to be the most relevant.

Full involvement of service user and carer co-researchers throughout the course of the project is built into the research design. The project involves stakeholders from within the NHS Trust, Local Authority and other mental health organisations. An expected outcome of the project, from an organisational perspective, are more empowered people who use mental health services, People, who can manage their own Personal Budget and take more control of their own lives by having a greater say in what personally tailored services they want. This suggests the use of a participatory AR approach therefore the research project will follow the AR cycle described by McNiff and Whitehead (2002) with an added degree of uncertainty incorporated into the cycle to allow for unexpected changes to the

programme and a degree of built in flexibility that the authors argue is required in AR.

Increasing complexity is certainly reflected in my experience of organisational management of change projects where unexpected events can change the course of outcomes despite tight planning. The growing emphasis in mental health services on partnerships with independent and third sector health and social care agencies, increases participants, and the likelihood of complexity within any AR project. In this AR project unanticipated pressures due to the nature and power of partner agencies is likely with resulting turns and twists that cannot be envisaged at the outset.

External influence from organisations with an overarching interest in the project's implementation and outcomes could also increase complexity: the Local Authority that provides the budget; local service providers whose businesses may be affected; or government agencies. Alterations due to internal reflections on progress so far could also cause the project and research to change course from what was expected. This reflects the experience of the organisational dynamics of this study where work with individuals, teams, across organisations and between different organisations impact on the orderly progress of the AR cycle and may cause the cycle to be interrupted.

.A model of AR incorporating the meta-cycle of inquiry as conceptualised by Coghlan and Brannick (2010) shows the AR cycle incorporating content, process and premise reflections that were categorised by Mezirow (1991). This meta cycle of inquiry includes studying and evaluating the content of what is diagnosed, planned, put into action; the process of how actions and decisions are taken and

evaluation is conducted; and finally the premises underlying actions and decisions including attitudes and assumptions that govern behaviour. Within an organisation there are further dynamics and extra layers of complexity due to working across different teams and groups with each having differing viewpoints, interests and possibly cultures. This AR project as it is across different organisations increases the likelihood of extra complexity due to the diverse political interests and alignments, cultures and resultant attitudes and behaviour.

Below (Figure 3.4) is a representation of the meta learning applied to this AR cycle including the added layer of organisational dynamics. The figure indicates the part of the enquiry, i.e. premise, content or process, which the different organisations appear to be most interested in influencing and the perceived intensity of that interest.

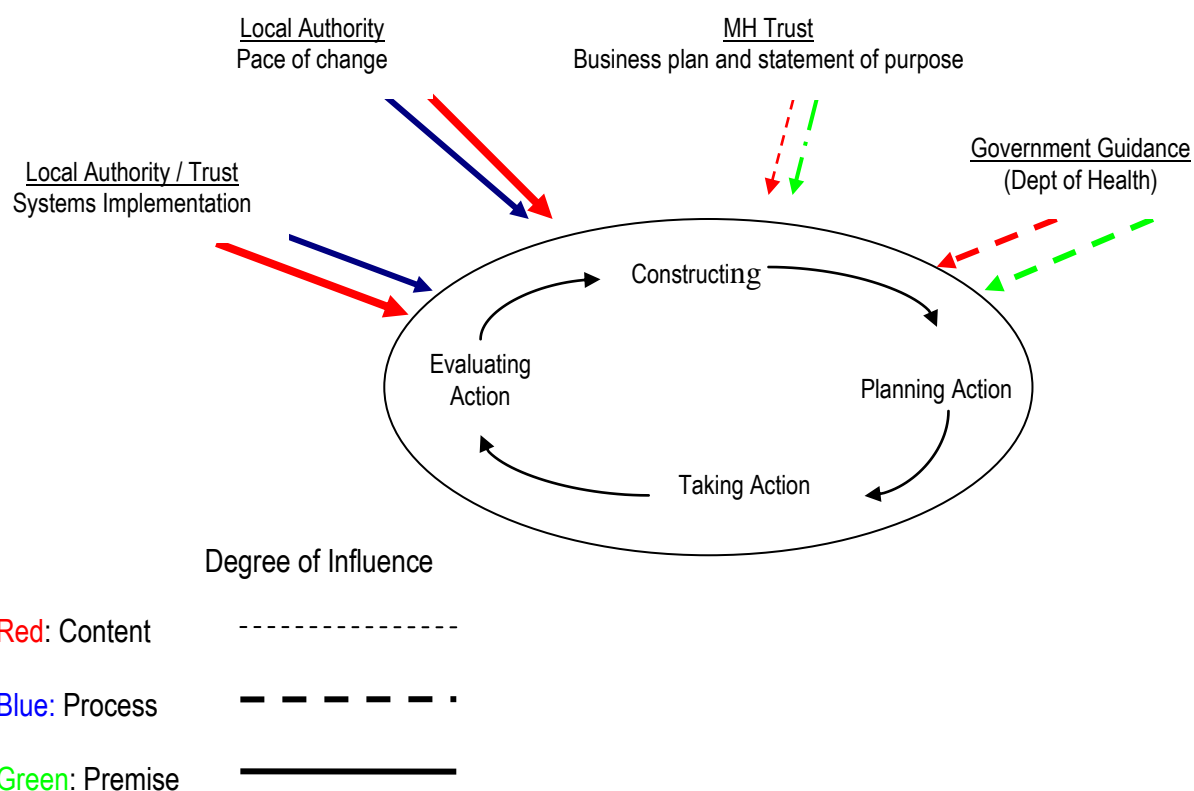


Figure 3.4: Meta cycle of inquiry incorporating organisational dynamics:  
Adapted from Coghlan and Brannick (2010: 12)



### **3.8.2 The implications of being an insider researcher**

This AR study was based in the lead researcher's organisation with the involvement of participants from other organisations and service users and carers. It is therefore described by Coghlan and Brannick (2010) as insider research as it is ones own organisation. The main work of the project will be changing processes and culture within the organisation in which I work this requires considerable input from other organisations, in particular the Local Authority, in the change process.

In my managerial role I work with the other key organisations with a partnership remit and a reporting role. I work also with service users and carers in explaining, advising and developing services. Part of my role is as an internal change agent and as such Coghlan and Brannick (2010) suggests low potential for role confusion between researcher and manager. Vulnerability to a range of competing academic, professional and managerial issues can be as a result of the competing demands placed upon the researcher: the managerial role and required outcomes expected from the organisation; the academic requirements which may not be understood by the organisation or all of the participants; and the collaborative role of the action researcher which may be compromised by either of the former demands (Hart and Bond, 1995).

I have relatively high status within the organisation as a senior manager immediately below Board Director level, but the project incorporates grass roots involvement with an aim of incorporating a 'bottom-up' approach. This might be treated with suspicion by some participants who may associate the research with senior hierarchy (Hart and Bond, 1995). However I have spent many years developing networks with individuals within and outside of the organisation; developing services using a non-hierarchical collective approach to improve

mental health community resources; and am regarded as someone with whom individuals from all levels, including service users, can make direct contact. My position enables access to most parts of the organisation and relevant parts of the Local Authority far easier than if an external researcher was commissioned.

The lead researcher may experience role duality as described by Coghlan and Brannick, (2010) in that the demands as a researcher and as a manager will be different. The researcher role demands rigour in the research process rather than the success of the implementation of the project. The demands as a manager however may be that the organisation has high expectations that the project will result in an efficient implementation of Self-Directed Support.

I had considerable 'pre-understanding' (Coghlan and Brannick, 2010) of the culture, key players and decision making processes both published and covert which provided advantages, requiring particular care to look objectively at processes due to the danger of being immersed in how the organisation works, and accepting this without probing and inquisition.

### **3.8.3 Quality assurance and rigour in this study**

Quality, validity and rigour are all ways of assessing whether or not an AR study stands up to scrutiny. As discussed when considering validity, rigour in AR studies is not demonstrated by the usual scientific methods employed by positivist research. This study was designed with four service user and carer co-researchers working with me who were able to challenge any personal interpretations and ensure rigour is paramount.

A reflexive approach using the collaborative steering group and the co-researchers to adopt a form of collaborative reflection about what constitutes data will be used. Discussions and the sharing of written material will be used to check out objectivity with the aim as far as possible of consensus of viewpoints and opinions or the recording of differences where consensus is not achieved. This provides a means of checking my interpretation of events by sharing these with other participants and being open to critique and challenge.

More specifically the work of two authors will be used to pose questions on how rigour is evidenced in this study:

Firstly, Coghlan and Brannick (2010) who suggest evidencing rigour by demonstrating:

- Discussion of the reflexive nature of the work.
- How different views of events are secured.
- How different views challenge the work.
- Multiple cycling of the AR cycle.

Additional they suggest that three questions need to be asked:

- What happened? - the telling of a good story. (In addition this would need to be an accurate account)
- How do you make sense of what happened? - rigorous reflection of that story.
- So what? This deals with extrapolation of usable knowledge or theory from the reflections on that story.

Secondly, the suggestions of Williamson et al (2012) will be used to test rigour in this study. These are that the study: generated new knowledge; produced change; engendered an ethic of participation; demonstrated rigorous methods and transferability.

In summary using the work of the aforementioned authors provides the means to check the quality, validity and rigour of this AR study in the telling of the story; processes, progress and pitfalls; data collection and analysis including methods and reflections on these and the final learning and reflections on the research project.

### **3.9 Summary**

In this chapter I have outlined the methodology of AR as research which aims to both generate new knowledge and to solve a problem by providing new solutions. It is concerned with improvements in practice, organisations and communities. AR is about taking action and studying that action as it takes place in a collaborative approach. Above all the skill required is that of critical self reflection and more particularly in this project combining advocacy with inquiry.

Having selected an AR design I then had to select the methods of data collection and analysis within that design to form my whole study. These are discussed in detail in Chapter Four.

## **CHAPTER 4: METHODS OF DATA COLLECTION AND ANALYSIS**

### **4.1 Introduction**

This chapter discusses the design of the project, the different methods of data collection employed and the data analysis. It is structured in five sections; section one covers the study's aims; section two considers the study's design; section three discusses service user and carer co-researcher recruitment; methods of data collection are considered in section four; section five addresses ethical approval; data analysis is considered in section six and section seven concludes by summarising the main data collection and analysis methods discussing their relevance to this study.

### **4.2 Section One: Aims of the study**

The aims of this study were to design, develop and evaluate Self-Directed Support within mental health services and to better understand service user, carer and practitioner views of this service development.

In the context of the overall aim the research objectives were to: explore obstacles and enabling factors to implementing Self-Directed Support with particular reference to service users, carers and clinicians in mental health services; better understand and learn from the process of implementing a new service development from organizational and personal perspectives; explore views on Self-Directed Support from service users and carers who have current or recent experience of using mental health social care resources; and increase understanding of the nature of involvement in developing services, from service user and carer co-researcher's perspectives.

### 4.3 Section Two: Design of the study

This study uses AR methodology, where the precise plan of the research project was not specified in advance, as it depended on the agreed actions of the collaborative steering group. However from the outset a series of focus groups with service users and carers were envisaged as part of the research study. The collection of data from meetings with practitioners, organisational reports and my reflective diary was proposed to provide additional qualitative data.

This study incorporated the approach of a steering group comprising a range of involved professionals and other stakeholders including the service user and carer co-researchers. This was one of the fundamental methods by which the collaborative process of the inquiry was conducted, and the spiral nature of the AR methodology process was applied to both conduct the research and produce change. The steering group was involved in agreeing the study design which was adapted from Coghlan and Brannick (2010)

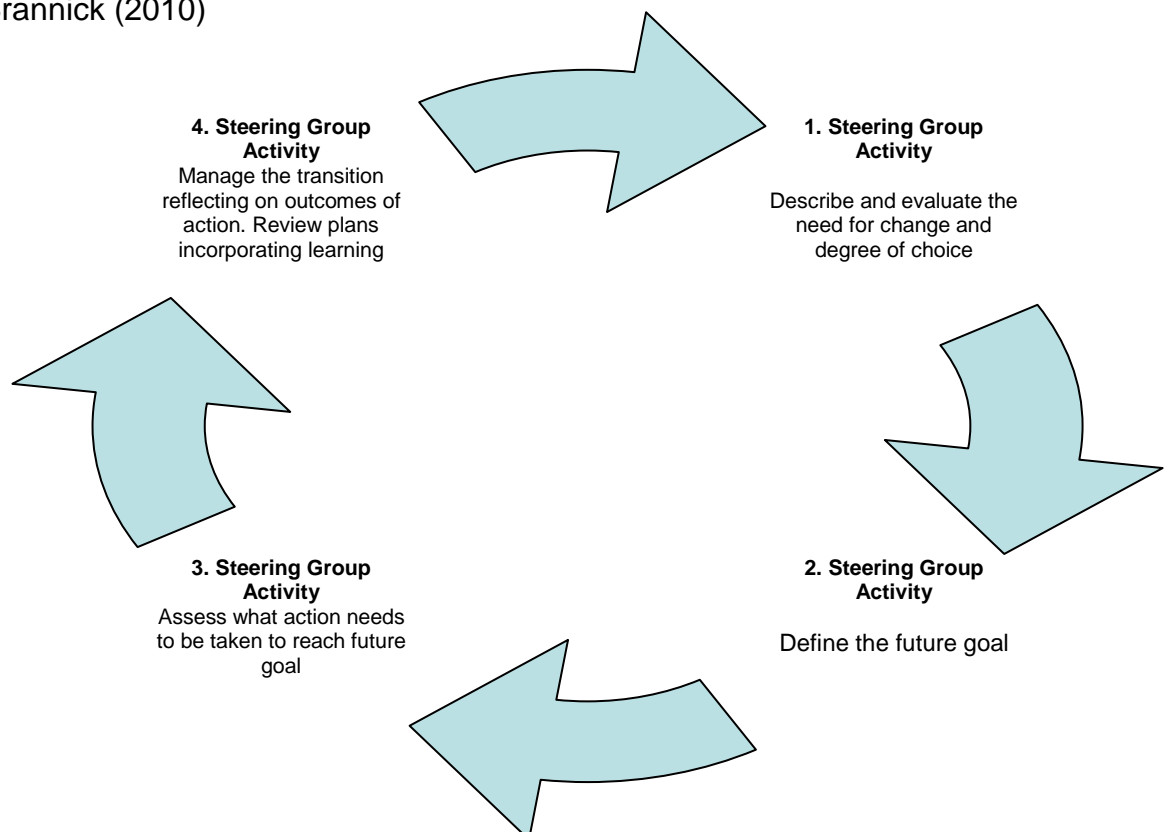
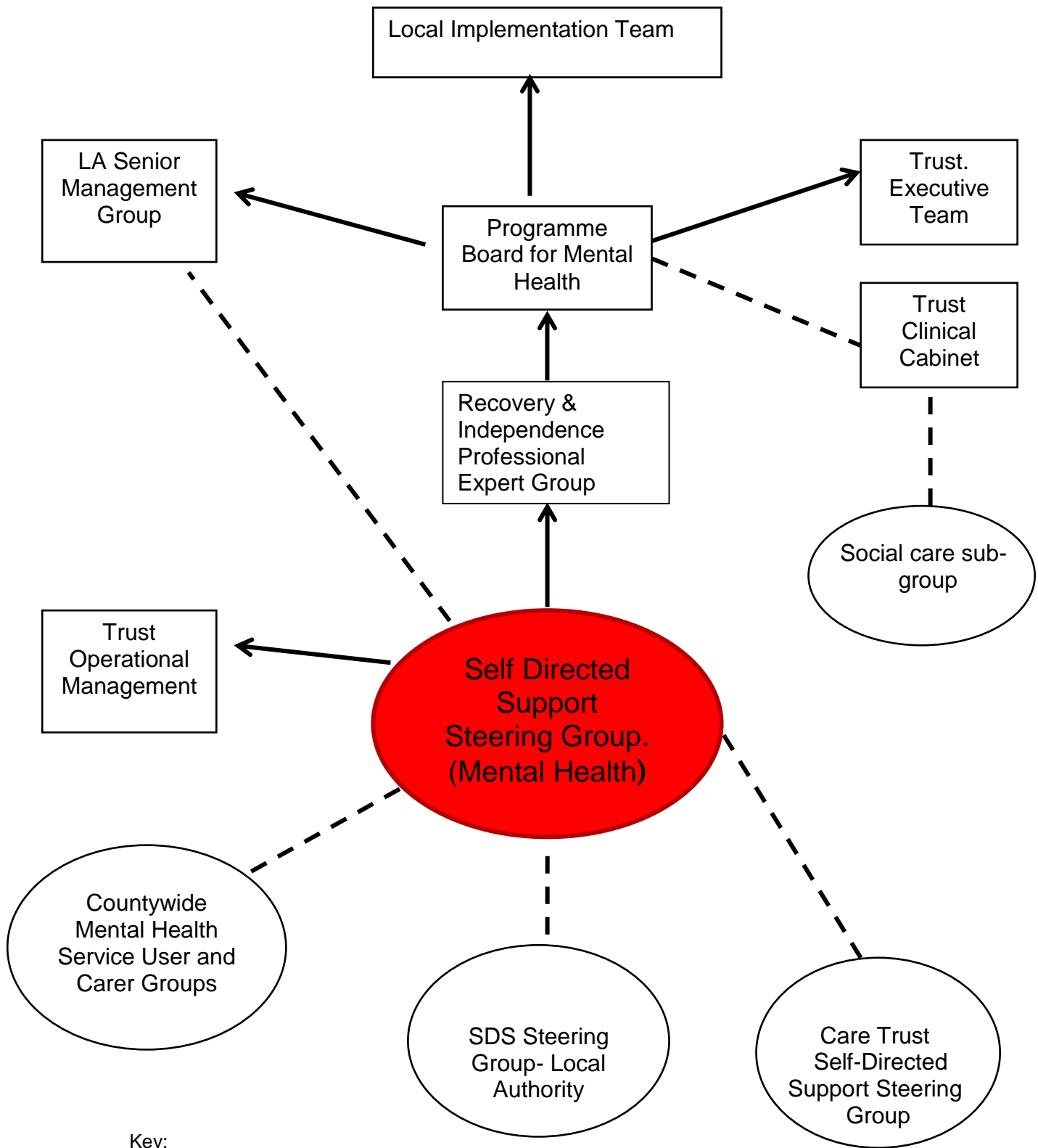


Figure 4.1: Study design showing the pivotal role of the steering group: adapted from Coghlan and Brannick (2010:8)

The role of the steering group however, needs to be viewed in relation to external and internal influences on the process and cannot be seen as stand alone. Figure 4.2 below shows where the steering group sat within the other strategic and decision making groups within the Trust, highlighting the complexity of organisational changes, decision and communication processes. This included the need for a dual reporting mechanism due to the Trust having Local Authority assigned budgets. Reporting was required to that organisation as well as the mental health Trust and the Local Authority was very influential in the development of Self-Directed Support using their assigned budget.

As the key to Figure 4.2 suggests, the steering group reported through a complex system. Provided the group functioned within the parameters that were agreed at its inception then there was little power coercion from the Trust or Local Authority. If however the steering group suggested means of implementing Self-Directed Support that were not deemed acceptable, or beyond its authority to put in place, then the Trust and Local Authority could exert power to bring the steering group back into accepted practice. Figure 4.2 shows the reporting system.



Key:  
 Bold lines: Direct accountability and reporting  
 Dotted lines: Consultation and information provision

Figure 4.2: Self -Directed Support group: Reporting, consultation and decision-making arrangements from 2007-2010



<b>Member</b>	<b>Role</b>
1.Head of Contracting and Provider Partnerships	Chair and lead researcher
2.Service User 1 (D)	Co-researcher
3.Service User 2 (S)	Co-researcher
4.Service User 3 (Ge)	Co-researcher
5.Carer 1 (G)	Co-researcher
6.Carer 2 (M)	Co-researcher
7.Service manager from the third sector	Third/independent sector representative
8.Contracts manager	Local Authority contracts expert
9.Commissioning manager- Unitary Authority	Unitary authority representative and provider of expertise in relation to implementation of SDS in Learning Difficulties
10.Direct Payments Team Leader	Direct Payments expert from Local Authority
11.Operational manager	North and Mid Trust representative
12.Operational manager	East and Central Trust representative
13.Operational manager	South and West Trust representative
14.Finance manager	Local Authority finance lead for contracted services

*Table 4.1: Membership of the Self-Directed Support steering group*

An underlying design principle of this project was that a number of people currently accessing services would be involved as user and carer co-researchers. Involvement incorporated both the aims of empowerment for those researchers and additional expected benefits to the research by bringing: additional diversity of views to the collaborative steering group; research authenticity through including experiences from people using services; positive contributions to the research design and methods; generation of new knowledge and understandings; more explicit and reflective responses from participants and ; enhancement of the data analysis by working together and coming to joint agreement. From the researcher's perspective Faulkner (2009) suggests motives for involvement of service users include: encouragement of involvement within policy guidelines; enhanced quality of the research and its outcomes; increased satisfaction from the research and a belief in social justice (Faulkner, 2009).

## **4.4 Section Three: Service user and carer co-researcher recruitment**

### **4.4.1 Recruitment process**

Recruitment of service users for Trust collaborative projects was not an embedded systematic process although in some parts of the county Service User Participation Workers were employed acting as the conduit for referrals. The Trust Research and Development Department did not have a pool of service users and carers trained and available for projects. To recruit a pool of service users who have accessed training in research processes, and were interested in involvement, was a future aspiration of the department. However future research is likely to require selective recruitment of people with recent experience of receiving particular services or with particular conditions. This may mean such a pool would not fulfil all requirements and may be self-limiting.

Faulkner (2009) agrees that the ability to recruit people who are particularly appropriate in terms of a common interest, knowledge and experience in a specific area of mental health service may provide a better solution and make the research more relevant. Research into improving user and carer involvement in commissioning and reviewing mental health services by Dickens *et al* (2006) considers this. They suggested that strategic recruitment of representative groups needs considering in future user/carers involvement. Recruiting service users and carers with relevant experience was a principle adopted in this project, designed so the co-researchers would have increased confidence in the research subject area, and be able to contribute their lived experience to the project. Banongo *et al* (2006) in their research with forensic mental health service user co-researchers demonstrated that users could not simply be advertised for but had to be actively sought out and encouraged to take part. They found that past experiences of research had discouraged many from wanting to take part. In this study it was not expected that service users would

have been previously involved as research participants, however encouragement and support may be needed to make initial contact due to lacking confidence through the debilitating effect of their mental health problems.

The values of transparency, openness, equality, empowerment, feedback and involvement are suggested as basic principles for any public and user involvement (Western Health and Social Services Board, 2005). In this project, to ensure that these values were applied, a contract was agreed with the co-researchers, and included in the design with the intention of alleviating cynicism and providing clarity about my motives.

The service user and carer co-researcher posts were advertised through the service user and carer networks set up by the Trust. The networks were groups that met facilitated by the Service User Participation Workers. Applications were invited by letter. A co-researcher job description was written with an attractive remuneration (nearly twice the minimum wage) and subject to signing an honorary contract with the Trust. The hourly rate was agreed by the Trust for people undertaking more complex roles such as research where full participation was required. Providing an estimate of the annual cost of payments ensured there were no obstacles to these payments being made on my authorisation. The Trust had standard honorary contracts in place, for the purpose of recruiting service user and carer researchers that covered ethical and practical issues of data protection, confidentiality and insurance cover. This indicated that the Trust had already considered how user and carer involvement could be legitimised and some of the ethical issues dealt with.

Informal interviews with the potential co-researchers were set up to assess their understanding, lived experience, knowledge and experience of social care resources

in mental health services, training needs and any other relevant issues or facts relating to the project. There was no defined or agreed process for recruitment of service users in research within the Trust. The recruitment process, and in particular the interview questions, were designed on suggestions found in the literature on service user and carer researcher recruitment (Carrick *et al.*, 2001; Alabaster *et al.*, 2002; Simpson and House, 2002; Barnes and Mercer, 2003; Rose, 2003; Involve, 2004; Tee and Lathlean, 2004; Branfield and Beresford, 2006). Recruitment was also undertaken in consultation with research and development staff, the Trust Head of Social Work acting as a critical friend in the research process, and my manager who agreed the job description I drafted. The roles were advertised in the service user and carer networks alongside information about the project and how to contact me for a discussion. Those people wanting to be considered were asked to write to me, explaining their interest in the role and their experience of receiving social care services.

It was planned to limit interviews to people who were actively using mental health services but not currently acutely unwell or detained under the 2007 Mental Health Act (DH, 2010a), and who had experience of receiving social care commissioned resources. An application deadline of three weeks from the advertisement date was set. This added an additional week to usual Trust practice and allowed extra time for service users and carers to access the advertisement considering the impact of any caring role or the effect of their mental health problem on the process. Additional support and time to come to a decision about making an application was likely to be needed. It additionally allowed for alternative means of knowledge such as service user and carer group meetings to publicise the recruitment.

Integral to the interviews was the opportunity to provide further information about the project, its aims and research methods; and the opportunity for the potential co-researchers to ask questions about their roles and any related matters. An interview schedule for each interview was drawn up and included specific questions designed to ascertain what motivated people to apply, as well as seek their relevant knowledge and experience.

The interview process was designed to recruit suitable people to the posts of co-researchers and to form part of the research process. The interview questions asked about their relevant experience and knowledge in relation to the role and practical issues such as availability of transport and their time (see Table 4.1).

<p><b>Interview questions for the co-researcher posts. Name of applicant.....</b></p> <p>Details of the role in both the steering group, and as co-researchers holding focus groups and interviews, to be given at start of interview. Context of action research to be fully explained. Level of hourly remuneration, contact details and the requirement to sign a Trust honorary contract (to ensure confidentiality, data protection, health and safety etc) to be given. Permission to be asked to take notes in order that information from the interview can be written up as part of the research project explaining informed consent and issues such as confidentiality.</p>
1. Did you find the information about the project easy to understand? If not what were the problems?
2. Have you ever been involved in a research project before?
3. Have you direct or indirect experience of social care services/Direct Payments/commissioned services?
<i>Did any of the following motivate your application?</i>
4. To gain more empowerment in your identity as service user/carer.
5. To be part of a process of contributing to social change.
6. To be involved in research on an equal footing with a paid professional and/or contribute academically to learning.
7. To be able to use your experiential knowledge.
8. To be able to voice your concerns about current services and aspects you would like to change/improve.
9. To gain more skills in order to increase your opportunity for employment.
10. To bring a service user/carer perspective to the project.
11. To gain recognition for your contribution.
12. To increase your confidence/self esteem.
13. To contribute to an area of service development that you feel very strongly about.
14. Do you have concerns about the role? Give example areas including the following. Provide information where appropriate about support available to address the concerns :
<ul style="list-style-type: none"> <li>• Participation in a large group</li> <li>• Will I receive appropriate training for the role?</li> <li>• Will I receive appropriate support for the role?</li> <li>• Will I be able to manage the time required?</li> <li>• Will I understand what is required of me?</li> <li>• Will there be lots of travel?</li> <li>• Do I possess the necessary skills for the role?</li> <li>• Will I be able to understand the language, keep up the pace etc?</li> <li>• Will I be able to challenge and effectively have a voice?</li> <li>• Will I be able to keep up the level of commitment required to see the project through?</li> </ul>
15. Please indicate any other areas of concern or issues that it would be helpful to share including practical issues such as preferred name, contact arrangements, dates/times not available etc.
16. (For service users only) If you are successful in obtaining the post do you give permission for your care coordinator to be informed of your role as a co-researcher on the project?

Table 4.2: Interview questions

#### **4.4.2 Training for co-researchers in research methods**

Training was provided for the co-researchers, introducing them to qualitative research methods, by Folk.Us, a user involvement in research group. All five attended taught days held locally. Additionally at the beginning of the study, I provided written information about focus groups and qualitative research methods supplementing teaching sessions. One of the co-researchers had been involved in research previously and used the training as refreshment, and one had a PhD qualification.

### **4.5 Section Four: Methods of data collection**

#### **4.5.1 Focus groups as a research method**

Focus groups consist of a small group of people who are brought together by a trained facilitator (researcher) to explore views and ideas about a topic. Focus groups are a long established and accepted social research method (Morgan, 1997; Kitzinger and Barbour, 1999; Finch and Lewis, 2003). In social science and health research focus groups provide an interpretative qualitative method designed to explore in depth data such as emotions, experiences and feelings. Focus group interviewing is an approach to information gathering that is both inductive and naturalistic (Kreuger and Casey, 2009) with the key characteristic being the insight and data produced by the interaction between the participants (Barbour, 2007; Litosseliti, 2007; Kreuger and Casey, 2009).

'A focus group study is a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment' (Kreuger and Casey, 2009:1)

Focus groups are particularly useful when there are power differences between participants and decision makers or when consensus in a particular subject needs to be explored (Morgan and Kreuger, 1993; Murray, 2006). Focus groups offer a strong

alternative to using single interviews in qualitative research, allowing analysis of experiences and events and also the interactional context of how those reports were produced (Barbour, 2007). Focus groups are valuable tools for exploring how points of view are constructed as well as how they are expressed (Kitzinger and Barbour, 1999, Koshy *et al.*, 2011). Additionally they may suit people who cannot easily articulate their thoughts, providing collective power to marginalised people, and opportunity to listen to local voices (Liamputtong, 2011). Due to these features focus groups were chosen as a research method to provide rich data in relation to service users, carers and Recovery Coordinators attitudes and understandings about Self-Directed Support.

Researchers disagree about the required number of participants for a successful focus group. Many prefer a group ranging from five to ten people (Kreuger and Casey, 2009), six and ten (Litosseliti, 2007), seven to ten (Greenbaum, 2000), six to eight (Krueger, 1998; Finch and Lewis, 2003), or five to six (Green and Hart, 1999). A balance is required between the need to have enough people for a lively discussion and the problems that an overlarge group size would produce, such as talking over one-another and general inhibition of discussion where numbers are large. In this study smaller group numbers were preferable: this enables people with mental health problems more confidence in speaking, and the facilitator to curb inappropriate discussion and encourage those who contribute little. Additionally group dynamics may be more difficult to manage within a focus group with people with mental health problems due to increased levels of anxiety, depression and inability to concentrate.

Focus groups were originally used in marketing research (Morgan, 1997; Fern, 2001, Barbour, 2007; Liamputtong, 2011). Like other types of interview they can be unstructured, semi-structured or highly structured. The role of the researcher in a



focus group focuses more as a moderator or facilitator, less as an interviewer, and the process is not the traditional question and answer as in the one to one interview (Punch, 2005). Discussions between participants enables the researcher to hear issues that may not emerge from conversations with the researcher alone (Liamputtong, 2011) stressing the interaction found in the group. The group situation can also stimulate people to make explicit their views, perceptions, motives and reasons (Punch, 2005). Finch and Lewis (2003) suggest focus groups are less influenced by the interaction with the researcher than in an interview and in a sense the group can take on the interviewer role and the researcher listens in.

Denscombe (2007) agrees that focus groups through their relatively informal exchanges can lead to insights that may have not been extracted from a conventional interview. He suggests that focus groups have three distinctive points: the sessions revolve around a prompt introduced by the facilitator to stimulate the discussion; there is less emphasis on the neutrality of the facilitator; and they place particular value on the interaction within the group as a means of eliciting information rather than just collecting each individual's viewpoint- there is a special value on the collective rather than the aggregate view.

Kreuger and Casey (2009:7) suggest 'the intent of the focus group is to promote self disclosure among participants' and that the researcher's goal is to create a comfortable, permissive environment in the group with the facilitator encouraging comments of all types but being careful not to make judgements about the responses.

The goal of the focus group is to collect qualitative data within a more natural environment than an individual interview as the participant is influenced and being

influenced by others as in real life. Using focus groups as a research method will not provide generalisability (Fern, 2001; Kreuger and Casey, 2009) however Kreuger and Casey (2009) suggest the findings may be transferable to other settings. Guba and Lincoln (1989) define transferability as parallel to generalisability except the receiver, not the researcher, decides if the results can be applied to the next situation. What may be transferred are not the specific findings, as the groups are small and selected using purposive sampling (Miles and Huberman, 1994) however the larger theoretical concepts may be able to be transferred to another situation. The most useful measure of validity may well be transferability, which asks whether the results are presented in a way that allows others to judge whether the findings apply in their context.

There are recognised benefits to focus groups such as the interaction allowing the researcher to gain data on participant's world views and the re-evaluation of those following interaction between participants (Kitzinger, 1995). The group effect where talk links into or falls out of preceding talk produces data and insights that would not be produced by interviews (Lindlof and Taylor, 2002). Also there are benefits to the participants themselves such as being valued as experts and involved in decision making which can lead to feelings of empowerment (Race *et al.*, 1994). However not all participants will experience this and shy participants in a group with some dominant members may find the experience intimidating and reveal little. This is particularly relevant with mental health service users who may be depressed or anxious in a group setting, reducing their capacity for active participation.

Whilst focus groups have many advantages criticisms of the method including participants not contributing or reluctance to discuss personal experience in front of colleagues, are relevant here. Some subjects may be too personal for focus groups,

(for example, sexuality or divorce) however problems depend on the group dynamics and the questions asked (Liamputtong, 2011). Further limitations to focus groups as a method include a lack of control over the data produced and the quality of this. If group members do not stick to the ground rules of speaking one at a time and speaking clearly so recordings are easily transcribed then data quality may be poor. The researcher has little control over the interaction other than keeping participants focussed on the topic (Morgan, 1997) and time can be lost on irrelevant subjects. Furthermore focus groups as a method may not be a reliable tool for ascertaining a participant's authentic viewpoint as affirmations of other participants' comments may be as a result of social norms such as being supportive rather than having a particularly strong view of the issues raised themselves. Full participation in groups requires confidence and self esteem both of which may be challenging for people with mental health problems and require more active facilitation than usual. Focus groups compared to individual interviews are however a potentially more enabling setting for vulnerable people to express their views (Barbour and Kitzinger, 1999; Lester *et al.*, 2006).

The co-researchers and I met to agree the trigger questions for the focus groups. All focus groups were designed to be co-facilitated with me and a service user or carer co-researcher, dependent on whether the focus group was held with service users or carers.

Below is the schedule of questions used in the focus groups with service users (Table 4.3).

1. What do you think of current social care services?
2. Do you think they are easy to access?
3. What do you think makes a good quality service?
4. What could make them better?
5. How do you think the social care budget spent on services should be prioritized?
6. How would you describe the difference between health and social care services?
7. What do you understand by Individual Budgets and/or Direct Payments?
8. What do you think of the idea of them?
9. What do you think of services being more personally tailored to individuals?
10. Individual Budgets and Direct Payments are designed to increase choice. Do you think that is a good idea?
11. They are also designed to increase service user control or ownership. What do you think of that?
12. Lastly they are designed to increase flexibility for service users needing support. What are your views about that?
13. What do you think the problems might be in service users receiving Direct Payments or Individual Budgets?
14. What opportunities might receiving a Direct Payment or Individual Budget bring?
15. What do you think that people with mental health problems might want to use their Individual Budgets for?
16. What help or support do you think that people might need in order to make Individual Budgets work?
17. What is your view on people with mental health problems taking more responsibility in this way?
18. Is there anything that you would like to say about Individual Budgets or Direct Payments that haven't been mentioned?

*Table 4.3: Focus group questions for service users*

The same questions were used for the focus groups with carers as for service users, with additional questions as shown in Table 4.4 below:

1. Do you think there could be any negative consequences to taking on more responsibility?
2. Do you think there could be any positive consequences to taking on more responsibility?
3. What implications might Individual Budgets and Direct Payments have for the service user –carer relationship?
4. What support do you think carers need to obtain and keep Direct Payments and or Individual Budgets?
5. Is there anything that you would like to say about Individual Budgets or Direct Payments that haven't been mentioned?

*Table 4.4: Additional questions for carers' focus groups*

#### **4.5.2 Reflective diaries as a research method**

Data from reflective diaries can produce rich data for researchers providing a source of personal reflection and interpretations of events, including accounts of the feelings and emotions associated with those happenings (Jacelon and Imperio, 2005; Denscombe, 2007; Valimaki *et al.*, 2007). The importance of Donald Schön's (1983) work on the reflective practitioner, as a new paradigm for practice knowledge, helped professionals faced with highly challenging problematic information, make judgements under extreme pressure or reflection in action (Ixer, 1999). Schön (1987) later described reflective practice as a process of 'reframing' experience or stepping back from experience in order to examine what that experience means (Kolb, 1984). However Schön's definitions were later challenged by Eraut (1995) arguing that as soon as one reflects one has left the action and therefore it is reflection on action not in action.

Despite the vast amount of literature on the nature and practice of reflection little is agreed about what it is. Ixer (1999) argues that until we can state what it is, we may

have to accept that there is no theory of reflection that can be adequately assessed;

others however have proposed definitions:

“a window through which the practitioner can view and focus self within the context of his/her own lived experience in ways that enable him/her to confront, understand and work towards resolving the contradictions within his/her practice between what is desirable and actual practice” (Johns 2000:34).

#### **4.5.3 Reflective diaries in action research**

The use of reflective diaries in AR is widely acknowledged as a means of assessing your own performance, personal reflections and the effectiveness of the programme from the researcher's perspective (Hart and Bond, 1995; Koshey *et al.*, 2011).

Journals can also be used to record co-researcher's reflections on project participation (Bellman, 2012b). McNiff and Whitehead (2002) suggest the use of diaries divided into action and learning (reflection) from action showing the development of thinking as the project develops. Collaborative diaries kept by researchers and participants are also suggested as a means of triangulating data by responding to each others reflections (McNiff and Whitehead, 2010). Rolfe (2006) goes one stage further arguing that: each qualitative study is individual and unique; there are no agreed generic criteria for making quality judgements in relation to research; and this behoves researchers to leave a quality audit trail. He suggests that in nursing research a detailed reflexive diary should be kept and read alongside the research report in order to include self critique and self appraisal and the moral, political and social stances of the researchers themselves. This approach suggests parallels with the view of McNiff and Whitehead (2002): that the quality of AR reports should be judged on how they demonstrate a 'lived experience' of learning through reflection. This appears to be a radical stance when there is little agreement on the purpose of a reflective journal. Moon (1999) in a review of over 100 papers on journal writing found 15 different purposes. Of those the relevant purposes to this study include: to record experience; to develop a questioning attitude; to facilitate

learning from experience; to increase active involvement in learning and personal ownership of learning; to increase the ability to reflect and improve the quality of learning; to explore the self, personal constructs of meaning and one's view of the world; and taking more thorough account of a situation.

In this study recording my individual experiences in order to enhance a questioning and more critical approach and compare thinking within the steering group was integral to the reflective and planning cycles of the AR process. It also enabled me to reflect on group interaction and consider what more work needed to be done outside of the steering group. Whilst the co-researchers did not participate in journal writing we held a reflective group after focus group meetings. These meetings gave the co-researchers time to collectively reflect on information, assumptions made and planning for action in the previous steering group meeting and voice any questions and challenges more effectively in the next meeting, as well as to me. This produced more creative and active involvement and an increased democratic process as I would argue assumptions made by professionals were able to be more open to challenge and explanation.

#### **4.5.4 Interviews, workshops and meetings with the co-researchers**

The interview questions about why the co-researchers wanted to be involved in the research (see Table 4.2) were designed to compare the principles and motives considered in the literature about service user researchers (Buckland and Gorrin, 2001; Faulkner and Thomas, 2002; Telford and Faulkner, 2004; Williamson, 2004; Minogue *et al.*, 2005; Connor and Wilson, 2006), with those suggested by this small sample of service users and carers. With the interviewee's permission, notes were taken during the interviews and typed up immediately into 'Microsoft Word'. This was in order to minimise misinterpretation and maximise understanding of what was

expressed by the interviewee however all notes were later shared with the potential co-researchers for accuracy.

I met with the co-researchers following every steering group meeting. The purpose of the meetings was to provide the opportunity for the co-researchers to feedback about the steering group and reflect on any aspect of their involvement in the project. I took notes during these meetings which were typed up immediately into 'Microsoft Word'.

The notes of the interviews and post steering group meetings, including any interpretations of what was said, were fed back to the interviewees within one week for agreement, omissions and alterations, providing opportunities for any differences in interpretation to be discussed and a consensus to be reached. This was a means to ensure rigour in the study covering two points suggested by Reason and Bradbury (2008) to demonstrate validity: the project encouraging the process of participation; and demonstrating reflexivity and being guided by practical outcomes. This was further addressed by my adopting a style of interviewing where any response given that was ambiguous or open to interpretation, was interrogated in order to agree a shared understanding of what was being said. This was intended to minimise the risk of misinterpreting answers and comments by seeking clarity immediately at the time. Additionally all written-up notes were shared, providing a double safeguard of reducing misinterpretations of meanings.

#### **4.5.5 Steering group and other meetings data collection**

Data was collected from the first seven steering groups by electronically recording the groups and transcribing verbatim all conversation within the meetings. In AR data is collected from interaction with all participants in the AR cycle. The steering group in this project formed the main vehicle for learning about the AR process of diagnosing,



planning action, taking action and reflection and evaluation with all participants. In this way it was an AR intervention as well as a means of data generation. This is illustrated in Table 4.5 below:

Date of Steering Group	Method of data collection	Why data was collected?
19.4.2007 23.5.2007 26.6.2007 30.8.2007 18.10.2007 3.12.2007 22.4.2008	Electronic recording of meetings	<b>Involvement:</b> To analyse levels of participation and determine levels of involvement of co-researchers including factors of agency, power, negotiation, respect and feeling valued. <b>Democracy:</b> To analyse communication between participants in relation to valuing involvement of service users and ensuring a carer and service user voice. To better understand evaluation, from the co-researcher's perspective in debriefing sessions, about the content and process of discussion in the meetings.
16.12.2008 10.2.2009 21.4.2009 22.2.2010 2.6.2010	Notes taken at meetings	<b>Knowledge generation:</b> To learn about perspectives and experiences in relation to personalisation and the implementation of Individual Budgets; to learn from the AR cycle of planning, acting, reflecting including reflection on action; to learn about organisational development

*Table 4.5: Data collection in the steering group*

Steering group data was collected to provide learning about how the group gets the work done for the AR project to progress, as well as the dynamics between participants providing data around involvement of the service user and carer co-researchers. The observation of groups at work including patterns of communication, power usage, group roles, decision making and leadership is important data to collect as a basis for inquiry into underlying assumptions and their effects on the work and life of the groups (Schein 1999).

Data was also collected from training sessions provided to practitioners by notes taken during sessions that were typed up within 24 hours, and by using group-work

with participants involving written responses to questions about Self-Directed Support that were provided to me. Additionally those providing training sessions met together afterwards to discuss their interpretations of the events and the key learning points which I wrote up and circulated to all those involved for amendment, additions and agreement.

#### **4.5.6 Documentation as a method of data collection**

Documentation from other sources including the Local Authority in relation to all aspects of implementing the personalisation agenda was available to me. This was due to my role as a senior manager in the Trust implementing the introduction of Personal Budgets. The most relevant of these documents were shared at steering group meetings with all participants and took the form of notes from wider steering group meetings across all sectors in the Local Authority, news articles relating to personalisation and published academic articles.

Documentation from internal and external organisational sources provides secondary sources of data as opposed to primary sources collected by researchers. This is due to those sources being authored by individuals where biases and viewpoints are unknown. This documentation was used to indicate the progress of the project in the overall context of the project within a larger project across the Local Authority.

The collection of documentation relating to a situation is a recognised data collection method in AR (Winter, 1996). It provides a means to tell us more than we usually know from memory alone and to increase knowledge in a particular area about the work of others.

Winter (1996) groups documentation into three categories:

1. That circulated and accessible to all members of an organisation such as letters from executives, policies and working group reports.
2. That internal to the central administration such as staff memos and summaries of policy developments.
3. Confidential documentation

In this project documentation in categories one and two was available and where relevant shared with the steering group. Data such as emails and letters from the co-researchers to me including reflections, questions and shared information were included as data during the course of the study. Additionally national information concerning Self-Directed Support was circulated to steering group members by me to generate discussion and help decision making.

Koch and Kralik (2006) describe 'empowering clients with information' (p.95) on an individual basis in relation to their own health. Here I provided local and national information about Self-Directed Support to all steering group participants for that purpose to empower and support them in their role.

#### **4.5.7 Triangulation and validity in action research**

Triangulation is a term meaning the application of different methods to the same subject matter (Flick, 2002; Veal, 2005). The fundamental principle of triangulation is the use of a combination of appropriate methods for assessing the same phenomena (Grbich, 1999; Flick, 2002; Bryman, 2004). It assumes that weaknesses in one approach are strengthened by adding another. It also can help to create a more accurate description of a phenomenon by revealing the varied dimensions (Fielding and Fielding, 1989).

Denzin (2009) distinguishes four ways of how triangulation can take place: data; investigator; theory; and method triangulation. Data triangulation is the use of a variety of data sources in a study including time, space and person. Investigator triangulation is the use of several different researchers. Theory triangulation is the use of multiple perspectives to interpret a single set of data. Method triangulation is the use of multiple methods to study a single phenomenon. Denzin (2009) classifies methodological triangulation into two types: Within-method using at least two data-collection procedures from the same design approach; and between method employing both qualitative and quantitative data collection methods in the same study.

Triangulation in AR is considered by relatively few AR authors. Zuber-Skerritt (1996) considers this as a process where, by using different methods, each method provides a point of comparison with the others. Several different methods may then provide an interpretation preferable to one method of investigation with one interpretation. At least three methods are needed for comparison and to allow conclusions to be drawn. McNiff and Whitehead (2002) describe triangulation as a main technique to ensure analytical rigour to arrive at agreed data interpretations. McNiff and Whitehead (2002) apply a slightly broader interpretation to triangulation including checking all participants' accounts are in agreement and scrutinising data from multiple perspectives as well as using multiple methods. Hart and Bond (1995) see combining techniques of data collection as offering the action researcher opportunities to compensate for the limitations of one method, by adding others.

Different perspectives from varied data sources are thereby gained being a key feature of evaluative research. AR incorporates evaluation alongside enquiry and

action. Triangulation within AR studies therefore adds rigour by overcoming the deficiencies in using one method alone.

However triangulation alone cannot guarantee a test of rigour and validity. Triangulation is a form of validation appropriate to qualitative research but other criteria to establish validity are needed. This would include the honesty of the respondent's account; the values of the researcher; the impact of the researcher on the setting and respondent validation where the findings are taken back to the subjects being studied for verification (Silverman, 2001). Silverman considers using triangulation as a test of validity problematic, in that comparing different methods collected in different contexts ignores the character of the social interaction in that context. This would suggest arrogance with connections and patterns assumed whilst being ignorant to the sense of each account in its own right. Relating this approach to this study, the different accounts should be compared and contrasted whilst acknowledging that data from different participants and contexts may produce either complementary or differing perspectives.

#### **4.5.8 Triangulation and validity in this study**

Triangulation will be used in this study to add depth to the findings and their analysis rather than as a test of validity (Silverman, 2001; Denzin, 2009). The table below (Table 4.6) illustrates the use of triangulation in this study using Denzin's (1989) typology of triangulation. Of the four categories, theoretical, and between methods triangulation were not considered relevant to this study. Investigator triangulation was considered highly appropriate to underline the importance of partnership and teamwork in incorporating different perspectives. The use of a variety of data sets and sources, gathered by different qualitative methods was also seen as adding depth to the study. Within method triangulation in this study also seeks convergence

between the results from the data analysis and complementary strengths such as illustration, clarification and interpretations from the results of one method compared to another.

Method of data collection	Type of triangulation	Data collected by	Method of analysis	Purpose/Goal
<b>QUALITATIVE</b>	<b>Within Method</b>			
<b>Groups:</b> Focus Groups	Investigator & Data (including time, space and person)	Lead researcher and co-researchers	Transcripts were coded for themes and concepts.	Evaluative data Participant feedback
Co-researchers meetings with lead researcher	Data and investigator	Lead researcher	Notes were coded for themes	Evaluative data Participant feedback
<b>Diary</b> Reflective Diaries including letters and emails	Investigator and Data	Lead researcher and co-researchers	Analysis of text	Reflexive understanding of action research process. Evaluative data.
<b>Meetings:</b> Steering Group	Data & investigator	Lead researcher	Recorded transcribed and analysed for themes and concepts	Evaluative data; reflection, agreeing strategy, evaluating action
Learning and Development meetings and workshops with practitioners	Data ( including time, space & person) & investigator	Lead researcher and co-researchers	Meetings, associated written material, and post-meeting discussions noted, collated and coded for themes and sub-themes.	Deeper understanding of perspectives
Choice and control theme Board	Data & investigator	Lead researcher	Reflective diary entry	Organisational influences and drivers providing deeper understanding

Table 4.6: Triangulation and validity in this study

The limitations of using triangulation in this study include the collection of a vast amount of data for analysis adding to the potential for false interpretations. Investigator bias may be a problem or a potential for disharmony if this conflicts with interpretations from the co-researchers in this study. Using triangulation should be viewed as dynamic and intertwined into the research process, rather than seeing the different types of triangulation in isolation or in any particular order.

#### **4.6 Section Five: Ethical approval and issues in this study**

Ethical approval for this study was obtained from the Local Research Ethical Committee and my employing Trust. This served as automatic approval for the University and the Local Authority who also requested this.

All potential and actual focus group and steering group participants received an advance letter outlining the focus of the research and the purpose of the focus group and steering group. The letter included a participant information sheet describing their rights as a participant in relation to confidentiality and anonymity both during the process and in any subsequent report or publication (see Appendix 9). This also included their right to withdraw at any point. Additionally before focus groups were held these rights were given verbally, confidentiality was discussed and all participants were asked to sign a consent form (see Appendix 2).

##### **4.6.1 Ethics relating to recruitment of service users and carers to this study**

Ethical issues relating to the co-researchers were considered including the risk of anyone becoming ill as a result of involvement in the project. A principle fundamental to my project design, underlying the recruitment process, was acceptance of the applicant's self-assessment of their ability to contribute to the project. An interview question asked whether there were any problems that I needed to be aware of in

order for the person to undertake the role of co-researcher, for example, whether they felt they could be appropriately supported by me alone or in conjunction with others.

The study was designed to include service users and carers as fully as possible as co-researchers however the need to ensure that the process of involvement did not contribute in any way to the person becoming unduly stressed or mentally unwell was paramount in my ethical commitment to the project. This could be likened to a 'duty of care' to the co-researcher's wellbeing, from me as lead researcher, ensuring that effective safeguards and checks were built into the research process to monitor this. In discussion with the ethics committee it was suggested that it would be good practice to explore whether the service users would be willing for their Recovery Coordinator, to be informed if they were successful in being recruited to the research project. Tee and Lathlean (2004) in their study of mental health participative research involving service user co-researchers, look at the guidance for safe practice in user involvement. They suggest that the lead researcher should constantly assess the co-researcher's competence to continue, including risk assessments in relation to the emotional demands awakening past experiences. The lead researcher was seen to be key to ensuring, through observation, interview and supportive sessions, the co-researcher's well being throughout the research period. They found that no studies had used any form of tool to monitor competence. Furthermore they found that the guidance for safe research did not give a definition of vulnerability but that the lead researcher needs to be able to use their knowledge of the research process, communicate fully the role of the co-researcher and continually review their ability to make informed choices. It is noted that a lead researcher with previous clinical experience can make use of this to support, debrief and enable co-researchers to participate as fully as possible.



Tee and Lathlean's (2004) approach is used in this study, placing value on service user involvement whilst trying to ensure no harm would result to the person's mental health. However, the ability to establish, if a person does become unwell, whether it is the involvement project or another trigger affecting that person's life, is clearly difficult. Additionally some cyclical mental health conditions cause regular periods of illness not usually attributable to external factors. One of the service users recruited to the project had an illness of this nature indicating likelihood of relapse within the time frame of the project. This suggested additional vigilance to that person's wellbeing was required. I was a qualified mental health social worker with over 25 years experience in working with people with mental health problems. This clinical experience and knowledge should be beneficial in averting any ill health resulting from involvement of service users.

#### **4.6.2 Ethical aspects of methods**

Fundamental to this AR study was consideration of the ethical aspects of the methods chosen. This follows the principles as listed by Winter (1996). First is consulting all relevant people beforehand about the principles guiding the work. In this study this included all those participating in the steering group, focus groups and within the Trust where they held a level of involvement in either the outcome or operational aspects of Self-Directed Support. Winter's (1996) second principle is to allow all participants to influence the work and respecting those that do not wish to participate; this corresponds to the democratic principle underlying the steering group and work arising from the group. Thirdly, Winter (1996) suggests developing work in a way that is open to other's suggestions. This is demonstrated here by my ensuring that the comments and suggestions of all participants whatever their status was considered equally, and that decisions were made following negotiation with all involved parties. Fourthly, obtaining permission for documents to be used or before

making observations is suggested. This was made easier by my position within the Trust and the knowledge of where to obtain papers that were not publically available. Additionally, Winter (1996) recommends negotiating around other's work and points of view before publication. This is built into this study by feeding back results to those who have participated, either as a co-researcher or other participant, to seek views on what is written and agreement that this can be published. Lastly, Winter (1996) recommends that the researcher accepts responsibility for maintaining confidentiality. In this research study confidentiality was ensured by data being securely kept and stored subject to the Data Protection Act. No patient identifiable data was shared with anyone other than me. Quotations were used in the final write-up of the study whilst maintaining effective patient confidentiality though accepting that this was difficult to completely ensure as SG members may be able to recognise other participants. All recordings, transcripts or other notes were securely stored and were only accessed by me and my tutors. Material gathered was used in the completed study however no names or any other identifying characteristics were included in the final report. All tapes and transcripts were destroyed at the completion of the study.

If the researchers and the participants collaborate closely then Williamson and Prosser (2002) ask how confidentiality can be guaranteed. If the AR project publicises membership and work then dependent upon organisational size and communication structures this may be difficult to guarantee. Informed consent similarly may be a difficult concept given that the research design is flexible and not fully known in advance therefore they cannot be fully aware of what they are consenting to. Additionally due to the political nature of AR avoiding doing harm to participants may be more problematic. This refers to the collaborative nature of AR and the consequences of agreed actions to change practice that may have political consequences that are linked to participants. Arguably researcher and participants

hold equal responsibility due to the nature of the project and therefore the political outcomes from any reports (Williamson and Prosser, 2002).

In this study confidentiality and focus groups was considered as this is an area where although the researcher can ensure confidentiality this may not extend to all participants. Here before the focus groups started I talked with the group about confidentiality with the agreement not to repeat people's stories and comments outside of the meeting. This was more relevant for some groups than others as in two focus groups it appeared that participants had heard many of these before. It is clear there are no set answers to these questions but that they need to be posed in relation to individual projects and discussed with participants as a means to agreeing ethical dilemmas as far as possible before the project starts.

In this study the documentation shared with participants was either notes from previous meetings which were circulated for comments and accuracy to all participants or organisational documentation that was considered non confidential and open to public scrutiny.

## **4.7 Section Six: Data analysis in this study**

### **4.7.1 Recruitment process data analysis**

Analysis of the notes from interviews involved the development of an initial coding scheme based on common data categories revealed by reading the notes from each interview (Coffey and Atkinson, 1996). Emerging themes were analysed to avoid duplication which involved repeating the categorisation process to refine the themes further. Coding reliability was checked in two ways. Firstly, intra-coder reliability (Miles and Huberman, 1994) was used whereby the same coding process was performed on the same data, after six weeks, to see if any new codes arose. This

enabled reflection and traceability between the two results. Traceability refers to the completeness of the information about every step in a process chain and is a soft systems approach to analysis. Draft analysis was shared with all participants for accuracy and to ensure that coding data represents group perspectives including user's mundane and more dramatic viewpoints. Reason and Rowan (1981) argue that tentative results should go back to the subjects for checking and refinement. Respondent validation was built in by returning findings to those studied to see if they conformed to their experiences (Silverman; 2001) and accorded with their feelings and behaviours (Denscombe, 2007) with revisions and additions agreed following feedback. Draft reports were shared with the wider steering group for comment.

#### **4.7.2 Focus group data analysis**

Kreuger and Casey (2009) state that 'focus group analysis is systematic, sequential, verifiable and continuous' (p.128). The authors define systematic analysis as deliberate and planned within a sequential process helping to ensure that results reflect what was shared in the groups. The process should mean that analysis is open for inspection and the strategy for analysis is documented and understood by all. By verifiable they suggest researchers must be careful to avoid selective perception based on their background, training, and experience and provide sufficient data to constitute a trail of evidence including notes, transcripts, summary of key points and debriefings with any moderators. By continuing process the authors suggest that focus group analysis is completed concurrently with data collection to inform data collection for a future group and to compare to past groups. This enables questions that the group found difficult and misinterpreted or did not want to answer to be amended for future groups.

In this study all focus groups were electronically recorded and analysis was based on unabridged transcripts supplemented by notes taken by me and the co-researchers on key themes and where discussion was particularly animated. Analysis was conducted using an approach suggested by Kreuger and Casey (2009) as shown below.

1. Each line of transcripts was numbered to enable quotes to be located in the transcript.
2. Focus groups were initially analysed within the three different participants of the focus groups; people using services; carers of people using services and Recovery Coordinators of people using services. There were two groups in each category making six groups to be analysed.
3. Each transcript was read through by me in its entirety initially as a reminder of what was said and then each focus group question was analysed in sequence.
4. Each comment was categorised in relation to what it said about the question: in this way comments of a similar content were categorised together in relation to the specific questions asked. This method of analysis is a systematic examination of similarities between cases to develop concepts (Punch, 2005).
5. Comments outside of the subject matter were also collected to be later reviewed to see if they had anything to add to the data in relation to the questions.
6. Following the categorisation of each quote under the questions asked. A descriptive summary of what each different participant group said in relation to the questions was written.
7. During the process weighting of specific concepts or themes and categories was considered in relation to: how specific the comment is and detailed in relation to supplying data in relation to the question; the intensity of the response in terms of emotion, passion or enthusiasm; the extensiveness of the comment i.e. how many

people made the same or similar comments, in order to assess consensus or conflict of views.

8. Additionally within the summary of each different participant group cross cutting themes were examined in order to consider whether the analysis was more appropriate in relation to cross cutting themes than particular questions.
9. Following a break from analysis of several weeks this was returned to after consideration of the overall aim of the study and its objectives in order to reconsider the import of some of the categories and themes with the wider aim in mind.
10. Quotes were used to highlight the essence of what was said and bring the data to life.

Denscombe (2007) advocates reflection on early analysis as new things might emerge as relevant or new interpretations being given to the same data. Where this was the case then notes as to what has caused the new line of thinking were made to provide evidence as to the process of data analysis. Denscombe (2007) also recommends a reflexive account from the qualitative researcher concerning the influence of self and their impact on the research. This may include their biographical details alongside experience, beliefs and values held that may influence data interpretation. As a means of being explicit and recognising the importance of researcher neutrality this was incorporated into the discussion of the findings at the beginning. Additionally each reflexive account was shared with the co-researchers involved in the focus groups for comments on interpretation.

#### **4.7.3 Steering group data analysis**

All steering groups were transcribed and analysed systematically in order to examine commonalities across the groups held, in an attempt to challenge or uphold concepts

around both the process of involvement and perspectives held about Self-Directed Support. Data analysis was based on the approach suggested by Kreuger and Casey (2009) as discussed in the focus group data analysis:

1. Each steering group transcript was read through thoroughly in order that I was re-familiarised with the data.
2. Comments were categorised to identify pieces of data, from one word to a paragraph, with a common meaning or description in relation to what it contributed to the group discussion. In this way comments of a similar content were categorised together in relation to the specific questions and discussions within the group
3. I suggested an initial list of coding that was expected to be produced and this served as a guide to the structuring of the data. Punch (2005: 206) states 'there must be clear links between data indicators and the conceptual labels (codes) given to the data'. In this way he argues that coding can be checked for reliability and audit trail by ensuring that another researcher would reach the same conclusions in their data analysis. In this research I described what each category included in an attempt to be explicit as possible about the breadth of data each category captured.
4. Further analysis once the initial coding was complete entailed more detailed examination of the categories to identify themes and concepts. This process required the researcher to interpret these into more abstract concepts and patterns thereby creating meaning to the analysis. To assist notes were made to record potential linkages in the data and patterns at an early stage and to start thinking conceptually about the data rather than descriptively.
5. This process was repeated for each steering group transcript in order to identify changing patterns and concepts as the project progressed.

#### **4.7.4 Co-researcher group meetings and workshops data analysis**

Following steering group meetings I met with the co-researchers to share reflections and issues about the meeting. Notes were taken by me and shared with the co-researchers to provide shared understanding of the main themes. Any discussion areas to be raised at the next meeting, needing clarification, or more in depth understanding, were raised. As the research question concerned the process of involvement as well as involvement outcomes, emotions raised through the co-researcher's inclusion in the AR were considered important and recorded for analysis.

Data analysis included reading through the notes from each meeting to ensure familiarity with the content and to identify the main themes from each debriefing session. Analysis was based on coding of what the group said about issues that were raised in the meetings, what they felt could have improved their experience of involvement and what actions were agreed for future meetings. This was undertaken by me and shared with all the co-researchers for comment, alterations and additions before being agreed as an accurate account.

#### **4.7.5 Reflective diaries and their analysis**

Reflective diaries and other written data from me and the co-researchers such as emails and letters were included as data for analysis. I alone kept a diary on a systematic basis throughout the research period. The diary was kept using guidelines suggested by Corti (1993) including the following:

- Entries were made very shortly after meetings or communications so that events and reflections were not left to memory.



- Entries collected data systematically with time periods relating to the entry always included, the nature of the event or activity, reflections and feelings at the time, who was involved and what was the outcome.

In this study the purpose of diary analysis was to increase understanding of my reflections as lead researcher in carrying out the AR including tracking how my thinking changed during the course of the project. This includes understanding the reflexive nature of the AR project and how this developed learning about the nature of involvement and participation. Analysis of diaries and co-researcher's written communications about events also adds triangulation by comparison with other data to see if there is corroboration or different versions of events (McNiff and Whitehead, 2005).

Data from my diary was analysed in its entirety using a holistic method rather than using textual analysis methods (Sarantakos, 2005). This is a method of analysis that enables those entries and reflections relevant to the objectives and aims of the research to be identified and used alongside other data collected to provide evidence of learning, changing perspectives, comparison and corroboration of data and deeper understanding of events and experiences. Quotations and extracts from the diary and written communications were used for illustrative purposes in the data analysis. These are anonymous in order to protect confidentiality of those involved.

#### **4.7.6 Documents and their analysis**

The documents included in this project include those written by the research participants in a collaborative process, those made available to me from the Local Authority and documents published nationally in journals or from the government. Apart from documents written by the research participants these are secondary data

sources and are useful for gaining better understanding of issues affecting the research but outside of the project's control or remit.

All documents written by me either solely or in conjunction with co-researchers were fed back to all participants for alterations and additions in a process of respondent validation. These texts were provided to those involved in the project though were available to anyone who was interested within the Trust on the Trust intranet. The documents were analysed by Sarantakos' (2005) holistic method as already discussed.

#### **4.8 Section Seven: Summary of data collection methods and analysis**

This study uses qualitative data collection methods as a means of understanding service user, carer and Recovery Coordinator perspectives on Self-Directed Support and additionally the nature of service user and carer involvement in the implementation of Self-Directed Support in mental health services. Consensus in relation to data analysis was achieved through negotiations of interpretations between me, the CRs and those being researched. This is vital to the ethos of the AR project as a collaborative form of research which actively seeks to empower those involved in the research (Mullender *et al.*, 1994).

A primary focus of data analysis within an AR project is using this to inform future action, as well as confirming thinking based on the experience of the researcher, in this study, an experienced mental health services manager. Critical reflection of the data, as a process of learning, is integral to the analysis as this forms the basis of the action of the next stage of the AR cycle (Winter and Munn-Giddings, 2001; Koch and Kralik, 2006). Therefore data analysis was ongoing throughout the project and should be described as such in this thesis.

Qualitative data in this study was collected using:

- Focus groups co-facilitated with co-researchers.
- Steering group meeting transcripts.
- Training sessions with practitioners and people using mental health services.
- Reflective group meetings between me and the co-researchers.
- My reflective diary
- Correspondence from co-researchers including e-mails and letters.
- Documentation.

Focus groups were selected as a method of accessing a wide range of relevant participants where attitudes and understandings can be explored on the research question and where rich data is produced (Morgan and Kreuger, 1993; Kitzinger and Barbour, 1999; Denscombe, 2007; Kreuger and Casey, 2009). They provide interactive data (Barbour, 2007), opportunity for local voices and can provide collective power to participants (Liamputtong, 2011). I considered these useful benefits. Data analysis used recognised coding techniques and analysis, was shared with participants for corroboration and agreement on interpretation.

My reflective diary and correspondence written by the co-researchers form part of the understanding of the AR process and examine learning of my practice and the process of involvement. Analysis of the sources of reflections on the project will also serve as a means of triangulation by seeing if these corroborate other interpretations of events (McNiff and Whitehead, 2010).

Analysis of transcripts of steering group meetings and other meetings will provide a historical record of the course of the project and the process of collaboration.. This

will include the phases of planning and activity, learning about the process of involvement and roles and experience of the co-researchers alongside me in this study.

Quotes and extracts will be used from the reflective diary and steering group transcripts where appropriate to illustrate activities and thinking during the course of this research.

This chapter together with Chapter Three brings together the methodology of AR with the methods used in my study design to provide a detailed conceptualisation of this research project. My methodology of choice was AR as this provided a strategy for inquiry and development and a form of social research linking knowledge to practice. AR is increasingly undertaken in health and social care organisations by practitioners and managers wanting to study and implement change and improvements in practice. The bringing together of planning, action, reflection and acting again in a collaborative approach was considered by me as highly appropriate for this particular project led by me as the lead researcher researching her own organisation whilst at the same time continuing my managerial role.

This study included the recruitment and full participation of service user and carer co-researchers and collected data using focus groups, steering group meetings, training sessions, diary entries and other written documentation during the course of the AR cycles. The AR methodology together with the chosen data collection methods formed my study design. In the next chapter I detail an account of how findings, using this chosen study design, were collected and analysed during the AR cycles spanning four years.

## **CHAPTER FIVE: FINDINGS OF THE ACTION RESEARCH PROJECT**

### **5.1 Introduction**

This chapter examines the qualitative findings from the study, using McNiff and Whitehead's (2002) refined conceptualisation of AR spiral methodology. The findings are presented in three sections corresponding to the three AR cycles within the study. The first two AR spirals represent the work to develop and trial two different self-assessment systems in order to use these to provide Personal Budgets in adult mental health services. Firstly, an adapted 'In Control' Resource Allocation System was developed; and secondly, a Personal Budget Allocation tool was developed and trialled. The third AR spiral represents acceptance of introducing PBs using existing systems as a compromise solution, pending a new RAS being designed by an externally contracted organisation.

Throughout the study the work of the co-researchers, their involvement and observations of the participative process is recorded, analysed and discussed. Their participation is integral to the design of this AR project.

### **5.2 The action research cycles**

AR is seen here as an evolutionary transformational process. The spiral movement is represented by figures 5.1-3. These appear to demonstrate smooth cycles of planning, acting, reflecting and re-planning; however within the spiral movement are unexpected added cycles additional to the main AR planned. McNiff and Whitehead (2002) refer to this occurring as a result of unexpected events and organisational pressures. This better reflects the complexity in this study where the AR cycle did not roll smoothly forwards but was compounded by

interaction from sources external to the steering group. This led to additional spirals of AR activity which was fed back into the steering group.

The first spiral (Figure 5.1) includes data collected from: individual interviews with co-researchers; five steering group meetings; two workshops led by me and a co-researcher; debrief meetings with the co-researchers; and eight countywide training sessions to Recovery Coordinators.

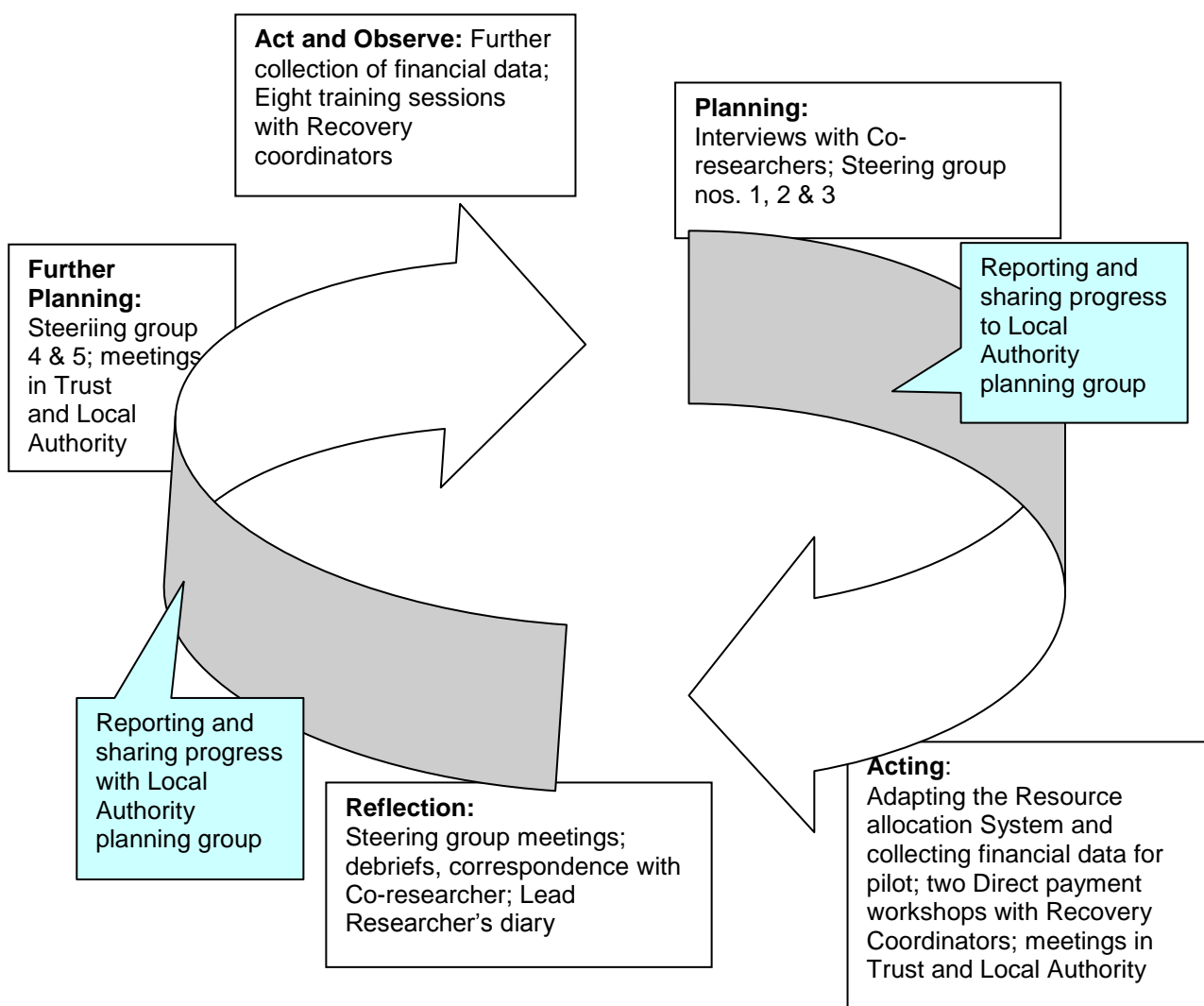
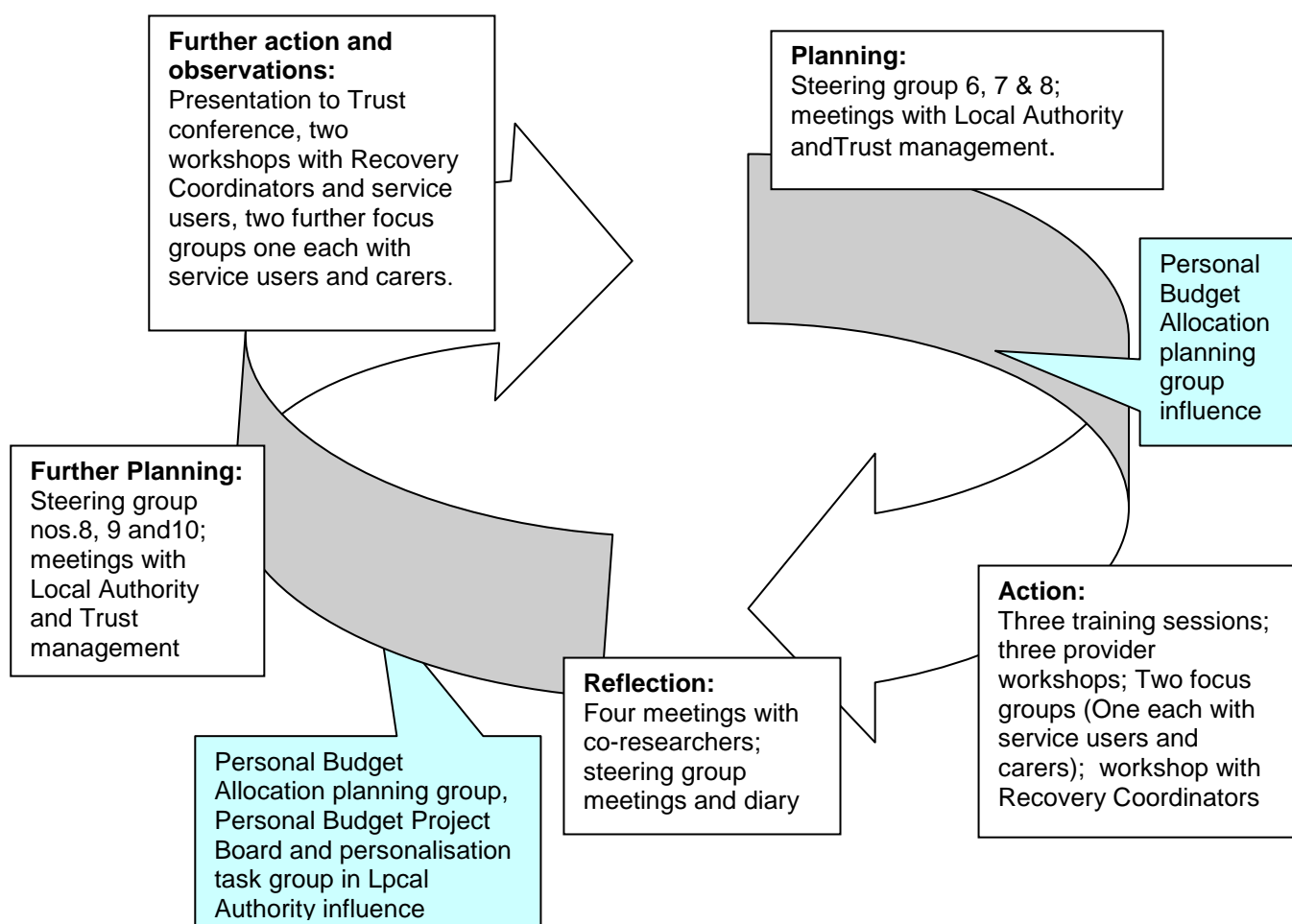


Figure 5.1: Spiral One: First phase of project

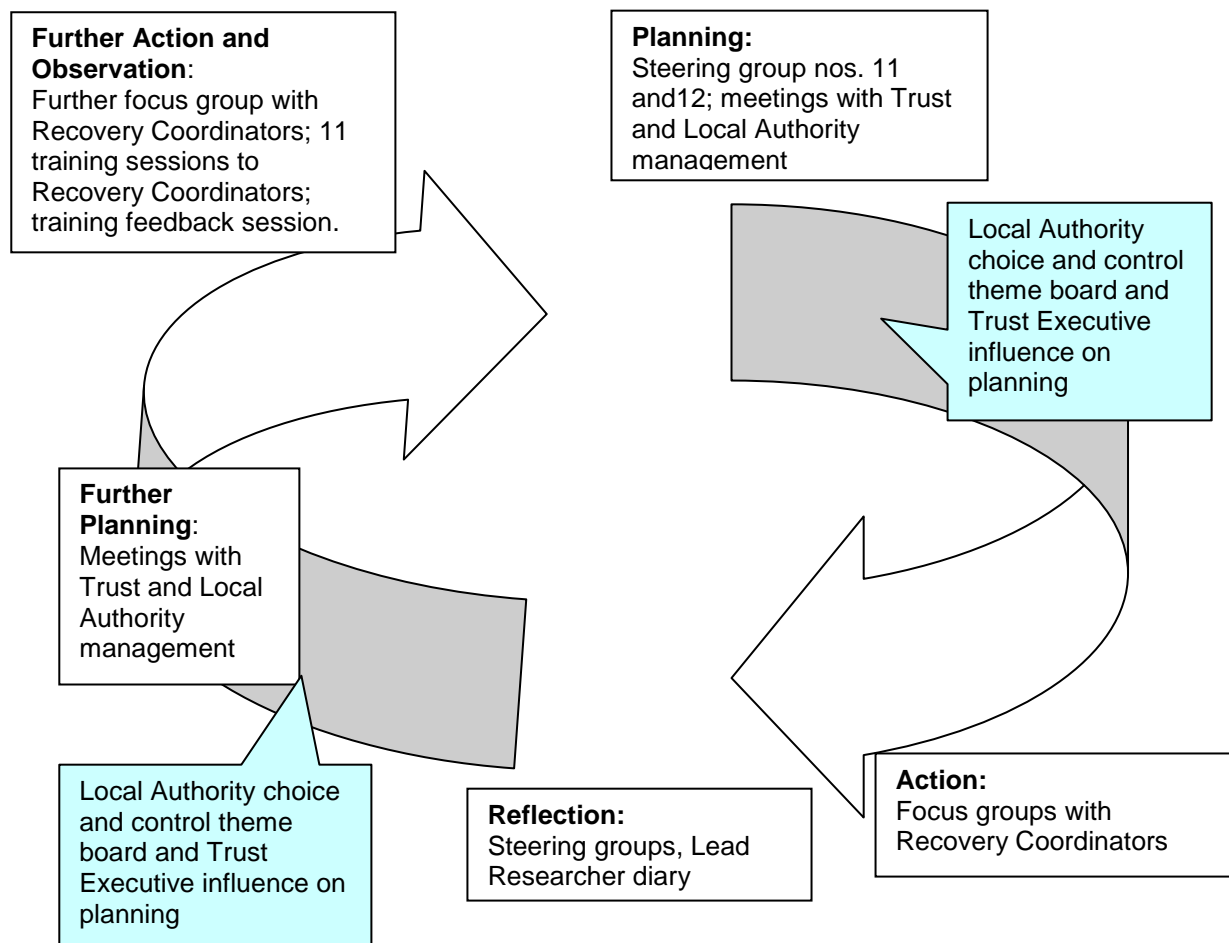
The second AR spiral (Figure 5.2) includes data from: five steering groups; debriefs with the co-researchers following these; four training sessions with

Recovery Coordinators; four provider workshops; three meetings with the co-researchers and four focus groups, two with service users and two with carers.



*Figure 5.2: Spiral Two: Second phase of the project*

The third AR cycle includes data from: two steering groups; two focus groups with Recovery Coordinators; seven training sessions with Recovery Coordinators and a training evaluation session.



*Figure 5.3: Spiral Three: Third phase of the project*

### 5.3 Project Chronology

This study has been conducted over a four year data collection period from March 2007 to May 2011. Data has been specifically selected from the plethora of rich data collected to illustrate and evidence the AR spiral methodology underpinning the project. The project began with the appointment of the co-researchers and examines three AR cycles each with different levels of planning, activity, observations, reflections and further planning. The level of the different steps in each AR cycle is summarised at the end of the chapter.

A detailed project chronology is shown in Appendix 3. This itemises all meetings and activities I was engaged in during the course of the study differentiating



activities where data were collected. The project was a collaborative process with data gathered in relation to involvement from the co-researcher's perspective, and the implementation process of Personal Budgets.

#### 5.4 Transcription Notations

The following conventions shown in Table 5.1 were used in the transcriptions of steering groups one to seven, and FGs.

<b>Notation</b>	<b>Meaning</b>
//	Someone else talking at the same time
[.....]	Transcript in brackets has been deliberately omitted
.....	Pause in speech
<u>well</u>	Added emphasis
(I think so)	Doubt of accuracy of material in bracket
XXXX	Unintelligible segment
= =	No discernable gap in turns of speech
*	Precedes omitted word(s)
Initial eg. S	Used instead of name or location for confidentiality

*Table 5.1: Transcription notations*

#### 5.5 Abbreviations

Table 5.2 shows abbreviations for the different participants, groups and other abbreviated data entries in the text. All focus groups are specifically identified and participants differentiated as below. As there are two focus groups in each designation of service users, carers and Recovery Coordinators, the prefix SU, C or RC and numbers one to 10 are used to represent different people attending these. The text however will make it clear which focus group entries relate to.

Abbreviation	Meaning
RC	Recovery Coordinator
FG1 or 3 (SU)1-5 or FG 2 or 4 (C)1-10 or FG 5 or 6 (RC)1-6	Focus group, number of focus group held and whether service users, carers or RCs differentiating individuals
LR	Lead researcher
CR, CRD, CRS, CRGe, CRG, CRM.	Co-researcher -non personalised Individual co-researchers (CRD, S & Ge- service users; CRG & M - carers)
SG1-12	Steering group one to 12
SGTM 1-3, SGLM 1-2, SGPR	Steering group members ; Trust manager one to three, Local Authority manager one to two, Provider representative
LAC	Local Authority consultant

*Table 5.2: Data entry abbreviation*

## 5.6 Representation of qualitative data

Table 5.3 indicates how qualitative data from different sources is represented.

Data Source	Representation :		
	Font and margins	Spacing	Shading
Commentary	Arial	double	None
Steering Group	Times New Roman Indented text	single	5%
Focus group	Times New Roman Indented text	single	15%
Interviews, meetings and other communications with co-researchers	Arial Indented text	single	None
Training, workshop and conference	Comic Sans MS Text Indented	single	None
<i>Meetings and notes from these</i>	<i>Times New Roman italic Indented</i>	<i>single</i>	<i>None</i>
Diary entries	Arial Narrow text Indented	single	None

*Table 5.3: Qualitative data representation*

## **5.7 Section One: Qualitative findings of the first action research spiral**

### **5.7.1 The project steering group**

I set up the project steering group with the aim, through participative process, of planning and developing the implementation of Personal Budgets. This included examining my and the co-researcher's work and providing feedback, reflections, technical assistance, ideas and proposals for work to be undertaken outside of the steering group. The steering group also provided a forum for discussing ideas and issues in relation to Self-Directed Support. Additionally I brought strategies, information, learning and decisions from the Local Authority Self-Directed Support planning groups to the steering group for consideration of their impact on our change programme.

The steering group comprised of me, initially five co-researchers and management representatives from the Trust, Local Authority and a service provider representative (see Table 4.1, page 112). I chose steering group members because of their direct involvement with Personal Budget implementation and social care commissioning in mental health. It was intended that steering group membership was consistent throughout the project's duration, bringing in additional people when required. However due to the project's lengthy duration and difficulties in maintaining Trust management representation at meetings, new members replaced previous members during the first five meetings. Prior to setting up the project steering group I had chaired a long running Direct Payment steering group with the aim of increasing the take up of Direct Payments. The new steering group assumed this responsibility within its remit as well as the implementation of Personal Budgets.

It was intended that steering group meetings would generate data for analysis of the project implementation process and learning about involvement from the co-researcher's perspective. Feedback meetings following steering groups and additional meetings in 2008 on 22/1, 28/2, 24/6, 30/7 and 10/12 provided additional data on involvement and ensured the wellbeing of the co-researcher participants by providing a debriefing opportunity with me, a qualified social worker and counsellor with many years experience of working in mental health services.

### **5.7.2 First steering group: 19.4.07**

#### *Research aims, ground rules and first steps*

The initial steering group discussed the AR project. I provided information to members about AR and their role as a participant. Draft ground rules for meetings were considered and agreed (See Appendix 4). The local and national context for the project, Local Authority vision and strategy for Self-Directed Support, and related project work in other service sectors was shared. I explained the process of obtaining research data and sharing this with the group to enable the planning, acting, reflecting, evaluating and re-planning process to take place stressing the ethos of constant evaluation and learning from the information and data gathered. Steering group member's involvement as participants in the research process alongside their role as project participants was discussed and explained.

#### *Project limitations*

The project's practical aim was to introduce Personal Budgets in the Trust using a resource allocation tool: individuals complete the Resource Allocation system questionnaire which asks questions about the nature and severity of their needs; this would then generate a score used to provide an indicative budget. The

steering group's power was limited to making recommendations not decisions, reporting to both the Trust and LA as detailed in the Terms of Reference (see Appendix 5). Social care funding arrangements in the Trust were complex and dually accountable to both the LA and Trust senior management team, executive group and the Local Implementation Team (see figure 4.2 on Page 111).

### *Planning Action*

Work was started to adapt the Resource Allocation System, as used by the Local Authority learning disability services, to the needs of people with mental health problems. We worked through the tool as a group to suggest changes. This generated comments from CRD and CRGe about the nature of risks and people's mental health.

CRD: I don't think that people who harm themselves and people that harm others should be in the same bracket at all. They should be totally separate=  
CRGe: =Yes, if we were in America it just wouldn't be done=  
CRD: =Things like agitated and aggressive are in the same box. You know what I mean, don't you? We all get agitated don't we? You know there are laws about aggression? I just don't think they should be together. People are automatically seen as somebody with a high risk but somebody may say that it is your own choice to want to harm yourself. However to harm anyone else is actually a criminal offence.  
SGLM1: I do wonder though if these were separated whether more emphasis would be placed on the fact that someone might deem themselves to be a risk to others. So.....there is somebody who is likely to go out and harm other people the authorities are more likely to react to that than if they are going to harm themselves. Whereas this way it almost treats them//  
CRD: // but whether they are ill? I know lots of people who harm themselves and I harm myself to be honest with you but I've no intention of going out and harming anyone else.

The co-researchers were vociferous in their opposition to the risk section format, wanting specific risk questions identifying risk from and to others, finding the joining these two aspects of risk together as unacceptable.

A discussion concerning the nature of social inclusion followed in relation to the questionnaire's domain on social contact, with further self disclosures from CRD and CRGe.

CRD: You can stop and have a conversation with staff, but the majority of people with mental health problems often go through days without having seen anybody and that is myself included. Outside of mental health it is different.

CRGe: I mean my life. I work full time, sometimes more than full time hours for many years and I became really, really ill and I came back to X a couple of years ago, got really unwell and I've gone back to working two days a week which I have never done and I actually feel more well now than I ever have done in years, but that's as a result of me, changing my life accordingly.

Discussion about generic and specific notions of disability preoccupied the group. The co-researchers viewed mental health as different in recognisability, stigmatisation and having a more profound effect on a person's social inclusion. Counter arguments relating to older people and people with learning disability facing similar problems were not accepted as comparable in terms of nature or degree. Each Resource Allocation System question generated considerable debate about the best wording to enable consistent interpretation, as well as philosophical consideration of the subject matter such as relationships, social inclusion and decision making ability. Plans to hold workshops with Recovery Coordinators and service users about Direct Payments for people with mental health problems were discussed and agreed aiming to learn from the questions and issues raised at these.

### *Reflections*

Following an initial critique of the Resource Allocation System questionnaire the group reflected on social inclusion, one of the domains the tool used to capture needs. The co-researchers thought the implication that living in the community

equated to social inclusion should be strongly resisted suggesting the Self-Directed Support agenda needed to link in with health rather than just social care.

CRS: Some people stuck in a bedsit, somebody going out to the cinema and then going home and not seeing anybody. It seems to me that these people's lives are stuck by a level of mental health treatment that is inadequate. Before they can start to make choices and take up financial support regarding doing things in their lives they need to go back and actually have psychological therapies and holistic treatments. Is self-directed support going to be far ranging? Is it actually going to do something for mental health?

The issue of people having more choice and control, moving out of a regulatory framework and taking on more responsibility was considered. The co-researchers thought checks and balances to ensure people taking up Direct Payments are not put at undue risk needed consideration. They had concerns about causing people unnecessary anxiety and providing Personal Budgets without adequate support.

#### *Meeting with the co-researchers*

During the post steering group meeting the following was stated:

CRGe: 'I learnt more about what we are actually going to be doing. And getting everyone's opinions and level of input.'

CRD: 'I thought that it was an experience and acceptance as well. Nobody said anything that led another to be "up in arms".'

CRS wanted clarification about who the professionals in the group were and what their roles were in relation to the project and why the managers from the Trust were missing.

CRM: 'I think that the meeting has given us something to focus on. The information is good and the different views interesting.'

Will it be possible to try to define the service user and carer participants in the group's power in terms of what they can and can't influence? They should be seen as whole members of the group and as influential as any other member including a Trust employee. The terms of reference need to be specific but make the point that the purpose of the co-researchers involvement is to improve the outcomes and be seen an equal contributor in the steering group.

The reference to self harming was the first of several self disclosures in the meeting from CRD and CRGe. It implies knowledge based on experience that brings a different critique to examining material in the steering group to that of the steering group professionals. My aim is to chair the group to allow it to be as democratic as possible though I know from experience that by including service users and carers this may slow down the process and be frustrating for other group members. There is a real tension between the need to enable co-researchers's empowerment but get the work done.

I should have been more prepared to talk at the beginning about the context of Self-Directed Support and what it was hoped we could accomplish from the project. These issues were touched on but on reflection perhaps it was my anxiety and my practical approach that led me straight into looking at the steps in a work plan rather than any philosophical considerations of where we were and where we want to get to. In short I presented this in a way that brokered little discussion about whether or not we should be doing this and the advantages for service users and carers. My approach was one of this is the goal i.e. implementation. However as project manager that is my goal! The overall premise wasn't challenged – probably because when I interviewed the co-researchers I stated the purpose of the research to them. Building in time to consider the underlying themes of Self-Directed Support, what it means to change, may enable some ideas to emerge that would be important for service users and carers throughout the project. I would have liked to explore the artificial barriers between health and social care that are highlighted by Self-Directed Support.

It was frustrating not getting operational managers on board at the outset. However with the Trust managers not turning up there were as many service users and carers there as professionals, helping them feel at ease and able to contribute more, than if they had been overwhelmed in numbers from the start. At the end of the group a round up session established that all members felt able to express their viewpoints everyone felt able to challenge views, appreciating that the group needed to do so in order to work together productively.

### **5.7.3 Second steering group: 23.5.07**

#### *Initial observations and reflections*

CRD had reflected on the revisions to the questionnaire asking for the steering group minutes to be changed to state concerns about social inclusiveness and how that is measured. The dialogue below captures this theme which is returned



to repeatedly in the meeting. Steering group members criticised the tool for being unable to capture the subtleties, yet needing to be simple to use.

CRD: I just don't think it measures social inclusion; it's as simple as that.  
It measures activities not what happens after them or whether it had any social inclusion impact. [.....] Do you know what I mean? Because I think that it's..... because social inclusion is one of the worst factors to do with mental health. It's not only in mental health, but it's throughout society. But when it comes to mental health, then it's doubly hard to combat=  
SGLM1:=To take the example of swimming. I mean sitting at home and not going swimming; just going swimming on your own or joining a club. I mean there are all sorts of degrees, you know, in a club you get an activity outside of the swimming=  
CRD: =With mental health service users the chances are that in a club no one will speak to them, they will speak to each other but not to any one else, that isn't really social//  
SGLM1:// I think the point I was trying to make is that the level of inclusion that you do is sometimes a matter of choice=  
CRM: =You can measure the number of times you are going out but whether somebody feels socially included is a very subjective thing isn't it?

Further group reflections concerned Trust managers not attending the steering group, seen as reflecting the status of social care within the Trust; described as clinically orientated and 'medical model' by the co-researchers. The lack of knowledge about social care was acknowledged by the Trust executive as problematic and steering group members felt this was highlighted by the implementation of Personal Budgets and general lack of engagement of Trust staff in the process.

SGLM2: Why is it that people aren't turning up?  
SGTM1: I think there are two issues. As you might imagine there is a capacity issue. There are a relatively small number of general managers. Ummmm and I guess it's something about this.....it's lifting the awareness and the prioritization of the concept of self directed care and that kind of cultural shift in the way that we work with services and service users. Erhhhh and I guess it's up to those of us who have an interest in this that we are sharing this with our colleagues. So there is lobbying to do to show how important it is=  
CRS: =I would like to point out that the redesign and recovery in the CMHT (Community Mental Health Team) groups held workshops and self directed support got a very, very small mention. It was like three sentences. It wasn't really pointed out as the way forward.....  
SGTM1: I think there is a really important kind of agenda going on outside of this meeting which is the concept of erhhhh .....I guess it's the issue of the Trust and lifting the profile of social care within community mental health services. It is an ongoing active process of bringing up those issues such as self directed care and contracting and brokerage and other types of provision to raise the profile in the CMHTs. I think that the development of recovery networks in the new network model, I think that will help. It's clearly well embedded in the principles of recovery and it will be absolutely essential, and so I think it is there we should start.

### *Action Planning*

The group agreed as preparation for Personal Budgets in mental health, service user groups and Trust Local Action Groups would be sent the steering group minutes. This was planned to communicate the proposed implementation and link it in with any other relevant developments.

### *Group reflections on Self-Directed Support*

The functionality of the Resource Allocation System dominated the remainder of the steering group; whether it captured social inclusion factors; how people with a fluctuating mental health condition self-assessed their needs and whether self assessment was the aim to work towards. There was no consensus despite lengthy dialogue. Views ranged from self-assessments causing people added stress through having to acknowledge functioning at their worst, to that of Self-Directed Support being compromised if assessments are assisted by another.

SGLM2 summarised the perceived culture change required to provide Personal Budgets.

SGLM2: I think that the issue here is that we have what is termed to be a 'professional gift model' where somebody assesses somebody and bestows this funding to the person in need. This is what we have at the moment. What we are trying to do is to take people out of that and put them in the community and in the centre of things, having a say about what they think their needs are. I think that's the shift.....it's about moving away from a professional arrangement.

### *Action*

Steering group participants finished amending the Resource Allocation System questions, planning to have a version to pilot agreed at the next meeting.

### *Post steering group meeting with co-researchers*

CRS and CRD felt some comments during today's meeting showed a lack of respect towards service users. They suggested that unless you live with a mental health condition you cannot fully understand it.

CRD: 'You are trying to normalise the service user experience by professionals likening it to their own experience.'

Concern about the language used in the group was shared. Names for organisational structures needed clarification. CRM thought it was like learning a new language with language complexity leading to communication problems. Some co-researchers did not want to ask questions repeatedly and let points go without understanding. They considered however that their contributions were generally respectfully listened to and thought they were learning more about Self-Directed Support, the tasks and stages of the Personal Budget implementation process.

A later email from CRS shared more criticism of the questionnaire wording

echoing the theme of respect in language used:

‘Being mental health professional speak [.....] a substitute for “work-mates” personally I find this word falsely cheery and if I want to exaggerate I might say it sounds condescending.’

CRS also apologised for answering her phone during the meeting, explaining why.

This typified the professional conduct of the co-researchers.

Lead researcher diary: 24.5.07

This steering group raised the philosophical questions I wanted to raise last time even questioning the need for a Resource Allocation System at all as a means to obtain a Personal Budget. It demonstrated a flexible approach to chairing is helpful to enable participants to raise and examine points after reflection and when they naturally occur to that person. Has to be balanced however with getting the business done. Researcher versus manager again!

Social inclusion featured heavily as a subject to be explored and more specifically defined by the co-researchers. This was fascinating as the whole context of Self-Directed Support coming after ‘Our Health, Our Care, Our Say’ and other government papers concerns empowerment, voice and choice for people. What sort of choice was raised, when people are limited by their mental health condition in their ability to make choices and are used to living restricted lifestyles?

The group also covered the wider issue of the lack of support and understanding about social care in the Trust and not being seen as the core role of Recovery Coordinators though it should be as important as clinical work. This was helpful as I see it as a potential stumbling block in the implementation.

I was concerned about the feedback from the co-researchers. I did not pick up any clues to the communication difficulties they were having. I need to be more vigilant and ask people to explain roles, acronyms and any other assumptions that are expressed.

At least T came along to represent Trust management. We have commitment to this project at executive level but trying to get local managers on board is difficult. I am not sure what more I could have done to ensure a better attendance.

The task of improving the Resource Allocation System for mental health enabled the whole group to participate and get to know one another. All members participated and until the end no one talked over one another, all listening respectfully.

As the co-researchers were keen to get going, the practical task within the first two sessions appeared well-received and initiated themes that the government has grappled with; eg. integrating the benefit system with Personal Budgets, self assessment or assisted assessment. All commented they learnt more about Self-Directed Support and how learning more about the context will aid the next steps.

#### **5.7.4 Direct Payment workshops: 9.5.07 and 7.6.07**

The first workshop was provided to local service providers, service users, Recovery Coordinators and managers with the aim to increase awareness and take up of Direct Payments. The second workshop was delivered to city based service users and Recovery Coordinators. I ran both workshops with CRD who had previous experience in providing Direct Payment training. Both workshops started with a presentation (see Appendix 6). Notes of issues and questions raised were taken during and after sessions. The following summary of subjects raised was provided by data analysis.

Subject area	Questions and issues
Knowledge and information	<p>One central source of information needed.            More information about process required.            Can a person change from a block funded service to a Direct Payment?            Direct Payment champions are needed in each team to give advice.            More information will empower people.            Can people without a care coordinator obtain a Direct Payment?            Can carers get Direct Payments?            Case studies of people receiving Direct Payments are useful.</p>
Greater choice about how money is spent	<p>Clarity is needed about what a Direct Payment can be spent on.            Flexibility needed without challenge.            Needs to allow people to increase independence.            Guidelines better than restrictions.</p>
How money is calculated	<p>Process needs to be fair and transparent not based on differing agency rates.            You can't expect people to work for the minimum wage.            DPs are refused if people have to contribute high amounts towards cost.</p>
Managing Direct Payments	<p>Guide to monitoring should be given at set up stage.            Make all forms more readily available.            More advisors needed.            All payment options should be explained from start.            Place more trust with service user.            Takes too long to set up and receive answers if queries.</p>
Supporting Direct Payments	<p>Service user led organisation needed to provide impartial expert guidance, advice and support.            People should be well supported through the set up period.            Need to provide lists of personal assistants "ready to go".            Assessments can be negative and threatening.            Who can help people with no relatives or supporters?            Need someone to turn to when problems arise.            Consider devolving the Direct Payment budget to providers.            Holding reviews suggests service may stop which is undermining and perceived to be about cost cutting.</p>

*Table 5.4: Themes from Direct Payment workshops 9.5.07 and 7.6.07*

### **5.7.5 Third steering group: 26.6.07**

The third steering group continued to agree the final version of the resource allocation tool. Following reflections, two participants raised fresh concerns

regarding the risk assessment. Two new members joined the steering group, CRG (a carer) and SGTM2.

### *Reflections*

SG member's reflections between meetings demonstrated continuing concerns about the questionnaire's wording and that it would not accurately capture individual needs relating to severity and frequency. Comments concerned the blandness of categorisation and the lack of differentiation about type of need.

### *Action*

Steering group members discussed Resource Allocation System amendments purposefully and collaboratively, considering language use carefully in view of predicted interpretation, intent on improving clarity. The co-researchers advocated plain English using non-professional terminology. All agreed and steering group members patiently examined questions regarding improvements. It was evident producing a simple-to-use tool to capture the complexity of a person's individual needs was extremely difficult.

CRD: It's about fitting in boxes and of course there's overlap and all sorts of different interpretations.

Using a tool, designed for self-assessment that required statements about people's problem areas was considered to give the wrong message about personalisation and recovery in mental health:

CRS: [...] Form filling, if you do it at your worst, is just carrying on as it has always been with the problem first, person second.

### *Further Planning*

The next stages needed to pilot the questionnaire were planned. The need to establish a price point using a 'desk-top' exercise trialling the Resource Allocation System with 50 cases was discussed: reliability of the Resource Allocation System could then be tested. This required accountancy expertise which I agreed to co-ordinate and report back to a future meeting.

SGLM2 suggested there may be cost savings in using the questionnaire to calculate funding compared to current reliance on market forces causing CRD to share his current unhappiness with mental health services:

CRD: Under the ethos of recovery there is money being saved at the moment with people being closed in secondary care and fobbed off to primary care.  
SGTM2: It's not across the County, this. As you say in X there are 300 people a year diverted out of the system and sign-posted elsewhere where they can get a service. In Y however it is exactly the opposite – everybody is assessed and gets a service. So there is great disparity. We need to invest in primary care and secondary care too.  
CRD: Well that's what I mean really. Already there is a saving being made from people right now, this minute, fobbed off the books of secondary care into nothing..... to go and see their GP.

Later in dialogue:  
CRD: I'm saying the answer is not over into primary care where there is nothing picking them up, just to clear the books of that backlog of cases to save money and manipulate figures. That is what is going on right now!

I closed the subject down suggesting that discussion had strayed from the focus of agreeing next steps. We agreed localised training sessions for Recovery Coordinators to introduce the questionnaire in the context of personalisation. Maximising impact was considered concluding that delivering training at team bases at agreed times would achieve greatest attendance. Further suggestions of developing a Personal Budget leaflet and flyer were agreed.



*Post steering group meeting with the co-researchers*

The co-researchers wanted further discussion about why a 'desk-top' exercise was proposed rather than a trial with a selected sample of people. I explained this was nationally recommended for consistency as the first trial stage before piloting it with people using services. This was accepted however the theme of obtaining local feedback was felt to be important. CRD described his frustrations:

CRD: 'conceptually recovery was talked about however the Trust has little real "sign up", with "lip service" paid to changing the culture from "them and us" to more mutually balanced relationships between workers and those receiving services.'

CRD apologised for his comments, concerning his perception of a Trust agenda to devolve more people to primary care, accepting his concerns were outside the steering group remit. He thought the ultimate test was not what was said but how services were delivered and rather surprisingly how the Trust was perceived to treat their staff. The consensus with the co-researchers was that the Trust's culture and front line delivery lagged behind its vision of recovery based services.

CRS summed this up as:

CRS: 'The existing service is being "wallpapered with another language" that people are going to use but not actually change the way they work.'

I felt pulled in both directions during today's steering group: as project manager wanting to get on with the business to establish an agreed course of action; and as researcher needing to encourage fuller dialogue, especially to allow the co-researchers time to express their views and be listened to. It was frustrating that the majority of the meeting was spent scrutinising the Resource Allocation System when this has been subject to considerable scrutiny by service users in other parts of the country.

CRD unexpectedly twice became animated during the meeting about people being discharged to primary care leaving me with mixed feelings. As manager I recognise research on service user involvement suggests professionals are put off by high expressed emotion putting it down to the service user's mental health problem. As researcher I welcomed his honesty and confidence in stating how he felt. It was difficult as the issue wasn't relevant to the steering group. I don't know whether it is personal to him or something he perceives as a problem for others. Steering group members responded well however giving information, listening to his concerns not discounting them. CRG said little during the steering group though says she felt OK, finding it useful. Coming in at the third meeting was difficult though I expected her to contribute more than she did.

Progress is much slower going than I anticipated – the next meeting is planned for two months so the financial mapping can be completed. We started four months ago and still haven't got a firm date to start the pilot. With the plan to train teams this will push the start date off further. I know this is necessary as the change requires full support from Recovery Coordinators. I am not sure why I feel under pressure to achieve the next step. Perhaps it reflects my managerial preoccupation with 'doing' exacerbated by having participated in projects that were talking shops producing little change.

#### **5.7.6 Fourth steering group: 30.8.07**

This steering group focussed on: work undertaken outside of the group to determine a price point; promotion and learning about Personal Budgets in preparation for the desk-top exercise; and reflection on learning from the Direct Payment workshops.

##### *Management Representation*

Concerns were voiced by the group about continuing poor Trust management representation at meetings though two managers arrived late.

CRD: [.....] this is the type of thing that needs enthusiasm and if they are not enthusiastic here it is not going to get promoted is it? They (Personal Budgets) will get left behind again as they have done in Direct Payments.

### *Observations following action*

CRD and I discussed initial findings from the Direct Payment workshops. Steering group members agreed the subjects raised should be incorporated into the training planned for Recovery Coordinators. Themes were considered individually to incorporate steering group member's views and experience. Some findings including establishing a service user-led support service and problems with financial assessments were acknowledged but agreed as outside of the group's current remit. Observations suggested people needed to know more about the process and application of Direct Payments in order to promote interest and take up of these. How best to do this raised different concerns.

SGTM1: How all that will be seen without it getting lost with all of the other stuff that we are asking these people to take on board needs to be thought through properly and carefully as it will be very important. [...] Getting people there to be receptive will be an issue not because they don't want to be but culturally it is against years of practice and there is a lot of change going around already.

SGTM3: I hope care coordinators would just see it as another kind of option that they would consider when drawing up care plans and things like that.

SGTM1: I potentially agree with you.

CRD: I'm not sure I agree with you. I don't think that the majority will see that at all. That's my opinion. I really don't, well I've seen it happening already, in DPs. They don't automatically.....they go to training and then go away and somebody goes and drills down because they want Direct Payments. But they don't bring it up. Even though they are supposed to bring it up at every review meeting, they are not. I'm not saying all of them are like this but we need to look at what most are doing, or not doing, most of them.

SGLM3: But they don't need to know about it all because they can always go back and get the information.

SGTM1: It is not yet another bureaucratic task but in fact is a set of principles that they need to kind of hold that fits for all concerned and there is access to information.

SGLM3: I think that a lot of us agree with what CRD said as it rests on the care coordinator introducing the idea of Direct Payments rather than giving all the information because that's too much for people to take in.[...] We need to get the message out with service users and carers. We also need to get staff saying it would be good to know more about it.[.....] , approaching it from both ends to try and meet up in the middle=

LR: =I think that the Recovery Coordinator needs enough information to be confident to share this with the people they see, information about how DPs can be used , a little about the process and what the key stages are.[.....] I think we are agreed that the principle of Self-Directed Support needs to be sold in terms of providing opportunity for people and not worry about having all of the detail. Secondly though I think we can approach this incrementally and on a local

level. We increased Direct Payment numbers by having champions in each area which led to growth in take up and help slim down the process of change with the champions acting as conduits for information and changes from management to local staff.

### *Action planning*

A new finance manager (SGLM4) attended to report on information needed to set the price point and explain the difficulty obtaining this. Discussion resulted in planning a meeting including me and Local Authority managers with service providers to explain what information was required and why.

The content of training to raise awareness about Personal Budgets continued to be planned. Themes and issues to be covered in a presentation were discussed and agreed in the overall context of recovery-based services promoting personalisation.

Issues shared in the group concerning Trust organisational changes; changes to roles and difficulties in promoting new ways of working, resulted in agreement to ensure the training product was directly relevant to Recovery Coordinator's workload. SGTM1 expressed concern about worker's knowledge in relation to procurement and commissioning issues. Discussion resulted in the idea of team champions providing local guidance being trained.

SGTM1: When you look at Direct Payments and Personal Budgets you immediately get questions about what is the difference. This is within a culture where what we know from a number of reports, is that actually they see contract monitoring, both individual and block, has not been well enmeshed in people's heads.....so a number of people particularly those of a predominantly health and therapy background have taken a very long time to get to grips with the whole concept of purchasing care under Local Authority rules. [.....] A lot find it confusing.

CRD suggested training must include team leaders, who can act as blockers of innovation, and not just rely on recruiting champions. CRS suggested promoting Self-Directed Support to emphasise potential to reduce a professional's workload whilst not compromising their professional integrity. Several agreed with this approach as professionals should enjoy helping people become more self reliant and innovative.

Problems around Recovery Coordinator's views of self-assessments undermining their professional assessment were discussed, acknowledging the continued legal need for professional endorsement of any self-assessment. Opportunities for people to self-assess, provided assessments are jointly conducted should allow for resolution of differences. SGLM2 informed the steering group of results from a recent learning disability pilot suggesting professionals assessed people as needing more support than the individual's assessment. SGTM1 argued that cultural change was needed to prepare workers and service users to take on more care and control.

SGTM1: [.....] as we start moving towards true empowering recovery based services, that actually some harsh realities are there waiting to be unmasked. People can't be sheltered from that. [.....] We have encouraged a level of dependence and blindness that isn't helpful in the longer run.

The steering group concluded by agreeing my suggestion of a newsletter to help promote Self-Directed Support and Personal Budgets to be drafted by me and the co-researchers.

#### *Post steering group meeting with the co-researchers*

Themes expressed concerned difficulties in keeping up with the dialogue, complexity of social care systems, and discussion being focussed on

organisational development rather than people receiving services. CRD felt the co-researcher's remit included focussing on the end service user. All acknowledged appreciation of meeting afterwards and talking issues through.

Lead researcher diary: 30.7.07

My concern is growing about lack of operational acknowledgement of the project and therefore its implementation. CRD thought that Trust managers not being enthusiastic early on, was likely to mean even less enthusiasm later. However when the two Trust reps did eventually arrive they were encouraging, thoughtful though realistic giving us the context of major changes being carried out in the workforce impacting on team's workload.

I think the frustrations shown by the co-researchers especially D and S display the tensions between vision and reality (of implementing Self-Directed Support and Personal Budgets in particular) with me as project manager and lead researcher having to navigate through both. The project highlights the weak role of social care in the Trust. It is seen by some workers as not their business to enquire about people's finances and not what they were trained to do. They resent taking on duties that mean asking questions about money, costs and putting a case to panels. They are used to working autonomously assessing a need and providing it for a person without the need for justification. This project brings that out in sharp relief.

Nevertheless I enjoyed the group today. It is an opportunity for real discussion and reflection. With the co-researchers present, discussion is always brought back to outcomes for people needing mental health services rather than government directives and targets. I believe the risk of a project with five co-researchers involved; slower pace and more detailed discussion about outcomes and motives; outweighs the difficulties of taking longer and needing more concentration to ensure the group is conducive to open discussion.

I am still concerned about the carer co-researchers as they are quiet compared to S and D. M does ask questions but G rarely contributes though tells me she is fine and keeping up with most of the dialogue. Missed CRGe who didn't turn up. I haven't heard from her so will make contact to find out if she is ok.

Following email and telephone contact with CRGe in August 2007 she explained she was off sick from work and consequently unable to participate. Whilst feeling better she could not continue project involvement as she hoped to move away.

A meeting with day opportunities providers on 17.10.2007 agreed a plan to share the information required for price point determination of the Resource Allocation System.

### **5.7.7 Fifth steering group: 18.10.07**

#### *Observations and reflections on action*

Difficulties in obtaining information from day opportunities providers prompted observations from the service user perspective about protecting their rights.

CRD: I think it's nice that the protection is there and that names of service users are not given.  
LR: That was their view, that they were people who don't actually want anything to do with formal mental health services, whether or not they have had anything to do with them in the past, we wouldn't know. Maybe not. [.....] I can see it from their perspective but from our perspective we are giving them huge amounts of money [.....] it is hard to know what money is being spent on.

Further discussion about day opportunities led to CRD suggesting providers needing to adapt to ensure they provide what people want.

LR: [.....] In relation to Self-Directed Support an example was given of groups about women's needs [.....]. I think that there is recognition that there are still going to be some things that people will want to go to that cannot be individualised. But all of the money is tied up in block contracts so how can we offer a choice when all of the money is tied up?  
CRD: They need to provide what people want as people will vote with their feet if they are not getting what they want in a particular area[.....]. The fact is there are more people out in the community and not coming into the traditional day centre. Some have already cut back their hours and times and days.  
SGTM3: What service users have done in T[local area] because the service that R was providing had become increasingly limited was to hire a church hall and have their own drop-in.  
CRD: That was the outcome of the day opportunities review – people really wanted to keep the social aspect of it.

A newsletter and Self-Directed Support presentation developed in Learning Disability services was shared leading to discussion concerning quality in care planning agreed as essential to develop a personalised approach

LR: [...] I can't imagine any care coordinators could go along and assess someone without involving them.  
CRD: Oh I can  
LR: Can you?  
CRD: Without involving them.  
SGLM1: They would have to be involved at some level though wouldn't they? I know that a lot of surveys say that people don't know they've got a care plan and I find that really hard to....  
CRD: A lot of people don't even know what they are for.  
CRS: I think that is very true.

The theme of empowerment through the Recovery Coordinator and service user working jointly was reflected in discussion about whether the questionnaire should be an assisted or a self-assessment. Lack of basic knowledge was identified as a problem and agreed to be included in the training programme to be planned.

CRD: I think we need to look at some way of doing it where it is just not removed from the service user's hands like that, which is historically what would have happened.  
LR: and done jointly?  
CRD: definitely, yeahhh, re-done jointly.  
LR: I think we would need to be upfront about it and say if a self-assessment comes through and is in huge variance to our previous understanding of that person's needs then the Recovery Coordinator will come back and discuss that with you. So it will be more open and upfront in that way. Which is what the business should be like if you were going to any High Street business; you would be told when you were going to be seen, what they would be doing for you, how much it would cost and what the choices were. I don't see why we should not aim to do the same.  
CRD: Can I just say? I think this highlights a problem that exists in some areas. Some areas. There is a gap between the managers and the care coordinators knowledge about Direct Payments. The care coordinators are supposed to be going and asking for something on behalf of the client but it is blanked by the manager.  
LR: This does highlight the need for more training and awareness-raising for managers as well as care coordinators.

### *Action planning*

Planning for increased Direct Payments in the context of the Trust's service reorganisation raised concerns about people retaining these if discharged from Trust services.



CRD: This is something that we ought to put on the agenda of the next PEG (Professional Expert Group) meeting really [.....].....you know, because with the advent of DPs in the particular case you know, they were stopped from getting it because of the machine out there which was nothing to do with the service user really [.....]

Participants agreed the need for people to retain Direct Payments without necessarily being on a professional's caseload would promote recovery principles.

Participants agreed that I, with co-researcher involvement, should develop a leaflet and presentation suitable for all stakeholders: carers; service users; Recovery Coordinators; and providers, before the next steering group.

*Post steering group meeting with co-researchers*

CRGe's decision to give up the project was regretted; she provided a lively addition to discussions. We agreed CRD would raise the issue of people being discharged but still able to receive Direct Payments at the Trust Professional Expert Group and I would make a start on the presentation and leaflet but we would make them 'user friendly' together.

Lead researcher diary: 19.10.07

I feel that the group is drifting somewhat as we are meeting obstacles outside of our control eg. the lack of financial information on day opportunities. On reflection this is something I could have ascertained earlier on in the implementation so work could have been undertaken at an earlier stage. However this is learning for me about how we do business with huge sums of money with a proportionately large amount of trust and faith that providers are providing good quality services.

The co-researchers still appear to be on board with the project and attending every steering group, apart from the loss of CRGe. CRD is repeatedly raising themes such as the Trust discharging 30% of their patients to primary care and Trust managers stopping Direct Payments through lack of knowledge-these are not always helpful to the discussion. Most of CRD's observations are balanced and helpful but today I found it difficult to know how to respond to some very critical views on the Trust and the service it delivers, wanting to defend it. With my researcher hat on however I reminded myself that for CRD this is his reality and based on his experience.

A meeting held on 7.11.2007 with Local Authority managers agreed I would join a working group to devise a new tool to replace the current Resource Allocation System being adapted, as recommended by Local Authority and Trust senior management group.

Lead researcher diary: 7.11.07

After all of the work to adapt the 'In Control' Resource Allocation System it was decided that this is not going to produce the results we need. Whilst I was invited to join the group to develop the new Personal Budget Allocation it is clear there was little choice if we want to implement Personal Budgets. Mental health, whether for good or bad, is too small an entity to develop a self-assessment questionnaire without the technical assistance and administrative backing of the Local Authority. In any event there is an ethos at executive level to join up services wherever possible so that there is an agreed approach across all services in the County. We are spending the Local Authority's money and they ultimately want to ensure this is allocated appropriately. This leaves me to have to tell the steering group that a lot of their effort will not come to fruition! This has increased my self doubt. Did I start the project too early? Should I have waited until more was known about the working of the Resource Allocation System locally? I am used to knock backs in project work but I can imagine the co-researchers reaction will be somewhat cynical and unhappy as the Local Authority ethos is to focus on similarities across the different service needs whereas one of the co-researcher's themes is to accentuate the difference in MH to other disabilities.

The presentation (see Appendix 7) of our study so far was presented in a question and answer session by me and CRD, to the Trust Professional Expert Group on 20.8.2007. Discussion highlighted the theme of recovery and Personal Budgets being intertwined.

#### **5.7.8 Training Recovery Coordinators in eight areas: 19.10.07 to 5.11.07**

I undertook this and was accompanied on three occasions by co-researchers. Due to logistics, difficulties in travel arrangements and other commitments; it was not possible to arrange more joint presentations.

In all sessions themes of Personal Budgets providing greater flexibility and control, due to individualised services, and improving people's lives were raised. All agreed with these as the central premise of personalisation. The social workers had studied the personalisation agenda and were particularly knowledgeable about the proposals. Links to the recovery approach were made and workers were seeing themselves as valuable in the process rather than concerned about their professional role being diminished. Concerns expressed were about how Self-Directed Support was going to be introduced, and changes to their role and whether the people they saw were prepared and able to take on Personal Budgets.

I took notes during and immediately after the workshops which were delivered using verbal presentations followed by a question and answer session.

The questions and observations generated from the eight workshops were analysed and themes identified from the data are shown in Table 5.5 in order of significance, indicated by the prevalence of comments on that theme.

Theme and Sub Theme	Examples of questions or observations expressed
<p><b>Concerns on behalf of Service Users</b></p> <p>Lack of capability and confidence</p> <p>Unrealistic self-assessments</p> <p>Advice and assistance</p> <p>Social exclusion</p>	<p>This assumes people's capability and confidence whereas they don't all have that. A lot of people can't manage the money side of their life.</p> <p>I am not sure self-assessments will work for everyone- some people will say they're OK when they clearly are not.</p> <p>People will need help and assistance with this. Who will provide it? People need life coaching about what is possible. If it involves technology, like the internet, then a lot of people won't be able to use it. Who is going to manage all of this for the service user?</p> <p>Strategy appears empowering but could it lead to social isolation? People don't always want traditional social care services but all this is going to depend on what other choices they will have and there isn't always a lot out there. Do people know they can have expectations?</p>
<p><b>Knowledge and Information</b></p> <p>Personal Budgets and legal framework</p> <p>Services knowledge</p>	<p>How does the requirement to provide a Community Care Assessment fit into all of this? How does Self-Directed Support fit with the Mental Health Act?</p> <p>Why can't health needs be met by a Direct Payment?</p> <p>It's going to depend on your local knowledge of what's out there. Can carers get help in this way?</p>
<p><b>Concerns about Recovery Coordinator role</b></p> <p>Changes to professional assessments and ways of working</p> <p>Bureaucracy, Funding systems</p> <p>Existing services</p>	<p>It's hard to think in terms of outcomes as distinct from meeting needs. How will we know what is an acceptable way of meeting a person's outcomes?</p> <p>Will it mean extra paperwork?</p> <p>Once the assessment is done does that mean an entitlement or do we still need to get the funding agreed? What is the system for agreeing a PB going to be?</p> <p>What will happen to in-house services?</p>

<p><b>Financing the change</b> Cost cutting exercise</p> <p>Unaffordable</p> <p>Means testing is off putting</p> <p>Controls</p>	<p>Is this just a means of cost cutting?</p> <p>Does it raise unrealistic expectations as there is no new money, just recycled budgets? The system isn't working now as we are always overspent, won't this just add to it?</p> <p>Having to contribute puts people off.</p> <p>How will giving cash payments be policed? How will you stop people abusing this?</p>
<p><b>Recovery</b> Recovery culture</p> <p>Independence</p>	<p>Fits well with the recovery model of working. Can it be used to help people move out of residential care?</p> <p>Will a Personal Budget/Direct Payment be a fixed amount or will it shrink if a person becomes more independent?</p>
<p><b>Clinical Evidence Base</b> Social Inclusion</p> <p>Moral Judgements (Added following last three sessions, Dec 07 and Jan 08)</p>	<p>How do I know that a Direct Payment provides better outcomes for a person?</p> <p>'We would all feel better if we were given money for a foreign holiday.'</p>

*Table 5.5: Themes from team training sessions*

### 5.8 Emerging themes during the first action research spiral

During the first AR spiral themes emerged from steering group meetings, meetings with the co-researchers, Direct Payment workshops and training sessions with Recovery Coordinators. I will discuss the emerging themes as they developed over the course of this first spiral.

In the initial steering groups themes concerned the complexity of the Resource Allocation System to produce an indicative budget, and mental health specific versus generic approaches in both the development of the self assessment tool and generally in relation to the Self-Directed Support agenda. All steering group participants contributed to the discourse but it was the co-researchers who made

clear their commitment to a mental health specific rather than a generic approach. This was based on their view that a specific approach would be more effective in capturing mental health needs. The comparatively low status of social care within the Trust was another steering group theme that was shared by all participants together with the need for culture change within the Trust towards less medicalised, more recovery orientated and personalised services. This theme was agreed by all steering group participants with discussion acknowledging the need for staff training and the adoption of easily understood processes to access social care resources. In the post steering group meetings with the co-researchers the theme of language complexity within the group was raised though this was acknowledged to be less problematic than the co-researchers' experience in other involvement projects.

During the Direct Payment workshops themes of lack of knowledge based on poor information and needing an external agency to provide support, help and advice for people taking up Direct Payments were raised. When this was fed back to the steering group it was accepted without demur as it was consistent with the group's experience of poor knowledge and understanding within the workforce. The steering group agreed that simple systems, emphasising the benefits of Direct Payments and promoting these within the teams was required in the form of interactive training sessions across the County.

The theme of the importance of language being explicit and easily understood was raised and agreed by all participants in later steering groups as was the linkage of the recovery approach with Self-Directed Support. All participants discussed and agreed that the Trust needed to improve its services to be more recovery-orientated and have more understanding about the importance of the

care management component of care planning as a pre-requisite for more personalised services.

Empowerment as a theme was also being raised in the steering groups acknowledging the required change in power relations between professionals and people using services for Self-Directed Support to transform the culture within services.

During the training sessions held towards the end of the first AR cycle the themes raised were those of: positive benefits of Personal Budgets and Direct Payments, links to the recovery approach, concerns about changes and extra work on professional's roles, capability to manage, lack of information about all aspects of Self-Directed Support, and concerns that this masked a cost cutting exercise. Many of the concerns were made by workers on behalf of service users which corresponded to discussion in the steering group about the existing paternalistic attitude of the workers.

At the end of the first AR cycle therefore the picture was that of a consensus of viewpoints across the steering group including the co-researchers and from the workforce highlighting a lack of information about Self-Directed Support, poor understanding of wider social care systems underpinning personalisation, an acknowledgement of the need for culture change whilst accepting that Direct Payments could be of great benefit to people. However barriers such as capacity to manage and needing independent support services to reduce worker's overload were acknowledged and it was suggested would need to be built into any new system.

## 5.9 SECTION TWO: Qualitative findings of the second action research spiral

### 5.9.1 Sixth steering group: 3.12.07

This meeting covered: the continuing work to establish an average price for social care services; the decision to change from adapting the 'In Control' Resource Allocation System to the Personal Budget Allocation tool designed collaboratively across the Local Authority; using brokers to procure care and support for people with complex needs; and continuing feedback about findings from the workshops on Self-Directed Support provided across the county.

#### *Observations and reflections on action*

CRD had emailed to me a copy of 'A voice and a choice' (Brewis, 2007) which I forwarded to steering group members. The paper considered mental health and Self-Directed Support nationally, providing some comfort that implementation was raising more questions than it was providing solutions, remarkably similar to our experience.

SGLM1: These national issues, you know, it seems that you could drop in on any area and they are experiencing the same problems, which is reassuring in some ways, in that we are no different to the rest, but depressing in other ways.

CRD: Well, how to get beyond that one; that's a big hurdle, isn't it?

SGLM1: Well I think that actually it's reassuring and that it is coming together hopefully nationally, once there is more investment in Self-Directed Support in mental health services and information from other areas where it has really taken off and we can learn more.

SGTM4: Yes.....I suppose that the comfort is that although we haven't got it right we are not actually any worse off than anybody else. I think everybody is in the same boat. That is what is identified. It shows we are thinking along the right lines.

Feedback from the Trust Professional Expert Group stimulated discussion in relation to Self-Directed Support and assessments in particular. Behavioural changes in people delivering and receiving mental health services were agreed as needed.



CRD: [.....] it is the shift from 'we say you can have this' to 'let's sit down together and do your assessment'. That's something that an awful lot, not all, but an awful lot of staff seem to have problems getting their head around. I think this is critical. Why, I don't know. It's probably more than one reason. I don't think we can change the whole culture, just like that, within the Recovery and Independence Professional Expert Group, but I can't see the number of these things (sic. Direct Payments) shooting up either until it is actually addressed somehow.

CRM: Or sometimes when people are in hospital and they haven't got anyone to speak on their behalf and they don't know what they want sometimes. It is giving them the confidence.

LR: You're right. It's culture amongst the professional staff, but also culture amongst service users who are used to being done to, if you like, or people helping them with their decisions or overly protective. It needs confidence raising for service users. But also, I think we need to acknowledge how professionals were trained, you know, I was trained in that way//

CRD: //But you got over it, didn't you?

*Everyone bursts into laughter lasting five seconds*

Staff culture being more receptive to promoting Direct Payments and more person-centred was considered a prerequisite to increasing take up of Direct Payments and the successful implementation of Personal Budgets. Participants acknowledged considerable work was needed to achieve this.

LR: I think that we often expect people to change with no input into the process

CRD: But what is going to make them change? You know I have been having discussions with many people and we keep tinkering around the edges rather than having a real drive in sorting it out.

LR: [.....] one of the main influences is management as an influence on how people function and work.

SGLM1: There is certainly a difference in terms of adopting a particular strategy and actually managing to get it down through to the 'coalface', if you like. And there is a gap in what senior managers say we are doing and what we actually are doing.

CRD: I am delivering training to the service users about Direct Payments. I mean I'm running my own research into this because I want to find out how much previous knowledge people had about Direct Payments. Out of the 30 there only one person knew and that was someone I had told myself. Whatever manager who is in charge of those people isn't telling them they need to offer Direct Payments to people. It's part of their job, do you know what I mean? I mean that worries me because if nothing happens about that then Self-Directed Support will go down the same route.

The feedback from the Professional Expert Group endorsed the strong connection between Self-Directed Support and recovery; observed as helpful to the required cultural change.

CRD: Definitely Self-Directed Support and Direct Payments are one of the biggest items in, and I hate the term, the recovery toolbox, you know what I mean, without a doubt. Because of the variety of people that you can use it for.

LR: Having cash in your pocket is quite empowering isn't it? We all know what it's like when we go to our purse and it is empty!

CRD: Sure and you know sitting down with somebody and doing an assessment, being asked do you want a choice, being allowed to have a choice has got to be an improvement. In the traditional medical model it is not there. But at the moment we have got some Recovery Coordinators where they don't go out of their way to help do it.....they may come back and say one should go to the Citizens Advice Bureau. Mine has a permanent two week queue to get to it [.....]

### *Action planning*

I informed the group about the proposal to abandon work on the 'In Control' Resource Allocation System and produce a self-assessment questionnaire to be used across all service sectors. The collaborative approach producing a single tool with modifications for each service was explained as endorsed by the Care Services Improvement Partnership recommending authorities develop a single tool and price point across service sectors.

The difficulty in resisting this proposal due to the Local Authority and Trust working collaboratively at senior management level and the direction from the Director of Adult and Community Services was considered including the possible positives of the decision.

LR: Reflecting on what we had developed it was extremely mental health focussed which is fine for people who have purely mental health problems. But a lot of people especially those with higher needs have physical problems as well as their mental health problem and some may also have learning disability. I am not sure we would have captured all of those needs. What we will be developing is a tool that captures all of those needs but whereby you only answer the questions that apply to you.

CRD: Mmmmm  
LR: I can see that you are not happy D.  
CRD: Well, you know, where does that leave us at the minute? A lot of people with mental health problems who have physical problems are sent to their GP but he doesn't want to know. That's the position that an awful lot of people are in. So I can just see by doing this that mental health will be the poorer sister out of the three services, definitely. I know nationally that mental health has the lowest budgets so there will be the least amount of needs met therefore I would argue that there needs to be the most amount of focus on capturing the mental health aspects because these are unique.  
LR: Those will be captured but what we wouldn't have done was capture people's other needs.  
CRD: Is there no way that we could keep the mental health specific questions and if people have physical or leaning disability needs we use those questions as well?  
LR: I think that would be too disjointed and difficult for the person and the care coordinator. When we have a draft of the Personal Budget Allocation tool I will bring this back to the meeting for you all to look at and feedback on. We need to ensure that mental health issues are not side lined and it has specialist sections to cover the complexity of mental health conditions especially around the risk areas.

Following discussion the group agreed that keeping the same domains as the previous questionnaire and adapting wording would make this acceptable.

SGLM1: I think that we can keep all of the same areas.  
LR: I don't think there is any question about that. It is making sure that we've got the questions within the sections that we really want. It is about tying them in with the others really.  
CRD: Well if we are not losing anything then I don't see why not really.

CRD and CRM voiced several concerns about the assessment process being as joined up as possible to reduce viewpoint differences. CRM stressed the notion of equality and having an opportunity to agree jointly the best outcomes from the assessment. SGLM1 and I suggested the care planning process provided greater opportunity for disagreements due to disparities of opinion about how much resource is required to meet defined needs and needed covering in the training.

A new brokerage system promoting outcome based recovery plans for people was discussed and workshops were planned with providers. CRD and CRS were

willing to attend to give a short presentation about personalisation. The group agreed this presented a good opportunity to promote Self-Directed Support to providers seen as another stakeholder whose culture needed to change.

Themes from the training provided to Recovery Coordinators were shared. No themes or subthemes surprised the group. It was their general perception that the SG shared most of the same concerns and questions. The co-researchers were interested that a major theme described concerns on behalf of the service users. They suggested this could reflect paternalism endemic in the Recovery Coordinator role, indicative of a need for culture change to allow people to take responsibility for their own risk management. Themes concerning knowledge and information, financial issues and links to recovery were accepted. Themes about Recovery Coordinator roles were discussed. Suggestions of reducing authorisation layers making the Personal Budget system simpler whilst ensuring people most needing resources were those receiving them were agreed. Three training sessions remained to complete county coverage. Any themes were to be brought to the next steering group for consideration.

Diary 4.12.07

I was not looking forward to this steering group and sharing that the work on the questionnaire had to be abandoned; however it was accepted with surprisingly little protest. Deliberately waiting until the group warmed up to raise it may have helped. They appear very supportive of each others views and work productively together, despite changes in the Trust manager's representation.

I am disappointed the project increasingly is led by the Local Authority decision making process. Mental health is too small in its social care commissioning activities to work alone so we accept the Local Authority decision making and strategies. They are not imposed and we work together on developments and it is hard to argue against the view of presenting a publically unified approach to new developments. It is Local Authority money we spend and Local Authority financial and contractual support we use. It is hard though – our systems are different, we don't just care manage, in fact we do little of that: we recovery coordinate, our computers programmes don't interface and there are lots of other subtle and obvious differences. **I feel the Local Authority is like a juggernaut steaming along the dual carriageway and here are we in our rather shaky bicycles left buffeted in the turbulent wake, pedalling hard but finding it difficult to keep up.\***

On a positive note the group were very interested in the themes from the training and this was a good end to the steering group which had over-run showing an ongoing commitment and interest. \* This is represented in Figure 5.4 below.

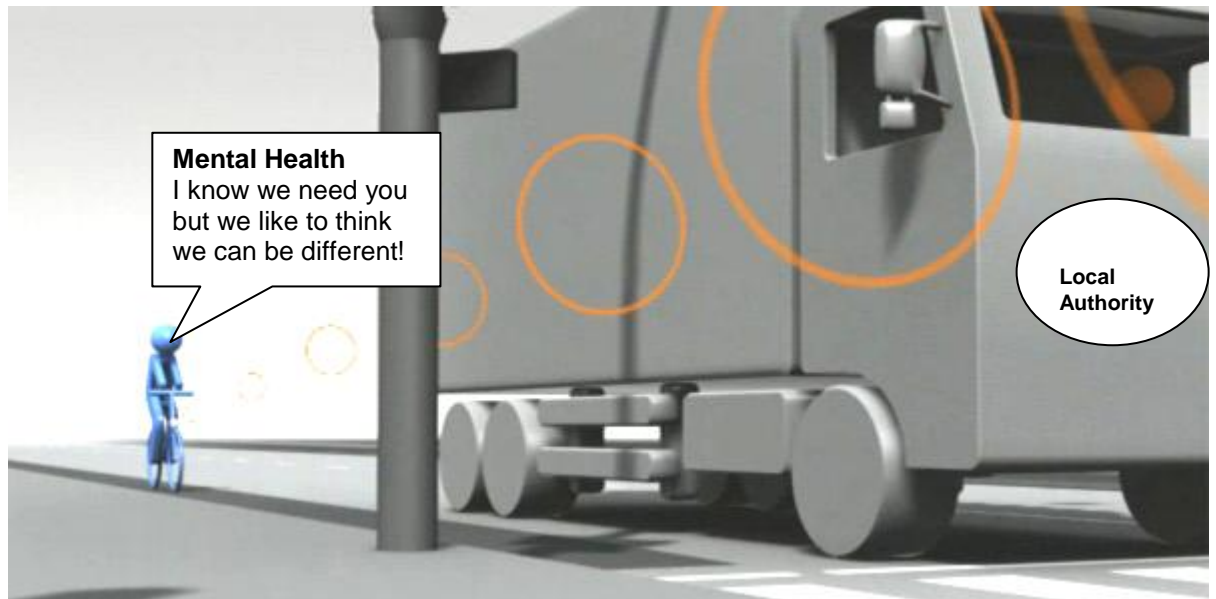


Figure 5.4: Analogy of juggernaut and bicycle (adapted from Google images)

On 13.11.07 I met with CRD, CRS and CRM to agree the final version of the Self-Directed Support newsletter and factsheet and discuss concerns about the first version of the Personal Budget Allocation tool and documentation for brokerage.

### **5.9.2 Further Recovery Coordinator training: 4.12.07, 8.1.08 and 16.1.08**

Three further training sessions were delivered. All the themes and subthemes shown in Table 5.6 were raised with a new theme raised by two workers concerning the clinical evidence base for Personal Budgets. This followed discussion about applying personal choice to produce desired outcome. The evidence base of Personal Budgets was contrasted to the evidence base required for pharmacological interventions or talking therapies. Two subthemes were identified in relation to promoting social inclusion and Recovery Coordinator's moral judgements, typified by an example of using Direct Payments for a foreign holidays rather than respite in a Care Home, with the worker stating that she could

not afford a holiday that year. Conversely others spoke of Direct Payments enabling people to join clubs and mainstream activities which meant they felt part of the community. These themes have been added to Table 5.5 shown on page 180.

Lead researcher diary: 25.1.08 and 2.2.08

Reflections on Self-Directed Support implementation

The Local Authority appears to be in the driving seat regarding the process and agreeing what can and can't be done. The Care Trust appears to have dropped out altogether which means there will not be one unified approach across the Trust. I am resigned to this as it is the usual pattern of differing priorities and time scales so I will concentrate on implementation across the Local Authority. There is a vast amount of technical work to be done in fixing the price point and testing the Personal Budget Allocation which is still being tweaked and improved. I don't find it an attractive tool even though it may have more accurate outcomes.

My main issue is how to maintain the high profile of Mental Health in light of the powerful Local Authority structure and make sure that assumptions aren't made about us, without us.

2.2.2008

Reflections on involvement

There is a real conflict in being an insider researcher. Namely the moral issue of being an action researcher with the agenda of changing things for the better and empowering people, contrasted with being the project manager where I am swept up in the pace of change and other organisational agendas. But what does empowerment really mean to people? It is clearly a concept that is personal to an individual with meanings of improving confidence, self esteem and your voice being heard, but additionally it has a social construct in terms of decent housing, employment, a family life and feeling social included. Mental health services can't give all of that to a person but they can provide the right environment, together with respect and support to allow a person to self determine and begin their recovery journey in gaining those things for themselves.

*I attended meetings during January and February 2008 to agree the Personal Budget Allocation tool. (See Appendix 8 for the final version).*

### **5.9.3 Workshops: 24.1.08, 28.1.08 and 13.2.08**

CRS attended the first, CRD the second, and CRG the third workshop, to promote service user perspectives on personalisation. The purposes of the workshops, held across the county, were to: introduce providers to a new system of brokerage to procure care and support services for people with complex needs; and to provide information and material about working in an outcome focussed, rather than needs led approach.

I met with the co-researchers beforehand to discuss the context of the workshops however did not brief them as to what to present or say. Between them the co-researchers raised the themes of;

- i) individualisation: the need to tailor services to people and recognise people's differences;
- ii) continuity being important for people particularly trusting relationships;
- iii) flexible services allowing people to have choice and control over their day to day life;
- iv) allowing people to set their own agendas even if this challenges the provider;
- v) the importance of social inclusion and enabling the person to feel part of the community through participation.

Provider Workshops

CRD attended and was a very impressive speaker promoting a service user perspective on personalisation. He didn't ask to be given a slot but naturally contributed and put very effectively in completely his own words why providers need to start working in a person centred way with people they care and support. The Local Authority managers were very impressed with both his and CRS's contribution at the workshops.

CRS echoed CRD's contribution and explained simply why personalisation is so important. Interestingly the issue of language was raised by one of the providers as brokerage uses the term 'to bid'. Their view was that using the term 'bid' or 'broker' when they are providing a service for people made it appear business orientated and impersonal. This links to some of the comments made by the co-researcher around use of language being important. Is it inevitable, that a process one stage removed from face to face contact between provider and commissioner, will lead to a more detached and impersonal approach? If so this is irony indeed, given the whole outcome is meant to be more individualised. Are there improvements to the system that can make it more personal?

Action: Discuss at the next steering group

*Meetings with Local Authority managers during March 2008 agreed improvements to the draft Personal Budget Allocation tool.*

#### **5.9.4 Seventh steering group: 22.4.2008**

This steering group was planned for 12.2.2008 and then 12.3.2008 however few members could attend. Eventually it met a month later.

#### *Observations and reflections on action*

The meeting began with an animated critique of the draft Personal Budget Allocation tool. The format was considered much less personal than the previous tool and likened to forms produced by the Department of Work and Pensions. Participants felt it encouraged people to complete as at their worst suggesting this encouraged dependency and the antithesis of promoting recovery.



CRS: Could we not start out with a very specific mental health specific one and then have appendices for dual or whatever additional needs?  
CRD: Yeh....the only reason we haven't got one [...] is that nobody wants us to sit down and specifically work on one.

CRS suggested the form was discriminating against people with mental health problems as the questions were so general. All agreed the complexity of ascertaining from a questionnaire the full range of a person's needs and desired outcomes, and systematically using that information to produce a Personal Budget for all disability groups. Steering group participants viewed the Personal Budget Allocation tool as appropriately illustrating the range of a person's disability, but not capturing the emotional and psychological support they needed, with poor regard to risk factors. CRD felt it was just 'scratching the surface' in its ability to capture needs; impersonal in approach; and that there were additional problems due to poor communication about services availability.

CRD: [.....] we know that mental health has such low figures of people accessing social care. They've not been told and they're not aware of it. That it is out there, you know, they have just been left out of it basically because they don't know. [.....]

CRS whilst arguing for a mental health specific tool was concerned it might be intrusive, stating until she had greater confidence in psychiatrists there were things she would not want to commit to a form. This stimulated a discussion about under-reporting of needs.

SGLM1: I think if the form did rely on self-assessment they would all end up with a lot less money because generally people will want to tick 'yes, I can do it' and don't want to admit to needing help in the night and so on.

SGLM3 disagreed and felt that people would quickly learn saying 'no' would mean receiving a bigger budget however accepted that all self-assessments would need to be moderated to ensure fairness.

### *Action planning*

The group agreed the Personal Budget Allocation tool should be tested with Recovery Coordinators and service users to collect their views. I agreed to arrange this in order to collect feedback on the form, ease of completion and correlation between the indicative budgets generated to the current service cost.

### *Further observations on action and reflections on implementation*

Workshop feedback was summarised as demonstrating good provider engagement. There were many examples of constructive working, with several seeing personalisation as a means to develop business profiles offering more individualised support. Some providers needed to change their working style to reflect a more recovery orientated approach rather than just maintaining people and enable people to move towards less dependency on services.

Discussion concerning the future direction of Self-Directed Support centred on Local Authority recommendations around the Social Reform Grant, nationally allocated, to prepare services and systems for personalisation. Proposals for a Centre for Independent Living were being considered including the recruitment of carers and services users as part of the organisation. Seen as a positive proposal nonetheless there were concerns about the nature of independence if this were provided by a Local Authority contract and how service users would be utilised.

CRS: It does seem quite disturbing that being a service user is seen as a career option. It's not recovery. I am not persuaded that 'service user-run and led' is the most fantastic thing.  
SGLM3: A group of service users could be managed from the Management Board and they would constantly change.....  
CRS: So long as they were there long enough to know what they were doing. I could be happy with the idea of a rolling programme of secondments for a fixed term.  
LR: But there should be the opportunity for service users to apply for jobs like anyone else. Having employment is a primary focus....

The Local Authority had finally agreed to commit to using a Resource Allocation System to generate Personal Budgets, promote Direct Payments and simplify the social care charging system. Alongside this was a proposal to provide a comprehensive information system about personalisation using all means of communication.

#### *Action planning*

The group reflected on the need to learn locally about people's views on Personal Budgets and suggested working with providers to ensure that a wide range of traditional and more bespoke services were available. Holding focus groups with service users and carers was agreed, with a proposal that existing day opportunity groups may provide a wide sample of people with varying needs and experience of using a range of social care resources.

Two focus groups were proposed covering different geographical areas in each category of service users and carers. It was agreed the focus groups would be jointly run with the co-researchers to gather data around support planning needs, options for managing and using Personal Budgets and potential risks and problems. I proposed meeting with the co-researchers to agree the focus group questions.

### *Post steering group meeting with co-researchers*

Meeting the co-researchers afterwards revealed no new concerns about the meeting's process, discussion or recommendations. CRD remarked that generally he found power relations in groups inhibiting but that the steering group was different:

'I find the power and communication at the Self-Directed Support group is actually a good example of how it can work if people, like yourself, are willing to go that extra mile and help make it work. I feel treated with respect there and as if my contribution is valued and does make a positive difference. Well done for having the foresight to do this.'

Lead researcher diary: 22.4.11

The Personal Budget Allocation form is bringing out some emotional challenges in the group and not all from the co-researchers. In trying to cover every eventuality and all levels of need the questionnaire has lost most of the revisions the steering group suggested to make it acceptable to MH. Developing a Resource Allocation System is extremely time consuming and frustrating. It feels an impossible task to produce something simple that covers an individual's complexities. This is just a tool and yet it is bogging the group down. An overall approach across the country would be welcome so that we can concentrate on the other aspects of introducing a Personal Budget such as information and training, support planning and being creative. This journey is going to take a very long time. Feedback from the provider workshops was positive, however, on reflection, there is much to do in order to change both our and their commissioning approach. Some providers will definitely see the implications and develop new ways of working but others will be left behind providing unchanged services. Our next task is to find a large enough sample to run some focus groups which is exciting. I know being a commissioning manager will help me in this task however trying to engage people to be interested enough to attend is going to be difficult.

Following a planning meeting a workshop was held on 15.5.2008 with Recovery Coordinators who completed the Personal Budget Allocation tool in relation to people receiving social care resources.

### **5.9.5 Meeting with the co-researchers 30.7.08**

The second collaborative meeting agreed the focus group questions (see page 122-3). Preparation for the co-researchers in their co-facilitator roles was provided

based on focus group literature which had been provided to them previously (Finch and Lewis, 2003). I steered the meeting with the co-researchers full involvement. They suggested the need to explore current knowledge of social care initially before moving to questions around Direct Payments and Personal Budgets. We agreed this should include positives and problems with current systems and what people see as important future considerations for Self-Directed Support so this can be fed back into the planning and evaluating cycle.

#### **5.9.6 Focus group findings**

Presentation of the findings from the four focus groups in the second AR cycle is presented as a whole rather than chronologically in order to show the themes that emerged across all four groups. The groups were planned to run consecutively however this was impossible to arrange, even with my insider researcher existing relationships with those acting as intermediaries in the process. The initial findings, as they were analysed following each focus group, were shared with the next steering group to be held.

#### **5.9.7 Focus groups with service users and carers: 5.8.08, 17.12.08, 5.8.2009 and 26.8.09.**

These focus groups were designed to hear what service users and carers thought about social care services and their views on the implementation of Personal Budgets. The results of the data analysis from the focus groups were fed into the steering group planning cycle in order that these influenced and were incorporated into the project planning process.

### 5.9.8 Focus group sample and conduct

The steering group proposed that focus groups would be held within a month or two of each other, recruiting people from mental health day opportunities, preferably those who also used other social care resources. A purposive sample would thus be provided as all participants had understanding of social care resources and were currently engaged with mental health services. However, the process of securing enough people to attend the service user focus groups proved lengthy and difficult. Two providers of day opportunities were approached. Both expressed willingness to engage in the process of recruiting people. I supplied full information however this had to be followed up many times. I eventually decided to abandon the second provider and try a third provider who proved enthusiastic and efficient. Once I had engaged the providers they recruited people interested in attending the focus groups based on my letter (see appendix 9) in order to preserve anonymity. I and the relevant co-researcher only knew participant's first names. All attendees were refunded expenses and the minimum wage paid for their time. The groups were held in a variety of venues, provided with refreshments and comfortable chairs in order to be as relaxed as possible. Group sizes differed considerably. The smaller sized groups were due to recruitment problems with service users. A sufficient number had been recruited beforehand to counter inevitable drop-out, however in the first group drop-out was greater than expected. Carers were easily recruited via two carers support workers working exclusively in adult mental health.

Participant recruitment is represented in Table 5.6 below:

Participant representative	Date, venue and home area of group	Number recruited	Number attended
Service Users	5.8.08 Providers meeting room, town/rural	9	5

Carers	17.12.2008 Community room, town/rural	11	11
Service Users	5.8.09 Providers meeting room, city.	7	5
Carers	26.8.2009 Trust meeting room, city.	10	9

*Table 5.6: Focus group recruitment*

I and a co-researcher co-facilitated the focus groups. This had been rehearsed and agreement reached that the questions would be asked alternately by me and the co-researcher. I coached the co-researchers in desired focus group conduct, degree of flexibility around questions and how to encourage participation.

The difference between the groups was noticeable. The carers comprising the second focus group were vociferous and difficult to control with consequent babble and problems in keeping to task. They used the opportunity to criticise mental health services. The group of carers were mostly well known to each other. Their familiarity with each other's personal stories may have contributed to the, at times, chaotic interaction. The first service user focus group was by contrast slow paced with measured participation. Again they all knew one another however had much more individual contributions. The remaining two focus groups were lively and interaction flowed steadily.

The questions initially agreed were used more flexibly as the focus groups met, with our awareness that some questions appeared repetitive and did not draw out any new perspectives. The co-researchers performed well, taking up cues appropriately, however occasionally appeared to forget they were facilitating, contributing personal comments of their own to the dialogue usually as an example to encourage further discussion.

### 5.9.9 Focus group findings summary

Findings are summarised after analysis of repeated themes across the four groups. Quotes and extracts of discussion are included to provide local perspectives in rich data following data analysis to find patterns in the spoken language (Creswell, 1998). The themes that emerged are shown in Table 5.7 below in order of importance as indicated by the volume of discussion on the issues.

<b>Theme</b>	<b>Sub-themes</b>
Service quality and accessibility	Accessibility Service quality: consistency; relationships; training & experience Service complexity Needs assessments including means testing Preventative services
Information and advice	Knowledge base Help and advice Administrative Processes
Service user capability	Effect on health Reduced capability Funding misuse
Outcomes	Individualisation Health and wellbeing Recovery Quality of life
Culture	Requires change to be more person-centred

*Table 5.7: Themes and sub-themes from focus groups with service users and carers*

#### ***Service Quality and Accessibility***

Service quality and accessibility was the main theme of all four focus groups particularly concerning carers who had many stories from their own and other's experiences of poor services. The topic was explored in relation to current services as well as implications for Personal Budgets.

#### *Service users*

The dialogue below describes residential care experienced by a service user participant.



FG1 (SU3): There was no care, it was containment; that was what it was all about. It was keeping people under lock and key. In some ways I was no trouble to them. [.....]they had other people with mental health problems and addictions and they did give trouble [.....] they didn't have the facilities to deal with it, they didn't seem to have the inclination to want to deal with it. [.....] I did make a complaint about the Home and actually that's one thing I am quite lucky in that I am quite articulate so I can fight my own corner, but I felt sorry for people who would still be going in there, you know.....and having that awful experience.

FG1(SU2) Yes, I have had a very similar experience in a private place. It was horrible, nobody did anything for you, they didn't even talk to you. It was just like being in hospital, meals were put out on a trolley. You couldn't even make your own cup of tea. There was a glass office and staff spent all their time sat in there. They never interacted with anyone.

Not all had poor experiences; some found the assistance they received in residential care and community support extremely helpful and supportive.

Services were improving according to several participants in the focus groups (service users) with excellent one to one support.

FG3(SU1): My experience of various groups that support individuals is that they are getting better. [.....] For me coming out of hospital a long time ago-services could have been a lot better then. It has improved now, for example, the XX (day centre), I go fairly often.

FG3(SU4): X have been very helpful. They treated me as an equal. I had a support worker that came around who was excellent. She listened to me and I built up a friendship with her. I really appreciate it. She has done a wonderful job.

Several service users felt that using Direct Payments for social activities was missing the point, viewing the need for basic services as overriding other needs.

FG3(SU5): I see all of this as icing on the cake. You need to get the basic services right. You need to get day to day help. You need to make services open and accessible. More individual yes, but we all have similar needs, maintaining our houses, living in our homes, organising our money. If you can get help with that, for example an hour a week of a cleaner, then it would, for me, take a great weight off and I would have the capacity to think about what else I could do as an occupation or social activity to improve my life. As it is most people spend all of their time worrying about how to organise the basic things in their life they never get beyond that.

FG3(SU3): It is important to get help with everyday life activities like social interaction, going out shopping and practical support. You need help with that.

FG3(SU5): If I could get help with cleaning which takes a lot of my time then I could get on with the social side of life myself.

The need for individual support was agreed by the focus groups (service users) as paramount. Staffing availability was important as was easy access and being treated individually. Most focus group participants thought services should be accessible at a preventative stage as well as for people in critical need.

FG1(SU4): I think there also needs to be more staff to spend time with you as an individual, find out what your needs are and then to help you really. Sometimes there hasn't been enough staff available to help people with what they need.  
FG1(SU2): For me I have struggled with an eating disorder. It has been part of my problem thinking that I am not entitled to care unless I am five stone and needing to go into hospital and so to get support at a level at which I am doing better and don't need to go into hospital but I still need the support is just priceless to me. I do think that it should be made available to people at the preventative stage, yeah.....

### *Carers*

Carers in second focus group found it difficult initially to differentiate between general mental health services and social care services. The majority of the group were scathing of what they saw as poor quality mental health services with complaints of unanswered phones and workers who did not want to engage in dialogue with carers even when they lived with the cared for person.

FG2(C3) My daughter was ill three years ago. She went back into hospital twice. She had, like X or whatever stopped, she went ill again. Every time they stop all the bits and pieces that she needs she goes downhill fast, within a matter of days.  
FG2(C7): I think that the low key part of it is very, very important because from my experience, again the horrible word discharge, I think shouldn't be used at all.[.....]

FG2 (C1): Rumour control has it that the council have hit upon this marvellous idea to subcontract this business of support for mentally ill to an agency.  
FG2 (C5): Well I have waited nine weeks. Because I am ill myself they said there would be all this support for her out there and I haven't seen anything yet. I phoned them up and said 'where is this support? I can't cope'. Nine weeks in my face continually. I said 'I can't cope, I have got to go to bed. I have to rest otherwise I will be no good to her.

Carers in the fourth focus group were not dismissive of current services though felt their main support was through their local carer support worker. Where they had a worker for the cared for person in a specialist team, such as Early

Intervention in Psychosis or Assertive Outreach, support to both the carer and cared for person was seen as excellent.

Most of the second focus group carers found systems for benefits and social care too complicated suggesting there are too many agencies with complex forms.

Often they could not complete forms on behalf of the person they care for without help, and found out about services haphazardly. Accessibility to services across all focus groups was seen as dependent upon where you entered the system; the quality of your Recovery Coordinator, if one was allocated and who else you could rely on for information and advice. This was described as 'pot luck' producing an inequality in service accessibility based on who you knew and chance.

FG4(C4): I think it is the people that come to you, how knowledgeable they are and can put you in touch with other people maybe.....  
FG4(C7): That is really important. Word of mouth is also one of the ways, meeting people at groups.

Another aspect of accessibility was location. The second focus group's carers felt their rural location limited choice of services as there were few community based support agencies. Without services they did not think Personal Budgets would work particularly if agencies concentrated staffing during daytime when support is less needed than evenings. This corresponded with the first focus group (service users) participant's comments that evenings were the worst time when loneliness set in.

FG1(SU2): Well a lot of people find evenings difficult because you are on your own. It is very lonely. It is quite something being on your own. I used to find it a big problem. I don't now but a lot of people do find that evenings are the worst time of day for them.

SG1(SU3): Yes, because at that time I used to self harm and so yes it was very difficult  
Many carers in the fourth focus group believed service quality depended on individual relationships between the person and their support worker. This

corresponded with similar comments from the focus groups with the service users who suggested consistency of workers was crucial to the recovery process.

FG4(C2): You have got various people arriving in your home. For my son with his mental health problem that wasn't a good thing and he saw that as an invasion of his space.....they were supposed to stay for half hour slots as per his care plan. They often came when he was asleep, sign the book and go. If he was awake they would make him a cup of tea and go and every time that I got back he was extremely upset and it just wasn't working because.....the agencies are just not policing, if you understand, what their carers do.  
LR: Right, they are not monitoring?  
FG4(C2): It is not regulated at all.  
LR: So, would you say you weren't happy with the service?  
FG4(C2): It is up to the individuals. If you happen to.....ah (deep sigh). A young girl came to me yesterday, to my home, who was a carer for B. [...].She was wonderful... So, if you happen to get a good carer within that framework you are very lucky and then that works. But when you don't and you get the Polish who don't speak English or understand the English way of things so you have a double communication barrier added to which she tried to feed him raw bacon between bread which is quite dangerous and not being able to boil eggs and you know, socially they do not understand necessarily the way we live and what we eat it is quite a=  
CRM- =Can you describe what the person did who did the job well?  
FG4(C2): She would stay her full length of time. She would always do what was expected, the place was kept brilliantly clean, immaculate, she would be extremely pleasant and was a ray of sunshine in the home, to be honest. I enjoyed her coming. She was a lovely girl.  
FG4(C7): They need to want to be there and not just there to get the money. They are sent to care for very vulnerable people, they pick up on the vibes, they know if somebody wants to be there or doesn't want to be there. That can just make the person more agitated.

Several carers felt that access to services required presenting the person in the worst possible light which was at congruence with recovery.

FG2(C6): And the other thing is that you have to write out the worst possible scenario and if you.....obviously it is the person who is sick who is supposed to fill it in and if they were to read all of that then X [name of person] would go absolutely bananas.

This was directly contrasted to workers being 'hoodwinked' into assessing people as much more capable than they actually were – a recurrent theme in both carer's focus groups.

FG4(C6): Sometimes they come in, like the CPNs, you know, like, sometimes they talk to us now where before they would just say 'Oh we have come to see T, can you go into another room?'

FG4(C7): That's not right!

FG4(C6): But you know if they talk to you as well, because we know what it is like and we know that he will just turn around and say 'yeh, it's ok, nothing to worry about' and then they go off feeling happy but actually if they spoke to, like, us, we would be able to tell them what he is really like and what day to day life is like with him, ummm....and you know they would see the whole picture and not just the tunnel vision picture that's coming from one person.

FG4(C3): I was told by the last CPN that I just had 'I don't want to know anything about B from you, from your perspective. I only want to speak with B. I don't even want to look at the back picture of what has been going on' [.....] and it's just failed miserably and is partly why he has ended up back in hospital.

FG4(C2): She has just come in and listened to him?

FG4(C3): Exactly – that's what she did.

FG2(C2): Well my son is 52 and I can't tell him what to do anymore. It took us a long time, G and I, to admit we might be called a carer. I wouldn't like it, of course, they don't like it. When his social worker comes, naturally he wants to be private, so his social worker doesn't really know the situation. He never goes out, he doesn't see anybody, he spends half of his time in bed partly because he is on so much medication. [.....] He needs help but will tell his social worker he doesn't need help, he is alright. The social worker won't realise.....

### *Service quality and accessibility summary*

Both carers and service users expressed concerns about the complexity, accessibility and quality of current services. Some, however, acknowledged good quality services. All valued services where consistent relationships were established but often had received services that were impersonal and poor quality. For some carers this meant returning to deal with an agitated relative and lacking trust in contracted services. All participants felt that access to services was a lottery due to poor information provision and lack of consistent services across the County. Carers did not feel they were listened to about their cared-for person or part of the ongoing needs assessment/review process.

### **Information and advice**

All participants stated that information and advice was fundamental to being able to access social care contracted services.

### *Service Users*

The focus groups with service users made particular reference to Recovery Coordinators as essential to gaining both good quality information about services and being the gatekeeper of commissioned resources.

FG1(SU4): I do really value having a care coordinator. Sometimes I feel too shy to find out about things by myself or to initiate things. I was just so glad that people were there to help me to put things in place.

FG1(SU2): If you haven't got a care coordinator or someone to fight your corner I think it's a little more difficult as an individual. As they tend to listen to someone who's more professional, rather than somebody who hasn't got a clue what they are doing.

LR: It sounds like you are saying someone you can trust?

FG1(SU2): Well, so long as you have got a good care coordinator who knows you and your needs then they can help you sort things out. But as an individual I think it is more difficult because you don't know how the system works and lot of you don't know how to access...so yeah, it's going to be more difficult to access as an individual.

FG1(SU4): I would agree with that. I've been fortunate really. I have spoken to people who don't have care coordinators and I think that makes it a lot more difficult for them. I really value my care coordinator to help me make decisions and to present me with what is out there.....yeah mmmmmmm

FG1(SU3): [...] it is not just a care coordinator, it is a good care coordinator, who as X says knows your needs and who understands you and knows the kind of thing that would suit you. You have got to have that rapport. I didn't know what services I could access until I discussed it with my coordinator. I don't think they are all that easy to find out about.

One participant in the third focus group with service users described the system as like a spider's web with QUANGO organisations existing on the periphery staffed with people who mean well but are ineffective. Others described passing on information they had discovered about services to organisations who should have been informing them. They described gaining awareness of services as enormously difficult.

FG1(SU3): If you speak to people you are passed to somebody else and then somebody else because they don't know what they are talking about and it just goes round and round and round. Somewhere central providing information where they know whether services are available or not..... all this passing around is just going to mess people up and a lot of people will just give up. You need a 'one stop shop' that you can ring and get the answer there and then and it is tailored to your needs rather than just a general answer.

FG1(SU1): If I wanted anything I wouldn't know where to go or contact to find out what is available. It's that simple. 'Where to go if I need some social care – I don't know' I haven't a clue, so yeah, information is vital really.

The first focus group's (service users) participants stressed not knowing where to get information suggesting a central information centre. In focus group three held with service users concerns were expressed about the Direct Payments process taking three months which echoed with other group participants concerns that the process will be bureaucratic, overlong and needing good publicity.

### *Carers*

Carers expressed the view that it was easy to access services if they were in touch with a knowledgeable worker. Whilst some enjoyed good experiences this was not the case for most, even when they asked mental health services specifically for social care advice.

FG2(C1): Just because we are carers, we are not dolts, we understand. We were four months into the illness and we didn't know half of the agencies. Nobody told us, nobody advised us what help we could get, who we could get money from, what support there was. Four months into it, we had seen the GP, a lovely guy but he didn't know anything anyway.....

FG2(C7): Mmmmm....I think from my point of view I wouldn't even have a clue what was out there or let alone how to access them and my only port of call would be to ring up L and ask her what there was.

FG2(C2): That is the only time things get done is when L gets involved. All of a sudden we find answers as to where to get this help and where to get this support.

LR: So having someone you trust and know is reliable and available...?

FG(C2): We know we only have to ring her

FG(C7): And she knows the full range of what is available.

Some carers expressed frustrations about not being able to access information and advice on behalf of their relatives and being passed from one agency to another in the search for services.

One carer described contacting seven different agencies for his son and none of them joining up in terms of information or advice. Several carers in the second focus group (carers) suggested amalgamating agencies would provide better availability for people to access information as well as vital services for those they care for. Carers with knowledge of Direct Payments felt that the process took too long and needed to be made simpler and speedier.

#### Information and Advice Summary:

All participants described information and advice as piecemeal though some carers and service users described contact with knowledgeable workers being key to accessing information. Proposals for less agencies and one stop advice facilities were suggested as a means of providing individualised direct information for people. Both carers and service users described not knowing where to start and giving up if it becomes too difficult due to frustration and lacking confidence.

### ***Capability to manage***

#### *Service Users*

Focus groups one and three, with service user participants suggested at times they would not feel able to manage a Direct Payment and they could see this as a problem for others. They thought that some people would be able to manage, some with help and some not at all.



FG1(SU2): I think for some people this is a good idea; for others it is not. I mean, it just depends on the individual. Some people are incapable of taking care of their own money and need someone to do it for them. People will be able to do more things than they would have been able to do but there are some people that won't be able to deal with the money themselves. They will need help with it.

FG1(SU3): [.....] I have manic depression and I know myself when I have gone on spending sprees. So, it could be quite dangerous because I could just go out and splurge all the money on nothing in particular, to be honest: I wouldn't even know what I've spent it on if I was that ill. So yeah.....there are those people that can.....but yeah, obviously it's all individually based.  
FG1(SU4): For myself I would find it quite daunting to go out and use that money. I would need someone to work with me, advise me and help me. I wonder if it would be possible to see your care coordinator and have some of that money, not all of it, to use, to start with and maybe work your way up to using all of it.

Participants were surprisingly candid about how they saw their own condition affecting their ability to self-manage and that there may be times in the course of their illness they would be incapable of managing money.

FG1(SU3): There will be times when you need help to make your own choices because you are not well enough to deal with it yourself.  
FG1(SU2): That is the problem. You might feel you are well enough and you are trying to convince other people and other people are trying to convince you that you are not well. But as far as you are concerned you are right and they are wrong. So you have to be well enough to take control.

The issue of people abusing the system, spending money on things outside of their agreed plan was raised in both groups. Several in the first focus group (service users) suggested those with drug and alcohol problems may abuse Direct Payments knowing they had money in an account. One participant in the third focus group (service users) suggested a layer of bureaucracy would be added before the agreement stage to reduce the potential for abuse.

FG3(SU3): What happens when you are too ill to ask for a Direct Payment? When I was very ill I just couldn't get off the sofa. There is no way I could have got on with that myself.  
FG3(SU5): I could see they would be wide open to abuse.

LR: You mean people might spend it on the wrong things? For Direct Payments people need to open a separate bank account and the accounts looked at every three months.  
FG3(SU5): But it is so wide open: it is open to abuse as it is not so identifiable in terms of outcomes. I think that due to this, the system to access it will become increasingly bureaucratic.

### *Carers*

Focus group's (carers) participants were more explicit in their views around capability to manage Personal Budgets than service users. In the second focus group (carers) some participants held unequivocal views of potential problems describing some service users as being deceptive to others outside of family networks, giving the impression of being more capable than they actually are.

FG2(C3): They don't see what we see. We were saying this before you came. The professionals never see the patient that we see, or the service user if we have got .....they never see the same person that we are dealing with because they put a different face on when they see them. They become a different person.  
FG2(C5): I say they act differently.  
FG2(C2): They pull the wool over their eyes.  
FG2(C4): And they can lie and cheat.  
FG2(C5): They know how to pull each person by going like that  
FG2(C3): They have still got that little bit inside that is very clever haven't they?  
FG2(C7): This is one of the talks that I give on staff induction. It is that you should always listen to what the person has to say after you have left the room rather than what they have said in the room.  
FG2(C3): Exactly!  
FG2(C7): Because they are never themselves when they are in the room. It gets very difficult.

In both focus groups concerns were expressed about people being too unwell to make rational decisions leading to money being spent unwisely. Money was seen by many participants in the second focus group (carers) as a source of friction between the carer and the cared-for person. Descriptions of tensions caused by carers not being reimbursed by their relatives – who were described as benefit-rich – were shared, with concerns that an allocated Direct Payment may increase

this stressor. Carers felt they would be obliged to step in if they saw any misuse of monies and this would lead to arguments between family members.

Carer participants described that they and their relative could find the offer of a Direct Payment quite frightening particularly if this were used to employ someone. Their concerns included the money management aspects which they saw as time consuming and complicated.

FG2(C1): One of the things with mental illness if they are really ill is that their reasoning goes so they're not going to be capable of doing it.  
CR(M): This [Direct Payments] wouldn't be for people in hospital but for people in the community.  
FG2(C1): But that's what I am talking about! You can't get help quickly ever, we have found that out haven't we D? You have got to wait before they are so ill before they go anywhere and by that time they have spent all their money. It's ludicrous! You just can't reason with them to hand it over to someone else.....and you can't win an argument. They will always have the last word and they won't see it. Once again, it is going to set up friction between the carer and patient.

Several participants in Focus Group Four (Carers) linked reduced capability to non compliance with prescribed medication. In some cases lack of ability to make choices was seen as the person having no confidence, with resulting reluctance to engage with people outside of the family. Others thought it would depend on the person and their situation but many agreed that it could cause friction between the carer and their relative.

FG4(C4): ....when it came they may want to spend it on something totally different to what it is meant for in the first place. And it is quite hard, keeping the peace anyway and to sort of say, 'no that's not what it is for' you know, you are just putting more stress into it all really so.....it wouldn't be very good.

#### Capability to Manage Summary:

Both carers and service users agreed there may be problems for some people having the capability to manage Personal Budgets. Service users had a more flexible approach suggesting it depends on the person; carers were more

concerned about Personal Budgets causing them additional stress and worry, in the context of money being a difficult area in their caring role often causing friction. Some carers were concerned people would present as more able than they are leading to inappropriate decisions. All participants thought there was a possibility of the monies being misused including some participants who self-disclosed around their lack of control when they are very unwell with resultant inability to make 'reasonable' judgements.

## **Outcomes**

### *Service users*

Several Focus group participants thought people need support, encouragement and new ideas given to them in order to improve their outcomes. It was emphasised that they need to do this in their own time and that a time limit should not be put on recovery. Individualisation was applauded as everyone was seen as different and this was a means of tailoring services and resources to an individual's needs. Direct Payments were seen as a means, for some, of improving their personal outcomes particularly social interaction and confidence; being able to choose options of daytime activities for yourself rather than being given a list of choices.

FG1(SU2): You can try different things and if something doesn't turn out right you're not tied to it, you can move on to another. Activities, now they are always good for people, getting them out and about, socialising, building your confidence, your self-esteem, build your health up.....

FG1(SU2): It should keep you well because you are doing what you want to do.

FG1(SU3): Yes I would agree that general well-being, again that holistic way of dealing with people has to be beneficial to the whole health of the person. Yes I think it lies with recovery quite well, the positive side, issues about choice, individualism and flexibility. I mean all of those things fit well with the recovery angle.

CRD: What about anyone else?

FG(SU4): Different social activities really and respite care.

Yeah.....things that make you feel better.

FG(SU)2: A weekend break, going away from your own environment, I

mean, it is bound to make you feel good about yourself.  
FG(SU)4: Training and courses could be included as well to make you feel more able to go into the world, more equipped.

### *Carers*

Carers agreed that Personal Budgets could provide opportunities to enhance people's quality of life, their recovery and allow more flexibility in the way you want to live your life; however some balanced this with a perceived additional burden on the carer. Examples of what had been tried in mainstream services and failed were provided. Carers welcomed the opportunity to build services personalised around an individual to increase the likelihood of better outcomes. Two carers described their sons as having given up going out because of confidence loss.

FG2(C6): I think it depends on the individual to start with. If you are actually getting services in then it can be more of a burden on the carer to manage the money, to manage the people coming in as I believe that you would actually have to get liability insurance or whatever...and it is very, very complicated but it does offer some flexibility if you want to go that way. In my case my wife wants to pursue hobbies to give her something meaningful to do, to keep her on the straight and narrow [.....] As soon as you are discharged you feel that you are on your own now. Living on benefits you have no money to pursue interests. We can't afford it and then basically you just sit at home watching the television, twiddling your thumbs, and that is a sure recipe for entering that dark place again. And so these payments, I think, are a good idea, it gives you some sort of meaning.....

Carers found it hard to grasp they could receive Direct Payments in their own right to improve their outcomes and had to be reminded to answer in relation to themselves as well as their relative. The extract below highlights the frustration that one carer was experiencing. This resulted in group laughter but revealed worrying discontent with their current life situation.

LR: Carers use Direct Payments mainly for respite however this has a wide interpretation. It could include buying a garden shed to use for hobbies.  
SG2(C6): or shut them in.....  
LR: Do what?  
SG2(C6): To shut them in. A garden shed to shut them in.  
LR: To shut them in. I don't think that would be approved...  
Group laughter for 5 seconds  
SG2(C6): It's creative though!  
Group laughter for 7 seconds.

### Outcomes Summary:

Service users felt that Personal Budgets could be used as part of a recovery approach to improve their quality of life and enhance people's social opportunities and self esteem.

Carers too felt that positive outcomes could result however were cautious about the impact on their caring role and creating more work. Carers found it hard to consider Personal Budgets being used to benefit them and need reminding of this.

### ***Culture Change***

This was a theme in two of the four focus groups.

#### *Service Users*

In focus group three (service users) participants wanted to see a change in the professional culture of some of the workers they had seen. One participant described their health professional as having a dehumanising approach, putting people into boxes. Another described very few practicing recovery and the service being, black or white; you either get help or don't qualify. Acknowledgement of high workloads was seen as a contributory factor.

FG3(SU5): There is a difference in service user involvement between voluntary and statutory organisations. Involvement is better in voluntary organisations.  
FG3(SU2): Social Services don't like anyone with intelligence. You are not meant to be able to speak for yourself or make your own decisions. You are constantly battling to do that. The system wants to keep you in your box.

## Carers

Some carers saw the service as dehumanising with people sitting behind telephones telling them information, remote from carers' actual circumstances.

FG2(C3): [.....] They are just reading off a piece of paper and asking the questions that you need to answer. It is not personal and is not designed to find out what is happening. That is the side of it that is missing- that personal touch coming round to visit you and sit down and assess the situation.

They looked forward to a more personalised service but only if that included carers being valued and included. One described being made to feel small by their relative's psychiatrist because they do not want to hear the reality of their patient's daily life. Several were concerned that professionals lacked their understanding of living with mental ill health despite their qualifications and experience. Some carers thought their culture needed to change to being more confident asking for help rather than carrying on because it is expected of them.

### Culture Summary:

Themes of the need to change professional culture to valuing people and carers with lived experience and providing more individual and humanistic services were present in two focus groups. Carers felt professional workers should live 'in their shoes' to understand the enormity of their roles suggesting carers needed to become more confident in speaking out. Reference was made by service users to workers being overloaded perceived as reducing their caring approach.

*Meetings were held during September and November 2008 to: further refine the Personal Budget Allocation tool; discuss with a local provider a service to support people applying for a Direct Payment; and discussions with managers about workers completing the Personal Budget Allocation when applying for resources.*

### **5.9.10 Meeting with co-researchers and Local Authority consultant: 10.12.08**

The purpose of the meeting was to involve the co-researchers in deciding the best means of obtaining feedback about the new Personal Budget Allocation questionnaire. The form was scrutinised and further changes of wording, arrangement of questions and information were proposed to make it more mental health friendly and easier to read. Examples, relevant to mental health, were added to assist understanding. CRD and CRS thought the form very problem orientated. They were disappointed it was not aligned with recovery preferring a less problem centred approach.

Suggestions about testing it out included asking service user groups, assisted by participation workers, whether they would self-complete the Personal Budget Allocation tool anonymously, or asking a local third sector agency. It was agreed to ask the third sector agency that was setting up a Direct Payment support service. They were likely to be able to interest a large enough group of people. I agreed to ask the agency to host a Personal Budget Allocation workshop and to help enlist participants. Following this a desk-top exercise whereby Recovery Coordinators completed the form in relation to a sample of 50 cases, the Local Authority consultant explained, was standard practice in determining the effectiveness of the tool as a predictor of indicative budgets.

### **5.9.11 Eighth steering group: 16.12.08**

#### *Observations and reflections on action*

The preliminary findings of the focus group with service users were imparted by CRD and I. Themes and subthemes around service accessibility; information and advice; capability to manage; outcomes and culture were shared. Discussion



produced agreement that Recovery Coordinators were in a pivotal role where Personal Budgets were provided, requiring them to be as informed as possible. Additionally the group confirmed that having a third sector organisation able to provide an advice and support role offered a valuable resource for people currently disengaged with mental health services. Steering group participants were unsurprised that findings revealed concerns about managing Personal Budgets and that most people acknowledged the need for support with this. Most thought that an independent information and advice service should have been set up as the first stage of Self Directed Support however understood there was no funding for this.

Steering group members also considered the government funded Individual Budget pilot sites research. This was cautiously positive in respect of mental health, reflecting findings that people felt more in control of their daily lives and the support they accessed. The steering group considered this a positive endorsement on the work they were undertaking.

### *Action planning*

The work to test out the Personal Budget Allocation tool with a named third sector provider was confirmed, prior to undertaking a desk-top exercise using 50 active cases. CRD and CRS fed back the changes agreed to the Personal Budget Allocation tool before it was tested. The group agreed this proposal, conditional on assured anonymity for workshop participants with results to be fed back at the next steering group or earlier via email if feedback suggests the tool is unfit for purpose.

*A workshop was held on the 28.1.2009 with six service users facilitated by myself with co-researchers CRD and CRS. Results concluded the Personal Budget Allocation tool was complicated and repetitive but usable. Support to complete this was thought beneficial in most cases.*

Lead researcher diary entry 28.1.09

Reflections on workshop. This was positively engaged in – the ethos of the exercise was well received. I think the results and individual feedback concerning time taken to complete the Personal Budget Allocation indicates the range of ability to grasp the meaning of the questions as well as a capability issue amongst people using services to undertake what others might see as routine form filling. Results suggest a supported process is indicated for most people.
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*Workshop with Recovery Coordinators: 29.1.09*

A workshop with 14 Recovery Coordinators was held. They completed 50 Personal Budget Allocation tools on a cross-section of people using different services, using their knowledge of people's needs. All felt able to complete the exercise.

### **5.9.12 Ninth steering group: 10.2.09**

*Observations on Action*

CRD, CRS and I fed back from the Personal Budget Allocation workshop that the form was seen as complicated and repetitive. People felt the need for support to assist completion or the minimum of easy read guidance. People's fluctuating needs as a result of variable mental health conditions caused problems in answering questions. The steering group endorsed the need for clear guidance on how to complete the form confirming their collective view that support with completion should be routinely offered.

I informed the group that mental health services will now pilot the tool by requiring its completion for all requests for funding of new social care resources. The indicative budget from the Personal Budget Allocation would then be compared to the actual cost required for the service. The desk-top exercise was described to the steering group however no results were available as yet regarding the correlation of the Personal Budget Allocation with existing prices paid for services indicating its reliability.

Together CRM and I fed back the themes from focus group two (carers). The theme of service quality and accessibility highlighted carer perception of not being heard and workers accepting that people are often functioning better than they really are. Carers also expressed the random nature of ascertaining information about services, according to who you were in contact with, bringing frustrations and lack of take up of services. Suggestions of one source of information were suggested as a solution.

The unequivocal views around capacity of people to manage Personal Budgets including carer views that many people were too unwell to make rational judgements and potentially this would cause friction between carer and cared-for person adding stress for the carer were discussed by the steering group. More positively carers did feel that personalisation was a valued step forward particularly if this meant more personal contact and empowerment for carer's views. CRM reported that most of the focus group participants were unaware they could receive Direct Payments in their own right.

*Group reflection and action planning*

The need for training in relation to carers around Personal Budgets was agreed as was the production of fact sheets for carers about how to access these. Training was seen as needed for Recovery Coordinators in their role with carers as well as awareness raising in carers groups around the county. Some of the themes were seen as outside the remit of the steering group to address. I was tasked with informing the Trust in relation to carers' services. The group reflected that the focus groups reported a high level of dissatisfaction with the level of support that they felt in their role and that personalisation could provide a means to improve this.

The steering group felt slow often painful progress had been made with the Personal Budget Allocation tool but accepted that the production of a tool was complicated and welcomed mental health being the first service to pilot this.

A meeting on 18.2.09 confirmed the alterations to the Personal Budget Allocation tool and the pilot start date in mental health services however analysis from the 50 completed Personal Budget Allocation samples indicated the tool showed a poor ability to produce a reliable indicative budget

#### **5.9.13 Presentation at Trust conference on recovery: 1.4.09**

CRD, a carer and I co-presented at the conference. Both CRD and the co-presenter were in receipt of Direct Payments and gave a personal account of the benefits derived from these. I outlined the Direct Payment process and we all answered questions. Participants were asked to complete feedback on positives and barriers to Direct Payments in small groups following our presentation. Feedback was received from 24 people.

The feedback included positive comments about the helpfulness of the Direct Payment team but that the process can be worrying. Others agreed it was stressful requiring money management which cannot be assumed. More information, particularly what Direct Payments can be used for was highlighted. The usefulness of well-informed Recovery Coordinators was acknowledged however several comments suggested the workforce lacked knowledge.

#### Departure of CRD

Following this meeting CRD left the project having obtained a part time job providing learning and development on recovery in mental health with a third-sector provider. This was a very positive achievement for him however meant he was unable to commit time to the project.

#### **5.9.14 Tenth steering group: 21.4.09**

##### *Observations on action*

Results of the Personal Budget Allocation pilot were fed back to the steering group. These were inconclusive, but did not indicate improvement on the previous correlation between the indicative budget and the actual service cost. The tool's effectiveness in matching prices paid was poor, worse than in other Local Authority service sectors. I suggested the tool was unreliable and likely to be abandoned in favour of the Local Authority commissioning a new tool to provide more accuracy. The Local Authority was researching commercially provided tools and would determine the most suitable one to take up via an option appraisal. It

was agreed to delay the next steering group until the future Personal Budget tool was decided.

### *Planning action*

I discussed the difficulties in arranging further focus groups due to non-engagement of service providers. This generated ideas to achieve a more positive response. It was agreed that I would undertake another focus group with service users and with carers before undertaking two focus groups with Recovery Coordinators.

Lead researcher diary: 22.4.09

This is the second tool to be abandoned if the Personal Budget Allocation is discontinued which looks likely. Will we ever find a tool that is going to be accurate enough? My concerns as to all the wasted effort in relation to refining the Personal Budget Allocation, and the previous questionnaire, are more accentuated knowing we have a group of people who have put in a lot of time and effort to this project. As a manager I am well used to putting in work which leads to nothing however the co-researchers may get the impression this is usual, which it isn't. Their patience and enthusiasm, however, is ever present and it is clear they believe in the desired outcomes and that it is worth persevering. As a researcher learning about the way in which organisations make decisions is being generated and in this case the intra-organisational dynamics between Local Authority and the Trust.

During meetings in June and August 2009 following an option appraisal the Local Authority agreed to use a tool developed by ABC (ABC is a pseudonym) for all service sectors including mental health.

### **5.9.15 Third focus group with service users: 5.8.09**

This focus group was held with five people attending a third sector day opportunities resource.

Findings from the focus group are incorporated with focus group one, two and four and start on page 193.

#### **5.9.16 Fourth focus group with carers: 26.8.09**

This focus group was held with nine carers currently engaged with support services.

Findings from the focus group are incorporated with focus group one, two and three and start on page 193.

#### **5.10 Themes from the second action research spiral**

Steering group meetings during this phase of the study showed a growing emphasis on the need for a culture change towards a more person-centred approach in particular when assessing needs and outcomes. This was acknowledged for both workers and people receiving services and demonstrated the continuing theme from the first action research spiral that services continued to be delivered in a paternalistic way. The theme linking Recovery with Self-Directed Support was reinforced by agreement from all steering group members that the Recovery approach was a helpful influence on developing more personalised services. Reducing bureaucracy, a thematic finding from initial training in phase one of this study, was agreed as a blockage to Self-Directed Support development and a priority within the steering group.

During further training sessions additional themes were shared with the steering group. Firstly they concerned the evidence base of Direct Payments which was raised as both an enquiry (what is the evidence base?) and a criticism that evidence for social care was anecdotal rather than scientific. The group acknowledged this was a widely held view that they too had experienced. They

considered it arose from inconsistent acceptance of the role of social care within the Trust and the dominance of the medical model as highlighted in phase one of the study. Secondly, the ability of Direct Payments to promote social inclusion was found. This theme included the means by which Direct Payments can promote citizenship by paying for mainstream activities open to all, which was acknowledged and welcomed by the group. Additionally workers' moral judgements about what it is reasonable for a Direct Payment to include was raised with mixed reaction within the group mirroring the Recovery Coordinators' range of views, for example, as to whether using a Direct Payment to pay for a holiday abroad was acceptable or not. The co-researchers had less difficulty in accepting this was a problem than the managers within the group who could understand worker's reluctance in the context of cuts in services and other priorities.

Problems with Resource Allocation System development continued to dominate the steering groups in particular concerning predicted difficulties of the tool to capture emotional and psychological aspects of a person's need for support and the perceived weighting of the questionnaire towards people with physical disabilities. This again reiterated the theme of generic versus specific mental health Resource Allocation System development with a clear view from the co-researchers that any generic tool would disadvantage mental health support recipients.

Themes from focus group one (service users) and two (carers) were discussed with the group. The themes from the first focus group included unreliability of service quality, current lack of a personalised approach from providers and poor information about how to access services in the first place. Recovery coordinators if they are informative were seen as good advocates as social care resources



were perceived as complex arrangements. A central information centre was seen as important as were: help with positive risk-taking; simple systems; and a holistic approach across health and social care. There was little knowledge about Direct Payments or Personal Budgets but they were seen as a good idea depending on a person's capability, reservations being about people's degree of mental illness and confidence to manage the administration and responsibility.

The philosophy of increased choice, control and individualisation underpinning Self-Directed Support was agreed by all with the condition that this included the right to decline Direct Payments as a choice. They felt that Direct Payments could make a big difference to people's lives by increasing flexibility and control, provided people could manage the decision making, and extending the range of opportunities a person could take up. Barriers were seen as poor information, inconsistency of service quality, money management for service users and budgetary context of cuts in spending.

Themes from the second focus group with carers were remarkably similar to those generated from the service users. They encompassed service quality seen as often poor and certainly inconsistent depending on where you lived and stability of workers employed. Carers described feeling not listened to and having to combat dehumanising and complicated systems. They too described poor access to information dependent upon having access to a knowledgeable worker. They thought that service user's capability to manage Direct Payments was a barrier and that often people considered themselves more capable than they really were. As money was often a source of friction between them and their cared for person they believed that this may increase the burden on them in administration and source of conflict. Despite these concerns however they welcomed Direct

Payments as an opportunity to enhance people's lives, increase flexibility of support and personalising a person's support package to their needs and preferences. They thought that mental health services' culture needed to change to provide more value and inclusion of carers from staff and they they needed to grow in confidence to ask more for help.

All of these themes were shared with the steering group. They were not contested and were seen to reflect member's experience of current services, barriers and benefits of Self-Directed Support implementation. The themes from the focus groups and training were consistent to conversations in the steering group where culture change towards more person centred services, better information and support systems and simple processes were advocated.

## **5.11 SECTION THREE: QUALITATIVE FINDINGS OF THE THIRD ACTION RESEARCH SPIRAL**

### **5.11.1 Eleventh steering group: 27.10.09**

#### *Observations and reflections on action*

At this steering group the discontinuation of the Personal Budget Allocation was confirmed with a decision to take up a new tool, being used by other Local Authorities. I agreed to communicate this decision throughout the Trust. This meant until work was started with ABC on the mental health tool, there was no solution to providing an indicative Personal Budget other than current market prices. Steering group members were not surprised but felt it inevitable given the Personal Budget Allocation's poor performance. They were concerned when a third tool would be ready and whether given the commitment to genericism this too would prove unsuitable.

Work on the wider personalisation agenda was shared including a new generic service user reference group which CRS attended representing mental health. Significant increases in Direct Payments were reported in mental health suggesting training sessions may have resulted in increasing applications.

Findings from the August focus groups were considered. Recurrent themes including the need for more training and publicity on Personal Budgets and more informed workers were discussed. Feedback from focus group four (carers), whilst suggesting less dissatisfaction with services, nevertheless confirmed many of the earlier focus group two (carers) findings concerning marginalisation and lack of knowledge. Both focus groups reported concerns about capability of people to manage Personal Budgets suggesting supportive services being invaluable.

#### *Action planning*

Action agreed included my meeting with ABC representatives to discuss adapting their tool for mental health; developing a Personal Budgets training package for the teams and arranging two focus groups with Recovery Coordinators to inform any knowledge gaps needing to be covered in the training.

The steering group has lost its initial enthusiasm. Whilst still attending and expressing views members consider our influence is constrained by decisions the steering group has no power over. None of this is surprising given the amount of effort that the group has put into developing tools that have been abandoned. I would not write off the efforts of the group however. The process of engagement has proved a beneficial learning experience for the research concerning the AR process, service user involvement and organisational learning. I feel it has personally benefitted the co-researchers who appear to have grown in confidence and knowledge over time. However, even I feel dismayed at the lack of tangible progress being made with the Resource Allocation System and due to mental health being different and smaller than the other service sectors we are often only included as an afterthought in LA considerations. The loss of CRD is also being felt as he acted as the unofficial spokesperson for the co-researchers having a deal of passion and energy for the project

During November 2009 and January 2010 I undertook work and attended meetings about the new tool and preparing this for mental health use.

CRG gave her resignation to the project in January 2010. As she was no longer a carer for her husband who was now in residential care, she wanted to 'move on with her life as new opportunities were opening up for her'. She agreed to write about her involvement with the project and as a co-researcher.

#### **5.11.2 Twelfth steering group: 22.2.10**

This meeting was postponed from January when most participants couldn't attend.

##### *Observations on action and more planning*

I gave an update on developments with the ABC tool including the appointment of a social worker to undertake a desk-top review. The Trust agreed the offer of Personal Budgets to eligible people by October 2010 in line with governmental guidance. Some Local Authority service sectors were using the ABC tool however it was incompatible with Trust technology systems. I agreed with steering group views that teams need preparation around the need to complete another new

stand alone tool. A training programme including carer and service user involvement was discussed and planned.

Letter from CRG: 28.2.10

Below is an extract from CRG's letter describing reflections on her project involvement;

'My three or so years working with you has been extremely important, and I shall always value that time and experience. Your readiness to help us non-professionals has made your research project a pleasure to be involved with [.....] On a personal level, you have helped me to grow out of almost recognition, from a frightened, defeated person consigned to obscurity and (it felt like) opprobrium as a carer for the rest of my life, to someone altogether more confident and in control, with my caring responsibilities more manageable. [.....].'

During April 2010 I collected feedback on using the ABC tool which suggested this was weighted towards people with physical rather than mental health needs. Recovery Coordinators demonstrated difficulties in completing the tool in many cases finding questions around people's social care needs often difficult to answer accurately.

Lead researcher diary Entry: 7.4.10

<p>This feedback reinforces the steering group's view of poor knowledge and understanding in the workforce. The tool appears designed primarily for older people/physical disability and may be a non starter from the outset. To discuss tool with the Local Authority consultant. Commitment to training workforce is a given whatever tool is used. Whilst the tool needs to be accurate and user friendly the process and outcomes of offering more choice and control is what is important – I need to keep reminding myself of this.</p>
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### **5.11.3 Thirteenth steering group: 2.7.10**

This was cancelled as only two people able to attend

*During July 2010 decisions were made to offer Personal Budgets based on actual spends using a ready-reckoner tool and to delay the usage of the ABC tool until this is adapted for mental health.*

Diary: 25.7.10

<p>Today it was agreed that in order to meet governmental targets for offering Personal Budgets these will be based on the market price we would currently pay for a support package rather than by a free standing tool. This is a pragmatic decision that I agree with rather than another trial of a tool that initially seems to offer little improvement on the last. What we need to ensure is the spirit of enhancing increased choice and control is not lost and that we do not end up ticking boxes yet nothing changing for individuals accessing services. Training is paramount to ensure the messages of individualisation and flexibility is not lost.</p>
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During August to October 2010 meetings were held with ABC to provide information from the desk-top exercise and training was provided on personalisation to Trust managers in preparation for the new process of offering Personal Budgets based on actual spend. A meeting in October with a third sector provider planned the Personal Budget training for teams.

### **5.11.4 Focus groups with Recovery Coordinators: 29.10.10 and 9.5.11**

Focus group findings are reported jointly rather than chronologically. Focus group five was co-facilitated with CRS. I alone facilitated focus group six.

The focus groups with Recovery co-ordinators were held much later in the project than planned due to participant recruitment. Each group required many separate rounds of communication agreeing dates, which then proved unsuitable for sufficient participants to make the group viable. Initial emails to two purposive

sample groups, working with people receiving social care services, in a city and a large rural patch, generated poor response. Thereafter I sent personal emails/calls to individuals rather than group requests. Reasons given for non reply when followed up with 15 of the first sample group included pressure of work (6), found subject area difficult (3), not seen as a priority (2), changed job therefore no longer relevant (2), and didn't receive/read the email (2). Whilst agreeing to attend, drop-out numbers when fixing specific dates necessitated a fresh round of communication. I have included this as it is indicative of the pressure that Recovery Coordinators were under within their workplace. The diary of approaches is represented in table 5.8 below.

<b>Focus Group Area</b>	<b>Initial approach: Date, target numbers and replies</b>	<b>Next approaches: Dates, target numbers and replies</b>			
City	Joint- 30.4.2010 26 Recovery Coordinators 4 agreed	20.8.2010 15 Recovery Coordinators 6 agreed	Joint-13.9.2010 28 Recovery Coordinators 6 agreed- all city area date set for 29.10.10	Focus group date 29.10.10 confirmed- 5 attended	
Rural/urban		5.6.2010 16 Recovery Coordinators 6 agreed		5.10.2010 16 Recovery Coordinators 3 agreed	10.3.2011 6 agreed- date set. 6 attended on 9.5.2011

*Table 5.8: Setting up focus groups with Recovery Coordinators*

### **5.11.5 Focus group findings from the third action research cycle**

The same questions were used as previous focus groups. Participants' agreement was sought during both focus groups to omit questions where it was evident the issues had already arisen from previous questions and the group had no new responses. All participants were provided with the questions beforehand. Five of the six focus group six participants were from specialist teams namely: Early Intervention; Residential Review; Accommodation Finding and Assertive

Outreach, in contrast to focus group five where all five were working in Recovery and Independence Teams.

The same themes emerged as from focus groups one to four though a different order of importance of themes and sub-themes were found, as indicated by intensity and extensiveness of responses. . Themes from focus groups (Recovery Coordinators)s are described in order of importance and summarised in Table 5.11 on pages 233 where they are combined with results from training Recovery Coordinators.

### *Culture change*

This theme featured predominantly in both focus groups; additionally the sub-theme of recovery was frequently raised. Culture change for both Recovery Coordinators and their clients was considered as needed in the context of teams working with people with increasingly complex needs; often physical problems as well as mental health difficulties; and 'old-style' services disappearing.

FG5(RC5): I suppose you have got to be able to think outside of the box and a lot of our clients they can't. They get frightened if you even suggest an alternative. They will say 'I'm not sure about that, I have always had X. I know what they do and they are reliable'

FG5(RC2): That is because services are so stretched now. The clients we are taking on are much more disabled by their difficulties aren't they? It is going to take a long time before they think they can go out on a bike or whatever and so they are more likely to fall back on tried and tested ideas like the old day services, you know, things that are disappearing really, aren't they? That is my concern. If people don't want or are not able to take up Direct Payments there will not be much left.

Additionally the context of families having increasingly higher expectations of services was raised, with resource expectation being more than Recovery Coordinators thought reasonably deliverable. This necessitated negotiation skills,



balancing expectation with what was possible, particularly with people entering the service earlier having supportive parents and other family members who advocate for them.

Some Recovery Coordinators admitted staying with the familiar, finding it difficult to think laterally and that imaginative thinking such as a Direct Payment for a bicycle, to get a person physically mobile, would not occur to them. However if the idea was suggested they agreed it was a good one and may follow this up provided the process was not too complicated.

Most participants had examples of how they felt Self-Directed Support fitted with a recovery approach in mental health, enabling more independence and normal activities for people rather than specialist services, though many expressed caution about people's capacity to manage Direct Payments. Some focus group (six) participants described a reduction in traditional services such as residential care helping them to be more recovery minded, and forcing them to think more flexibly about other options. Recovery Coordinator (one) in focus group (five) suggested being in an interim period, big institutions having closed and replaced with day services, but day services now being withdrawn encouraging people to join mainstream activities and Personal Budgets being used to encourage people to access everyday things. Other participants suggested both they and their clients were getting used to that idea and events like this focus group enabled them to consider issues and encourage discussion. Some felt the drive for change would come from Recovery Coordinators discussing it with clients, keeping it on the agenda, being positive about the achievable outcomes, effectively changing people's mindset.

Recovery was particularly discussed in focus group (six) possibly reflecting the nature of the participant's roles. Participants considered there were pockets of resistance to working in a recovery orientated way and some workers appeared unable to adapt.

FG6(RC4): Maybe because I am in a specialist team we have a different approach to recovery and our actual philosophy is different because we are part of the EI (Early Intervention) drive.  
FG6(RC5): I would hope that X (Trust) is more fertile ground to do that. I have been working in another Trust and I didn't see any individual or any team trying to work in that manner and they would really struggle to get recovery work off the ground. [...] though the recovery focus is not always there it is more along the line than I have experienced before.  
FG6(RC4): That is interesting, as working in teams like AOT we perhaps don't recognise it is not working outside of those (teams) as well as we think it is working.

Examples of the disparity of culture change amongst workers were provided in focus group (six). Direct Payments used for respite breaks were seen to fund holidays, described as horrifying colleagues. This was perceived as a limiting factor for Recovery Coordinators trying to promote Direct Payments and colleagues who had a fixed view. These views were considered more frequent in the current financial climate and examples extended to providing learning opportunities, equipment and accessing physical exercise.

FG6(RC1): I have come across colleagues who have said 'we are not in the business of arranging holidays'  
FG6(RC3): So they would sooner the person ended up in hospital?  
FG6(RC1): I am not sure they have thought through how or why they think except that it is so alien to their training, to their previous role, that they cannot accommodate the idea. [...] I have a client who in fact arranged his own holiday. He was a different shape when he was on holiday than he is in everyday life. Looking back I am not sure why we couldn't have funded him because it must have cost him a lot of money... but justifying it to some other people would have been exceptionally difficult whereas more day to day access to something in your village may be seen as more appropriate.

## Summary:

Recovery Coordinators perceived changes: increasing complexity of needs; old style services disappearing, finances being more questioned and higher expectations from carers and relatives. They reported difficulties in embracing Self-Directed Support however felt they were in the driving seat of change acknowledging their need to adapt and tackle pockets of resistance amongst some staff.

### *Service quality and accessibility*

Recovery Coordinators in both groups reported service quality ranging from poor to very good with accessibility difficulties occurring frequently. Some thought that whilst they were meant to know what was available, they needed a directory kept up to date for them to reduce wasted time and frustration when trying to access services. Recovery Coordinator participants in focus group (five) said they generally knew what was available, but with insufficient knowledge to be confident it would meet an individual's needs. Keeping updated with who was providing a 'good' service was described as equally daunting, particularly in community based support. Concerns about loss and stability in the voluntary sector were expressed in focus group (six) where several projects had closed due to funding cuts. Lack of specialist mental health knowledge was considered problematic and sometimes dangerous, even amongst nursing agencies. One example concerned a man with obsessive compulsive disorder receiving support from an agency worker with no understanding of the complaint, causing more distress than help. Lack of knowledge created extra work for them sorting out problems caused, changing agencies or training staff which they did not consider their remit. Training and experience was seen as lacking. Consistency of staffing was seen as crucial in both FGs, vital to providing a good quality service, however even when this was

provided there was concern it would not last. One Recovery Coordinator summarised it as requiring providers not to be professionals but needing to know their limitations so they seek advice when they need to. He felt professional roles interfered with providing support and that someone without a professional label can be more self-directed providing a quite different relationship to the client, more of an employee role.

FG5(RC2): [.....] We have some terrific floating support staff and they may go, you know, and it is very hard to know whether the next person is going to carry that service through and sometimes they just don't and it is quite dispiriting what they are able to offer.[.....] Often changeover in these organisations is very rapid using students or people wanting short term work which doesn't fit with mental health clients who need continuity in a relationship.  
CRS: What could improve this?  
FG5(RC2): A clear statement of what is on offer and what they can't offer and a sense of continuity of staff is really important.

Recovery Coordinator participants in focus group (six) thought that a holistic approach to services was important to enable both health and social care to contribute towards a person remaining at home and having a good experience. Current organisation of Local Authority services including mental health was seen as contributing to funding delays, often causing arguments between sectors around financial responsibility particularly when people had multiple needs.

Changes relating to person centred assessments and their impact was raised in both groups where being more individually tailored was agreed as a goal. However this was seen as more difficult to apply in mental health than other service sectors. Obtaining clarity about the causes of a person's problem and what would specifically meet their needs thus improving outcomes, was described as difficult.

FG6(RC5): We used to have very defined services saying this is what we do for these types of people. Easy to define and then communicate that message. The other side of the pendulum is the more flexible approach of supporting someone and that can mean lots of things to someone else and it is hard then to define them. [.....] Now we are saying what do you need? Let's see what we can fit around that.

FG6(RC4): What a service does for one person may not do for another.

Most participants in both groups had experience of people refusing Direct Payments following financial assessments determining a contribution towards costs. Means testing was seen as an ongoing barrier to increasing future take up of Personal Budgets.

### Summary

Recovery Coordinators felt services were patchy and their knowledge about them was usually outdated. They wanted a directory of services provided. Their view of contracted agencies was that services lacked specialist mental health knowledge and consistency of staffing both of which increased risks to clients and pressure on them to provide training and sort out problems. They thought service providers should know their limitations and communicate more and viewed assessments becoming more complicated as flexible support plans were harder to define.

### *Capability to manage*

Participants predominantly reported that most people they worked with wanted them to continue making contractual arrangements, acknowledging that people appreciated others arranging things for them. Recovery Coordinator (one) in focus group (five) likened this to people having the perception that the 'state will provide' leading to unhelpful behaviours. She acknowledged attitudes individually varied however thought many held the view that the Recovery Coordinators knew their

needs and would arrange meeting these for them. She thought Direct Payments could provide a means of helping people take more responsibility and control of the interventions they needed. Others agreed, giving examples of people not wanting to take responsibility for a Direct Payment in case it went wrong leaving them to sort it out, adding to their anxiety.

FG5(RC4):[.....] some people don't want that choice. It is too overwhelming. They don't want that responsibility to choose who comes in to do whatever they need. They don't want that and would rather someone else would do that for them and not have to worry about it. And I can understand that. If you are really unwell that is the last thing that you want to worry about –if you are going to get the right person coming in to see you.  
FG5(RC2): But you can change your mind can't you? Over time as you become accustomed to the idea and more informed about it. When you are well you can consider it and weigh up the pros and cons, talk to family and friends and move forward on it. People are fearful of pressure and getting it wrong but theoretically choice is a good thing.

However, an example of a person, who the previous year was in a secure unit but now received a Direct Payment for respite, provided sharp contrast. His Recovery Coordinator suggested timing was all important in securing his engagement with the idea. Participants acknowledged this success but thought it may be disastrous for others and they would be the ones 'mopping up the mess' if it went wrong.

Money management was agreed as a problem for many people with examples given of people who wouldn't open bank accounts, being poor managers of money or being financially exploited as vulnerable adults. Focus group (five) participants suggested some people saw Direct Payments as an additional source of income like Disability Living Allowance rather than to meet defined needs.

Both focus groups felt that people needed additional help with Personal Budget administrative processes. Several participants stated they were reluctant to provide help due to work pressure.

FG6(RC6): I think there are some people that maybe could benefit from the scheme but actually don't want to take ownership. Does that make sense?  
LR: Could you explain some more?  
FG6(RC6): They feel it's too....it's beyond them to address issues that way. They will choose a different route and lose opportunities but they don't feel able to use it.  
LR: Why do you think that is?  
FG6(RC6): Probably due to their mental health. I think that the options to support people to financially manage a DP are helpful but I think that the whole thing about finding the right person....I think for some people it is not what they want at all, they want a provision.[....] They have got choice and control but they are giving the job to us, you know, is that the same as us doing it all in the first place?

## Summary

Recovery Coordinators thought that many people preferred services to continue to be arranged for them, particularly if they envisaged problems arising from arrangements. They described people being unused to taking on the level of responsibility required but this individually varied; money management presents real problems. Personal Budgets offered a possible means over time to grow confidence.

## Outcomes

The social model of mental health was acknowledged by only a few. Participants in focus group (five) reported some positive outcomes for people in receipt of Direct Payments that were in their view working well.

FG5(RC2): [....] It worked very well, using respite on a rolling basis to keep her out of hospital. In another instance it was applied to have massage and that worked well as well. For her it was pleasurable and enjoyable and they both managed....were able to manage their finances. It treated her as an adult, making

her aware what was helpful when her condition was problematic and it was positive.

FG5(RC1): Through using DPs I had someone who was able to employ a cleaner, that meant her flat stayed clean and she felt better in herself, becoming more ordered so that responsibility had a knock on effect in general.

FG5(RC4): I know we mentioned that this can be negative as taking responsibility for a DP can be stressful and people drop out but there is something normal about it as well. This is what happens in real life really.

Rather than relying on Recovery Coordinators to arrange services the flexibility of Direct Payments were considered to provide real benefits for people. Examples of respite breaks and personal care arranged to suit individual preferences were provided. However outcomes for some people resulted in less independence due to how their Direct Payment was used. This posed difficulties if the Direct Payment was assessed as no longer required to meet needs.

Focus group (six) participants discussed 'gold standard' outcomes of people using personal assistants to address needs informally rather than relying on agencies. Direct Payments allowed them to 'think outside of the box' to improve peoples' outcomes, enabling increased opportunities for recovery and normalisation using mainstream services.

FG6(RC5): To attend a tai-chi class that links in with mindfulness or learn to play the guitar, when you can't afford the lessons, maybe just to get them started. Actually just to take away barriers when someone is in a very negative frame of mind, to be able to offer a chance of these things is very helpful.

## Summary

Recovery Coordinators acknowledged, where Direct Payments were in place, people usually gained positive outcomes with more opportunities for recovery.

Usage of Direct Payments for respite, personal care or activities increased well being and provided real benefits for recipients. Participants considered this



approach to be highly individualised but cautioned that people were loathe to give up Direct Payments even when they were no longer needed.

### *Information and advice*

Recovery Coordinators saw themselves being relied on as providers of advice. Several felt they had lost direct knowledge due to the multitude of services unknown to them. Recovery Coordinators in focus group (five) described being deluged via email about services and not keeping information well. Some participants acknowledged poor computer skills and poor confidence about being able to offer precise information needing to contact specialist staff within the Trust for clarity.

Two participants raised the issue of not wanting to raise expectations by giving information when no authorisation for funding was agreed. Several Recovery Coordinators in focus group (six) raised the process for Direct Payments and contracted support being too complex requiring simplification, citing Local Authority contract and finance language as difficult to understand. Additionally systems were not understood or readily accessible. This was echoed in focus group (five) with views of keeping forms simple and relevant. One contact point of information was seen as ideal; eminently preferable would be another organisation sorting out Personal Budgets on their behalf.

### Summary

Recovery Coordinators felt they were relied on to provide information however lacked confidence and knowledge to provide this. Some worried about raising expectations if passing on service information where funding may be doubtful.

Processes required simplification. Some would prefer another agency to take on the role of procurement of services from them.

#### **5.11.6 Training and evaluation with community based staff: January, February and March 2011**

Training was delivered to 113 people in 11 sessions across the Trust. I provided seven sessions with a third sector provider, service development manager, and service user on four occasions. I took notes, during and after sessions, of questions raised by participants. Forty seven feedback forms were completed including comments. An evaluation meeting of those providing training provided further data which was collated and contrasted with focus groups held with Recovery Coordinators resulting in either a new theme, or providing results within the same themes as previously shown.

##### *New themes*

##### *Evidence base*

In four sessions questions were asked about the evidence base of Personal Budgets. Reliance on evidence from qualitative case studies was not viewed as necessarily legitimate. The need for a clinical evidence base was stated.

##### *Commissioners' influence*

In five sessions comments were made about tight financial controls due to the extremely difficult commissioning climate; this was viewed non-conducive to considering imaginative Direct Payments. Participants reported

contradictory messages of promoting individualised solutions yet being directed to explore cost effective resources already block funded.

#### Protection from risk

This was a new sub-theme within the theme of capability to manage, arising in two sessions concerning providers where the Local Authority had withdrawn contracts, due to safeguarding issues concerning vulnerable clients. Recovery Coordinators expressed concern people had chosen to use these providers despite advice. The recurrent subtheme of workers having to resolve matters if services went wrong, was voiced. Transfer of personal responsibility, including risks, to clients was seen as problematic.

#### Social care and health divide

The commissioning divide between health and social care was considered unhelpful. Many Recovery Coordinators wanted Direct Payments for health based needs such as therapy. Holistic assessments but separated solutions were thought inflexible. The issue of what is health or social care was raised in several sessions, with acupuncture and medication supervision given as examples of whether they fit Direct Payment eligibility.

## Self-assessment

Several participants felt self-assessment should be available suggesting some people are put off by having to come into the mental health system to access resources.

## Themes consistent with focus groups held with Recovery Coordinators

### Needs assessments

The leap from well-defined care plans, to using Direct Payments to meet needs in an outcome based assessment, was seen as providing more choice but more complexity for Recovery Coordinators. They wanted to know what was acceptable to support clients to apply for, expressing a fear of applications being turned down resulting in a poor outcome for their client.

### Knowledge base

In all sessions participants expressed concern about their lack of knowledge around all aspects of personalisation and generally about social care resources, referral routes and the funding of these.

### Means testing

Concerns voiced in four sessions suggested means testing put off people applying for Direct Payments due to perceived high financial contributions expected.

The evaluation meeting comprising the Service Development Manager, third sector provider and I, agreed the sessions and feedback demonstrated a need for improved awareness of social care resources and systems for accessing these. All participants however expressed openness to consider PBs acknowledging their role in mental health recovery. Many felt the training provided greater clarity, intending to consider Direct Payments more often however cautions included raising expectations only to be refused funding and being held responsible if arrangements go wrong.

Table 5.9 below shows the themes from the focus groups and training sessions with Recovery Coordinators, with new themes highlighted in blue.

Theme	Sub-theme
Culture Change	Changing commissioning context Difficulties in embracing choice and control agenda
Service Quality and accessibility	Patchy cover of services lacking staff consistency, agreed briefs and specialist knowledge Service directory would be helpful Needs assessments complicated due to flexible support planning
Capability to Manage	Contracted support preferred by many People unused to taking on required levels of responsibility Money management is problematic Roll out of Personal Budgets should increase people's confidence <b>Protection from risk</b>
Outcomes	Direct Payments produce positive recovery based outcomes Direct Payments for respite, personal care and activities beneficial Removing Direct Payments can be difficult once set up
Information and Advice	Recovery Coordinators are seen as providing information but lack knowledge Concerns about raising expectations Process simplification needed External provider of information, advice and support welcomed
Evidence Base	Qualitative evidence base of Direct Payments questioned Social model of disability not wholly accepted
Commissioners Influence	Budget cuts produce contradictory messages about personalised support
Social care and health divide	Unhelpful separation for care planning purposes
Self Assessment	Self assessment welcomed

*Table 5.9 Themes from focus groups and training with Recovery Coordinators*

*Local Authority Choice and control board meetings between March and May 2011 agreed the Local Authority resource allocation project would provide guidance and advice to mental health in developing the new tool with ABC. Trials to confirm the tool's suitability for use to be undertaken before using the tool is agreed.*

## **5.12 Summary of the themes from the third action research spiral**

Themes from the third focus group with service users and the fourth focus group with carers were shared in the first of two steering groups held in the third AR spiral. During the second steering group in this last phase of the study further training was planned with the workforce using thematic knowledge gained from the four focus groups, earlier training workshops and discourse within the steering group.

No new themes were found in the third and fourth focus groups however some sub-themes were introduced. Under the theme of service quality service users acknowledged their experience of some good quality social care resources, felt that services were improving and that they were treated often as an equal by staff. They also expressed the benefits of Direct Payments as being able to pay for basic practical support which they felt they struggled with most. Carers in the fourth focus group also spoke of excellent service from the specialist mental health teams where workers were less pressured. They did however acknowledge concerns about inconsistent sometimes dangerous practice of contracted agency support workers. They agreed with the earlier focus group with carers that the cared for person was thought often to be more capable than they were with a propensity to underplay problems. Service users thought there was a great variability amongst people using services in their ability to manage Direct Payments and also risks about abuse of trust and increasing bureaucracy to mitigate that. Carers were concerned whether people would be well enough to make rational decisions and as described in phase two were worried about adding to their stress in trying to 'keep the peace'.

Information and advice was again acknowledged as a problem area likened by service users to a 'spiders web' and carers described giving up with frustration when finding out information. Both service users and carers wanted to see a culture change towards more personalised recovery orientated services and for carers more acknowledgement as their role as a partner in support.

The focus groups with the Recovery Coordinators were held after the steering group drew to a close with the function for taking forward the Self-Directed Support agenda reverting to the lead researchers role and members of her team to influence within the Trust. The themes following analysis are shown on pages 244-245 with four new themes of: questioning the Direct Payment evidence base, the influence of commissioners and budget cuts, the unhelpful nature of the social care and health divide and self assessment being welcomed. These additional themes were not therefore discussed with the group although questions about the social care evidence base had been raised before during earlier training sessions and acknowledged by the group.

### **5.13 OVERALL SUMMARY OF THEMES AND FINDINGS**

Throughout this study themes have been found using data collected from the interactive steering group, training workshops and focus groups. The steering group was preoccupied with developing a Resource Allocation System, the complexity of which produced a theme in its own right. Discussion generated from the group working on the Resource Allocation System provided data where other themes such as social inclusion, culture change and generic versus specific systems were discussed. The training workshops and first four focus groups provided themes that were taken to the steering group for learning, discussion and contrast with views within the group. It was evident by the end of the project



that there was considerable consensus in viewpoints from all participants namely service users, carers, recovery co-ordinators and those within the steering group outside of these categories such as managers. Carers appeared to have additional concerns about their recognition, status and inclusion within mental health care and support planning services. However in relation to Self-Directed Support thematic findings supported the need to: influence service user, carer and recovery coordinator culture towards person-centred support planning; provide better access to information and knowledge about Self-Directed Support; implement simple processes and systems; acknowledge people need extra support to manage Direct Payments; acknowledge that workers feel unable to keep up with the personalisation agenda or to provide dedicated support in this area; improve current social care resources which are described as providing variable quality and encourage the take up of Direct Payments in acknowledgement of the consensus of views that these could with support provide people with a better quality of life by offering more choice, empowerment and control in everyday living.

The three AR spirals demonstrated varying levels of activity and findings as indicated in Table 5.12. Spiral one spanned nine months and included six elements of planned activities. This AR spiral was slow moving: the steering group took time to embed and work effectively and the project lacked a sense of urgency moving forward. The second AR spiral spanned 22 months and included five elements of planned activities. During this phase the project gained momentum, the steering group functioned effectively and considerable work was undertaken in preparation for implementation of Personal Budgets. The third AR cycle spanned 19 months and included two elements of planned activities. By the third cycle enthusiasm and participation in the project had waned due to the inability to

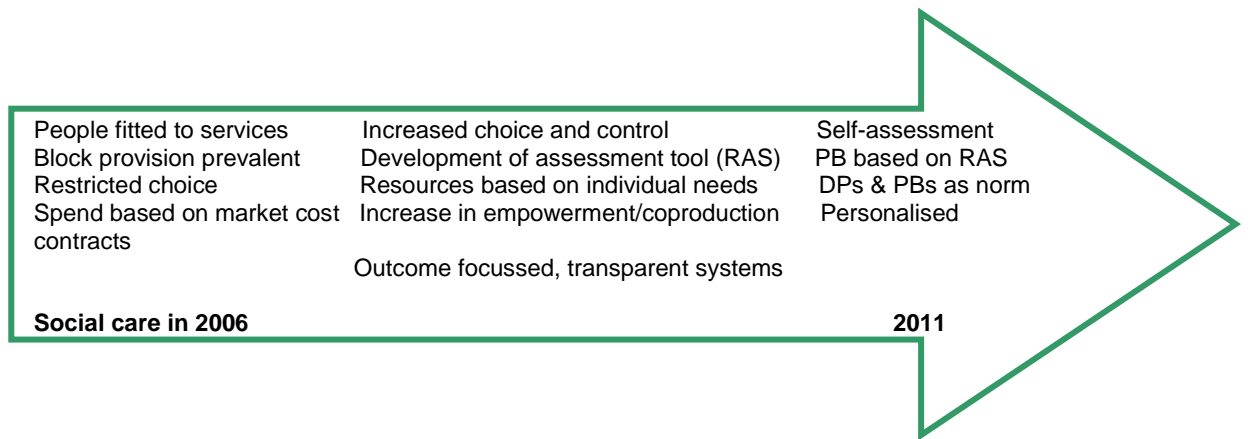
develop a reliable Personal Budget tool causing frustration and disenchantment. The nature and length of the project demonstrates the need for a high degree of tenacity to maintain involvement studies particularly when desired outcomes are elusive.

<b>First AR Cycle: Activities</b>	<b>Second AR Cycle: Activities</b>	<b>Third AR Cycle: Activities</b>
1. Co-researcher Recruitment & analysis of motivation	1. Training sessions with Recovery Coordinators and analysis	1. Focus groups with Recovery Coordinators and analysis
2. Setting up steering group	2. Co-researcher meetings to explore involvement and analysis	2. Training with community staff & analysis
3. Adaptation of resource allocation system and trialling this	3. Development of Personal Budget Allocation and trialling this	3. Introduction of Personal Budgets
4. Two Direct Payment Workshops & analysis of themes	4. Personalisation workshops	
5. Recovery Coordinator Training & analysis	5. Focus groups with service users and carers & analysis	
	6. Recovery conference presentation and feedback	

*Table 5.10: Activity levels of the action research spirals*

Figure 5.5 below represents the stage at which data collection ended in relation to the implementation of Personal Budgets in the Trust.

## Vision



## Reality in the Trust

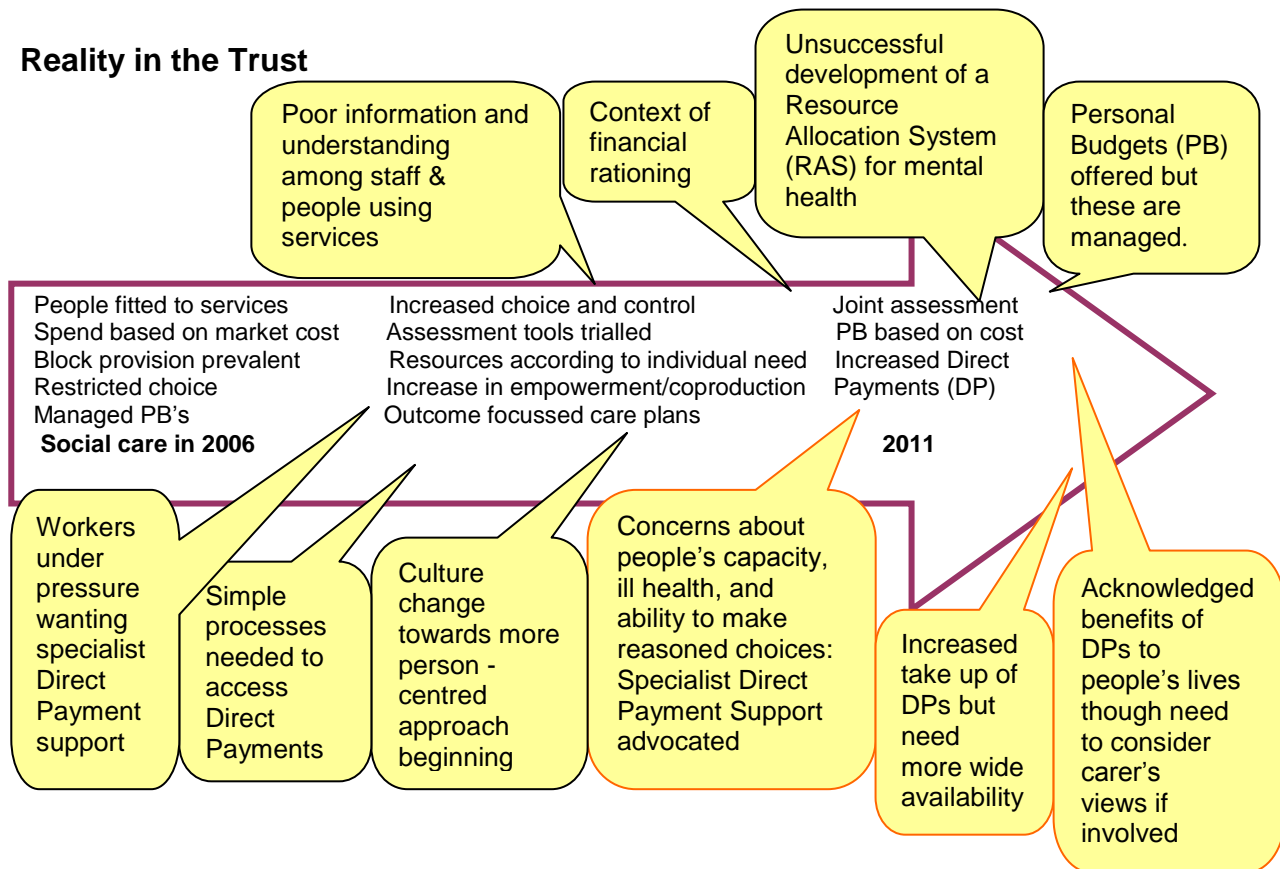


Figure 5.5 Personal Budget implementation progress

The way in which this AR project has progressed provides rich learning about improving practice in the context of managing complex changes within organisations. Understanding and reflecting on my actions, the nature of involvement from the co-researcher perspective and organisational impacts will be discussed in the next chapter together with the AR project findings.

## **CHAPTER SIX: DISCUSSION OF FINDINGS**

### **6.1 INTRODUCTION**

This chapter is presented in three sections. The first section addresses the impact of using AR in this study including the spiral framework of AR and the work of the steering group. The rationale for choosing AR and whether the anticipated strengths and outcomes of using this approach were evidenced is then discussed. Consideration of the dilemmas relating to this study's political context including ethical problems and any limiting factors follow. The unique contributions into the theoretical aspects of AR generated in the study; and whether collaborative working with the co-researchers has led to increased empowerment, are then considered.

The second section considers the rigour and reflexivity of this study. This examines: my role as an insider researcher; how findings have been interpreted and challenges considered; and how critical reflection has been used in this study including what I have learned personally. Criteria, as proposed by Coghlan and Brannick (2010) and Williamson (2012), are then used to assess the quality of this study.

The third section focuses on the learning from the study in relation to the introduction of Personal Budgets including Direct Payments. I discuss the findings from the project in relation to evidence-based research literature on Self-Directed Support to ascertain whether this study has produced any new contributions and/or substantiated existing knowledge. Finally I consider whether any findings could be considered transferable.

## **6.2 THE IMPACT OF USING ACTION RESEARCH IN THIS STUDY**

This section starts by looking at the AR spiral methodology. The work of the steering group, fundamental to the AR process, including collaborative work with the co-researchers is then examined. Following this, political and ethical issues, and any limiting factors or dilemmas relating to the study is discussed concluding with a consideration of the unique knowledge contributions this study has made.

### **6.2.1 The Action Research Spirals**

The iterative, AR spiral of planning, action, evaluation, and reflection has been used in this study based on McNiff and Whitehead's (2002) refined conceptualisation of the spiral methodology: firstly, initial planning, adaptation, trialling and resultant discontinuation of the initial Resource Allocation System incorporating training sessions with staff; secondly, planning and trialling a new Resource Allocation System, service user and carer focus groups, and further workforce training and thirdly the final spiral focussed on the preparing the organisation for the introduction of Personal Budgets by adapting existing systems including accrued learning from the study and from the Recovery Coordinator focus groups. This summary of the spirals does little, however, to convey the stop-start complexity of the project which spanned four years using AR methodology to implement Personal Budgets. At each stage work was planned, agreed, put into action and then critiqued by a democratic group process.

McKay and Marshall (2001) emphasise the dual imperatives of research and action, shown in Table 6.1 below. This differentiates the stages of this study in the problem solving and research cycle. I have included this as it explicitly shows the steps in this project as both contributing to action and research.

Steps in the problem solving cycle	Steps in the research cycle
1. Problem identification- <i>Development of a tool to determine Personal Budgets, adaptation of systems and training workforce for this change</i>	Research Question- <i>How will Personal Budgets benefit service users. What is the best way to implement Personal Budgets?</i>
2. Finding out about the problem- <i>Use of steering group, co-researchers and my role to obtain relevant local and national information</i>	Fact finding in literature- <i>Obtaining knowledge from literature search to widen understanding</i>
3. Planning the activity- <i>steering group planning to train staff groups, planned trialling of different Resource Allocation System versions</i>	Research Design planned to address research question- <i>focus groups and discussion groups with staff planned</i>
4. Define and implement the action steps- <i>Resource Allocation System trialled, training sessions and focus groups held</i>	<i>Findings considered in relation to national research</i>
5. Reflect on the problem solving efficacy of the steps taken- <i>Feedback to steering group of data from training and focus groups. Reflection in the steering group and by lead and co-researchers</i>	Reflect on the efficacy of the steps taken in terms of research interests- <i>Planning of further focus groups and sessions with staff</i>
6. Amend the plan if further change is needed and return to step 4- <i>further training, trialling new Resource Allocation System and so on</i>	Amend the plan and design further research as required and return to step 4- <i>further data collected from focus groups and staff training</i>

*Table 6.1: The problem solving and research cycle in action research: adapted from McKay and Marshall (2001:50-1)*

Common themes in AR are that it embodies reflection in order to put knowledge into practice, is grounded in local context and uses collaborative and democratic principles. This study demonstrates all of these themes in the process of implementing a change to practice. AR is considered appropriate for use in: innovation and developing new services; improvements in healthcare; developing knowledge in practitioners and involvement of users and NHS staff (Waterman *et al.*, 2001). This study therefore used an appropriate methodology which is explained further in the next sub-section.

### **6.2.2 Action research rationale and researcher neutrality in this study**

Why did I choose AR for this research project? What are my beliefs, values and experience that helped shape this study? I believed that AR had strengths that met my commitment to conduct collaborative research whilst delivering a desired change. Firstly, AR focuses on research in action, rather than about action (Coughlan and Coughlan, 2002). The cyclical stepped AR process was a process that I was familiar with as it shared some parallels with project management (Whitehead, 2005). Both provide a high degree of flexibility and enable the introduction of change management projects internally, rather than by an external facilitator where the process is less likely to be favourably received. Moreover AR is a participative process involving those affected by the change in the planning process, allowing more ownership and likely to effect an easier change process. As the project manager introducing Personal Budgets in the Trust I did not want to perform as a lone professional implementing her vision of Self-Directed Support and sought a research process that enabled collaboration, vision and voices to other participants. AR encourages people to speak, think and act for themselves. Each person is entitled to make their contribution to public debates and should be listened to respectfully (McNiff and Whitehead, 2010). This resonated with my values of being person-centred, non-elitist and putting the people, that LAs and Trusts provide services to, at the centre of service developments. My experience and training as a social worker additionally reinforced my views on the high value of importance of collaboration with people using services as the most effective means of developing services that are most relevant.

AR offers an additional research interest cycle alongside the problem solving cycle (McKay and Marshall, 2001; Nogeste, 2008): this enabled me and others to



conduct research into the proposed service reform. I wanted to explore and provide evidence to examine my contention that the implementation of personal budgets needed to be considered in relation to processes, user and carer feedback on real or perceived outcomes, and organisational learning. This could enquire into what difference it would make for service users rather than the less inquisitive considerations of a project management process. AR is participative: this meant involving people using services whilst facilitating change aimed at improved services and practice. 'AR is enquiry with people, rather than research on people' (Altrichter *et al.*, 2002: 130). This attracted me, meeting my personal ethos of working with all stakeholders in a collaborative and democratic partnership rather than from any professional expert stance, and my self-view as being self critical and open to influence from others. Perry and Zuber-Skerrit (1992) suggest that AR is best conducted by practicing managers and many authors (Bawden and Zuber-Skerritt, 2002; Dick, 2002; Coghlan and Brannick, 2010) conclude that AR is an appropriate methodology to use in management and organisation research problems.

AR aims to develop practical situations and competencies of participants without making this objective prescriptive. To ensure collaboration of participants, data are jointly owned rather than held by the researcher(s) alone (Altrichter *et al.*, 2002). This aspect of AR resonated with the subject matter of this research: how to improve outcomes for people receiving social care resources? I considered it would be more appropriate and arguably more ethical to undertake a research approach that advocated democratic principles and involvement. The project outcomes were projected as providing increased choice and control, namely empowerment, for those receiving Personal Budgets. Nationally, development of the government directive to provide Personal Budgets to all disability groups

involved service user participation, however I reflected that local service user and carer involvement would provide local context, influence and meaning to the research project. Shared concerns, critical examination of processes, tools, training, generated data and other aspects of Personal Budget implementation could thus be explored alongside the implementation process.

AR is data-driven research (Dick, 2002), in other words it is open to exploring the research situation as fully as possible recognising that the initial research question may be considerably altered by the end of the project. I felt that this was a prerequisite in this project. Without this assumption of flexibility the local imposition of a national change would be assumed without any discourse about the context, preparedness for change, agreement that this would provide better outcomes for service users and a myriad of other similar questions. In this way AR poses ethical dilemmas from the outset regarding the requirement to provide a schedule of the proposed research. Justifying your research project to your organisation and to the Local Research Ethics Committee when you are uncertain exactly what research methods and resources may be required, or whether the project will result in a favourable outcome for your employer, in this case, to be able to report on to the DH, may cause dilemmas.

AR is designed to improve your own practice, improve your work situation and benefit your organisation (Waterman *et al.*, 2001; Dick, 2002a; Earl-Slater, 2002), however whilst many advocate the use of AR in health settings (Hart and Bond, 1995, Waterman *et al.*, 2001; Meyer, 2006; Bridges and Meyer, 2007) it was not well recognised by my organisation, requiring initial explanation and discussion to enable agreement to the study. Whitehead (2005) suggests that AR has yet to gain widespread acceptance within health service management despite it working

well as a method for implementing organisational reform. Bjorkman and Sundgren (2005) argue the importance of having supportive sponsors in management has been evident in all AR projects in various ways. I concur with that view. In this study my manager was extremely supportive and enabled the research to be undertaken without restrictions however I believe that in today's context of continual cost-cutting it may not have been agreed.

Titchen and Binnie (1993), in their study of change to patient centred nursing, used AR to examine the perceived need to change nursing practice. Their study included; establishing the need for change; devising a bottom up change strategy; developing appropriate structures; providing support; feeding back data; creating a non judgemental climate; enabling critical awareness of practice; sharing ideas about change and facilitating communication/resolving misinformation. Whilst their subject area was considerably different from this study I wished to consider a very similar range of issues in order to take account, as far as practicable, feedback from those implementing the proposed changes, those receiving services and other stakeholders in the process. In this study the need to change was imposed centrally. The proposals had in-built assumptions that recipients of Personal Budgets would have improved outcomes. I believed these assumptions needed to be tested in a bottom up strategy whilst enabling all participants to be able to share ideas in a non judgemental climate in order to feed into the change process. This would allow local ownership of the change as well as tailoring any processes to the needs of people with mental health problems. Table 6.2 shows the AR aspects of this study:

Participation	Interviews and appointment of co-researchers with 'lived mental health experience' Setting up of a multidisciplinary steering group including co-researchers Researcher as project facilitator and steering group member Views on proposed change collected from all participants
Democracy	Aim to empower co-researchers and recipients of Personal Budgets Collaborative, non-elitist working in the steering group Steering group members provided with data as part of the planning process
Contribution to social change	Findings applied to system set up to provide Personal Budgets Dissemination of findings
Evaluation Methods	Case study of oneTrust implementing Personal Budgets Qualitative methods to determine key themes raised by stakeholders
Main AR Cycles	Revising and piloting of tool to implement Personal Budgets Training and involving staff in self-directed support Development of second tool to implement Personal Budgets Introduction of Personal Budgets incorporating learning from all stakeholders

*Table 6.2: Aspects of action research in this study: adapted from Meyer (2006:127)*

AR provided a framework that, due to its cyclical nature, could collect data from participants about the proposed change and feed that into the project process within a flexible time frame. At the start of this project whilst there was a nationally proposed end date for implementation of April 2012 there was little internal pressure for Personal Budgets to be provided by that date if an agreed system for doing so or a knowledgeable workforce was not in place

In this study knowledge was generated that questioned the assumption that Self-Directed Support would provide positive benefits for all those with mental health problems (Spandler and Vick, 2006; Browning, 2007; Glendinning *et al.*, 2008; Homer and Gilder, 2008; Newbronner *et al.*, 2011). This will be discussed further

in Section Three in relation to the research literature on Self-Directed Support however it was the AR cycles of planning action and reflection that set the context for a critical examination of espoused benefits from Personal Budgets. This resulted in collection of data from a range of stakeholders using workshops, focus groups and training sessions. Whilst the provision of a tool to calculate Personal Budgets was not achieved, considerable learning from service users, carers, practitioners and managers provided rich data for use in designing systems, training and collective knowledge. The AR research method enabled the organisation to learn by formulating a series of exploratory solutions based on evolving an untested Personal Budget tool in mental health services. Additionally, challenges to the assumed benefits of Personal Budgets and to the organisation were evidenced concerning the best way in which to meet governmental directives whilst acting on the findings from the project.

### **6.2.3 Steering group collaboration**

This project used a collaborative steering group in order to discuss, plan and implement action, critically reflect on observations or data from those actions and then to re-plan interventions in the cyclical process. The steering group was a driving force behind the project. All major decisions were discussed and finalised through this forum. Participants were updated and informed of developments here. Ideas and information were generated and discussed with full input from participants who provided a broad knowledge base.

The role of steering groups in AR appears to have been little researched however they are generally regarded as a good idea. Coughlan and Coughlan (2002) state that it is common for action researchers to have a project steering group which enables them to manage the project by providing a team to plan implement and

evaluate by building insider knowledge of the organisation. Zuber-Skerritt (1996), writing about educational research, states that AR must consist of a group process of rational reflection generating a critique of the social and educational milieu that the members operate in.

In this research the steering group provided the group by which the project was guided however there are significant differences between this AR project and one where a research topic is collaboratively agreed and a group formed to steer the research process. This research project was initiated as I was responsible for interpreting governmental policy to introduce Personal Budgets and wanted to do so collaboratively whilst researching the process at the same time. The focus of the research therefore was externally provided and whilst the steering group had considerable discretion and flexibility over timing and how to design the implementation programme it was limited in its decision making power reporting both to the Local Authority and the Trust.

Bushe and Shani (1991) proposed the concept of a parallel action learning structure in action learning programmes that included a steering committee setting directions and providing authority. The main body of the structure promoted a climate conducive to learning, innovation and group problem solving, with members having a formal position but not constraining their relationships within the parallel structure by their formal position. This enabled people within the parallel structure to think, talk and act differently from their usual work role providing a setting where organisational norms can be questioned and doubts are acceptable. The steering group in this project mirrored the Bushe and Shani (1991) steering committee acting as a learning group with terms of reference agreed at the outset, a commitment to challenge assumptions and treat all

participants as peers. Whilst the steering group provided a 'safe' place for people to challenge and question organisational practice, professional participants in the steering group did not appear to take on an 'informal' role as Bushe and Shani (1991) suggest. I observed most behaving as professionally as they did in other work-based group setting however in the steering group they were encouraged and able to consider in greater depth and emphasis on paradigms influencing their views. In this way reflections, dialogue and differing perspectives were encouraged with an emphasis on constantly returning to consider the impact of the study on what difference it would make for service users. As lead researcher, process facilitator and project manager I chaired the steering group encouraging a collaborative approach, where participants could express their views whether or not these were compatible with organisational or national ethos, and ask for explanations where information was needed. This approach provided, as far as possible, equality for all to participate with equal weight given to their contribution.

Problems were encountered however: there were numerous occasions where the co-researchers were unable to comprehend all the nuances and acronyms used in conversations and the post steering group meetings were vital to ensure understanding and learning was taking place. Steering group conduct had been addressed in the first meeting where suggested ground rules (see Appendix 4), including the adoption of the 'Chatham House Rule'<sup>2</sup>, were agreed however

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<sup>2</sup> The Chatham House Rule reads as follows:

professionals in the group found it difficult to maintain speaking 'Plain English'. The lack of consistent representatives from the Trust to the meetings also compounded the problem with new representatives needing to acclimatise to an emphasis on inquiry, making assumptions explicit and a slower pace within the meeting.

'Collaboration provides the key to working across stakeholder groups to develop services, make enquiries and work more effectively together' (Hitchen, 2007:23). Zuber-Skerrit (2005) suggests that within action learning and AR the value of collaboration, team spirit and 'symmetrical communication' accepting uniqueness, differences and people's capacity to contribute to problem solving, leads to synergy and systemic development. O'Brien (1998) confirms the AR principle of collaborative resource, suggesting that this presupposes each person's ideas are equally significant as potential resources for analysis, and that the insights are gleaned from contradictions between many viewpoints and a single viewpoint. In assembling the participants for the steering group I aimed to reflect a wide range of perspectives coming from participants across management and professional roles, finance and service providers with carers and service users represented by the co-researchers. This provided direct questioning from those that were not immersed in day to day social care matters generating more of an inquiring reflexive approach. Questions starting with 'why', 'where', 'what' and 'how' were encouraged allowing underlying assumptions and philosophies to be surfaced.

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**"When a meeting, or part thereof, is held under the Chatham House Rule, participants are free to use the information received, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed".**



Coughlan and Coughlan (2002) suggest that the steering group may not have the time to engage with a lot of introspective monitoring and may resist efforts to do so, however the steering group in this project was enabled and encouraged to be more inquisitive by the constant attendance of the co-researchers and their questioning approach.

As lead researcher and project manager I held responsibility for data collection and analysis as well as ensuring that the project was moving forwards, agreeing strategies and developments for change. However I shared the research role with initially five then four co-researchers all of whom consistently attended the steering group, and were involved in data collection from the focus groups and training sessions with me. I performed the initial data analysis which was shared with the relevant co-researcher for verification, and then the wider steering group. I was therefore concerned with practical outcomes which the steering group focussed on whilst simultaneously building up knowledge resulting from the enquiry process. Through the use of small group and one to one meetings with the co-researchers I developed a close collaborative working relationship with them demonstrated by their relaxed behaviour and communication with me and their direct feedback by email, conversation and letter. This enabled the co-researchers to be more confident within the steering group with the awareness that they had a supporter in the group, as chairperson, who valued their perspectives and contributions and could help them, if necessary, make valid points. I am a senior manager in the Trust. Chairing the steering group where I was actively supporting two carers and two service users to fully participate provided legitimacy to their roles. Additionally the co-researchers were working alongside me collecting data and feeding this back to the group; this raises the question of what influence this bore on other steering group participant's

behaviour towards them. Did this afford a level of increased respect and acknowledgement of their 'expert by experience' contribution? They believed they were acknowledged differently, more respectfully, in this steering group than in other involvement groups they had previously participated in due to these reasons.

Coughlan and Coughlan (2002) consider that directly observable behaviour is an important data source in AR suggesting the critical issue is how to improve the client system whilst inquiring into what is being observed. The steering group in this study provided two levels of observation for me as the lead researcher. Firstly; into group dynamics relating to the acceptance of the co-researchers in a project steering group that is traditionally the preserve of professionals and, secondly; in relation to the subject matter of Self-Directed Support and enquiries generated in the group from both professional and service user perspectives. The observations of the steering group provided data to build an emerging picture of service user and carer perspectives of current services, which together with data from the focus groups and training sessions provided recommendations for change. Emphasis was placed on using participant's experiences as a resource with particular reference to participants who were or had recently received social care mental health services. Howell (1994) discusses a management development action learning set, with a mixture of graduates and hands-on managers without degrees, where surprise is expressed by a graduate that his fellow associates without qualifications reached the same end completion point. This can be contrasted with the steering group where the co-researchers were qualified by experience to talk about mental health services. They expressed an active enthusiasm to be involved in order to implement organisational change to provide better services. This was recognised by all professionally qualified steering group

participants and no comments or behaviour emanated from professionals to question the co-researcher's unique contributions.

#### **6.2.4 Political and ethical issues in this study**

Undertaking an AR project in one's own organisation is political and may even be considered subversive (Coghlan and Casey, 2001). The authors suggest that the AR emphasis on examining everything, listening and questioning, fosters courage, incites action, abets reflection and endorses democratic principles. These characteristics can be threatening to the organisation's norms and the action researcher's commitment to them, in the process of generating data to inform change, is an intensely political act.

In this study the degree to which the project could be considered subversive was influenced by two factors. Firstly, the nature of the project goal itself; to implement a different way of providing social care resources that was more empowering for the recipients, moving from a 'professional gift' model (Duffy, 2003) of providing resources and services to people, to Self-Directed Support; secondly, the commitment of the Trust to the 'Recovery' approach at all levels of the organisation, defined here simply as enabling people to regain active control over their life (SCIE, 2007b). The goals of Self-Directed Support and recovery share a similar theme of enabling more choice and control (DH, 2011) and require a change in organisational culture towards working with people as equals emphasising their strengths rather than concentrating on their problems. The Trust had a record of involving service users and carers in setting up or evaluating services and including them in projects. However despite this context the nature of this AR study was substantially different and more challenging to the organisation

due to degree of involvement of the co-researchers and the AR cyclical process providing data that was critical of current services.

AR diagnosis is a collaborative activity, raising questions and applying judgements to issues that may have severe political implications (Coghlan and Brannick, 2010). The action researcher is required to be politically astute which involves understanding and managing key relationships. These include the: relationship with the sponsor; relationships the sponsor has with other managers; intra-organisation relationships between managers; relationships with the executives and the relationship between the researcher and their subordinates (Rowley, 2003). In this study the most important relationships were that of: me and my manager, the research sponsor; me and my subordinates; intra-Trust managerial relationships and relationships between the Trust and the Local Authority managers. During the course of this study I maintained openness with participants, my sponsor and other managers that I frequently worked with both in relation to Self-Directed Support and other areas of my work. Being open about my reflections and project findings did pose some political challenges that I needed to manage. This was due to the challenge that findings in relation to people's capability to manage Self-Directed Support posed to the prevailing premise that Self-Directed Support was a 'good' innovation for people with mental health problems, and also the consistent findings criticising current services. As previously mentioned the testing of assumptions, in this case that Self-Directed Support a better way of meeting needs, is one of the strengths of AR. My organisation required me to make the changes required to deliver Self-Directed Support full dialogue, arguments and exploration of issues was needed before any changes were implemented. This was to enable the local context and criticisms to be taking into account before implementing change. Without this

process implementation may be hampered by the Recovery Coordinators who were in the role of gate-keeping access to Self-Directed Support. To reframe criticism I chose my words carefully, suggesting the need to address additional aspects when delivering services in order to provide these based on local research and reflection on service provision. Coghlan and Casey (2001) suggest the key to success lies in accessing power and interests of relevant stakeholders in relation to the project. In this study I needed to develop good working relationships with the Local Authority stakeholders who provide the financial resources to the Trust for social care and performance manage its outcomes in using those resources. Due to that investment I needed to demonstrate that mental health was working with the Local Authority, as far as possible in developing Self-Directed Support. I also needed to use my influence with other stakeholders in the organisation to increase the importance of Self-Directed Support on the Trust's business agenda which I did by raising it at every available public opportunity.

We published a paper from my early research findings in the study including the difficulties that the co-researchers experienced in their involvement roles (Hitchen *et al.*, 2011; see Appendix 10). My sponsor and other executives were complimentary about the publication indicating a level of awareness and acceptance in the Trust concerning aspects of service delivery and involvement processes that need to improve and a welcome of positive criticism. Increased public expectation for accountability and openness together with governmental policy driving patients and service users' involvement in a patient centred NHS (DH, 2000) together with the acceptance of the recovery approach at board level may have all contributed to enable the Trust to adopt this ethos.

Coghlan and Brannick (2010) suggest several ethical issues additional to their assertion that ethics in AR involves authentic relationships between researcher and participants. For me as lead researcher this meant conducting my relationships with honesty and integrity, sharing information fully and allowing participants an equal voice by encouraging an inquiring approach. Coghlan and Brannick (2010) list additional ethical issues as: negotiating access; data and information confidentiality; the right not to participate; keeping relevant others informed; seeking permissions; showing you can be trusted; checking for misunderstandings; and negotiating how you will publish the research including participant's viewpoints. Protection from harm including participation without 'subtle exploitation' (Hart and Bond, 1995) is relevant to this study. I wanted to ensure as far as possible that participation and working as a co-researcher would not subject them to undue emotional pressure that could negatively affect their mental health. I was the lead researcher who had recruited the co-researchers and as such held this responsibility. Holding debriefing sessions following the steering group and other face-to-face meetings throughout the study was acknowledged by them as an invaluable means to discuss concerns or misunderstandings and included talking about any emotional impact of involvement. Early in the study I observed that two co-researchers on occasions became animated with raised voices during meetings and used the post steering group meeting to act as a mutual support group and to ventilate what had caused those emotions to surface. This provided additional learning for me on the emotional nature of involvement however I wanted to ensure their wellbeing and so offered the group meeting and one to one sessions as they required for use in a self-directed way. Williamson and Prosser (2002) suggest the action researcher has a duty to protect or shelter their co-researchers. That is particularly relevant here where the co-researchers were in receipt of mental health services or caring

for a person receiving those services. What they told me of the support I provided was that it made them feel valued and protected in contrast to other involvement projects to which they had contributed. The fifth co-researcher dropped out very early on, having suffered a relapse in her mental illness which alarmed me.

However she assured me afterwards that her involvement in the project was not a factor in her becoming unwell. Of the other co-researchers two remained with the project until the end of the fourth year and two left in the third year one to take up paid employment and one to retire from her role as a carer. I would suggest their commitment over such a long time period suggests that they felt secure in their role and that my role acted as a safeguard for them.

The nature of informed consent can be controversial in AR (Bellman, 2012a). As AR is a journey where the destination is not fully known from the outset, informed consent is a more difficult concept than in other research methods (Williamson and Prosser, 2002). In this study all participants including the co-researchers were given written information about the research and written consent was obtained. As the co-researchers worked alongside me in steering group meetings, public presentations and training events the transparency of the project developments was made explicit in that they had access to the information that I received. Additionally in AR confidentiality is difficult to guarantee due to the nature of organisational life, where others may know who participated (Williamson and Prosser, 2002). It is often difficult to disguise data or individuals in specific roles (Lathlean, 1996). The co-researchers in this study agreed to forgo confidentiality and co-author a paper about their involvement in the process. Whilst individual quotes were not attributed to any particular co-researchers, they were individually acknowledged for their contribution to learning. The traditional concepts of confidentiality, anonymity and informed consent were provided to participants in

the focus groups where data collection and analysis was subject to these ethics. The ability to withdraw from the research was made explicit to the co-researchers however was more difficult to apply to those members of the steering group who were paid members of staff. In effect however they withdrew themselves from attending if they prioritised other work. Meyer (2000) talks of continually re-negotiated consent in AR due to the changing project. I did not attend to this formally however by virtue of the process of continued participation through the planning, acting, evaluating and reflecting cycle this was implicit.

Baskerville (1997) describes AR conflicts arising from contrasting values of academic and management cultures, epitomised in the contrast between the need for critical reflection and direct action. This role tension was evident within me as researcher-project manager needing to slow the project down in order to enable critical reflection to take place but also aware of the need for outcomes that the organisation required in order to comply with governmental policy. However, as neither Resource Allocation System that was adapted or built proved suitable for its purpose, this allowed the project additional time in order to collect and analyse more data before the introduction of Personal Budgets, without the need for me to justify the length of the project and the integral research. As a paid employee of the Trust I was, however, constantly aware of my obligations to 'deliver' the end product of the project and that I may have been required at any point to defend the length of time and continuing employment of my co-researchers.

### **6.2.5 Limitations**

There were several limitations to this study. Firstly, the sample size of the focus groups was small except in the case of the first carer's focus group which was large and suffered from resultant difficulties of people talking over one another.



The carers in this focus group expressed the more extreme views which may have been exaggerated due to the group effect of telling 'atrocious tales' (Kevern and Webb, 2001) where participants seek to compete to tell the most distressing story. The last two focus groups, held with Recovery Coordinators, posed extraordinary participant recruitment problems eventually being held with five and six participants respectively. This is lower than the recommended number of between eight and 12 for good practice (Kitzinger and Barbour, 1999), though others (Krueger, 1998; Finch and Lewis, 2003) recommend between six and eight and Green and Hart (1999) suggest between five and six participants, the number I obtained. The discussion in these groups was considered and thoughtful, however with additional participants a more lively discussion may have ensued.

A further criticism relates to how action researchers may influence findings due to their proximity to the participants (Waterman *et al.*, 2001). Their proximity and involvement is an important strength in their work given their understanding of the issues and increased credibility with participants however, negative aspects, in particular, familiarity clouding perception, may be considered a weakness. My own familiarity with the situation could have suggested I was unable to bring a fresh perspective to the problem. The appointment of co-researchers was incorporated into the research design to combat this as was the appointment of a wide cross section of professionals to the project steering group. Without my close relationship and collaboration with the co-researchers and participants in the steering group the project would not have been driven forward and may have been seen to lack relevance.

There may have been concerns that participants would not reveal their true viewpoints to me due to my role in the organisation. I was the manager with the

remit to implement the change process. My role is strategic rather than operational and so none of the participants in the steering group or training sessions were managed by me. This may help to counter concerns but it could still be suggested that some may have been reluctant to reveal negative comments to a senior manager. However all but one focus group and most training sessions were held with a co-researcher alongside me which was designed to encourage a more open dialogue.

Participants in the steering group had varying degrees of commitment to the project. This was demonstrated by the frustrations expressed by the co-researchers about gaining operational management representation. My inability to secure consistent representation from this group was unhelpful in the first cycle of the AR. It did not appear to be a priority for those managers and reflected the status of social care within the Trust as below other competing priorities within the mental health operational agenda.

#### **6.2.6 Contribution to new knowledge**

Learning from this study would suggest that AR can provide a suitable methodology to enable people to undertake first time research as co-researchers under the guidance and support of a lead researcher. From the outset the way by which the co-researchers were recruited to this AR study provides my first unique learning point about the method of involving service users and carers through a formal recruitment process, with two-way learning built into this between me as lead researcher and the co-researchers. I would suggest this gave authenticity to their roles as seen by others, and confirmed to them that they were being recruited to a valuable and meaningful role in a professional manner.

This co-researcher model provides more research capacity within the project and also provides a dual learning process: the co-researchers have a direct relationship with the subject matter of the research; and the lead researcher can observe, interview and collect data from the co-researchers. Magnusson (2003), researching the introduction of new telephony systems, concluded that users contribute ideas that hold greater user value, are more original and can be used as a learning tool to understand users better. I would suggest this can also apply to health and social care research.

Involving service users within health and social care research is recommended practice by government (DH, 2005), service users including their organisations, and researchers and their organisations (Beresford and Croft, 2012). It should therefore be established practice. In 1996 the emergence of *Consumers in NHS Research* (subsequently INVOLVE) established an advisory body for members of the public involved in health research expanding in 2011 to include social care and public health (INVOLVE, 2011). INVOLVE aspires to forge a partnership between the public, researchers and others involved in health and social care research in order to improve the health and wellbeing of the nation. INVOLVE aims to improve the quality of public involvement in research and to remove some of the institutional and cultural barriers to achieving that. Research is thus defined as being carried out with or by members of the public rather than to, about or for them (INVOLVE, 2012). The philosophical approach of INVOLVE therefore resonates with the beliefs and approach that underpins this project with its democratic impulse and egalitarian methodology, and also an AR approach.

An evaluation of mental health involvement studies (Stacey, 2012) which considered 41 studies selected at random from the Mental Health Research

Network portfolio found only four (10%) included service users as co-researchers. Stacey (2012) acknowledged difficulties in recruiting people with specific knowledge so they would better match their research role, recommending that formal recruitment mechanisms including advice on best practice should be considered to enable involving people with mental health problems:

‘In summary, it seems that some researchers would benefit from advice on more formal processes of recruiting service users to involvement roles’. (Stacey, 2012: p34).

Additionally the study suggested that researchers needed to be more innovative and include service users beyond membership of a steering group (Stacey, 2012). Stacey’s research (2012) suggests that my co-researcher recruitment and involvement approach accords with current thinking and recommendations within mental health and was therefore innovative.

Participants in a Norwegian study into how co-researchers with a mental health background viewed the co-researching process described it as both enriching and demanding. It required that they self-defined their own value when contributing in research projects as well as finding their position within the community. The authors suggest that participatory research can be organised in a way that empowers service users to active and constructive participation and puts weight on the expertise of the first person perspective (Moltu *et al.*, 2012). In this study the collaborative process enabled the co-researchers to become more empowered both within the project, their own lives and to share their lived experience within the group.

Within this study additionally carers were appointed alongside service users as co-researchers as a means of including diverse perspectives and acknowledgement of both contributions to discourse within the study. The Mental

Health Research Network (MHRN) in their 2012 guide for including carers in research state that carers are rarely included in mental health research generally stemming from a lack of appreciation of their contribution and a lack of skill in facilitating meaningful involvement. The guide suggests carers provide novel insights to improve researcher's understanding, and that it is necessary to include them in terms of meeting democracy and current mental health policy whereby carers are respected, included and valued for their contribution to the mental health system (MHRN, 2012). This confirms my research design whereby carers alongside service users were included as a key player in the research topic that acknowledged their unique perspectives. The co-joint involvement of both service users and carers as co-researchers is not prevalent in the literature and there are few examples (Glasby, 2010; Springham *et al.*, 2011).

In this study the incorporation of service users and carers provided learning for them about organisational processes including decision-making, culture, and how to become a more effective voice influencing that organisation; and for me as lead researcher about the process of involvement as experienced by service users and carers as well as seeing services through the eyes of service users and carers.

I would further propose that AR using service user co-researchers may be more easily applied in mental health Trusts. This is due to their less hierarchical organisational cultures than general health services and the adoption of values and priorities enshrining the Recovery concept and personalisation for those receiving mental health services endorsing more equitable relationships between provider and recipient of services. The reflexive nature of AR is conducive to this learning as it provides the lead researcher and co-researchers with a method with which to surface their underlying concerns and issues about the context of the

research and the perceived goals. The co-researchers being highly interested in the potential end research outcomes, as demonstrated by their recruitment and sustained reliable involvement, add richer data to the research and may reveal more authentic data than from a lead researcher conducting the research alone. A second unique contribution to knowledge in this study concerned the way in which the co-researchers throughout the steering group, training sessions and focus groups, added their own experiences and insights to provide personal examples, and so added emphasis or opposed viewpoints. This encouraged fuller discussions and more reflection about assumptions held by other participants. The co-researchers were able to do this in a way that, due to their personal accounts of mental health services they or the person they cared for had received, enabled a very explicit understanding of their thinking and arguments and what these were based on. This proved to set a standard within the steering group and focus groups of each participant providing examples for their comments or facing questions if they did not do so. Contrasting this to the Mental Health Research Network study (Stacey, 2012) these outcomes appear very positive as there were few examples of positive outcomes within the 42 studies considered there. It may be the careful way in which the co-researchers were supported within and outside of the steering group based in an AR approach that enabled the co-researchers to gain enhanced confidence in their contributions.

However the collaborative nature of the steering group enabled dialogue without blame for opposing viewpoints and listening to the co-researchers experiences was as a learning tool to better help their understanding. Koch and Kralik (2006) describing participatory AR suggest the primacy on practical knowing is empowering as it focuses on the potential for development rather than any deficits of the participants. This is shown in this project where the co-researchers were

very willing to share details of their experiences not as weakness but for learning purposes.

The steering group introduced the co-researchers as organisational actors. The lead researcher's support can provide them with legitimacy and confidence before they move on to conducting enquiries with organisational staff and people receiving services. This provides the study's third unique insight by demonstrating that the steering group provides a pivotal structure for conducting an AR study in which to introduce the co-researchers working alongside me as lead researcher as an insider-researcher. The steering group also provided the co-researchers with full information alongside professional managers which enhanced their ability to participate fully and equally.

#### **6.2.7. Closure for the co-researchers**

Three of the co-researchers in this project described being more empowered as a direct result of their role and the value that they placed on this. An extract from a letter from one of the carer co-researchers, by comparison a quieter participant of the four, spoke of the time spent as a co-researcher being very important and valued, helping her to grow almost out of recognition from being frightened and feeling obscure to someone more confident and in control. She was the first of the co-researchers to leave the project due to her husband moving into residential care and wanting as a consequence to return to full-time employment.

Consequently she decided to relinquish her role as a carer which included her participation as a co-researcher on this project and, as she described it, move into a new chapter in her life. When I met with her she expressed her gratitude for being included in the study which she clearly believed had contributed to her well-being.

The male service user co-researcher went on to gain a training post with a third sector organisation and continued to be a vociferous advocate for Direct Payments within his new role and the area where he lived. The learning from the project helped him in his new role. For over a year after the end of the project he and I were still in communication and he did participate in some additional workshops in respect of the Recovery and personalisation agenda.

The female service user co-researcher immediately following the end of the project was recruited to represent mental health across wider service developments in social care. She was one of two service user representatives on a county wide generic consultation group for all aspects of personalisation. I maintained contact with her until early 2012 as she continued to send me interesting items she read in relation to Self-Directed Support showing a continuing interest in the subject area,

The second carer co-researcher went back to her art work which she exhibited alongside part time teaching and continuing to support her son with mental health problems. She remained with the project until the very end and I believe is still contributing to involvement projects albeit in more of a consultative role.

The increased confidence that the co-researchers experienced as the project developed correlates with Koch and Kralik's (2006) work in participative AR who suggest that participants' commitment increases as people identify therapeutic benefits from their involvement and how the telling of their personal stories can be empowering. The authors describe this as giving 'voice to the voiceless' (Koch and Kralik, 2006:19) allowing some to feel validated, empowered and



experiencing an increased self awareness providing an impetus for change. Whilst it is impossible to evidence whether the co-researcher's self-growth was directly attributable to their co-researcher role I would suggest that the democratic style of their involvement and the responsibility that they held in the project group was influential in their lives.

I did not meet up with the co-researchers as a group after the study ended. I did, however, meet or communicate with them individually in the subsequent year. Two of the co-researchers left before the study actually finished both to take up employment and expressing at the time how much they had benefitted personally from being included. The other two co-researchers worked until the end of the study and so were aware of the dissipation of energy within the group given the length of the project and amount of work that had been undertaken. They both expressed feeling valued and appreciated within the project and interested in being involved in future research or involvement projects in order to continue providing their perspectives on mental health services.

### **6.3 RIGOUR AND REFLEXIVITY IN THIS STUDY**

In this section I will examine my role as an insider-researcher, and rigour in this study in relation to interpretation of findings. The quality of this study will be considered including evidence of reflexivity and other measures by using AR criteria proposed by Coghlan and Brannick (2010) and Williamson (2012).

#### **6.3.1 My role as an insider-researcher**

Managers taking on a researcher role within their own organisation has become increasingly common (Coghlan, 2001; Coughlan and Coughlan, 2002; Coghlan and Brannick, 2010). Being an AR insider-researcher can be very effective as it helps

to solve practical problems, forcing us to 'ground' work in everyday issues as experienced by those involved, learn about ourselves and others in organisations and how our practice can be more effective (Smyth and Holian, 1999). The breadth of pre-understanding of the corporate environment, systems structure and conditions of their business is all useful knowledge that the insider action researcher brings to the project and can help them not to compromise their career or the research project (Coglan and Casey, 2001; Coughlan and Coughlan, 2002). Bjorkman and Sundgren (2005) suggest that the insider action researcher needs to have credibility interpreted as loyalty, organisational knowledge and acceptance, useful networks and reputation as a high performer. When I embarked on the project I had worked for the organisation for three years, had a role that required external and internal networking and was highly regarded as someone with tenacity and drive. This placed me in a good position to take on the manager-researcher role with credibility.

As an insider-researcher in this study I needed to reduce my usual managerial/professional expert role and trust service user and carer collaborators to a far greater degree than my manager role would usually allow. This allowed more opportunity for the co-researchers to voice their perspectives on organisational values and performance which was challenging for me to hear and report on.

Additionally this may challenge health and social care organisational rules where professionals are cast in the role of experts which does not equate with collaborative involvement (Hitchen *et al.*, 2011). Whilst the DH (2007) espouses an equal value being placed on expertise that people bring, whether as professionals or users, in practice service users and carers lack pre-

understanding and experience in public speaking therefore this aspiration may be compromised.

As the insider-researcher I had the authority from the organisation to lead on the service change and to provide the training, with others, to effect a change in clinical practice in the workplace. Whilst my role was strategic, operational managers worked in partnership with me to improve and ensure that the social care component to mental health service delivery was of good quality. Stark (1994) describes the generation of a supportive environment as being an element of inside AR. This can be evidenced in this project by the steering group and the enactment of the AR cycles that enabled inquiry and reflection about the project including the provision of training sessions with staff facilitating questions and critiques of the Self-Directed Support implementation process.

Smyth and Holian (1999) consider risks as an insider-researcher in relation to bias, due to the nature of their organisational membership, the relationships held and their ability to acquire sensitive information possibly not available to external researchers. Previously 'undiscussable' issues could be aired and unwelcome observations on organisational practice may be made. During this study no information was made available to the steering group or other stakeholders that was confidential or could not have been publicly available if requested. As an insider-researcher I was able to obtain information speedily knowing who to ask and where to go if there were any obstacles.

Bjorkman and Sundgren (2005) suggest a well-conducted insider/outsider project may result in the insightful vantage of the third person. This can also enable challenge from outsiders who do not share the assumptions and ethos of those

within the organisation. In this study observations and data generated from the steering group, suggest that the co-researchers were more critical of both organisational and national policy assumptions. For example: assumptions about the generic nature of disability; how social inclusion is measured; and how contracted providers were right not to share user information with the Trust. This challenged some of my assumptions and those held by other steering group participants. Whilst this was good in many ways as it enabled full discussion about the underlying issues it often had to be managed by me as lead researcher and steering group chair. This required being clear about what could and could not be influenced, for example agreed national or local policy was in this category, despite a critical perspective on some aspects of this from the co-researcher. I also asked for examples or evidence for expressed opinions in order to reduce generalisations being voiced as realities based on limited scenarios.

### **6.3.2 Personal learning**

Personal learning from the project includes increased awareness of my management/facilitator style particularly evident from typing steering group transcripts. It was very apparent that whilst I listen well and reflect back to participants a précis of their comments I am the group member who impels discussion forward whilst seeking active agreement to an emerging plan. This may indicate my immersion in a culture of 'getting things done and decisions made' which had to be relaxed to allow more active participation within this project. This tension was clear in my diary entries: the researcher role wanting to maximise the influence of the co-researchers and other steering group members, and my manager role working to produce an agreed outcome.

The involvement of service users and carers in the study particularly the focus groups increased my knowledge of their views and perceptions of the Trust. As strategic lead for carers in the Trust this broadened my understanding of required work to work better in partnership with carers. Their appreciation of being asked to take place in the study was surprising. Several wrote thanking me after the focus groups. Many following the focus group said they had learned a lot, enjoyed participating and hoped they had not appeared overcritical of what mental health services were trying to do. I learned that they appreciated being listened to and asked their opinion, superficially a very simple action, but nonetheless one that may not be offered routinely.

I consistently learned from working with the co-researchers indeed it was co-learning with shared responsibility for the learning experience. They shared their world view which caused me to review my beliefs or look at an issue with a fresh understanding. For example, their comments on risk and people with mental health problems: we had fundamentally different experience, me as a former assessor and manager of risk, and co-researchers from being personally risk-assessed. This produced a cognitive conflict whilst we established a shared understanding from the two perspectives and incorporated this into our joint learning. Additionally working with the co-researchers tutored me in the art of precise speech as any glib remarks were picked up and interrogated to enable shared comprehension of meaning.

### **6.3.3 Rigour and quality in this study**

The ideas of Coghlan and Brannick (2010) provide four suggestions of ensuring quality in AR which are: discussion of the reflexive nature of the work; how different views of events are secured; how different views challenge the work, and

demonstration of multiple cycling of the AR cycle. I will examine each of these in turn in relation to this study.

### *Reflexivity*

AR is traditionally linked with critical reflection (Fook *et al.*, 2006). Reflection is the critical link between experience, interpretation and taking new action, and is key to learning as it enables action researchers to uncover and make explicit to themselves what they have planned, discovered and achieved in practice (Coughlan and Coughlan, 2002). Reflecting involves: programme content; issues; what is happening; process; and how things are being done, their premise, underlying assumptions and perspectives (Coughlan and Brannick, 2010). Reflection is not confined to the lead action researcher but to all participants and groups whose experience includes struggles, conflicts and satisfaction (Hitchen, *et al.*, 2011).

In this study the steering group, workshops and training sessions with Recovery Coordinators provided a means of public reflection whereby my and the co-researchers assumptions and interpretations about Personal Budgets and related issues were challenged and exposed to critical inquiry. The steering group provided an ability to do that with participants encouraged to consider all enquiries and contributions democratically providing a context of allowing awkward questions to be heard and challenges to underlying assumptions made.

Interestingly often the co-researchers in the steering group would raise issues that were then raised by staff in the training sessions though these provided a sharper conversation particularly as some Recovery Coordinators were critical of assumptions of people being able to manage Personal Budgets and what additional work this would mean for them.

I also kept a reflective diary using guidelines suggested by Corti (1993). Entries were made shortly after meetings and included the nature of the event being reflected on and my feelings and thoughts at that time. This was useful to trace my developing ideas regarding the collaborative steering group, how I chaired this as the project manager and ideas developed within the group. My diary was a means of putting down on paper feelings about my role both as researcher and manager, often expressing the tension between those two roles and looking back at my performance from a self critical perspective about what I could have done more effectively. It notes my concerns and frustrations in relation to progress and obstacles to overcome. It tracked the nature of relations in the group between me and the co-researchers and between other participants. The diary also revealed the growing knowledge base and confidence of the co-researchers

Hart and Bond (1995) suggest use of diaries as: a chronology of events; a form of field notes; a means of assessing your own performance; and of evaluating progress. I believe that my diary entries are used for all four of these reasons and capture data that would not be revealed by other methods unless I had been interviewed at regular stages throughout the course of the research and that data was made available.

Diary entries provide a means of assessing progress and are also a personal record of events, in this case from my perspective only, and are edited as I was aware that some entries may be included in this thesis. This may have resulted in moderating some of my expressed feelings as a means of being self-protective nonetheless they reflect, as accurately as possible, my feelings and thoughts about the research and project at the time of writing. Borg (2001) suggests that journals can assist researchers in acknowledging, expressing and reacting to

emotions from the research and can provide a therapeutic role in dumping frustrations. My diary was used in this way to express my feelings about the progress and impediments to the research. Stuart and Whitmore (2006) describe institutional constraints on research and critical reflection and needing to negotiate ensuing conflicts and contradictions by not being deconstructive but by using a simultaneous critical and 'reconstructive' approach. I believe that I was to some extent constrained in my diary entries with an inner conflict between writing what I truly felt with what I thought to be organisationally acceptable.

Coghlan and Brannick (2010) consider journal writing as a significant means to develop reflective skills and McNiff *et al* (2010) describe the use of a research diary as: a systematic record of events; a self evaluative account of the researcher's personal experience; a way to dump painful experiences; a reflective account for interpretations; and an analytic tool for data generation. Coughlan and Coghlan (2002) further suggest that writing a journal regularly imposes a discipline and captures key events close to when they happen and before perceptions of them change.

Using my reflective diary revealed another unique insight to me about the Trust-Local Authority relationship that would not have been revealed otherwise. This is in relation to decision making in social care and the relative political might of the Local Authority. I drew an analogy between a juggernaut and a bicycle with the Local Authority having a strong influence on the social care agenda in the Trust, what it can and should provide and how it should provide it, plus having considerable more human resources to provide the support and business management to strategic developments (See Figure 5.4, page 183). The juggernaut and bicycle analogy may reflect the emotional component to my



feelings at the time as looking back it is a rather exaggerated comparison however represents the level of frustration I was left holding at that point in the project when I felt that our freedom to act was being externally curtailed.

The co-researchers did not keep diaries however I met with them after steering group and held a series of other face to face meetings that I recorded, collected data from and analysed. I also encouraged telephone calls, emails and letters, according to their preference, following meetings which they all took up as an opportunity to reflect on the work of the project. This provided unique insight into their perspectives and reflections on the nature of collaboration in this project but also including other projects they had been involved in with the Trust.

Collaboration, exposing emotional service user and carer voices (Hitchen *et al.*, 2011), shows how reflexive practice in this project revealed significant new insights into how service users as co-researchers experienced the process.

### *Different perspectives*

Different views of the project were secured and challenged through the project steering group. Agreed actions made in the steering group enabled progress to be communicated within mental health services. These actions included: presentations to an influential group redesigning the Trust structure; presentations at a Recovery conference; workshops with providers; and training Recovery Coordinators. The workshops and training sessions were not delivered in a one directional didactic style but using an approach encouraging people to speak out if they were unsure of the proposals, and to ask questions for both clarity, and to challenge propositions that they disagreed with. Coughlan and Coughlan (2002) describe action researchers needing to present their inferences, opinions and viewpoints as open to testing and critique and making reasoning testable in the

service of learning: that was what I and the co-researchers tried to do. Additionally data collected from focus groups were agreed within the steering group, to enable the incorporation of perspectives of the main stakeholders in the process of Self-Directed Support: service users; carers and Recovery Coordinators. Findings were analysed and fed back to the steering group and the AR cyclical process. It was planned to hold the focus groups with Recovery Coordinators much earlier in the process however sufficient numbers could not be recruited and therefore these were held at a much later date than planned.

### *Multiple Cycling*

In this study multiple cycling occurred through the McNiff and Whitehead (2002) complex spiral AR methodology (see Figure 3.5, page 74). There were three spirals to the project: the first relating to the development work with the first Resource Allocation System tool to provide Personal Budgets; the second relating to the work developing an alternative tool and preparing the workforce for change; and the third where the tool was abandoned with further preparation of the workforce undertaken and Personal Budgets introduced. Within all three of these spirals there were other spirals relating to my working across other inter-related steering groups; workshops and meetings to help produce and test the respective tools; presentations and workshops with staff, providers and service users including preparations for these; and internal management meetings. The overall aim at the beginning was to introduce Personal Budgets in an agreed timeframe using a recognised tool. This was not possible as both tools proved unreliable however the workforce was trained and Personal Budgets were introduced based on market prices rather than assisted or self-assessment. Additionally the number of Direct Payments taken up increased dramatically throughout the duration of the project reflecting increased willingness of Recovery Coordinators to encourage

people to take up Self-Directed Support. This could not have been envisaged at the start of the process and helps to show how the project whilst successful in some areas proceeded haltingly at times with obstacles and unforeseen problems. The cyclical spiral provided a framework within which the steering group worked using flexibility to change direction and incorporate new knowledge as the project developed.

The cyclical nature of AR provides an infrastructure to the inquiry process, acts as a foundation for a more robust inquiry (Hope and Waterman, 2003) and helps to meet the demands for rigour (Kock *et al.*, 1997). This allows for the collection of data from different sources about the same events and allows for comparisons over time. In this study successive iterations allowed for data collection at different times over a four year study period and also allowed for issues and questions that were observed and discussed in early iterations to be studied longer term.

It is suggested that the proximity of the action researcher within the organisation is more likely to produce results (Williams *et al.*, 2008) and is necessary for the change process (Waterman *et al.*, 2001). However the principal threat to validity for AR is the lack of impartiality of the researcher (Coughlan and Coughlan, 2002) therefore it needs to be demonstrated that rigour has been applied to the findings, their analysis and interpretation. Whilst personal over-involvement from the researcher is likely to bias research results it is inherent in AR as it is impossible for the researcher to be both detached and exert positive intervention into the system being studied. Perceptions are more likely to be distorted when emotional events are experienced such as those generated by change (Kock *et al.*, 1997). In order to avoid over-involvement in this study I tried to avoid personal identification with the Resource Allocation System tools that were being adapted and

developed as part of the AR project, and allow full and critical discussion in the SG about these and any other aspects of the Self-Directed Support implementation process. Whilst I may have been cast in the 'expert' role I needed to maintain my integrity as a researcher as well as project manager and not be overly influential in decision making.

During this study the collaborative nature of the steering group and project design with four co-researchers has enabled a more rigorous approach where data, decisions and the direction of the project were critically scrutinised. Additionally the work of the group was communicated publically at a Trust conference on Recovery, meetings with service providers, in other organisational meetings and by newsletter. Training sessions and workshops with Recovery Coordinators facilitated feedback and encouraged critique on proposals regarding Self-Directed Support, and data collected from these were discussed in the cyclical process through the steering group.

Williamson (2012) has usefully synthesised the key areas of the work of: Waterman *et al* (2001); Herr and Anderson (2005); Gomm *et al* (2005); Bradbury and Reason (2006); Koch and Kralik (2006); and Coghlan and Brannick (2010); into five areas of similarity regarding the evaluation of AR. These are generation of new knowledge; producing change; an ethic of participation; demonstration of transferability and rigour. Change can be directly evidenced in this study by the introduction of Personal Budgets at the end of project however the more important issue is whether the workforce and those involved in the project have changed in their future actions and behaviours. The project began the process of bringing in change to the culture of the organisation to enable service users and carers more active involvement, choice and control over the social care resources they need.

The impetus towards this was started by the project and whilst there were challenges I would suggest that the project began that journey which will be continuing beyond the end of the study. It is therefore difficult to judge this study's success in producing change however the majority of relevant staff actively participated in the training and workshops which evidences their willingness to learn how to work in a different way, and the number of Direct Payments increased suggesting more staff were embracing personalisation and promoting this to people they were seeing.

I have already discussed and demonstrated the evidence relating to the generation of new knowledge, the collaborative nature of the project and rigour in this project but will now discuss whether the findings from this study are transferable.

AR projects are situation specific, not aiming to create universal knowledge however they must have some implications beyond the knowledge needed for the particular project (Coughlan and Coughlan, 2002). Waterman *et al* (2001) describe the advantage of AR is that practitioners develop their own hypotheses to enhance their own and other practitioners' understanding of their work. This study is able to satisfy areas of quality and rigour as suggested by several academic contributors to AR. Denscombe (2007) warns of making grandiose claims on behalf of AR projects however French (2009) argues that though practice driven and small scale, AR can apply and test research propositions and offer evaluation of existing knowledge. Readers of this study will need to consider the context of the research and whether this is similar to their context in order to consider if any of the learning is transferable. It is likely, given the many mental health trusts in Great Britain, that there are a substantial number with integrated health and social

care services that have embarked or are embarking on introducing personal budgets, and/or working collaboratively with service user researchers, and may find this study relevant to their context.

#### **6.3.4 Rigour in Data Analysis**

Transcripts were made of all six focus groups which were analysed using Krueger and Casey's (2006) approach. The transcripts were read through by me several times to become familiar with the content, each focus group question was then analysed in turn and coded by me into themes. Weighting was applied to themes in relation to intensity and extensity of comments. Focus groups comprised three different participant groups: service users, carers, and Recovery Coordinators, therefore cross cutting themes were examined, as well as those relating to particular questions in order to see which was more relevant. The process of coding was repeated after a few weeks to ensure I reached the same results and had not missed any new codes to test intra-coder reliability (Miles and Huberman, 1994). The resulting codes were then shared with participants from the focus groups and the co-researcher that co-facilitated, inviting comments to check respondent validation (Reason and Rowan, 1981; Silverman, 2001).

Transcripts from the first seven steering groups were analysed, coded in the same way and shared for comment and discussion with steering group participants at the following steering group.

Notes from interviews for the co-researcher role, training sessions with Recovery Coordinators, the remaining steering groups and meetings with co-researchers were taken and word-processed within 24 hours. These were analysed using the

same methods and shared with the relevant co-researcher where sessions were co-facilitated and with steering group participants for comments.

## **6.4 LEARNING FROM THE IMPLEMENTATION OF PERSONAL BUDGETS**

### **6.4.1 Discussion aims**

In this section I will discuss the themes from this study's findings in relation to my literature review. I will identify and discuss themes that are consistent, challenge or add to the literature, taking the principal themes one at a time. I will use findings from my literature review to see if they add further understanding of my findings either confirming or disconfirming my interpretations. I start with positive outcomes from Self-Directed Support, followed by barriers to implementation, and then Resource Allocation System development. In addition I discuss the advantages and disadvantages relating to specific mental health and generic versions of Self-Directed Support with reference to discourse in the steering groups.

## **6.5 Benefits of Direct Payments and Personal Budgets**

### **6.5.1 Choice and control**

The workshops held in this study raised increased flexibility, choice and control as positive outcomes, framed by the co-researchers as; allowing people to set their own agendas even if this challenges providers. Service users in the focus groups valued individualisation as a means of tailoring services to a person's uniqueness, acknowledging that Direct Payments afforded the ability to choose options rather than selecting from a list. This finding correlates with studies of Direct Payments with mental health service users (Ridley and Jones, 2003; Spandler and Vick, 2006; MIND, 2009; Coyle, 2011; Newbrunner *et al.*, 2011) and research across all

disabilities (Hatton *et al.*, 2008; Rabiee *et al.*, 2009; Stevens *et al.*, 2011) where flexibility was seen positively, increasing creativity and choice.

Carers in this study also welcomed flexibility, adding the caveat of ensuring this did not place extra burden on them. This is reflected in the literature (Glendinning *et al.*, 2009; Moran *et al.*, 2011; Newbronner *et al.*, 2011) including the ability to choose how to hold a Personal Budget adding to choice and control. However it is noteworthy that many of the Individual Budget pilots had poor representation of carers: the IBSEN (2007) reporting a lack of statistical relevance for many of its findings including carers (Netten *et al.*, 2007). Carers in this study were concerned with the potential negative aspects of Direct Payments namely: adding to their workload; increasing stress; and propensity as a source of conflict with those they care for.

Recovery Coordinators viewed the flexibility of Direct Payments as positive providing several examples of individualised support that brought real benefits for people, suggesting Direct Payments enabled them to think laterally about people's outcomes and increased opportunities. Again this is found in the literature (Glendinning *et al.*, 2008; Henwood and Hudson, 2007, 2008; Coyle, 2011) together with workers also limiting choice by controlling it through prevailing attitudes and norms (Stevens *et al.*, 2011). Recovery Coordinators here express degrees of ambivalence particularly where people are deemed very incapacitated, shown in comments during training and focus groups.

The literature and my study demonstrate broad agreement that increased choice and control is beneficial however both sets of participants are often limited by a lack of working knowledge of Personal Budgets and Direct Payments. Theoretical



agreement with principles rather than experiential or truly informed viewpoints dominate. Additionally concepts such as 'choice' and 'control' are open to individual interpretation, in other words what one person may see as additional choice, another may see as a right. Choice would be better seen on a scale with the right to say 'no' to Self-Directed Support at one end and maximum control at the other. Choice as an outcome is flawed if between numerous poor services or one excellent service and when information is limited. It also provides constant tensions for workers with expectations of increasing people's choice in the context of vigilance in safeguarding, guarding the public purse and implementing local Personal Budget eligibility guidance.

### **6.5.2 Quality of life**

The co-researchers cited, as a measure of quality of life, the importance of social inclusion and enabling a person to feel part of the community through participation. Recovery Coordinators in the focus groups described improved quality of life for the Direct Payment recipients they supported: increased chances and opportunities for normalisation; treating people as adults; and keeping people out of hospital were cited as benefits. Service users thought Personal Budgets could be used as part of a recovery approach to improve their quality of life and carers too felt positive outcomes would result however expressed cautions about increased work for them.

Improved quality of life is a key measurement outcome for Self-Directed Support in the literature including: 'In Control' evaluations, Hatton *et al* (2008) citing improvements for most participants; and Tyson *et al* (2010) reporting higher levels of satisfaction across all areas of life. The IBSEN evaluation however found little difference between the control group and Individual Budget holders except in

mental health Direct Payment recipients where significant improvements were reported (Glendinning *et al.*, 2008) though cautions to interpretation are noted in my literature review. Mind's (2009) research found positive responses in enhancing people's quality of life and Homer and Gilder (2008) were clear that Self-Directed Support resulted in a much fuller life for participants. Daly *et al* (2008) and Newbrunner *et al* (2011) all confirm this picture of increased satisfaction for the majority.

Whilst this outcome appears to be positive, data is patchy and open to interpretation with different disability groups experiencing the outcomes of Self-Directed Support in different ways. Most of the service user participants in the study did not receive Direct Payments and were considering the capability of Direct Payments as being transformative. The previous system has constructed the belief 'you will never get a job or a life and you are dependent upon mental health services'. Now this is being challenged by Self-Directed Support with the ethos of 'you can change your life with this budget'. It is not surprising therefore that people see potential life improvement both in my study and other studies with mental health participants. Equally the Recovery Coordinators could see that people's lives could be changed but that stifling bureaucracy and other obstacles could prevent this. However mental health has been the smallest component of larger scale studies with small sample sizes and in most cases it is not clear if data is collected from people receiving services from integrated health and social care trusts or those not using statutory services which makes comparisons difficult (Glendinning *et al.*, 2008; Homer and Gilder, 2008; Daly *et al.*, 2008; Rabiee *et al.*, 2009; Newbrunner *et al.*, 2011; Moran *et al.*, 2011).

### **6.5.3 Health and well-being**

It is interesting to note that health and wellbeing as an outcome did not appear in my findings however may have been assumed when recovery was discussed.

Health and wellbeing is measured in several studies with improvements across all disability groups where Personal Budgets are in place (Glendinning *et al.*, 2008; Tyson *et al.*, 2010). Rabiee *et al* (2009) linked increased wellbeing in people with variable conditions to having flexible support and Coyle's (2011) study found Personal Budgets enhanced recovery amongst people with mental health problems from previous dependency on statutory services.

## **6.6 Barriers to Personal Budgets and Direct Payments**

### **6.6.1 Assessment and application processes**

This study found service users wanting fair and transparent systems with all options explained from the outset. They expressed concern about overly long processes to access resources and review processes causing anxiety once resources were in place. Carers too voiced the desire for simple, accessible processes that were 'joined up' without having to provide information repeatedly. Recovery Coordinators were worried about additional paperwork and increasing complexity. Steering group discussions highlighted a lack of awareness of care management tools and principles within the Trust.

These concerns are confirmed in the literature with processes described as overly bureaucratic (Newbiggin and Lowe, 2005; Homer and Gilder, 2008; Glendinning *et al.*, 2008; MIND, 2009), lengthy (Newbronner *et al.*, 2011) and an obstacle to take-up of Personal Budgets (Ridley *et al.*, 2011). Assessment processes are also criticised as reflecting: organisational priorities rather than people's needs (Ridley and Jones, 2003); and difficulties in distinguishing needs

from wants, the latter being ineligible for funding (Williams and Tyson, 2010). Ellis (2007) along with others (Spandler and Vick, 2005) suggests processes may also provide considerable discretion for front-line workers about who they promote Direct Payments to.

This is likely to be multiplied in mental health services where workers are less conversant with social care processes and have more pressing agendas to implement, which may directly contribute to mental health Direct Payment numbers being so low.

One of the principle tenets of Self-Directed Support was transparent and more explicit systems (DH, 2010) however both this study and existing research suggests there is still a long way to go before this is achieved.

### **6.6.2 Information and training**

Findings in this study, from all groups of participants during workshops, focus groups and training events, reiterated that more knowledge and information was needed. Information was described as piecemeal unless you were favoured with a knowledgeable worker. Training needs were advocated by the steering group for professionals, people using services, carers, and particularly managers to influence practice.

This finding matches the literature on Personal Budgets where training is found to be a priority need in the IBSEN study and other evaluations (Glendinning *et al.*, 2008; Manthorpe *et al.*, 2009a; Mind, 2009; Manthorpe *et al.*, 2010; Scottish Government, 2010; Newbronner *et al.*, 2011). Manthorpe *et al* (2010) recognised the training of managers as important to influence culture. Training as a theme is

hardly surprising given the enormity of change that Self-Directed Support proposes. Training in social care is traditionally offered as a solution when key policy changes fail to be grasped by the workforce. In this study, and relevant research literature, training is seen as crucial due to the gate-keeping role of staff that could effectively compromise Self-Directed Support implementation (Glendinning *et al.*, 2008, Manthorpe *et al.*, 2009, Newbrunner *et al.*, 2011). Training sessions in this study provided data to be reflected and acted on within the AR cycle. This corresponds directly to Manthorpe *et al* (2009) who suggest those providing Individual Budget training may have much to contribute to service re-design, given their awareness of local context and practitioner's potential reactions.

Lack of information about Direct Payments for service users and carers is a consistent theme in the literature (Maglajlic *et al.*, 2000; Ridley and Jones, 2002, 2003; Brewis, 2007; Glendinning *et al.*, 2008; Mind, 2009; Newbrunner *et al.*, 2011) which is evidenced in this study. The service users in this study suggested one Self-Directed Support information point. This is recommended by Henwood and Hudson (2008) and Tyson *et al* (2010) suggesting internet based solutions to matching providers with people, Ridley *et al* (2011) recommending a central information point and Newbrunner *et al* (2011) suggesting active outreach through networks and groups.

### **6.6.3 Support and advocacy**

Findings from this study indicated that for people moving out of a regulatory framework and taking on greater responsibility, more support would be necessary to ensure that their anxieties are not increased. Front-line staff were worried they would be called upon to provide this, whereas service users wanted this provision from an impartial service user led organisation. Focus group findings suggested that not all people would want to manage their own money or be able to do so. Carers were almost unanimous that money management would cause them more stress; Recovery Coordinators thought people would over-estimate being well enough to manage a Direct Payment when it was evident they were not. Continuity in relationships reflected in trusting relationships was suggested as important.

These views echo those of Newbiggin and Lowe (2005) who stress the importance of independent support services and many service users having poor experiences of statutory services. Creativity, can-do attitude, inclusiveness, being visionary and having an understanding and personal experience of mental distress were cited as necessary for any support service. Newbronner *et al* (2011) suggests that in mental health people were less likely to use support from provider organisations and Campbell *et al* (2011) also suggest people have poor experience from statutory services but were happy with user led organisation support. Users and carers may not want the responsibility of managing their own money (Ridell *et al.*, 2006; Davey *et al.*, 2007; Manthorpe *et al.*, 2011).

### **6.6.4 Resources**

Recovery Coordinators' feedback in this study was that choice is important but services were lacking and choice depends on knowing what is available. Some

thought that Self-Directed Support was a cost cutting exercise that would raise expectations but not meet in the current economic climate. Carers and service users were concerned about the complexity, accessibility and quality of current commissioned services, some describing poor experiences with untrained agency staff. They wanted consistent relationships and likened services to a 'lottery'. Recovery Coordinators described service quality as patchy with inconsistent staffing and workers lacking specialist knowledge. They considered their own knowledge as always out-dated, suggesting an accessible services inventory needs to be maintained.

Much of what participants expressed in this study concerning resources is also found in the literature. Ridley and Jones (2003) explored people's experience of paid support finding that whilst many appeared satisfied others were frustrated with poor choices and support that didn't meet their individual needs. Better quality information on Personal Budget options was vital to improve choice for people (Glendinning *et al.*, 2008; Newbrunner *et al.*, 2011). Stevens *et al* (2011) reported that inequities result where people do not have access to an information network about service availability, cost and quality. Manthorpe *et al* (2008) suggest that prospects for Self-Directed Support are highly dependent upon the development of the social care market to develop new personalised services and Newbrunner *et al* (2011) highlighted the need to improve the supply of services.

Social Workers' concerns about resource constraints and cost tensions are reported by Williams and Tyson (2010) and Jacobs *et al* (2011). Stevens *et al* (2011) explore resource choices and legitimate decision-making in connection with public scrutiny of appropriate resources: for example, using a Direct Payment to buy a computer may be seen as an extravagant item. This has direct correlation

with this study with Recovery Coordinators expressing concerns about provision under Direct Payments equating to luxuries particularly where cuts in public funding is constant.

### **6.6.5 Differences in mental health services**

Participants in this study were concerned about the health and social care divide within mental health services, with separate budgets and processes often hampering effective work across both. The medical model was seen as prevalent within Trust culture and practice, reducing the status of social care due to prioritising clinical orientations. Additionally people's fluctuating needs resulting from variable conditions were acknowledged as problematic for assessors and people's capability to manage Direct Payments. The evidence base for Direct Payments was questioned to satisfy curiosity 'What is it?' but also expressing concern that it does not have a clinical evidence base. It is clear that in this study the Local Authority had a powerful influence on the Trust Personal Budget implementation process as seen in the Resource Allocation System development process and wanting a seamless approach across the Local Authority and Trust. This resulted in helpful joint working processes but conversely hampered the scope of the project steering group to work independently and explore innovative solutions.

The final IBSEN (2008) highlighted difficulties in the NHS-social care interface and disaggregating social care funding responsibilities with a lack of understanding of personalisation within the NHS culture. It also found people with mental health problems were awarded the lowest Direct Payment amounts yet reported the highest positive outcomes from Individual Budgets (Glendinning *et al.*, 2008). Over-medicalisation is a theme in the NHS Confederation (2011) service user and



carer research into Personal Health Budgets with mental health professionals being unconvinced that Personal Health Budgets would lead to better outcomes; inadequate evidence being rated as the second highest obstacle to implementation by all professionals (NHS Confederation, 2011a). However not all mental health practice is evidence based, even NICE guidance is only evidenced as beneficial for 80% of those treated. There is a trade-off between responsibility and duty of care in a personalisation approach where the individual takes on more control: from a paternalistic system to a radically different approach. It is the relationship of trust between the system and the professionals working with the person that makes them safe rather than the professional being held responsible for the person.

#### **6.6.6 Carers**

Many carers in this study expressed concerns about the quality of mental health services that their cared-for individuals received, feeling not listened to or ignored during assessments and reviews. They felt they needed to gain confidence in speaking out so others could comprehend the enormity of their roles. Few had any awareness of Direct Payments or Personal Budgets or comprehension that they personally could benefit from these in their own right. They agreed with the principles though were cautious about this increasing friction in their caring role. The steering group agreed that training for carers was very important. Only a few carers had personal experience of Direct Payments and therefore these findings mainly relate to views based on theoretical considerations.

Carers clearly play a major helping role with many Direct Payment recipients (Newbrunner *et al.*, 2011). Individual Budgets were associated with an improvement in the carer's quality of life resulting generally from having more

choice and control over how they spent their time (Glendinning *et al.*, 2009; Moran *et al.*, 2011) with which the carers here agreed in principle. However whilst there are many reported benefits from Self-Directed Support to carers including increasing choice and flexible services challenges remain, particularly concerning the administrative burden and potential employment responsibilities (Ridley and Jones, 2002; Homer and Gilder, 2008; Manthorpe *et al.*, 2011). Focus group carers here found administration systems complex and managing money a source of friction. Newbronner *et al* (2011) suggest carers' roles are not fully recognised and that they need to be involved at all stages of the Personal Budget process if they and the recipient want this. Recognising carers' central role is needed, highlighted in national research and this study, in order that their burden is reduced not increased by Self-Directed Support implementation.

#### **6.6.7 Risks**

The nature of risk appeared to produce emotive reaction from two of the co-researchers. In particular people who harm others needed to be completely separated from people who self harm when assessing needs under a Resource Allocation System. Risks to budgets becoming overspent; assumptions being made about people's ability on money-management and spending on items not related to a person's agreed plan were highlighted. Safeguarding of vulnerable clients with Self-Directed Support removing the protective factor of managed services was expressed by Recovery Coordinators. Concerns were also voiced about people taking on Personal Budgets who then may become more anxious and unwell due to the added burden of responsibility, with some workers suggesting that people preferred arranged services or lacked capability to manage the level of responsibility required.

These findings correspond with the study of safeguarding in the 13 pilot IB sites acknowledging that potentially DPs carried more risks for abuse, increasing lack of wellbeing and exploitation than conventional services (Manthorpe *et al.*, 2008). However the study was based on interviews, not statistical analysis, interviewing safeguarding leads where prevailing attitudes are likely to be cautious. Any longer term analysis of safeguarding alerts with Personal Budget recipients would need to be contrasted with those arising in contracted services to assess whether there is any significant increase in the number and nature of incidents. Concerns about misspending of monies and fears that people will commit fraud more easily were also reported (Manthorpe *et al.*, 2009a) as was expressed by respondents in this study.

#### **6.6.8 Impact on workforce**

Concerns expressed from staff in this study included: extra paperwork; increasing complexity, particularly in assessments where emphasis on flexibility meant extra work; older style service reduction; not keeping up-to-date with service information; lacking confidence and knowledge about Self-Directed Support; and higher expectations from carers and family. Extra complexity and concerns about lacking skills are identified in the literature (Witcher *et al.*, 2000, Manthorpe *et al.*, 2009; Mind, 2009) as well as additional workload (Jacobs *et al.*, 2011). Most major changes include added workload and complexity concerns until changes are fully implemented. Findings from future studies may therefore report less concerns in this area once training and systems are fully established. Recovery Coordinators here were used to providing information directly to people but could not be confident their information was accurate. They wanted a central information source akin to service user suggestions. This is a practical solution that supports the Self-Directed Support information 'transparency' principle.

### **6.6.9 Staff Culture**

Findings from this study suggest that paternalism and the 'professional gift' model of working is still apparent and that whilst the Trust espouses working in a recovery approach some workers foster a dependency culture. Co-researchers suggested that how the Trust treated staff indicated practice lagged behind vision and that more value needed to be placed on lived-experience. They perceived Recovery Coordinators' work overload reduced their caring approach however considered them as drivers of change, needing to adapt and tackle other staff's resistance. The need to train people receiving services was recognised, in order to influence their culture and become more confident in this new landscape. The focus groups findings reported that worker's moral attitudes, akin to old-fashioned 'deserving and non-deserving', still exist; for example in perceptions of Direct Payments used for luxury items. Working in a more outcome-focussed, person-centred way was considered a pre-requisite to Self-Directed Support.

These findings align with the need for a culture shift, evidenced in the literature (Glendinning *et al.*, 2008; Manthorpe *et al.*, 2009; Coyle, 2011; Newbrunner *et al.*, 2011) as needing to move from traditional, gift-bestowing to rights-based services with staff endorsing personalisation principles rather than seeing them as a threat. Positive staff attitudes are crucial to promoting Self-Directed Support (Spandler and Vick, 2004, 2005; Newbigging and Lowe, 2005; Riddell *et al.*, 2006; Newbrunner *et al.*, 2011). These may be compounded where workers perceive themselves already overloaded and unable to keep up with new policies and change innovations as several reported.

## **6.7 Resource Allocation System Development**

A major prerequisite for Self-Directed Support is having a Resource Allocation System capable of 'indicating' an individual's personal budget (Poll *et al.*, 2006). This pre-occupied the steering group as a necessary piece of work causing much frustration and deliberation. This study used three tools: firstly an adapted 'In Control' Resource Allocation System later abandoned for a locally developed Personal Budget Allocation Tool which, following trials was found to be unreliable. Finally the ABC commercially-purchased tool was rejected due to incompatibility with Care Programme Approach documentation. At the end of this study Personal Budgets were implemented and Direct Payments continued to be provided without using a Resource Allocation System, contrary to national guidance and Local Authority practice.

Resource Allocation System development is discussed in several reports but most prominently by 'In Control' (Poll *et al.*, 2006; Browning, 2007) as a mechanism to turn an individual's assessment into a fixed sum. This uses a process attempting to objectivise need whilst also including a cost-abatement multiplier (Browning, 2007) in order to reduce costs post assessment whilst remaining 'transparent and equitable'. People with complex problems are suggested to be losers using Resource Allocation System (Henwood and Hudson, 2007) and 'In Control' (2008) acknowledges this. Whatever tool is used, the problem this study found is having one of sufficient sophistication to genuinely reflect a person's unique needs and have confidence in its application. Both here, and in reviewing the literature, concerns about the Resource Allocation System process to produce budgets (Manthorpe *et al.*, 2008) and the make-up of the questionnaire are reported (Glendinning *et al.*, 2008, Rabiee *et al.*, 2009). Resource Allocation System development is identified as costly (Jones and Netten, 2009) which is echoed here in the time spent on developing later-to-be discarded tools. Early research

into Direct Payments (Newbiggin and Lowe, 2005) noted the problems of staff being put off if paperwork was not integrated with Care Programme Approach which was the case in this study. The Resource Allocation System therefore has practical and philosophical shortcomings illustrated here and in the literature. Whilst money is only one part of Self-Directed Support implementation, difficulties in Resource Allocation System development shown here highlight the complications of providing 'simple' solutions to complex situations. It is interesting to note that Henwood and Hudson (2007)'s national evaluation recommended developing a national tool to remove 'wasteful duplication of local effort' (P.81) which was not taken up.

### **6.8 Generic and specific approach to Self-Directed Support**

The Individual Budget pilot site development undertaken by 'In Control', DH and Care Services Improvement Partnership (CSIP) during 2007-8 recommended developing a high level generic Self-Directed Support process validated through peer review on the pilot sites. Their aim was to develop a guide for other Local Authorities to follow, advocating one process and one set of principles. The process suggested aligning the various information sets from different organisations with the self-assessment process. This included a standardised approach so that people with similar needs were treated equitably receiving similar amounts of support regardless, but where individuality was recognised (Murray *et al.*, 2009). 'In Control's second phase development (Hatton *et al.*, 2008) described Self-Directed Support and the Resource Allocation System as viewing all categories of need in relation to ordinary aspects of everyday life focussing on the outcomes of support. Duffy (2008) describes Self-Directed Support as a system for all however not all share his views with the widespread assumption that labels within social care represent substantial differences

between the needs of people, often with differences so substantial that they require distinctive approaches and additional support needs. Duffy (2007) therefore acknowledged the challenge of whether the 'In Control' model could work for all people in different categories of need and if not how to adapt it.

This study's steering group showed that the co-researchers argued that mental health was different to other disability areas due to the effect of stigma, social exclusion, the application of mental health legislation which could result in detention in hospital, and inaccurate portrayals of people with mental health problems presenting as a risk to others. The argument of difference was mainly applied to discussion about the Resource Allocation System as all participants including the co-researchers agreed that the process of Self-Directed Support was one that should be available to people with mental health problems as it was to other disability areas. Their major concern was that the Resource Allocation System was seen to be weighted towards people with physical or learning disability and did not effectively capture the more complex needs of people with a mental illness.

Duffy (2007) argues that the process of classifying needs into mental health, learning disability and so on acts as process of control suggesting needs can only be remedied by professional interventions whilst acknowledging the paradox that people coming together who share a common identity can then act to challenge the legitimacy of professionals. Duffy (2007) suggests that the labels, whilst acknowledging real differences, can distract people from seeing that they are people and citizens. Glasby (2009) also suggests that the legacy of the service led system prior to Self-Directed Support was to place individuals in specific boxes and that Individual Budgets can help to mitigate against this. Rather than trying to

determine whether a person has a mental health problem or learning disability cross cutting needs can be acknowledged and people's identities reinforced. This is also suggested by Needham (2011) who argues that person centred approaches reflect the way that people live rather than artificial departmental boundaries. The different disability divisions that the government use is not how people think of themselves and just describe one aspect of a person rather than their reality. Self-Directed Support was therefore underpinned by the premise of equality of opportunity, open to all, based on common humanity and not withheld based on diagnosis (Brewis, 2007).

Beresford (2009) also takes the view that Self-Directed Support should be available for all service users regardless of impairment providing a universal offer to all those eligible based on need. Different groups experience different issues but people share common difficulties and gain an understanding of working together, avoiding crude categorisations, but reflecting the reality of people's experience and growing solidarity.

Brewis (2007) suggests that Self-Directed Support can help people with mental health problems, one of the most marginalised and socially isolated groups in society, to move away from segregated services and access mainstream activities. She acknowledges that in mental health the amount allocated per person is generally lower than in other disability areas but that a generic Resource Allocation System could help to rectify this and allocate budgets based on the same levels of needs being given the same levels of resources. The rationale for a generic Resource Allocation System as a means of making transparent inequities between disability groups is therefore argued (Brewis, 2007; Henwood and Hudson, 2007; Duncan-Turnbull, 2010; Newbronner *et al.*, 2011) and a



standard Resource Allocation System is recommended as essential (Haworth, 2009; Duncan-Turnbull, 2010). However the more transparent the allocation of resources to people with highly variable needs the more this brings equity issues into sharp relief and controversially questions the appropriateness of a universal system compared to processes where professional judgement and discretion play greater roles (Glendinning *et al.*, 2008).

The one-size-fits-all approach could be argued to not be designed for all those with needs, particularly those who start using services after a crisis or those who have unstable levels of need where managing a care package will be harder work (Newbrunner *et al.*, 2011) This may apply more in mental health and older people's services and may present additional barriers to taking up a Personal Budget or Direct Payment than those already discussed.

Mental health services have long been emphasised as a specialist area and it may be that the co-researchers in this study reflect that specialism and separateness even whilst acknowledging the need for social inclusion and great dissatisfaction with the medical model. The focus on difference and dissatisfaction may have pervaded the co-researchers' thinking, and many of their concerns about being seen as a special case centred on their view that mental health relative to other NHS and social care sectors was under-resourced. Certainly all of the co-researchers fully embraced the concept and philosophy of Self-Directed Support and wanted to ensure that people with mental health needs were fully acknowledged within a fair Resource Allocation System process and were able to obtain a fair share of resources.

## 6.9 Summary

Thematic findings, from multiple sources, concerning Self-Directed Support implementation in this study are predominantly substantiated by the evidence-based literature review findings. One of the problems for action researchers is whether the data collected and the report written is a true reflection of what was studied and that threats to validity have not been posed by the researchers vested interests (Waterman, 1998). The similarity of this study's findings, with national research helps to provide credibility in this AR study. The truth value relating to internal validity is proposed as one criteria of rigour in qualitative research (Guba and Lincoln, 1989). In AR however credibility can also be demonstrated through the reflexive nature of the study demonstrated here in the steering group, in my research diary and co-researcher related data. Triangulation in investigator and data methods, based on focus groups, training workshops, steering group transcripts, and co-researcher interviews also strengthens this study's credibility.

The literature studies Personal Budget implementation predominantly using qualitative methods in order to elicit rich data relating to the process of implementing Personal Budgets and the impact for recipients and other stakeholders. Evaluating the impact of Self-Directed Support on people's quality of life, health and wellbeing and those supporting recipients, is a complex area of work where participant's own interpretation is detailed and is best suited to a qualitative approach. As I wanted to give a voice to service users, carers and practitioners about the implementation process in a non-hierarchical and empowering inquiry process I used AR. The tenets of Self-Directed Support include extending people's choice and control therefore this methodology was additionally justified as relevant both as a practical solution and a means of inquiry.

This is a small-scale, reflexive, contextual AR study designed to change practice, at the same time as researching the process, in order to learn about the organisational and structural obstacles, prevailing attitudes and indicative outcomes for people. The findings and outcomes of the study however may be of interest to readers in other mental health Trusts who are implementing Self-Directed Support: it is likely, based on the similarity of these findings to the national picture, that some of the themes described here will be of relevance to them.

Unique learning in this study is in relation to the recruitment method of co-researchers into an AR study and the dual learning this afforded; the co-researcher involvement in AR steering groups adding an extra dimension of challenge into a collaborative process; and the steering group as a pivotal structure for conducting AR using co-researchers. Unique learning concerning the emotional impact of involvement from the co-researchers is also evident in this study and is discussed in detail in the published paper from this study attached as Appendix 10.

Additionally this study provides a unique long term inquiry into the introduction of Self-Directed Support in a mental health Trust using AR methodology and incorporating service user and carer co-researchers in the process. The findings echo those of the national generic research (Glendinning *et al.*, 2007, 2008, 2009; Manthorpe *et al.*, 2008, 2009, 2009a, 2010, 2010a; Rabiee *et al.*, 2009; Jacobs *et al.*, 2011; Jones and Netten, 2010; Moran *et al.*, 2011; Netten *et al.*, 2011; Stevens *et al.*, 2011). Mental health specific research has been undertaken (Mind, 2009; Coyle, 2011; NHS Confederation, 2011, 2011a, 2011b; Newbronner *et al.*,

2011) however there were no mental health specific studies on Self-Directed Support using an AR approach published at the point of this study ending. In both my study and the national research the changed relationship between professionals and service users from a professional gift approach to a new citizenship model, in which individuals negotiate services based on entitlement (Jackson, 2008) was agreed as part of the culture change needed.

Duffy (2010) argues that the real choice underlying Self-Directed Support is whether the welfare state wishes to move from paternalism to the citizenship model where people are provided with money as an entitlement rather than to the needy person as a gift. This means that people are in control of their own lives, making choices based on clear information. Self-Directed Support is the system giving the citizen the maximum degree of control over their own support (Carr, 2008). It assumes that people with a disability can and should still be in control of their lives as far as they are able and this turns the old paternalistic regime on its head. Duffy (2010a) describes the citizenship theory as believing that all people no matter what their diversity are of equal worth and that human diversity in all its forms is essentially a good thing. The theory includes three principles; firstly that of all members of society treating each other with respect; secondly, that the grounds for respect are so defined to enable everyone to achieve active citizenship; and thirdly that of a fair society whereby everyone gets sufficient support to be able to achieve active citizenship. The process of Self-Directed Support is therefore able to ensure people get the resources they need to achieve citizenship and is consistent with the principles it upholds. In both this study and nationally, findings demonstrated that all participants agreed that more choice and control is valued but it is more than this that personalisation and Self-Directed Support offers (Duffy, 2010a; Duffy *et al.*, 2010). Self-Directed Support offers a

promotion of social justice, social change, citizenship and personal responsibility however workers must believe in the power people have to change their own lives, embrace this new way of empowering those they are working with and in this way reform welfare services.

A further unique learning point in this study concerns the political relationship between the Trust and the Local Authority and the difficulties specifically in mental health services due to social care being afforded less priority than healthcare in the Trust. Fragmented care between the NHS and social care is intended to be addressed in the Health and Social Care Bill (DH, 2011a) by placing a duty on the proposed Joint Health and Wellbeing Boards to consider partnership arrangements, for example, pooled budgets:

‘It is impossible to deliver high quality or efficient services when the patient is passed like a parcel from one part of the system to another’  
(Stephen Dorrell, 2012).

The different environment of mental health Trusts are evidenced as adding another layer of obstacles to the implementation of Personal Budgets. In this study the Local Authority had a power relationship with the Trust that provided both support but required compliance with their targets, local policies and procedures. This was both a help but also an obstacle due to mental health services being set up very differently to Local Authority teams using Care Programme Approach not care management processes with different financial, information technology and assessment processes. Social care innovations were not high on Trust agendas, therefore support from senior managers was vital to ensure that training and change processes were prioritised, attended and implemented. Mental health services have to operate legislation under the 2007 Mental Health Act (DH, 2010a) but front-line teams in the Trust are predominantly

staffed by nurses rather than social work practitioners. The social model of disability is not the predominant model of working and whilst recovery as a principle is promoted, the medical model of service is still highly visible as a driving force. This means that it was vital that training was taken up and Self-Directed Support supported within higher levels in the Trust.

The topics discussed in this chapter will be used to draw conclusions and make suggestions for future research in the next chapter

## **CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS**

### **7.1 Introduction**

This chapter is divided into two sections. The first section considers conclusions. It begins by considering the aims of this study and what conclusions can be drawn from the findings in relation to those aims. It considers these in relation to: Self-Directed Support implementation; service user and carer involvement; the use of AR in this study; and the data collection methods. In the second section recommendations for future research are suggested.

### **Section One: Conclusions**

#### **7.2.1 Conclusions regarding Self-Directed Support**

The first aim of this study was to implement and research SDS in mental health services, to understand from service users', carers' and RCCO's perspectives what the benefits and obstacles were to implementation, in order to provide a more effective, efficient and responsive Personal Budget service. These aims were met through the findings generated by the study. The qualitative findings in this study show a strong similarity with national findings from the evidence-based literature review and substantiate this study's findings. External validity has been provided through the checking of my knowledge claims against national theoretical knowledge. Findings have also been checked through the critical feedback of others in the steering group, focus groups and with Recovery Coordinators. Transcript excerpts have been included in this study as a sincere and open method of providing evidence for readers of this thesis to critically evaluate. My self-critique, in the form of diary extracts, has been included to show my learning and ability to be reflexive and deconstructive about my emerging understanding.

Findings here show that Self-Directed Support involves: balancing relationships between the professional, the person and the system and is about more than the central tenets of choice and control. It involves considering service users more equally with professionals, making them like a quasi-professional in charge of their own care-plan. Self-Directed Support takes a different approach than was traditional in mental health requiring people and staff to change their ways. Different relationships between service user and professionals are required that allow more empowerment to the person needing help and services. The professional role should concern quality and respect and not impose control. Power relationships should alter to put the service user not the professional in control.

Findings here and nationally show that staff attitudes and culture needs to change (Glendinning *et al.*, 2008; Manthorpe *et al.*, 2009; Coyle, 2011; Newbronner *et al.*, 2011) however inevitably some workers want to retain control and remain sceptical. Concerns about quality assurance and safety are evidenced and need building into new processes. Individually this can be considered relatively easily however this study shows that Self-Directed Support is a complex process to devise and implement strategically; building a functional Resource Allocation System is particularly time-consuming and fraught. On a practice level systems need to be simple to attract and protect over-worked professionals and reduce barriers to implementation. Additionally in mental health services the health and social care barriers are unhelpful in promoting the culture and system change needed. Unless Personal Budget recipients experience positive differences from Self-Directed Support implementation, this will only have evidenced the



corresponding key performance indicator rather than effect meaningful improvements.

One of the main findings here and nationally was the importance of providing information about Self-Directed Support and the process for accessing this (Maglajlic *et al.*, 2000; Ridley and Jones, 2002, 2003; Brewis, 2007; Glendinning *et al.*, 2008; Mind, 2009; Newbronner *et al.*, 2011). Service users and particularly carers do not know what is being offered, find communication is poor and cannot make comparisons. Many Recovery Coordinators find social care systems complex and off-putting. Support structures are not in place to aid implementation. High levels of confusion and ignorance exist in professional and public environments. There is evidence of strong support for the existing system to change however a concern remains that in mental health services control will still remain with the services rather than service users (NHS Confederation, 2011).

During early government planning and the current economic climate there was an agenda to reduce costs through Self-Directed Support. However excessive bureaucracy will result in less innovation and achievements. Recovery and personalisation share similar roots; both see patients as people first and incorporate hope, control and opportunity for people. If people are able to take up Self-Directed Support then outcomes that reduce dependency on services, improve people's social functioning and employment chances can be achieved. Self-Directed Support facilitates shared decision making between professionals and individuals within an ethos of increased individual engagement and responsibility aiming to improve peoples' outcomes through a personally owned and tailored care plan. It should empower individuals but still respect professionals.

The co-researchers in this study were clear that the medical model, typifying people as patients needing professionally diagnosed treatments, was evident within the Trust. For Personal Budget and individualised services to be successful then they need to be given equal importance with clinical treatment to try to reduce the dominant medical model. This will need considerable effort given the newly introduced national 'Payment by Results' programme (DH, 2009) and the responsibility of all clinicians including social workers to provide initial diagnoses to people they assess. Self-Directed Support assumes a therapeutic value to individuals having more control over their care plans, expanding their options beyond clinical treatment. It has a holistic focus rather than diagnostic: effectiveness is judged on the person's personal objectives and individual outcomes. For example, imagine that a man uses a Personal Budget to buy a dog. This then gives him the reason to get up in the morning, develop an emotional attachment, take exercise, develop routines and then the rest of his life falls into place. If he had been assessed clinically he would have been described very differently perhaps as depressed and in need of a course of Cognitive Behavioural Therapy or treatment by antidepressants. Of course both actions may be recommended and could complement one another. Recovery Coordinators here questioned the evidence-base for social care and saw some social interventions as 'treats' suggesting a problematic acceptance of the value base of Self-Directed Support.

This study evidenced all the dilemmas discussed here and implementation showed the complexity of attempting to put into place a process of Self-Directed Support enabled people to improve their outcomes and receive more individualised support. However where service users and carers are really

empowered to manage their budgets through Direct Payments there can be real benefits to their outcomes.

### **7.2.2 Conclusions regarding service user and carer involvement**

The second aim of this study was to learn from involvement of the co-researchers in this study and improve awareness of service user and carer involvement in the change process. This was achieved in two ways: firstly, using data obtained from meetings and interviews with the co-researchers a paper, early in the research process, was published about their experience of involvement; and secondly, through the data collected from their role in the steering group.

The co-researchers suggested three themes that affected them during involvement projects: communication; power relations and emotional impact. Considerable improvements to the way in which individuals are engaged in involvement projects need to be achieved to lessen the adverse emotional effects on participants with lived experience. Debriefing meetings and preparatory sessions are advocated alongside acceptance by professionals that emotional reactions are not necessarily symptomatic of a person's condition. More care, time and explanations are required to reduce communication problems and improve an individual's capabilities when engaging in involvement projects. Finally sensitivity in attitude, communication and processes need to be practiced to enable involvement to be an empowering rather than a disempowering role for people.

The steering group provided a fundamental role in bringing legitimacy and authority to the co-researchers roles and a providing a data source evidencing their perspectives on Self-Directed Support mental health services. The steering group was deliberately collaborative with an emphasis on equality of contribution

from professional, managerial and experiential viewpoints. It provided a safe environment for the co-researchers to voice their opinions, share their experiences and display emotions. However even with full preparation and agreement to underlying democratic principles, separate meetings with the co-researchers were needed. These ensured full understanding, de-escalation of any adverse interpretations of comments or discussion, and re-enforcement of the vital value of their contributions. In conclusion the employment of a steering group and a designated worker, in studies employing service user and/or carer co-researchers, is a necessary and effective means of supporting, valuing and providing legitimacy to their role.

### **7.2.3 Conclusions regarding action research**

In conclusion the use of AR in this study has been evidenced to provide a method that is highly appropriate to this study's aims. AR is flexible as it focuses on research in action enabling changes to plans following analysis and reflection and is well suited to internal researchers like myself who possess knowledge about processes, key stakeholders, organisational structures and politics. AR is also a participative process allowing a more democratic approach to shared problem solving. This met my objectives of involving people and carers as fully as possible during the course of the study and provided an effective means of bringing lived experience into the planning, acting, reflecting and re-planning process. The spiral nature of the AR cycles provided the context for the critical evaluation of Self-Directed Support and how the implementation of this would be best undertaken.

Success in meeting Coghlan and Brannick's (2010) four suggestions of quality can be shown in this research. Firstly, discussion of the reflexive nature of the research is shown in the steering group and diary entries detailed in the findings

chapter. Secondly, different views of participants were made open to critique through the work of the steering group and the research design where co-researchers with lived experience could directly challenge any assumptions from a legitimate power base. Thirdly, different views of events were evidenced through the methods used to collect data, using co-researchers and a wide mix of professionals and managers in the project steering group where open discussion was promoted. Lastly, multiple cycling was evidenced in the three spirals of the study relating to development work, workforce training and Resource Allocation System development and finally introduction of Personal Budgets. The AR spirals provided the framework for the study to incorporate new knowledge, change direction and develop.

This study also met the five evaluation criteria suggested by Williamson (2012). The generation of new knowledge is evidenced by learning around involvement of service users and carers in the study, the role of the steering group and its relationship to the co-researchers effectiveness in AR and learning from the process of implementation of Self-Directed Support in my integrated health and social care mental health Trust. Secondly change was evidenced through the AR spirals of planning, action, reflecting and acting again. Thirdly an ethic of participation was evidenced by the steering group and involvement of the co-researchers. Fourthly, rigorous methods were demonstrated in data collection using different qualitative methods and the employment of the co-researchers to undertake data collection alongside me as the lead researcher. Data analysis was also rigorous using intra-coder reliability (Miles and Huberman, 1994) and respondent validation (Reason and Rowan, 1981; Silverman, 2001). Finally, Williamson (2012) suggests the AR needs to be transferable. I would conclude that learning here may be transferable to similar Trusts who are working with Self-

Directed Support and attempting to modernise social care services to be more personalised and person-centred. Additionally researchers in AR who want to involve individuals with lived experience may find learning around the steering group and findings from the co-researchers helpful when planning their studies.

This study also demonstrated the value of collaboration, team spirit and 'symmetrical communication' accepting uniqueness, differences and people's capacity to contribute to problem solving and therefore met the principles of systemic development espoused by Zuber-Skerritt (2005).

#### **7.2.4 Conclusions regarding data collection methods**

This study used a qualitative methods data approach which allowed for different interpretations of the same events from different data collection sources with a wide range of participants over a period of time. This adds depth and rigour to the analysis and triangulates the findings as each method offers a point of comparison with the other methods (Zuber-Skerritt, 1996).

Data collection did have methodological challenges however, for example, critical appraisal of the focus group data, in particular, the well-attended first carers group where most participants knew one another, may be subject to exaggerated stories or 'atrocious tales' (Kevern and Webb, 2001). The data from the training sessions also was complex and difficult to reduce to much condensed themes and sub-themes. All of these limitations have been acknowledged and discussed in the text. Collectively however data from different sources over a four year period of time has enabled this study to present findings that provide service users, carers and Recovery Coordinator's views and concerns about Self-Directed Support.

## **7.3 Section Two: Recommendations for further research**

The conclusions from this study lead to recommendations which are discussed here in the areas of: action research; involvement; Self-Directed Support and the Trust. Finally recommendations for future research are considered.

### **7.3.1 Recommendations concerning action research**

- That AR is disseminated and publicised more widely in mental health NHS Trusts as a credible and appropriate research methodology for practitioners and managers to use when researching service/practice developments.
- That the AR methodology using a steering group to move the spiral of planning, acting, reviewing, reflecting and re-planning forward, is a primary means of providing legitimacy and engagement of all stakeholders, and is particularly enabling where service users are co-researching.
- That 'insider' action researchers need to be aware of the political and personal implications of their research where unexpected criticisms of their organisation may be reported; these may not be within the original scope of the research but constitute relevant contextual findings.
- That longitudinal research on service development and implementation is very suitable for an AR approach: AR is able to illustrate and provide data analysis at different intervals for comparison and contrast adding depth and rigour to learning.
- That lead action researchers need to be explicit at the outset with participants and relevant others, for example, ethics committees and approving bodies, about the flexibility and nature of AR generating different directions of action and research methods than is originally proposed.

- That action research can be successfully used for projects where the need for change comes from external drivers to provide: local context; understanding of the preparedness for change; and adaptations required within the particular setting.

### **7.3.2 Recommendations concerning service user and carer involvement**

- Involving people using mental health services in research requires consideration of what support and knowledge building processes should be included, to ensure full understanding, participation and protection is provided to participants throughout the study.
- Group and individual support processes should be structured to meet service user-participant's particular needs; these should be timely and allow sufficient space for ventilation of emotions, ideas and concerns using an open but contained approach.
- Involvement of service users and carers in research can help to increase their confidence, self-esteem, and development of transferable skills enhancing employment prospects.
- Involvement of service users and carers in research can evoke and resurface hidden emotions requiring vigilance from those leading the research.
- Employing people with lived experience and carers as co-researchers ensures that assumptions are made explicit; language is understandable; and grounds the research in people's lived experience as a means of testing proposed service improvements with their perspectives. Research projects should routinely consider employment of service users and carers where this is relevant.



- Employment of service user and carer co-researchers adds richness and local meaning to service improvements and may enable more varied and meaningful findings than research projects using professional researchers. People using services should be recruited to provide a pool of people willing to be involved in service developments.
- National mental health service changes developed with people with lived experience also require local involvement from service users and carers to provide legitimacy and ownership to the local implementation.

### **7.3.3 Recommendations concerning Self-Directed Support**

- The profile of social care within mental health integrated Trusts needs maintaining through structures, processes and plans in order to combat the drain of expertise and knowledge on social care matters and supremacy of the medical model. The vision, values and priorities of Trusts needs to demonstrate a commitment to social care principles including personalisation and involvement and reinforce this commitment through organisational structures and leadership.
- Implementation of Self-Directed Support within mental health integrated Trusts needs to take account of the level of social care awareness and understanding within the workforce and not assume practitioners have knowledge of social care. This needs addressing through supervision, training, communication and information structures and business planning in Trusts.
- The relationship of mental health integrated Trusts and their Local Authority partners need to be taken into full consideration when designing tools, processes, support and training on Self-Directed Support for mental health services. Mental health Trusts need to devote sufficient resources to

partnership working with their Local Authority colleagues to ensure joint understanding of relative differences in resources, business support, information technologies and priorities.

- In mental health Trusts the value of the social care evidence base needs to be confirmed as legitimate and worthy of as much attention as clinically approved evidence, for example, National Institute of Clinical Excellence (NICE) guidelines. This needs addressing through training and communications, for example, with stories of how social care interventions have enabled people to live improved lives. The appointment of people in strategic and managerial posts who are able to influence local thinking is also recommended.
- The support structures to provide information, advice and help to guide people through the Self-Directed Support application and support planning process needs to be put into place and be accessible if Self-Directed Support is to reach all those intended to benefit from personalised services. Resources need to be prioritised to commission independent support services to encourage the growth in the number of people taking up Direct Payments.
- Joint commissioning of health and social care budgets in mental health would reduce bureaucracy and improve take-up of Direct Payments and Personal Health Budgets better reflecting people's holistic needs and outcomes. Agreement between commissioners, mental health Trusts and their partner Local Authority to pooled budgets with defined risk sharing arrangements, eligibilities and shared priorities, would need to be negotiated to enable a shared approach.

### **7.3.4 Recommendations for the Trust**

- A bespoke application and support service for Direct Payments and Personal Health Budgets should be set up to provide people with advice, information and support about Self-directed Support including the piloting of Personal Health Budgets.
- Consideration is given to new structures to support carers of people with mental health problems external to the Trust; this would provide a more powerful voice and advocacy role for carers.
- Information for carers in relation to Self-Directed Support be developed and disseminated widely across carers groups and providers of carers' services.
- A social care improvement plan should be drawn up to develop and reinforce social care within the structure, processes and work of the Trust with associated improvements in knowledge, understanding and importance of social care at all levels of the organisation.
- Responsibility for Self-Directed Support be embedded in a senior leadership role at Board level in the Trust and implementation continues to be developed and refined alongside recovery services acknowledging their inter-related themes and direction.
- The formal agreement between the Local Authority and the Trust should be revised to make explicit expectations of both organisations of one another and the support and structural arrangements to enable expectations to be met including the differences in processes and agendas as well as similarities in desired outcomes.
- Action research should be promoted by the research department and potential future researchers are encouraged to use this approach.

- People using services and carers should be involved in future service developments as fully as possible to ground change in personal experience and add richness, relevance and depth to improve services.

### **7.3.5 Future research recommendations**

This study identified benefits and blockages to Self-Directed Support but was not designed to quantify patient outcomes associated with the implementation. In order to really take forward the implementation of Self-Directed Support in mental health services this need to be undertaken. It would be difficult to establish that improved outcomes are as a result of people taking up Personal Budgets, as it would be difficult to control other variables affecting people's lives, however it could be tackled using some of the widely used measurement tools for mental health.

It would be helpful to explore if there are any similarities to those people with mental health problems taking up Direct Payments rather than managed Personal Budgets. Understanding if blocks and obstacles to Direct Payments are due more to poor information, staff attitude, processes or people's conditions, for example, would enable more concentration of resources on the relevant parts of the system to increase opportunities for Direct Payments.

Research to explore how to increase the link between personalisation and recovery within mental health Trust's workforce; and whether this leads to increased take up of Personal Budgets is also suggested. There was an assumption that Self-Directed Support implementation would result in cost savings, however as people are more satisfied with their self-designed support plans they may be disinclined to give these up even if they no longer need them.

This may be counteractive to their recovery and would suggest research to look at the uses of Direct Payments in mental health services and explore to what extent these may be disempowering.

This research was not designed to specifically examine the needs of carers however it has indicated a level of dissatisfaction with services both for themselves and the cared for person. Further research into the provision of Direct Payments specifically for carers and whether this increases their stability in their caring role is indicated.

Finally further research is required into whether, using mental health co-researchers alongside professional researchers, different, more authentic data relevant to the priorities of people with mental health problems is collected. This may further strengthen the ethos of participation of people with lived experience in service planning and implementation.

#### **7.4 Afterword**

The dialogue that I had with the co-researchers in this study is one that I wish to continue, albeit in other ways with carers and people who use mental health services. This constitutes my recommended approach, as a result of learning from this project, for all service developments and redesigns, from the beginning proposals to the conclusion. This will ensure that those providing services remain grounded in the reality of those they are working hard to provide better services for.

Whilst acknowledging that there is still much to do to ensure that Self-Directed Support is embedded in front line practitioner's everyday practice, this project has

been successful in raising awareness and developing more open and transparent systems for people receiving social care resources in this Trust. Since the AR project ended the numbers of people receiving Direct Payments has significantly increased and there are many more people receiving personalised services living in community settings than five years earlier. Currently we are just about to advertise for an organisation to provide a specialised mental health support service for Direct Payments and Personal Health Budgets directly acknowledging the findings of this study. Challenges and set-backs were apparent in this project and will continue however Self-Directed Support and Recovery are now considered linked agendas within the Trust. This increasingly challenges the predominance of practitioner's knowledge over those with lived experience and will shape future services. I am very pleased to have played a part in that process.

## Appendices

### Appendix 1

#### Quality Assessment Scoring Grids for Literature Search

All the papers identified in this study's literature review were marked yes, partially or no, in answer to the ten questions of the Standard Quality Assessment Criteria for Evaluating Primary Research Papers, reproduced in table one and two (Kmet *et al*, 2004). The articles were then ranked in order of highest scores in the 'yes' and 'partial' column as shown in tables three and four. Where there are two papers describing the same study the results are the same for both papers.

Criteria	Yes (2)	Partial (1)	No (0)
1 Question / objective sufficiently described?			
2 Study design evident and appropriate?			
3 Context for the study clear?			
4 Connection to a theoretical framework / wider body of knowledge?			
5 Sampling strategy described, relevant and justified?			
6 Data collection methods clearly described and systematic?			
7 Data analysis clearly described and systematic?			
8 Use of verification procedure(s) to establish credibility?			
9 Conclusions supported by the results?			
10 Reflexivity of the account?			

**Table 1: Checklist for assessing the quality of qualitative studies (Kmet *et al*, p. 5)**

Criteria	Yes (2)	Partial (1)	No (0)	N/A
1 Question / objective sufficiently described?				
2 Study design evident and appropriate?				
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?				
4 Subject (and comparison group, if applicable) characteristics sufficiently described?				
5 If interventional and random allocation was possible, was it described?				
6 If interventional and blinding of investigators was possible, was it reported?				
7 If interventional and blinding of subjects was possible, was it reported?				
8 Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?				
9 Sample size appropriate?				
10 Analytic methods described/justified and appropriate?				
11 Some estimate of variance is reported for the main results?				
12 Controlled for confounding?				
13 Results reported in sufficient detail?				
14 Conclusions supported by the results?				

**Table 2. Checklist for assessing the quality of quantitative studies (Kmet *et al*, 2004: P.4)**



<b>Reference</b> Note: References are shown together when reporting the same project	<b>Yes: Question (Q) Nos.</b>	<b>Partial: Q. Nos.</b>	<b>No: Q. Nos.</b>	<b>Score Out of 20/ up to 1.0</b>
Rabiee <i>et al</i> (2009)	1, 2, 3, 4, 5, 6, 7, 8, 9,10			20/1.0
Ridley <i>et al</i> (2011)	1, 2, 3, 4, 5, 6, 7, 8, 9,10			20/1.0
Ridley and Jones (2002) Ridley and Jones (2003)	1, 2, 3, 4, 5, 6, 7, 8, 9,	10		19/.95
Riddell <i>et al</i> (2005) Riddell <i>et al</i> (2006) <i>mixed method</i>	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
Glendinning <i>et al</i> (2009) Moran <i>et al</i> (2011)	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
Daly <i>et al</i> (2008)	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
Manthorpe <i>et al</i> (2009a)	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
Jacobs <i>et al</i> (2011) <i>mixed methods</i>	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
Netten <i>et al</i> (2011)	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
Newbronner <i>et al</i> (2011)	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
Spandler and Vick (2006)	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
Coyle D. (2011)	1, 2, 3, 4, 5, 6, 7, 8, 9	10		19/.95
NHS Confederation (2011)	1, 2, 3, 5, 6, 8, 9, 10	4, 7		18/.9
NHS Confederation (2011a)	1, 2, 3, 5, 6, 7, 8, 9	4, 10		18/.9
Campbell <i>et al</i> (2011)	1, 2, 3, 4, 5, 6, 7, 8, 9		10	18/.9
Glendinning <i>et al</i> (2007) Glendinning <i>et al</i> (2008) Manthorpe <i>et al</i> (2008)	1, 2, 3, 5, 6, 8, 9, 10	4, 7		18/.9
Witcher <i>et al</i> (2000)	1, 2, 3, 4, 5, 6, 7, 8, 9		10	18/.9
Stevens <i>et al</i> (2011)	1, 2, 3, 4, 5, 6, 7, 8, 9,		10	18/.9
Manthorpe <i>et al</i> (2010a)	1, 2, 3, 4, 5, 6, 7, 8, 9	10		18/.9
NHS Confederation (2011b)	1, 2, 3, 5, 6, 7, 9, 10	4	8	17/.85
Tobin and Vick (2004)	1, 3, 4, 5, 6, 7, 9,10	2	8	17/.85
Maglajlic <i>et al</i> (2000)	1, 2, 3, 6, 7, 8, 9	4, 5,10		17/.85
Manthorpe <i>et al</i> (2009)	1, 2, 3, 4, 5, 6, 7, 9	10	8	17/.85
Manthorpe <i>et al</i> (2010)	1, 2, 3, 4, 5, 6, 8, 9	7	10	17/.85
Leece and Leece (2011)	1, 2, 3, 4, 5, 6, 9,10	7	8	17/.85
Homer and Gilder (2008)	1, 2, 3, 5, 6, 8, 9	4, 7, 10		17/.85
Newbiggin and Lowe (2005)	1, 2, 3, 4, 6, 8, 9	5, 10	7	16/.8
Jones and Netten (2010)	1, 2, 3, 4, 5, 6, 9	7	8, 10	15/.75
Davey <i>et al</i> (2007)	1, 2, 3, 4, 5, 6, 9	7	8, 10	15/.75
Spandler and Vick (2004) <i>mixed methods</i> Spandler and Vick (2005)	1, 2, 3, 4, 5, 6, 9	7	8, 10	15/.75
Henwood and Hudson (2007) Henwood and Hudson (2008)	1, 3, 4, 6, 9	2, 7, 5,	7,8, 10	13/.65
Hatton <i>et al</i> (2008)	1, 3, 5, 6, 7, 9	2	4, 8,10	13/.65
Tyson <i>et al</i> (2010)	1, 2, 3, 6, 9	4, 5, 7	8, 10	13/.65
Evans and Carmichael (2002)	1, 2, 3, 4, 6, 9	5	7, 8,	13/.65

			10	
Foster J. (2010)	1, 2, 3, 4, 5	6, 9, 10	7, 8	13/.65
Scottish Government (2010)	1, 2, 3, 5, 6, 9,	7	4, 8, 10	13/.65
Poll <i>et al</i> (2006) Sanderson <i>et al</i> (2006)	1, 2, 3, 6, 7,	4, 9	5, 8,10	12/.6
Commission for Social Care Inspection (2004)	1, 2, 3, 5, 9	4	6, 7, 8, 10	11/.5
MIND (2009)	1, 2, 3, 9	5, 6,	4, 7, 8, 10	10/.5
Audit Commission (2010) <i>mixed methods</i>	1, 2, 3, 6	4, 5, 7, 9	8, 10	10/.5

**Table 3: References ranked in quality order for qualitative research**

Reference	Yes: Q. Nos.	Partial: Q.Nos.	No: Q. Nos.	Not Applicable: Q. Nos.	Score
Glendinning <i>et al</i> (2007) <i>mixed methods</i> Glendinning <i>et al</i> (2008) Manthorpe <i>et al</i> (2008)	1, 2, 3, 4, 8, 9, 10, 11,12,13, 14			5,6,7	11/11 .1
Fernandez <i>et al</i> (2007) <i>Quantitative</i>	1, 2, 3, 4, 8, 9, 10, 11, 13,14			5, 6, 7, 12	10/10 .1
Spandler and Vick (2004) <i>mixed methods</i>	1, 2, 3, 4, 8, 9, 10, 11, 13, 14			5, 6, 7, 12	10/10 .1
Riddell <i>et al</i> (2005) Riddell <i>et al</i> (2006) <i>mixed methods</i>	1, 2, 3, 4, 9, 10, 13, 14			5, 6, 7, 8, 11, 12	16/16 .1
Jacobs <i>et al</i> (2011) <i>mixed methods</i>	1, 2, 3, 4, 9, 10,	13, 14	8	5, 6, 7, 11, 12	14/18 .77
Audit Commission (2010) <i>mixed methods</i>	1, 2, 3, 9,	4, 13, 14	10, 11,	5, 6, 7,8, 12	11/18 .61

**Table 4: References ranked in order for quantitative research**

Key:

Rejected Papers	MH Specific	Disability unspecific
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## Appendix 2

### CONSENT FORM FOR RESEARCH STUDY

**Title of Project: Implementing Self Directed Support in Mental Health Services**

Researcher Sherrie Hitchen

Please Tick to confirm

- I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. •
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my care or legal rights being affected. •
- I understand that the data collected during the study may be looked at by the lead researcher and co- researchers. •
- I agree to take part in the above research study. •

.....Date.....Signature.....

Name of service user

.....Date.....Signature.....

Name of person taking consent

(If different from researcher)

.....Date.....Signature.....

Researcher

## Appendix 3

### Project Chronology

Activity and Purpose	Date
<b>1.</b> Co-researcher Interview	20/21/26.2.2007
<i>Appointment of Co-researchers</i>	7.3.2007
<b>2.</b> First steering group setting out AR project and terms of reference	19.4.2007
<b>3.</b> Direct Payment workshop with CRD for people using services, Recovery Coordinators and providers	9.5.2007
<i>Self-Directed Support Project Group- Local Authority meeting</i>	16.5.2007
<b>4.</b> Second steering group considering different versions of the Resource Allocation System tool	23.5.2007
<b>5.</b> Direct Payment workshop to Recovery Coordinators with CRD	7.6.2007
<i>Self-Directed Support Local Authority meeting</i>	11.6.2007
<i>Training workshop for co-researchers on qualitative research with Folkus</i>	13.6.2007
<b>6.</b> Third steering group adapting and planning the piloting of the tool	26.6.2007
<i>Self-Directed Support Local Authority Steering group: Progress report provided from lead researcher</i>	9.7.2007
<b>7.</b> Fourth steering group planning financial data collection, promotion and learning in preparation for the implementation of the Resource Allocation System tool	30.8.2007
CRGe drops out of the project	August 2007
<i>Self-Directed Support Local Authority steering group: Progress report provided from lead researcher</i>	10.9.2007
<i>Meeting with mental health day opportunities providers</i>	17.10.2007
<b>8.</b> Fifth steering group continuing planning towards implementation of Resource Allocation System tool	18.10.2007
<i>Meeting with Local Authority managers and consultant regarding Personal Budget Allocation tool</i>	7.11.2007
<i>Presentation, on the work of the project so far, to the Professional Expert Group for Recovery and Independent Living in the Trust</i>	20.11.2007
<b>9.</b> Training with mental health teams in eight areas	19.10.2007 to 5.11.2007
<b>10.</b> Sixth steering group meeting: planning and evaluation of proposals to work more collaboratively with Local Authority	3.12.2007
<b>11.</b> Training Recovery Coordinators in two areas	4.12.2007, 8.1.2008 & 16.1.2008
<i>Meetings to produce Personal Budget Allocation tool with Local Authority managers and Local Authority Consultant</i>	11/16/21/23/30.1.08 & 6.2.2008
<b>12.</b> Meetings with co-researchers	22.1.2008 & 28.2.2008
<b>13.</b> Workshops with Residential Care and community based support providers	24.1.2008, 28.1.2008 &

	13.2..2008
<i>Personal Budget Allocation Meeting with Local Authority managers</i>	6.3.2008 & 26.3.2008
<b>14.</b> Seventh steering group looking at the Personal Budget Allocation tool, its implementation and planning for focus groups	22.4.2008
<i>Personal Budget Allocation Meetings with Local Authority managers and Personal Budget Allocation Workshop with Recovery Coordinators</i>	30.4..2008 & 15.5.2008
<b>15.</b> Meeting with co-researchers	24.6.2008 & 30.7.2008
<b>16.</b> First focus group with service users with CRD	5.8.2008
<i>Personal Budget Allocation Meetings with Local Authority Consultant</i>	30.9.2008 & 27.10.2008
<i>Meeting with a local provider wanting to promote Direct Payments and provide a Dired Payment information and support service</i>	4.11.2008
<i>Meeting with Community Team Leaders regarding Personal Budget Allocation implementation</i>	25.11.2008
<b>17.</b> Meeting with co-researchers and Local Authority Consultant working on Personal Budget Allocation tool	10.12.2008
<b>18.</b> Eighth steering group evaluating focus group results with people using mental health services	16.12.2008
<b>19.</b> Second focus group, with carers with CRM	17.12.2008
<i>Workshop with people using mental health day opportunities</i>	28.1.2009
<i>Workshop with Recovery Coordinators</i>	29.1.2009
<i>Personalisation task group meeting with Local Authority</i>	30.1.2009
<b>20.</b> Ninth steering group planning for Personal Budget Allocation pilot and sharing of preliminary findings of focus group with carers	10.2.2009
<i>Personal Budget Allocation meeting with Local Authority managers</i>	18.2.2009
<i>Personalisation task group meeting with Local Authority</i>	26.2.2009
<i>Presentation to the Local Implementation Team (local commissioning body for adult mental health)</i>	4.3.2009
<b>21.</b> Presentation to countywide Trust conference with CRD and carer in receipt of Direct Payments	1.4.2009
<i>Personal Budgets Project Board Meeting in Local Authority</i>	7.4.2009
<b>22.</b> Tenth steering group evaluating results of the Personal Budget Allocation pilot and planning of remaining focus groups	21.4.2009
<i>Personal Budgets project board in Local Authority</i>	12.5.2009
<i>Meeting with Local Authority consultant</i>	18.5.2009
<i>Personal Budgets project board in Local Authority</i>	2.6.2009
<i>Lead researcher talk to Trust social workers forum about Self-Directed Support and local implementation</i>	8.6.2009
<i>Meeting with CRD to plan for presentation at regional conference</i>	13.7.2009
<i>Presentation at regional conference with CRD</i>	23.7.2009
<i>Personal Budgets Project board in Local Authority</i>	4.8.2009
<b>23.</b> Third focus group with people service users with CRS	5.8.2009
<b>24.</b> Fourth focus group with carers with CRM	26.8.2009

<b>25.</b> Eleventh steering group planning for new tool as work on Personal Budget Allocation is discontinued	27.10.2009
<i>Workshop with commissioned external providers of new tool to provide assessment for personal budgets</i>	6.11.2009
<i>Choice and control theme board in Local Authority</i>	24.11.2009 & 26.1.2010
<i>Interview of social worker to undertake desk top pilot of new tool</i>	27.1.2010
<b>26.</b> Twelfth steering group planning for work in relation to the new tool and further training and focus groups	22.2.2010
<i>Choice and control theme boards in Local Authority and Putting People Forward Event</i>	23.2.2010, 5.3.2010, 23.2.2010
<b>27.</b> Letter from CRM	28.2.2010
<i>Feedback session with social worker</i>	7.4.2010
<i>Choice and control theme board in Local Authority</i>	27.4.2010
<i>Meeting with regional personalisation lead and mental health Commissioner to provide progress report</i>	13.5.2010
<i>Steering group Meeting cancelled</i>	2.7.2010
<i>Trust and Local Authority management meeting</i>	25.7.2010
<i>Meeting with external provider of new tool for Personal Budget assessment</i>	17.8.2010
<i>Training event for Community Team Leaders</i>	15.9.2010
<i>Meeting with Trust managers to explore impact of Personal Budgets on Trust funding decision panels</i>	12.10.2010
<i>Training planning meeting</i>	20.10.2010
<i>Choice and control board in Local Authority</i>	26.10.2010
<b>28.</b> Fifth focus group with RCs with CRS	29.10.2010
<i>Meeting with Local Authority consultant</i>	10.12.2010
<i>Choice and control board in Local Authority</i>	14.12.2010
<b>29.</b> Training with Recovery Coordinators on Direct Payments and Personal Budgets	4/12/18/24/25/26. 1.2011 & 9.2.2011
<i>Training to Recovery Coordinators on Direct Payments and Personal Budgets</i>	12.1.11 & 1/3 & 8.2.2011
<i>Choice and control board in Local Authority</i>	22.2.2011
<b>30.</b> Training Evaluation meeting	9.3.11
<i>Choice and control board in Local Authority</i>	22.3.2011, 26.4.2011 & 24.5.2011
<b>31.</b> Sixth focus group with Recovery Coordinators	9.5.2011

## **Appendix 4**

### **Suggested Ground Rules for the Self-Directed Support steering group meetings**

1. To respectfully listen to another person's point of view, allowing them to finish what they want to say and without talking over them.
2. To express your point of view in as few words as possible but allowing others to understand your contribution to the discussion.
3. To speak in plain English without the use of jargon, abbreviations and terms that cannot be easily understood by others in the group.
4. To respect the chairpersons need to apply timekeeping to the meeting in order that the agenda can be covered in the time available.
5. To anonymise any descriptions illustrating points made by not referring to the people involved by name or in ways that would mean they are identifiable if permission has not been given for their stories to be shared.
6. To explain any points of disagreement to help others understand your different point of view.
7. To make the chairperson aware that you wish to make a point should you not be able to contribute to the meeting when you would like to speak.
8. To ask for clarification from any other participant at the meeting if points are made that you do not understand
9. To not repeat outside of the meeting any confidential or person identifiable information.
10. To contribute to clarifying the purpose of the group
11. To support the group in achieving the work for which it was convened
12. To share personal experience or stories unless it is stated beforehand that you wish these to remain confidential.

2<sup>nd</sup> version following discussion 13<sup>th</sup> June 2007

## Appendix 5

### Self-Directed Support (Mental Health) Steering Group Terms of Reference

#### Purpose

- To develop a model for Self-Directed Support and implement this across X's mental health services
- To incorporate an Action Research project with project leader as lead researcher researching the process and outcomes of the project.
- To incorporate service user and carer perspectives on involvement and the proposed Self-Directed Support implementation.
- To identify and enable discussion, prioritisation and resolution of issues in relation to the roll out of Self-Directed Support.
- To confirm issues for reporting at other meetings
- To facilitate the increase of choice and control for service users

#### Reporting Arrangements

- To the Trust Programme Board on a quarterly basis
- To the Local Implementation Team on a six monthly basis
- To Local Authority Self-Directed Support Group when this meets (6-8 weekly)

#### Input to the Group

Agenda items will be taken primarily from:

- The chairperson and any steering group member
- 

This may also include items resulting from:

- The Trust Programme Board
- The LA Senior Management Group

#### Membership

- Social Care Modernisation Manager (Chair)
- Service user co-researchers (3)
- Carer co-researchers (2)
- Local Authority Contracts Officer.
- Direct Payment Team manager, LA.
- Interim General Managers, Trust (3)
- Service Development Manager, Trust
- Provider Representative (Rethink)
- Finance representative (Local Authority and Trust)

#### Quorum

- At least five people with at least one from the Local Authority and two from the Trust.

#### Frequency of Meetings

- Monthly second version 27.4.07
-



## Appendix 6

Direct Payment Workshops Presentation: 9.5.07 and 7.6.07

### ■ Direct Payments Implementation

#### Mental Health Services

### ■ What is a Direct Payment?

- Provision of money instead of services
- Different method of getting support you need- you can buy this instead of having it arranged for you.
- Can be used in variety of ways to provide social care support
- Anyone who is assessed as eligible for help from social care can be considered for a direct payment.

## Why choose a Direct Payment?

- Direct payments (DP's) offer greater choice, control and flexibility when arranging the support that is needed.
- It provides the means to design your own care plan around your own unique needs and lifestyle
- Direct payments can be used to employ a personal assistant, purchase existing services or a mix of both
- Research shows that DP's enable service users to gain greater self esteem, control and confidence over their lives.

## When can't DP's be used?

- DP's can only be used to purchase social care needs and therefore health needs cannot be met through DP's
- DP's cannot be used to fund long term residential care however short periods can be funded in this way
- DP's cannot normally be used to pay for a relative that lives with you and provides care and support except in exceptional circumstances
- DP's cannot be used to purchase any in-house provided social care services

## Who can help me get a DP?

- DP's should be offered to all people requiring social care resources at their CPA review
- Talk to your care coordinator who will see if you meet the Fair Access to Care eligibility criteria
- An application will then be made for consideration based on your needs assessment and care plan
- Specialist support can be arranged following this from Devon's independent living team who are experts in DP's
- Your care coordinator and independent living advisor will help you with making the arrangements you want to meet your assessed needs

## Blocks and Obstacles

- Getting the message out to care coordinators about DP's and their benefits
- Simplifying the system of application for a DP and reducing the length of the process
- Some service users with care plans suitable for DP's have not been able to take them up due to their mental ill health and capacity issues
- Excluding health from DP's does not fit with the holistic approach in mental health
- Where do some services such as complementary therapies sit in relation to DP's?
- The provision of independent advice and support is not yet available and needs to be developed

## How is Devon increasing DP take-up in Mental Health?

- Steering group established November 2005
- DP process agreed within the Trust and County Council for mental health applications
- DP champions trained within most CMHT's acting a local focal point for care coordinators
- DP interactive workshops starting October 06 across all localities for service users, carers, care coordinators and managers
- DP's in mental health leaflet has been written by a group of service users
- Numbers of DPs have increased significantly in the past year

## Future Views

- The introduction of Self directed support (SDS) is currently being proposed in Devon's mental health services.
- SDS will include service user self assessment and a range of other means, including DPs, of empowering service users needing social care resources.
- Service users will be encouraged to participate in shaping these developments by involvement from the outset of the project
- Need to ensure join up of DPs/SDS implementation with other mental health priorities ensuring service users and carers receive maximum opportunity for recovery, support and improving quality of life

## Appendix 7

Slides of Project Presentation 20.8.2007

### **What are the Outcomes of Implementing Self Directed Support from a service user and Organisational Perspective?**

**An Action Research study into the Change Process in Devon's Mental Health Services.**

**Sherrie Hitchen**

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### **Introduction: How to offer more choice and control to service users**

- What is Self Directed Support (SDS)?
- Why is research needed about introducing SDS?
- What has research told us so far?
- Why do current commissioning arrangements need to change?
- My role as combined project manager and researcher

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## Research Methodology

- Participatory Action Research
- Co-researching with service users and carers
- Collaborative steering group central to the research project
- Qualitative methods of focus groups and interviews incorporated into the research design

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## Research Plan

- Advertised for and recruit co-researchers
- Set up steering group
- Agree resource allocation system
- Pilot self assessment questionnaire
- Develop preferred support brokerage system
- Pilot use of SDS
- Conduct focus groups and interviews
- Introduce SDS across Devon Mental Health Services
- Write up study and disseminate learning

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## Progress so far.....

- Ethical approval obtained
- Co-researcher posts offered to 3 service users and 2 carers
- Steering group set up with TOR
- Working on the production of a paper investigating the concept of collaboration with service users and carers as co-researchers

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## Learning so far.....

- Use of language- “It’s like learning a new language”
- Involving service users and carers will require more time
- Academic research is not valued by some service users- “ a dry mushroom cloud that hangs over the poor little lives of the service user. More understanding and respect are what is required.” but is by others- “ I have done a lot of research on my own condition and across all of mental health. This means that I am not a victim and keeps me well, keeps me alive.”
- More empowerment is needed for service users- “To me those who improve and move forward in their lives are the ones that don’t follow the medical model ” “If people feel they have some control and can make decisions then that has got to be good for everybody.”

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# **X County Council & X Partnership Trust**

## **Adult Social Care**

### **Individual Budget Self Assessment Questionnaire**

**This is a questionnaire for people, who under Fair Access to Care Services (FACS) are considered eligible for social care support, to complete with their families and carers. If you are worried or would like help, please ask your Adult Social Care worker or Care Coordinator.**

**Currently X County Council has set the threshold for eligibility for services at Substantial or above. Please ask your Adult Social Care worker or Care Coordinator to explain.**



## Introduction

This questionnaire is produced by X County Council & X Partnership Trust **for you**. It will help us create your Indicative Individual Budget which will allow you to get the support you need.

It will also help us to make fair and open decisions about who gets support or money to meet their needs.

The form is designed to find out about problems you have which affect your day-to-day life. You can complete this yourself or with help from people you trust – your family, friends, carer, Adult Social Care worker, Care Coordinator or people who know you well.

We will then let you know whether you are eligible for support and an initial estimate of how much funding you will receive.

You are expected to use all relevant sources of funding available to you, for example Independent Living Fund, Disabled Facilities Grant etc. If you are eligible for help from other funding sources we will give you the information about these after you have completed this form.

Please tick the statement that best fits your situation.

You will notice that a column has been included for your worker to record their views on your needs. If you feel there is a difference in opinion, please discuss this and come to an agreement.

At the end of each section there is a space for any comments you may wish to make. Please include brief statement as to how final agreement was reached (if applicable). At the end of the questionnaire there is a further sheet for supporting information if needed.

## NOTES ON COMPLETING THE QUESTIONNAIRE

Your Adult Social Care Worker or Care Coordinator will explain how you should complete this questionnaire.

Please tell them if there is anything about this questionnaire, or completing it, that you do not understand

When completing the questionnaire you need to take into account the amount of unpaid and/or informal support you currently receive.

For each question please complete only the column heading "**My View**"

There are five Sections for you to complete.

Section 1 – About you

Section 2 – Your needs

Section 3– Anything else you want to tell us

Each section contains a number of questions.

For each question choose the row which best describes you, over the past twelve months to date; only one of either (a), (b), (c) (d), or (e) etc.

Do not worry if not all of the statements in the box apply to you; you will be able to provide more detail when you write your Outcome Statement.

## Section 1 – About you

### Contact Information

<b>Name</b>	
<b>Address</b>	
<b>Postcode</b>	
<b>Telephone Number</b>	
<b>Mobile Number</b>	
<b>Email Address</b>	
<b>Date of Birth</b>	
<b>Ethnicity</b>	
<b>Religion</b>	

<b>CAREFIRST NUMBER</b>	<b>NHS NUMBER</b>

<b>I currently receive support from (please specify).....</b> ..... ..... ..... ..... ..... ..... ..... ..... .....
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## CURRENT BENEFITS

I currently receive the following benefits –

Disability Living Allowance (amount)	High Rate Care .....
	Mid Rate Care .....
	(amount)
	Low Rate Care .....
	(amount)
Attendance Allowance (amount)	High Rate .....
(amount)	Low Rate .....
Mobility Allowance (amount)	High Rate .....
(amount)	Low Rate .....
Income Support	..... (amount)
Housing Benefit	..... (amount)
Pension Credit	..... (amount)
Severe Disablement Premium	..... (amount)
Does anyone receive Carers Allowance on your behalf?	Yes ..... No .....
	..... (amount)
ILF (Independent Living Fund) (hours)	..... (amount) .....

I consent to this information being shared with other departments as part of assessing my Personalised Budget Allocation

Signature.....  
.....

## Section 2 – Your Needs

### 1. MY PERSONAL NEEDS DURING THE DAY

This part is about looking after yourself – things like washing, dressing and going to the toilet.

	My view	Worker's view	Final agreement
a) I manage all my personal care on my own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I need help with personal care, approximately 2-3 times a week.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need help with personal care, approximately 3-5 times a week.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need a daily support with personal care (washing/dressing/going to the toilet. I can manage these tasks with the assistance of one person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I need daily support with personal care (getting in/out of bed, washing, dressing or going to the toilet). I sometimes need two people to help me with these tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I need daily support with personal care (getting in/out of bed, washing, dressing, going to the toilet). I always need two people to help me with these tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting Information:

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## 2. MY PERSONAL NEEDS DURING THE NIGHT

This part is about help you may need during the night for example, getting in and out of bed to use the toilet.

	My view	Worker's view	Final agreement
a) I do not need any support during the night. If something happened during the night I would know who to call to get help. (e.g. my doctor)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I am usually fine during the night. I may need support during the night on 2-3 nights per month when I am ill or in an emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need support during the night, 3-5 times a month. This is because: <ul style="list-style-type: none"> <li>• My behaviour during the night may place myself or other people at risk; or</li> <li>• I have a medical condition that means I need support during the night on a regular basis; or</li> <li>• I need support with personal care during the night. (e.g. going to the toilet)</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need support during the night – several nights a week. This is because: <ul style="list-style-type: none"> <li>• My behaviour during the night may place myself or others people at risk; or</li> <li>• I have a medical condition that means I need support during the night on a regular basis; or</li> <li>• I need support with personal care during the night. (e.g. going to the toilet)</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I always need support during the night. This is because: <ul style="list-style-type: none"> <li>• My behaviour during the night may place myself or others people at risk; or</li> <li>• I have a medical condition that means I need support during the night on a regular basis; or</li> <li>• I need support with personal care during the night. (e.g. going to the toilet)</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting Information:

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### 3. MY NUTRITIONAL NEEDS

This part is about looking after yourself staying fit and well nourished – eating and drinking properly

	My view	Worker's view	Final agreement
a) I do not need any assistance in this area	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I can manage to prepare snacks and drinks but require help with a hot meal each day, e.g. Frozen meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need all my meals/drinks to be provided or prepared for me every day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need all my meals/drinks to be provided or prepared for me every day. I need help, encouragement and prompting to eat and drink enough to stay well on a daily basis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I need all my meals/drinks to be provided or prepared for me every day. I need support to eat and support to drink on a daily basis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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#### 4a. PRACTICAL ASPECTS OF MY DAILY LIFE (Home)

This is about day-to-day life and coping in your home for example; shopping, cleaning, cooking, housework, doing your laundry and general home maintenance.

	My view	Worker's view	Final agreement
a) I manage all practical tasks around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I occasionally (when I am unwell) need help with some of the things around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need help about half the time (when I am unwell) with some things around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need regular help with many things around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I need regular help with most if not all things around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting Information:

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## 4b. PRACTICAL ASPECTS OF MY DAILY LIFE (Money)

This is about day-to-day life and coping in your home for example; managing your finances, paying your bills and correspondence.

	My view	Worker's view	Final agreement
a) I manage all practical tasks around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I occasionally (when I am unwell) need help with some of the things around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need help about half the time (when I am unwell) with some things around my home.			
d) I need regular help with many things around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I need regular help with most if not all things around my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting Information:

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## 5. MY RELATIONSHIPS AND MY COMMUNITY

This part is about doing things in your community - using local shops, the library, going to a luncheon club, community centre, church or other place of worship, visiting neighbours, or being involved in local organisations/activities, or having people visit you in your home. Relationships – friends/family/partner.

Your community might be the people and places that are in your local area or people and places that are important to you because of your religion or ethnic origin.

	My view	Worker's view	Final agreement
a) I have no involvement in my community and am happy with this.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I do lots of things in my community. I don't really need support – just now and then. I've got a lot of relationships. I don't need support to keep them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I do lots of things in my community and need support to do these. There is a danger that without support I will lose important relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Sometimes (but not often) I do things in my community. I need support to do more. I am quite lonely and have one or two relationships, but this is not enough for me. I need some support to make relationships – and keep them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I don't / am unable to do much in my community. I am very lonely and don't really have any relationships. I would benefit from having more social contacts and need a high level of support to make relationships – and keep them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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## 6. MY CHOICES AND MY DECISIONS

This part is about who decides important things in your life – things like where you live, who supports you, who decides how your money is spent. You may have less control over your life having become forgetful or confused, or you may be depressed.

	My view	Worker's view	Final agreement
a) I do not need help to make choices or decisions, I make all the decisions. I sometimes just need a bit of advice.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) With some support and advice I am able to make all the decisions related to my life. I would benefit from support to help build my confidence and self-esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I am able to make most day-to-day decisions, but need more support to make important decisions about my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Other people make most of the decisions about my life. I need support to make more decisions, and take more control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Other people make all the decisions in my life. I need a lot of support to make decisions, and take more control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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## 7. STAYING SAFE FROM HARM

This part is about keeping safe, for example when going out on a bus, using a gas cooker, moving from one room to another, or going downstairs - but staying safe is about different things for different people.

In some situations risks can be managed by using technology. If you need support to manage risks you should, find out about what is available e.g. community alarm, equipment, assistive technology

	My view	Worker's view	Final agreement
a) I don't need any support to stay safe. I'm happy and no-one says they are worried.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I can keep myself safe at home but I would need someone to check on me 2-3 times a week and would need support quickly if something went wrong.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I sometimes need help to stay safe and I need someone to check on me 3-5 times a week. People worry a bit about my safety.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need help daily to stay safe. There have been some instances where my safety has been at risk in the home or when I go out and people have been worried about me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I need someone with me on a daily to make sure I keep safe. There have been a lot of instances where my safety has been at risk in the home or when I go out, and people have been very worried about me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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## 8. MY COMPLEX NEEDS AND RISKS (if applicable)

	My view	Worker's view	Final agreement
a) I have never done things that could hurt me or others. There are no concerns about my behaviour being a risk to the physical safety of myself or other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Some things I do are a problem for other people, but there is no physical risk to either myself or others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I do things once or twice a week that people find difficult, and there is some risk of minor physical harm to either myself or other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I do things once or twice a month which may cause serious harm to either me or other people. There is some risk of serious physical harm to myself or others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I do things daily that are dangerous and could cause serious harm to either myself or other people. There is a very real risk of serious physical harm to myself or others – I need somebody with me at all times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I do things daily that are dangerous and could cause serious harm to either myself or other people. There is a very real risk of serious physical harm to myself or others – I need two people with me at all times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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## 9. WORK, LEISURE AND LEARNING (if applicable)

This part is about having a job, learning new things and enjoying life

	My view	Worker's view	Final agreement
a) I am happy with the opportunities that I have for learning, working, doing new things and enjoying life. I do not need any support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I am happy with the opportunities that I have for learning, working, doing new things and enjoying life. I would like support to keep these going.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I am not happy with the few opportunities that I have for learning, working, doing new things and enjoying life. I would like support to do these more.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I am not happy with the very few opportunities that I have for learning, working, doing new things and enjoying life. I would like support to do these more.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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## 10. MY MOBILITY AND GETTING ABOUT

This is about getting around and whether your condition affects your capacity to move around the home, make journeys and get yourself out and about?

	My view	Worker's view	Final agreement
a) I don't need help to make journeys inside and/or outside of the home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I am capable of making most of my journeys without help inside and outside of the home. I would sometimes like assistance with long, difficult or unfamiliar journeys.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need some help to make journeys inside and/or outside the home. There are some journeys I can manage, mostly inside.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need some help to make journeys inside and/or outside of the home, several times a day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I need help daily with all journeys inside and outside of the home (such as going to the bathroom or following a familiar route to the shops). There are no journey's I am able to undertake unassisted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I need help daily with all journeys inside and outside of the home (such as going to the bathroom or following a familiar route to the shops). There are no journey's I am able to undertake unassisted and I require 2 people assisting me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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### 11. MY CARING/ MY PARENTING (if applicable)

Caring could be for a child or dependent. This is someone you help to care for on a regular basis.

	My view	Worker's view	Final agreement
a) I do not need assistance in caring for my children/dependents.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I need occasional (once or twice a day) practical assistance with caring for my children/dependents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need some (at least 3 times a day) practical assistance with caring for my children/dependents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need considerable assistance (at least 5 times a day) with practical tasks of caring for my children/dependents – including their personal care, preparing meals and ensuring their safety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I need assistance all the time with practical tasks of caring for my children/dependents – including their personal care, preparing meals and ensuring their safety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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**12. MY UNPAID CARER (if applicable)**

Name of Carer completing this section .....

Relationship to the Cared for Person .....

Do you receive a Carers Allowance? YES / NO

How much do you receive? ..... per week / per month

To be completed by your main **unpaid carer** to show how their caring role affects them on a day-to-day basis – (unpaid includes people who may receive carers allowance)

	My view	Worker's view	Final agreement
a) I am able and willing to continue in my current caring role. My caring responsibilities have no negative impact on my daily life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I have some difficulty and stress in carrying out my day-to-day caring tasks. This has some impact on my lifestyle and leads to minor stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I provide a substantial amount of personal care/support each week. Although this has a big impact on how I organise my life, I am willing to continue in this role. I need regular breaks throughout the year to enable me to continue caring at the present level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) My caring role has a substantial impact on my lifestyle. Playing this role has led to high levels of stress and some health problems. I need regular breaks throughout the year to enable me to continue caring at the present level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Ensure a Carers Assessment is offered if any of the above is ticked**

Supporting information:

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## **Section 3: Supporting People**

	YES	NO
a) Do you have less than £21,500 in Savings?		
b) Are you in receipt of Housing Benefit?		

If you have answered **yes to both** of the above questions please continue answering the questions in Section 4 as you may be eligible for Housing Support through Supporting People.

If you have answered **no to either one or both** of the above questions please go straight to Section 5 (if appropriate).

### **YOUR ACCOMODATION**

What type of accommodation do you live in? (eg – sheltered housing, supported living, residential home, nursing home, tenant, own home with/without mortgage)

(answer)

.....

Who is responsible for managing your accommodation? (eg – self, landlord, other)

(answer)

.....

(Name and address of landlord/other)

### 15a. SUPPORTING PEOPLE – FINANCES

	My view	Worker's view	Final agreement
a) I do not need any support to maximise my income (including welfare benefits) or to reduce my overall debt / manage my finances.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I need occasional support to maximise my income (including welfare benefits) or to reduce my overall debt / manage my finances.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need regular support to maximise my income (including welfare benefits) or to reduce my overall debt / manage my finances.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need ongoing support to reduce my overall debt / manage my finances.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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**15b. SUPPORTING PEOPLE – LEARNING/LEISURE/WORK**

	My view	Worker's view	Final agreement
a) I do not need any support to access any desired training / educational needs or to participate in my chosen leisure / cultural / faith / informal learning activities or to access work like activities (paid / unpaid / work experience) or to support to contact external services, groups, friends and family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I need occasional support to access any desired training / educational needs or to participate in my chosen leisure / cultural / faith / informal learning activities or to access work like activities (paid / unpaid / work experience) or to support to contact external services, groups, friends and family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need regular support to access any desired training / educational needs or to participate in my chosen leisure / cultural / faith / informal learning activities or to access work like activities (paid / unpaid / work experience) or to support to contact external services, groups, friends and family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need ongoing support to access any desired training / educational needs or to participate in my chosen leisure / cultural / faith / informal learning activities or to access work like activities (paid / unpaid / work experience) or to support to contact external services, groups, friends and family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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### 15c. SUPPORTING PEOPLE – YOUR HEALTH / YOUR CARE

	My view	Worker's view	Final agreement
a) I do not need support to access assistive technologies and adaptations or any support to manage my physical health, mental health and/or my substance abuse better and this does not prevent me from managing my own accommodation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I need occasional support to access assistive technologies and adaptations, and/or to manage my physical health, mental health and/or my substance abuse better in order for me to manage my own accommodation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need regular support to access assistive technologies and adaptations, and/or to manage my physical health, mental health and/or my substance abuse better in order for me to manage my own accommodation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need ongoing support to access assistive technologies and adaptations, and/or to manage my physical health, mental health and/or my substance abuse better in order for me to manage my own accommodation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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### 15d. SUPPORTING PEOPLE – OTHER SUPPORT

	My view	Worker's view	Final agreement
a) I do not need any support to maintain my accommodation and/or to avoid eviction and/or to improve my compliance with statutory orders and related processes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I need occasional support to maintain my accommodation and/or to avoid eviction and/or to improve my compliance with statutory orders and related processes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need regular support to maintain my accommodation and/or to avoid eviction and/or to improve my compliance with statutory orders and related processes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need ongoing support to maintain my accommodation and/or to avoid eviction and/or to improve my compliance with statutory orders and related processes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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### 15e. SUPPORTING PEOPLE – RISKS

	My view	Worker's view	Final agreement
a) I do not need any support to manage any self harming / or harm to others / or being harmed by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I need occasional support to manage any self harming / or harm to others / or being harmed by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need regular support to manage any self harming / or harm to others / or being harmed by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need ongoing support to manage any self harming / or harm to others / or being harmed by others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information: \_\_\_\_\_

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**15f. SUPPORTING PEOPLE – CHOICE AND CONTROL**

	My view	Worker's view	Final agreement
a) I do not need any support to develop more confidence and ability to have greater choice and/or control and/or involvement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I need occasional support to develop more confidence and ability to have greater choice and/or control and/or involvement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I need regular support to develop more confidence and ability to have greater choice and/or control and/or involvement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I need ongoing support to develop more confidence and ability to have greater choice and/or control and/or involvement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Supporting information:

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**Section 5 – Further Information**

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**Assessment Officer Name .....**

**Signature.....**

**Managers Name: .....**

**Signature.....**



**Appendix 9**

Letter to Focus Group participants

**Trust Headquarters**  
Address

To Focus Group Participant  
Name & Address

Telephone: XXXXXXXXXX

Dear .....,

**What are the outcomes of implementing self-directed support from a service user and organisational perspective? – An action research study into the change process in X’s Mental Health Services.**

I am writing to invite you to participate in a focus group for the above named research project that I am undertaking with the Peninsula Postgraduate Health Institute for the award of PhD. It is researching the introduction of self-directed support in mental health services in X. Self-directed support (SDS) means that people who are eligible for support will be told how much money they can use for Local Authority contracted community support and provide people with an individual budget. Currently Devon Partnership Trust (using X County Council or X Care Trust assigned monies) controls the whole process of funding, designing and commissioning support and care. With the aim of giving service users and carers more control and choice, the way in which resources are allocated is being improved and a self-assessment system developed. An information sheet and newsletter about SDS is enclosed for your information.

The group will be held on the 5<sup>th</sup> August at 10.30 am at  
XXXXXXXXXXXXXXXXXXXX

The focus group will involve a small (6-8 people) number of people in a discussion, for approximately one hour, led by myself and one other co-researcher who is a current mental health service user. The group is designed to obtain your views and opinions about what sort of social care services you would like to see developed in the future. As a current recipient of contracted services your views are valuable in considering how to develop self directed support across X and X for mental health service users. If you agree to participate then a guide to the subject areas to be covered will be sent to you in order that you have a chance to consider these in advance of the meeting. Further information can also be given to you before the focus group where questions can be asked about self directed support. Additionally your consent to being involved and participant information forms will be given to you and fully explained.

The cost of any travel expenses incurred by yourself in order to attend the focus group will be reimbursed and an allowance of £5.52 per hour paid for the time that you participate. Receipts for travel costs will be required in order to claim by completing a form. I will bring forms along to the meeting in order that you can be paid on the day of the group.

Thank you for taking the time to consider this. If you are interested in participating please can you contact A at X

I look forward to meeting you on the 5<sup>th</sup> August at 10.30 am at X

Yours Faithfully,

Sherrie Hitchen  
PhD Student  
University of Plymouth.

## Participant Information Sheet

What are the outcomes of implementing self-directed support from a service user and organisational perspective? – an action research study into the change process in X's Mental Health Services.

### **Introduction**

My name is Sherrie Hitchen and I am undertaking a PhD with the working title of "Implementing Self-Directed Support within Mental Health Services" with the University of Plymouth. The study is about a whole system change that enables each person to be told how much money they can use for Local Authority contracted community support. This means providing people with an individual budget. Under the current process X Partnership Trust (using X's assigned monies) controls the whole process of funding, designing and commissioning the support and care. The study aims to focus on self-directed support from a service user perspective looking at whether satisfaction levels and quality of life is improved as a result of the implementation. It is anticipated that the study will be written up within three years of your participation in the research project and a shortened version of the study will be published in an appropriate journal.

### **What I would like you to do**

You have been selected to be invited to participate in this study, as you have first hand experience of receiving contracted community services

- If you agree to take part in the focus group I would like you to attend a small group of 6-8 people led by myself and a co-researcher to discuss issues in relation to the project. A letter will be sent to you beforehand giving an outline of the topics likely to be discussed. The group is likely to last around one to one and a half hours and be held at a local venue.
- All focus groups will be tape recorded and transcribed.

## **Your Rights**

As a focus group member you have very definite rights.

Firstly, your participation is entirely voluntary and you are under no obligation to take part. You are free to withdraw or refuse to participate at any point with no need for explanation. You can refuse to answer questions at any point.

Secondly, all information will be treated as confidential. This means that it will not be divulged to a third party and will be available only to the researcher, her co-researchers and her tutors. All tapes, transcripts or other notes will be securely stored and will only be accessed by the researcher, her tutors and external examiners. Material gathered may be used in the completed study however no names or any other identifying characteristics will be included in the final report. All tapes and transcripts will be destroyed at the completion of the study.

As this is a study especially valuing the opportunity for individual participation the information gathered in the focus groups will be shared with you to check for accuracy in representing your views. Again this is not a compulsory requirement but an attempt by the researcher to reflect your views as closely as possible and therefore should you not wish to comment on information gathered, then this is your right.

Any out of pocket expenses such as travel costs will be reimbursed to you and you will be paid the current minimum national hourly rate for the time that you participate in the project.

If you would like a copy of the summary of the research report please inform the lead researcher who will ensure that a copy is sent to you.

Thank you for agreeing to participate and enable learning from the implementation of self-directed support to inform any future developments in this area.

Sherrie Hitchen

Lead Researcher

Student with Peninsula Postgraduate Health Institute

## Appendix 10

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### ***Lone voices have an emotional content: focussing on mental health service user and carer involvement***

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#### **The Authors**

Sherrie Hitchen, Department of Planning and Contracts, Devon Partnership Trust, Exeter, UK

Mary Watkins, University of Plymouth, Plymouth, UK

Graham R. Williamson, Faculty of Health, University of Plymouth, Plymouth, UK

Susan Ambury, Devon Partnership Trust, UK

Gillian Bemrose, Devon Partnership Trust, UK

David Cook, Devon Partnership Trust, UK

Maureen Taylor, Devon Partnership Trust, UK

#### **Abstract**

**Purpose** – The purpose of this paper is to describe learning gained from involving service users and carers as researchers in an action research study. The researchers aimed to introduce self-directed support in mental health services – part of the government's personalisation agenda, which requires a move from current social care commissioning, where a person is matched to available services, to one where a person self-assesses, has an agreed support plan and then with appropriate help, purchases his or her own services to lead as independent a life as possible. This development is allied closely with the mental health service recovery approach.

**Design/methodology/approach** – Three service users and two carers were recruited to work alongside the lead researcher. Service users were fully involved in the steering group – part of participatory action research project. Data were collected from: debriefing meetings with co-researchers between April and December 2007; a group interview held by the lead researcher; and participants' journal comments and self-reflections.

**Findings** – The main areas in which service users and carers found involvement difficult were: overcoming professional language barriers; emotional impact; and power imbalances between themselves and professionals. Findings suggest that considerable improvement is required by mental health professionals and managers if service users and carers are successfully involved in projects.

**Research limitations/implications** – This is a small study within a larger action research project. Findings are not generalisable owing to the small sample; however, findings are supported by the service-user involvement literature.

**Originality/value** – Few studies explore participation effects on service users and carers from their perspective. This research provides insights into what needs to be addressed to improve service user and carer involvement to improve mental health services.

**Article Type: Research paper**

Keyword(s): Mental health services; Employee involvement; Learning organizations; Change management; Empowerment; United Kingdom.

**Journal: International Journal of Health Care Quality Assurance**

**Volume: 24**

**Number: 2**

**Year: 2011**

**pp: 164-177**

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**ISSN: 0952-6862**

**Introduction**

Service user and carer involvement is central to social care and NHS activity. The National Health Act 2006 Section 242 confirms a statutory duty to consult and involve service users in ongoing service planning, proposal development and decisions about general service delivery, not just changes and new proposals ([Care Services Improvement Partnership, 2008](#)). Increased public expectation for openness and accountability has influenced health needs identification, treatment and care, developing and planning services ([Smith and Ross, 2007](#)). Designing services that involves users and carers practically, based on the premise that involvement should positively affect service accessibility and acceptability, is an underlying value in most mental health service development. This approach is endorsed by government policy in four overlapping areas:

1. Generic health and social care.
2. Mental health services.
3. Patient and public involvement in health and social care.
4. Research governance in health and social care ([Mental Health Foundation, 2003](#); [Department of Health, 1999, 2002](#)).

Little evidence exists about the effectiveness and impact of involving users in mental health service delivery and evaluation, and more formal evaluation is required ([Simpson and House, 2002](#); [Crawford et al., 2002](#); [Minogue et al., 2005](#)). However, one research study concluded that users contribute ideas that hold greater user value, are more original and can be used as a learning tool to understand users better. This can inspire professionals to think more innovatively ([Magnusson, 2003](#)). Whilst Magnusson's research was in mobile telephony innovation, it raises interesting questions for service user involvement and the potential health and social care benefits. However, involving patients in health research can be far from straightforward with patients having different objectives and interests from researchers ([Rhodes et al., 2001](#)). Separating specific contributions from patients/consumers is a difficult task ([Smith, 1988](#); [Williamson, 2001](#)), which can be compounded by service user and clinicians' different perspectives on successful outcomes. Service users, for example, value choice and control ([Read and Reynolds, 1996](#)) while clinicians view symptom alleviation as more important ([Perkins, 2001](#)). Service users, however, are not homogenous and different groups have different priorities. The “ideal”

approach, therefore, is to identify an agenda for change and through co-researching, determine a means to change together ([Hostick, 1998](#)).

We describe preliminary findings from a participatory action research project about the nature of involvement from service user and carer perspectives. This mental health trust project explored the early stages of implementing self-directed support, and providing individual budgets to people instead of contracted social care services. Service user and carer involvement in the research project was based on the premise that it would strongly influence the project's design. This provides a viewpoint and critique from those that knew the reality of receiving services, thus making research process and outcomes more relevant. Self-directed support is part of the government's social care service personalisation agenda, tailoring care and support to:

- better fit a person's individual needs;
- offer greater choice; and
- use transparent processes to better inform service users and carers.

User involvement should mean letting service users set the agenda, contribute to decisions, challenge the status quo and ultimately change the balance of power crucial for commissioning personalised care ([Commission for Social Care Inspection, 2004](#)).

Five participants, recruited as co-researchers, formed part of a steering group including participants from various organisations implementing self-directed support. All participants were white British; two were female carers aged 52 and 59; three were service users, one male aged 50 and two females aged 34 and 55. However, the younger, female service-user dropped out after six months.

## Study design

Participatory action research focuses on power and participation issues ([Coghlan and Brannick, 2010](#)). It actively focuses on change and problem solving ([Reason, 1998](#)) where power structures are explicitly challenged (Alabaster *et al.*, 2000). The premise is to develop relevant and meaningful outcomes ([Falkner and Thomas, 2002](#)). Where a democratic approach to involvement is taken, the concern is improving people's lives rather than involvement being used to improve service delivery ([Beresford, 2005](#)). We detail findings from a larger project using a collaborative action research approach to study mental health support structures, processes and outcomes. The main study used focus groups and semi-structured interviews within an action research framework.

Action research is a simultaneous inquiry and practical action ([Winter and Munn-Giddings, 2001](#)). It is social research based on collaboration between researchers and their clients, aiming to problem solve and generate new knowledge ([Coghlan and Brannick, 2010](#)). Kurt Lewin first described action research processes as cyclical ([Waterman \*et al.\*, 2001](#)) involving diagnosing a changing situation, planning, collecting data, taking action and then reflecting on results in order to plan further action ([Coghlan and Brannick, 2010](#)) ([Figure 1](#)). Health and social care service reform and improvement, and increasing expectation that individuals and communities will collaborate and consult suggests action research has an increasing role in achieving NHS goals ([Hart and Bond, 1995](#); [Waterman \*et al.\*, 2001](#)). We define collaboration as “agreeing the facts and conclusions in an ethos of shared knowledge and understanding” ([Hitchen, 2007](#), p. 24). Action research, together with a second reflection cycle, is a continual enquiry into how steps are conducted and what is learned. Reflecting involves:

- programme content;
- issues;
- what is happening;
- process; and
- how things are being done, their premise, underlying assumptions and perspectives ([Coghlan and Brannick, 2010](#)).

Reflection is not confined to the lead action researcher but to all participants and groups whose experience manifests in, for example, struggles, conflicts and satisfaction. Reflection is crucial for learning, problem solving and decision making throughout the project's life. In this venture, the steering group reflected on all action research stages ([Figure 1](#) at end of paper).

## Aim

Our main aim was to understand involvement from a service user and carer perspective and recommend improvements to the process. We drew on service user and carer co-researcher experience to address this aim.

## Ethical considerations

This study is “insider” research – the manager leading the change project was also the principal action researcher. Studies of this nature require constant vigilance in relation to potential compromise – demonstrated by the manager's need to produce outcomes within short timescales. As a researcher, on the other hand, more protracted consultation and involvement is required, resulting in a lengthier and more critical interpretation of the proposed change. The manager is employed to get the “show on the road”, but as a researcher, supports service user and carer involvement, ensuring they are met and not tokenistic. [Williamson and Prosser \(2002\)](#) describe three potential action research dissonances:

1. asking how we can do things differently;
2. asking whether we have the power to change structures and practices; and
3. potential conflict between power relations.

[Coghlan and Brannick \(2010\)](#) describe insider researcher role duality and conflict alongside the political implications of questioning organisational practices and the inevitable compromises when balancing organisational needs with the researcher's desire for change. Insider researchers, in a collaborative study, need to reduce their traditional managerial/professional expert role and trust service user and carer collaborators to a far greater degree than their manager role allows. This may challenge health and social care organisation rules, where managers are experts, which do not equate with involvement. An equal value is placed on expertise that people bring, whether as professionals or users, to the discussion ([Department of Health, 2007](#)). Action research encourages people to speak, think and act for themselves. Each person is entitled to make his or her contribution to public debates and should be listened to respectfully ([McNiff et al., 2003](#)). Risks need to be considered beforehand and strategies for supporting service users and carers need to be in place. [Houndsell and Owens \(2005\)](#) suggest the benefit of support particularly when emotional challenges arise, while [Rose \(2003\)](#) writes about insufficient support for service-user researchers. Ethical approval for our research was granted by the local NHS research ethics committee. Additionally, NHS research management and governance approval was given by mental health trust managers.



## Recruitment

We wrote job descriptions for service user and carer co-researchers and placed an advert in all local, independent service user and carer group newsletters. Following screening, short-listing and interviews, three service users and two carers were recruited. All co-researchers were given an honorary contract with the trust and paid an hourly rate nearly double the minimum wage, agreed for trust research projects involving service user researchers. All co-researchers had received social care services and been involved in mental health work.

## Methods

The action research project was designed around a steering group that included one lead and five co-researchers. The group comprised 12 people including local authority and mental health trust staff, managers and a third sector representative. The group met approximately bi-monthly for two hours and all meetings were recorded and transcribed. Consequently, data were collected from:

- six debriefing meetings with co-researchers held between April and December 2007;
- a group interview conducted by the lead researcher; and
- comments and self-reflections written in journals.

All steering group meetings were electronically recorded. The recording was then transcribed by the lead researcher who played back the recording and then dictated verbatim using voice recognition software onto a computer. This process was repeated twice to ensure accuracy. Debriefing sessions lasted half-an-hour and provided opportunities for co-researcher involvement aspects to be discussed.

## Data analysis

Analysing transcriptions involved developing an initial coding scheme based on common data categories revealed by reading each interview/meeting transcript ([Coffey and Atkinson, 1996](#)). Emerging themes were analysed to avoid duplication. The main categories corresponded to themes identified from the lead researcher's field notes, which were refined by repeating the categorisation process. Coding reliability was checked in two ways. Firstly, intra-coder reliability ([Miles and Huberman, 1994](#)) was used whereby the same coding process was performed after six weeks to see if any new codes arose. Coded transcripts were given to all participants who challenged the lead researcher's interpretations and assumptions, which ensures that coded data represented group perspectives including mundane and more dramatic viewpoints. Data findings were written in a draft form and given to co-researchers to check accuracy. [Reason and Rowan \(1981\)](#) argue that tentative results should go back to the subjects for checking and refinement. We achieved respondent validation by returning our findings to those studied to see if they conformed to their experiences ([Silverman, 2001](#)) and accorded with their feelings and behaviours ([Denscombe, 1998](#)). Revisions and additions were made following feedback. Draft reports were sent to the wider steering group for comment.

## Findings

Three key findings emerged ([Table I](#) at end of paper).

## Language and communication

Difficulties understanding some of the language used in meetings was expressed by all participants. For one carer, language was extremely off-putting and was described as “jumping into a pool of language, it is English but not plain, everyday English”. Another thought it was like learning a new language. There was group consensus that complex language led to service user and carer participant communication problems. There were considerable variations in the difficulties language raised depending on who was communicating. The worst case was that service users and carers did not understand what people said in meetings. The engagement process was, therefore, seen as taking a while to get used to, with additional time required to understand and start working effectively. We felt that this slowed down service users and carers' ability to usefully contribute to the group. Another communication difficulty expressed by group members was appearing stupid and unable to grasp what was being expressed because information and briefings were poor. Participants described this as disempowering, summed up by one carer participant as “You feel a bit daft if you are asking questions all the time”.

Emphasis was placed on having background information in order to understand discussion contexts – expressed by one participant as basic knowledge about how the system works. The group considered that communication in the self-directed support steering group was easier compared to their experiences participating in other mental health service groups, and that ground rules agreed at the outset, designed to ease communication in the meetings, were beneficial. However, whilst this led to better communication, it did not remove all communication difficulties. One participant summed up how involvement for some people can be an intimidating process:

It is hard to get service users and carers on board. It is frightening.

Communication obstacles were felt to put-off others who may otherwise have wanted to contribute to mental health service delivery.

## Emotional content

Understanding emotional content was believed to be service user and carer core contributions – described by a carer participant as being “Where all the richness and reality and truth lie”. The comment suggests that it is the depth of feelings experienced by carers that are important for those providing services to learn from. The emotional aspect of involvement was seen as crucial to carer participants and needs to be understood alongside the emotional exhaustion that most carers experience. The emotional effect of involvement for service users and carers was not felt by group members to be acknowledged by professionals and other members. Group members did not feel this aspect of involvement was acknowledged by professionals. One participant described this as others not understanding the emotional impact that working in the group has such as not sleeping properly afterwards. Participants said that meetings often involved discussions that triggered memories or feelings about their own experiences. This meant that meetings can be experienced differently by professionals and service users “You interpret things in relation to your own personal experience”. One carer participant, commenting on the draft manuscript, felt that:

There were times that she could not do this [involvement] anymore; that it was not doing her any good, and when your relative is doing badly you can be feeling negative and angry.

Involvement was described as a different language, highlighting both conflicting and complimentary roles. There were two groups: those doing their job and going home at the end of the day; and those who live the reality every hour each day. They were seen as inhabiting different worlds. One participant criticised professionals who said they understood how that person felt and his or her problems:

You are trying to normalise the service user experience by professionals likening it to their own experience.

The group construed it as diminishing their contribution to a general rather than a personal viewpoint. Depersonalisation was seen as a recurrent theme in organisational language with which service users and carers found it hard to identify. Concerns were voiced about agendas focused on organisational rather than service-user needs. Importance was placed on the organisation rather than people, not even its own workforce's mental health. One service user described this as:

A lot of stuff that you hear is about the organisation and not about people.

If emphasis is placed on organisational issues rather than how services are provided to those needing them, then group members experienced frustration and disenchantment.

### *Power relations*

One service user participant believed that involvement meant an immediate power imbalance. Group members felt that power relations are firmly set at the outset as professionals are paid salaries to undertake work. This is in contrast to service users and carers who are paid the national minimum wage plus expenses, unless the work is of a specialist nature such as research where this amount is doubled. Some professionals held a “tick-box” attitude. Rather than being seen as useful, adding a richness or different perspective to the process, service users and carers were often included because they are required rather than being clear what their perspective adds. Whilst guidance states that service users are at the organisation's heart, this is not the impression with which group members were left. Often they did not feel equals or their contributions were given the same relative worth as professionals'. This was described by one participant as having to justify his or her contribution and role to managers. This could be improved by those leading projects thinking through the involvement role and what they are looking for from participants. The group's view was that more valued involvement occurs if their role was clearly defined and agreed at the outset. The need to clarify both what is paid and contracted, covering basic facts and expectations was seen as vital to any paid work, project or involvement and some managers might need training on this issue.

Despite recovery being a corporate principle at the organisation's heart, the group thought a culturally accepted power imbalance existed. One service user felt that lip service was paid to changing the “them and us” culture describing it as:

The existing service is being wallpapered with another language that people are going to use but not actually change the way they work.

Group members felt that there was no sense of urgency for tackling power issues and that programmes designed to change staff attitudes were helpful but ultimately may not be effective. Participants discussed the difficulties associated with changing culture in a mental health trust employing many staff, acknowledging that many employees adopted recovery principles, incorporating more empowerment for service users, but that this

needed to be more widespread in the organisation for any meaningful shift in the power balance.

The nature and quality of service user and carer involvement was considered important. The group had experienced different attitudes from professionals and managers during their involvement including feeling invisible. This was summed up by one service user participant who expected acceptable behaviour and attitudes:

A certain mindfulness of language, patience, respect, non-judgmentalism, acceptance, serious power imbalances and most important, not dismissing us and our opinions because you can.

## Discussion

It is no surprise that professional language hinders service user and carer understanding, which leads to significant communication blocks. Focus group research by [Connor and Wilson \(2006\)](#) into service-user involvement experiences found that agreeing an acceptable language was one of their four main findings. [Steel \(2005\)](#) considers language use significant when involving vulnerable people in research. If this is not addressed then there is a danger that non-specialist involvement remains tokenistic. Our findings suggest that even in meetings where this has been considered carefully beforehand, language barriers blocking full understanding and communication are likely. Combined with pressures on professionals to produce speedy positive change project outcomes, and time-limited meetings, assumptions that service user and carer representatives understand what is said is increased, especially if they have not expressed otherwise. In our study, users and carers felt they were seen as stupid if they are always the ones asking questions. A lack of respect may result if service user and carer learning needs are not considered as a necessary prerequisite for fuller meeting contributions.

Our second main finding was that being “involved” has an emotional impact not always recognised by professionals. Participants believed that contributing to groups, drawing on personal experience as a service user or carer, has a lasting emotional cost. Moves to involve users for designing and delivering services imply a value to their experiences, which should be as valuable as the professional perspective ([Telford and Faulkner, 2004](#)). Service user experience is an important resource that can improve care and support that individuals receive in the community ([Tait and Lester, 2005](#)). However, professional reservations about user involvement include service user participation being distorted by anger, illness and expressed inappropriately ([Crawford, 2001](#)).

Our findings suggest service user reservations need to be acknowledged. Their reference points are their mental health service experiences, which may cause feelings to surface that are unknown to professionals. Service users and carers in our study argued that emotive language needs to be in the forefront and that there is little learning without it. Using experiences productively is indicated, particularly in mental health organisations, where they are seen as a symptom of either a particular service user's condition or one of the less-welcome “side effects” of involvement. Consequently, involving users and carers in service planning is a challenge. Assumptions that people with mental health problems have a diminished ability to define their wishes, problems and needs may cast doubt on their views and ideas, giving precedence to other stakeholders ([Perkins, 2001](#)). Group members believed that careful and contained discussions, where emotions are either openly or tacitly suppressed, do little to change strongly held attitudes. Expressing feelings that get to the heart of what matters, which challenge thinking and rationales for working in particular ways, are important. Emotions act as powerful motivators and have a pervasive influence on human behaviour and beliefs ([Marsella and Gratch, 2002](#)).

Recognising emotional input's importance needs to be encouraged and used positively if we are to encourage user involvement in service development, delivery and improvement.

Power imbalance was our third major finding. [Holosko et al. \(2001\)](#) suggest that service user input and empowerment are necessary for public service organisational effectiveness. Additionally, organisations that solicit service user input and then ignore it not only fail to empower but may actively disempower service users. Those involved in research conducted by [Rhodes et al. \(2001\)](#) saw education and information empowering and enabling people to take more control over their lives and use resources wisely. [Hill et al. \(2000\)](#) describe power imbalance as an unresolved issue in user involvement particularly where users are introduced to existing planning groups. Large mental health organisations mean there are inevitably people holding disempowering attitudes. Our service user and carer co-researchers did not sense any urgency tackling power issues. Power relations underlie most user-led change difficulties. We need continuing awareness of power relationship contexts ([Carr, 2004](#)). Programmes have been designed to change staff attitudes but these may be ineffective, so tackling underlying professional attitudes is unlikely to change attitudes. Developing involvement cultures begins in the workplace at all levels. Openness and willingness to change in order to feel secure about involving people in planning services is important ([Western Health and Social Services Board, 2005](#)). Trusts with a workforce in their middle years may be inclined towards professional paternalistic approaches reflected in their earlier training and this may reduce their capacity for cultural shift ([Cole and Perides, 1995](#)).

Fundamental principles underpinning good practice for involving service users and carers have been addressed in Care Services Improvement Partnership guidelines ([Care Services Improvement Partnership, 2006a, b](#)). However, without beliefs that involvement produces better services than a “tick box culture” dominates. Cultural change needs to come from service users and carers, developing confidence and louder voices, to ensure change is driven from all directions.

## Policy implications

Government policy has addressed the user involvement agenda in its NHS Plan ([Department of Health, 2000](#)), which emphasises a patient-centred NHS. Those using the service are central to service design and delivery. Mental health services and in particular Working in Partnership ([Department of Health, 1994](#)) and Building Bridges ([Department of Health, 1995](#)) encourage user involvement. Policy documents present user involvement as a quality issue, attributing this with service improvements ([Fudge et al., 2008](#)). Policy is less clear how service user involvement should be undertaken and how NHS managers and practitioners should interpret and implement user involvement policy. Our study highlights the gap between involving service user and carers meaningfully, achieving mutually agreed outcomes and the experience from the service user and carer perspective. It is suggested that NHS staff need to equip those leading involvement projects with skills and awareness to make this a meaningful and productive experience for all, which ensures that more people participate and stay involved and that outcomes are achieved on which that both service providers and receivers collaborate.

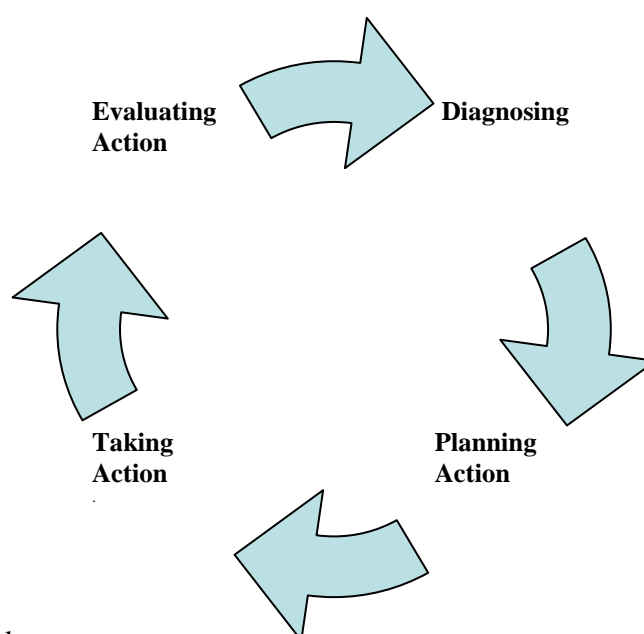
## Limitations

This small study in a larger action research project examined self-directed support within mental health services. Service user and carer co-researchers were recruited and fully participated as both researchers and participants. The lead researcher worked closely with

co-researchers to obtain involvement perspectives. Research findings were shared for comment and interpretation. Working relationships developed over 18 months, enabling the lead researcher to understand their involvement. Contributions about involvement were considered and modified over time. There was no concern about the content of what was shared. Participatory research means researchers collaborate with minority groups that may not represent the community from which they are drawn ([Macaulay et al., 1999](#)), which raises bias issues. Concerns that users are not representative are well documented ([Crawford et al., 2002](#); [Rose, 2003](#); [Tait and Lester, 2005](#)), which may indicate why expert patient experiences are less open to criticism. Our study is not generalisable owing to the research group's small size, but data gained are supported by user-involvement literature. Our study highlights participation's effects on service users, which few have explored ([Crawford et al., 2002](#)). The service-user perspective has systematically failed to be acknowledged in health research; individual, experientially-based knowledge does not fit comfortably within the medical-scientific arena. Service-user based research should be viewed as a different way of seeing the world by encouraging reflection on the impact that involving consumers has ([Hodgson and Canvin, 2005](#)). Without this perspective, research may have less impact on healthcare practice ([Beresford, 2003](#)).

## Conclusion

Our study suggests that service user and carer participant themes: communication; emotional impact; and power relations are important areas that need addressing if user involvement is to be improved. Emotional impact appears to be an area lacking research in mental health services. New studies may improve user involvement. Our findings suggest that considerable improvement is needed to engage service users and carers in mutually beneficial working relationships for developing services. Implementing self-directed support in mental health services, which aims to provide more flexible, person-centred services, including user and carer choices, will need to consider how to use collaborative processes and increase service recipient involvement in the most effective way. This should ensure that services and processes are developed that people want and own.



*Figure 1* Action research cycle

<b>Language and Communication</b>	<b>Emotional Content</b>	<b>Empowerment</b>
Limited understanding	Contribution devalued	Power imbalance weighted towards professionals
Unacknowledged by professionals	Adverse emotional effect	Tick box attitude to involvement
Lack of plain English	Depersonalisation	Service user and carer participant roles need clarity
Lack of information or insufficient briefing		Challenge to organisational culture
Appearing stupid		
Using ground rules is helpful		

Table I: **Findings**

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### **Corresponding author**

Sherrie Hitchen can be contacted at: [sherrie.hitchen@nhs.net](mailto:sherrie.hitchen@nhs.net)

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