**Abstract**

Personal Budgets provide people with more choice and control over how their needs are met and, allied to new thinking concerning individualisation of mental health care, are increasingly a feature of international governmental responses to long term care. This study was based in an English National Health Service Health and Social Care Trust covering a large predominantly rural area. We aimed to develop Self-Directed Support and understand more fully service-user and carer involvement in the process, using an action research design. Data collection took place between 2007 and 2011, and the project ran in three sequential spirals collecting qualitative data. Findings showed users and carers, and trust Recovery Coordinators acknowledged the need for cultural change, Personal Budgets’ effect on outcomes, and service-users’ capacity to manage these responsibilities. We conclude that moving to Personal Budgets can be empowering for mental health services users but is problematic and may present challenges to service-users with fluctuating mental health. Recruiting service-users and carers to participate in research illuminates their otherwise-hidden perspectives, and our use of service-users as co-researchers is a process that others might want to emulate.

*Declaration of interest:* none.

*Key words:* health care utilization; action research; empowerment; qualitative research; focus groups; service-users and carers; personal budgets; direct payments.

**Introduction**

A key concept behind personal budgets (PBs) for mental health service-users and carers is flexibility for them to organise support around their own lives rather than passively accepting professional services: it is a philosophy of independent living (Spandler & Vick, 2006) encompassing benefits such as social inclusion and opportunities for mental health recovery. Those being offered direct payments (DPs) should take a central role in identifying and controlling the outcomes they desire within an allocated budget (Stevens et al., 2011).

The term Self-Directed Support (SDS) is often used interchangeably with personalisation. Both refer to the provision of individualised services. In this study a Personal Budget refers is an individual budget where allocated money is managed by the Local Authority (LA), and a Direct Payment (DPs) is where the person receives cash to direct their own services.

PBs and the individualisation of mental health care are increasingly international features of governmental responses to long term care. For example, ‘cash-for-care’ solutions are becoming common in European states, with similar trends in the USA, as ‘self-directed’ programmes reported in the international literature highlight how PBs can be used to harness people’s attributes to help them recover, empowering them to make their own care decisions (Carr & Fisher, 2010).

When this study began (early 2007) little was known about the impact of PBs in mental health and there was confusion about the terminological differences (Carr & Dittrich, 2010; Henwood & Hudson, 2007; Reid Howie Associates, 2010). DPs were offered to people with mental health needs but they were the least likely group to use them (Fernandez, Kendall, Davey, & Knapp, 2007), and this was poorly understood. The organisation *In Control* was conducting a UK national pilot (Duffy, 2006, 2007) but there was a low representation (14%) of people with mental health problems. *In Control’s* implementation results were positive but findings from other independent research projects were yet to be published. These inconsistencies in terminology and application lead to a number of knowledge gaps which we discuss below.

Its appears that service-users experience many potential gains from DPs, and that PBs can shift the balance of power towards the recipient, giving people a greater role in assessing their own needs and making choices regarding services; this challenges power dynamics between professionals and service-users (Coyle, 2011). . Improvements are evident across all disabilities (except older people, (Glendinning et al., 2008). Increased choice and control are evident, and flexibility over PB spending enables greater socialisation, freedom and independence (Rabiee, Moran, & Glendinning, 2009). One knowledge gap, however, concerns potential gains for carers, as carers’ research is scant, but the Social Care Institute of Excellence (SCIE) indicates that carers could have a central role in enabling people with mental health problems to take up and manage their budgets (Newbronner et al., 2011).

A major inhibiting factor in the uptake of DPs in the UK was uncertainty about whether unwell participants could handle the payments and there were concerns about misappropriation of payments (Ridley & Jones, 2003). Thus a knowledge gap exists concerning how best to implement of PBs whilst accounting for these concerns.

Professional workers’ views differ on the legitimacy of different types of spending (Stevens et al., 2011): they can be anxious that PBs may potential increase risks of exploitation and stress when service-users manage new processes (Ridley & Jones, 2003; Spandler & Vick, 2005; Davey et al., 2007; Glendinning et al., 2008; Manthorpe et al., 2008; Mind, 2009), as well as for their own jobs if services close. Workers also fear loss of professional control, extra administrative complexity, and can be resistant to change (Witcher, Stalker, Roadburg, & Jones, 2000; Manthorpe et al., 2009; Mind, 2009). It is likely that major shifts in culture, roles and responsibilities are required for front line staff to champion PBs. Training and communication activities (Glendinning et al., 2008; Manthorpe et al., 2009) may help staff change attitudes and enable PBs’ implementation. Staff with traditional notions of social care and ‘appropriate’ uses of PBs constrained their usage and reduced conversations about individual options (Spandler & Vick, 2004, 2005; Newbigging & Lowe, 2005; Newbronner et al., 2011).

*Mental health and action research.*

Many AR studies have taken place in mental health, but their recent focus has been therapeutic: for example, Hutchinson & Lovell (2013) describe the transformative effect that their study had on their service-user co-researchers, who gained greater control over their lives. Fieldhouse (2012) documents the positive impact that assertive outreach practitioners had on recovery for socially excluded mental health service-users. Leighton (2005) illustrates how AR enabled re-designed care and therapeutic activities in a mental health unit, and Clements (2012) used AR to embed recovery principles in community mental health services. However, only one study since 2003 has evaluated the establishment of SDS for mental health recovery: by combining the use of evidence-based practice and community consensus as a tool for system change in Texas (USA, Cook et al. 2010), and so our study offers a unique perspective on how SDS can be implemented in the UK.

*Contextual issues*

The national policy drivers and knowledge gaps discussed above were contextually important for this study, however, the direct imperative to change practice was governmental, as the Department of Health (2005, 2007) now require implementation of DPs (Webber et al 2014). There is also a legal duty to involve service-users in the design and conduct of research and this is beneficial because it positively affects the quality and relevance of studies and achieves more effective service redesign (Staniszewska, 2009).

The trust in which this research took place serves a predominantly rural area in Devon, in the South West of the United Kingdom. There are three small conurbations in a large geographical area, with a population of approximately 850,000 people in the county. The trust employs 2,500 people to provide integrated mental 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. The trust uses LA care monies to purchase independent, voluntary, and third sector organisation services for clients.

Lead researcher SH was Head of Contracting and Provider Partnerships and managed a team undertaking projects to bring in new services. She worked alongside partnership agencies providing housing, community and social services; led on carers and commissioning social care services, residential and nursing care, and community based services. Her role concerned modernising services to reduce residential care reliance, encourage development of community services to enable recovery and independence, and ensure that service-users access the support they need within budgetary limits. This remit covered adults with mental health problems with affective and psychotic disorders.

**Aims**

To develop Self-Directed Support in this mental health Trust and understand more fully service-users’, carers’ and Recovery Care Coordinators’ involvement in the process.

**Methods**

An AR approach was used in this study, comprising three spirals of planning, action, evaluation and reflection (Williamson, Bellman, & Webster, 2012). Qualitative data were utilised as a means of understanding service-users’, carers’ and Recovery Care Coordinators’ views. (RCCOs are professionals from backgrounds including nursing and social work with responsibility for leading care management for service-users as part of a community mental healthcare team. They assess, plan and co-ordinate the delivery of care and will liaise with a variety of other professionals and services to ensure that the service-user obtains support in areas including mental health and medication, social inclusion and employment.)

Action research was an appropriate methodology because AR focuses on research in action (Coughlan & Coghlan, 2007). Its cyclical stepped AR process is participative, flexible and allows the introduction of change management by internal sources, so that the participative relationship of those affected by change fosters collective ownership (Whitehead, 2005).

*Recruitment:* Service-user and carer involvement was based on the premise that it would strongly influence the project's design and provide a viewpoint and critique from those that knew the reality of receiving services. These assumptions and the recruitment process have been explored elsewhere (Hitchen et al, 2011; Hitchen and Williamson, 2014 *in press*). Five service service-user and carers were recruited to be co-researchers, who had current lived experience of trust services. They were appointed following advertisements through existing Trust networks, with a job description, remuneration and an honorary Trust contract. They undertook qualitative research methods training by Folk.Us, a group that helps mental health service-users and carers design and participate in research projects in South Devon (UK, see http://www.folkus.org.uk/ for further information).

A total of thirty seven service-users and carer were invited for four focus group meetings and 32 attended. Table 1 shows figures for each group.

INSERT TABLE 1 HERE

Professional staff participants to the action research steering group were recruited by the lead researcher for the relevance of their roles in implementing PBs, including trust, LA and third sector staff. The steering group was the vehicle for agreeing proposed actions, implementing changes, observing and reflecting on outcomes changes and agreeing future direction and included SH as lead researcher and five service-user and carer co-researchers. The group comprised 12 people including LA and trust staff, managers and a third sector representative. The group met approximately bi-monthly for two hours

*Methods of data collection:* Focus groups with service-users, carers and RCCOs were utilised to explore attitudes and produce rich data (Denscombe, 2007), and were wide ranging and loosely structured, being topic-based and focused on the research element in hand. Participants were free to raise issues and concerns and there was flexibe questioning to allow for a breadth of dialogue within the general topic generated by the question. Group durations were not fixed but lasted between an hour and 90 minutes. In addition to focus group data, analysis and interpretation was facilitated by data from steering group meeting transcripts; training sessions with practitioners and people using mental health services; reflective group meetings, emails and letters between the principal researcher and the service-user and carer co-researchers; and the lead researcher’s reflective diary. Quotes and extracts reported here are those from the focus groups as they demonstrate dynamic interaction of participants and the key themes from the study.

*Methods of data analysis:* All focus groups were electronically recorded and were analysed using Kreuger and Casey’s (2009) sequential analysis process. This process took place with reference to the three different focus group participants, people using services, their carers, and the RCCOs. Each line of transcripts was initially analysed according to the group involved; similar content was categorised together in relation to the broad questions asked, and so a systematic examination of similarities between cases developed concepts (Punch, 2005). A descriptive summary of the emerging themes was subsequently constructed. To assure rigour, a reflexive account concerning the influence of self and its impact on the research was constructed, and following steering group meetings the lead researcher met with the co-researchers to share reflections to gain a shared understanding of the main themes (Denscombe, 2007). Thus, consensus in relation to data analysis was achieved through negotiations of interpretations between the lead and co-researchers.

*Ethical issues:* National Research Ethics Service and local trust governance approval were obtained. Guarantees concerning protection from harm, honesty, confidentiality, and right to withdraw were made. Written informed consent was secured from all.

**Findings**

Between 2007 and 2011 four focus groups took place with service-users and carers, two focus groups with recovery coordinators, and 12 steering groups. In phase one, user and carer participants were recruited, steering groups met, and training and development took place. In phase two, these activities continued, and user and carer focus groups took place. In phase three, steering groups and development activities took place, as did focus groups with the recovery coordinators. The three action research spirals were the vehicle by which SH learned from and communicated with the co-researchers and other staff in the trust. Throughout the study the work of the co-researchers, their involvement and observations of the participative process was recorded, analysed and discussed, and change activities discussed and agreed. The processes involved in each spiral are shown in figures 1, 2 and 3.

INSERT FIG 1 HERE

The first two AR spirals (figures 1 and 2) represent the work to develop and trial two different self-assessment systems in order to use these to provide Personal Budgets. Firstly, an adapted *In Control* Resource Allocation System was developed; and secondly, a Personal Budget Allocation tool was developed and trialled. Spiral one included evaluative data collected from individual interviews with service-user and carer co-researchers; five steering group meetings; two workshops led by SH and a co-researcher; debrief meetings with the co-researchers; and eight countywide training sessions to RCCOs.

INSERT FIGURE 2 HERE

The second spiral included data from five steering groups; debriefs with the co-researchers following these; four training sessions with RCCOs; four provider workshops; three meetings with the co-researchers and four focus groups, two with service-users and two with carers.

The third AR spiral (figure 3) represents the results of changes developed in the initial two spirals, and indicates the acceptance and implementation of PBs.

INSERT FIG 3 HERE

The third AR cycle included data from two steering groups; two focus groups with RCCOs; seven training sessions with RCCOs and a training evaluation session. It was here that the main changes in care delivery resulting from the project happened.

*Findings from user and carer focus groups*

Table 2 shows a summary of the key themes and issues discussed within each theme concerning Direct Payments. Data not related specifically to DPs is not reported.

INSERT TABLE 2 HERE

*Capability to manage.* An important aspect of receiving a DP concerned whether the recipient would be well enough to manage it.

Service-user 1: For some people this is a good idea; for others it is not... 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 will not be able to deal with the money themselves.

Service-user 3: I have manic depression and I know I have gone on spending sprees. Therefore, it could be quite dangerous because I could just go out and splurge all the money on nothing in particular.

Participants were 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.

Service-user 3: There will be times when you need help to make your own choices because you are not well enough to deal with it yourself.

Service-user 2: 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.

Abusing the system by spending money on things outside of agreed plans was raised. Several in the first focus group suggested those with drug and alcohol problems may abuse their monies, and some carers described some service-users as being deceptive to others outside the family, giving the impression of being more capable than they actually were.

Carer 3: The professionals never see the patient that we see. 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.

Money was seen by many carers as a source of friction between themselves 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 DP 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.

*Outcomes .*Several carers thought people need support, encouragement and new ideas offered to improve their outcomes. Individualisation might tailor resources to an individual’s needs, improving outcomes including social interaction and confidence through increased choice.

Service-user 2: 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.

 Service-user 3: Yes I would agree that general wellbeing, 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.

Carer 6: My wife wants to pursue hobbies to give her something meaningful to do, to keep her on the straight and narrow…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 DPs in their own right to improve their outcomes and had to be reminded to answer in relation to themselves as well as their relative.

*Culture Change.* Service-users wanted to see a change in the professional culture of some of the workers they met, as they believed that some staff had a shared understanding and approach to mental health care not always sympathetic to service-user and carer needs. 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 you don’t qualify.

Carer 3: 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 designated [sic] 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. Several were concerned that professionals lacked their understanding of living with mental ill-health despite 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.

*Findings from recovery co-ordinator focus groups*

Table 2 shows a summary of the key themes and issues discussed within each theme concerning DPs.

*Culture Change.* This theme featured in both focus groups and was considered in the context of working with people with increasingly complex needs, often including physical problems as well as mental health difficulties.

RCCO 5: I suppose you have got to be able to think outside of the box and a lot of our clients can’t. They get frightened if you even suggest an alternative.

Most participants had examples of how SDS fitted with a recovery approach, enabling more independence and normal activities for people rather than specialist services, though many expressed caution about people’s capacity to manage. Some participants described a reduction in traditional services such as residential care helping them to be more recovery minded, forcing them to think more flexibly about other options, and that they could effect change through discussions with clients.

Using DPs for respite breaks to fund holidays was described as ‘horrifying’ to colleagues, which limited RCCOs’ promotion of such DPS, but they gave examples including learning opportunities, equipment and accessing physical exercise**.**

RCCO 1: I have come across colleagues who have said “we are not in the business of arranging holidays”. 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.

*Capability to manage.* Participants reported that most clients wanted RCCOs to continue making contractual arrangements, acknowledging that people appreciated others arranging things for them. One participant likened this to people having the perception that the ‘state will provide’ leading to unhelpful behaviours.

RCCO 4: 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…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.

Money management was agreed as a problem for many people with examples given of people who couldn’t open bank accounts, being poor managers of money or being financially exploited as vulnerable adults. Participants suggested that some people saw DPs as an additional source of income like Disability Living Allowance rather than to meet defined needs. RCCOs said that they were reluctant to provide help due to work pressure.

RCCO 6: Some people maybe could benefit from the scheme but actually don’t want to take ownership. They feel 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.

*Outcomes.* The social model of mental health received limited acknowledgement; participants reported some positive outcomes for people in receipt of DPs that were in their view working well.

RCCO 2: It worked very well, using respite on a rolling basis to keep her out of hospital…it was [also used] to have a massage and that worked well. For her it was pleasurable and enjoyable and they both managed their finances. It treated her as an adult, making her aware what was helpful when her condition was problematic and it was positive.

RCCO 1: 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.

Focus group participants discussed ‘gold standard’ outcomes of people using personal assistants to address needs informally rather than relying on agencies. DPs allowed them to ‘think outside of the box’ to improve peoples’ outcomes, enabling increased opportunities for recovery and normalisation using mainstream services.

RCCO 5: 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.

*Information and Advice.* RCCOs provided advice but several were confused by the large range of services now on offer. Two participants did not want to raise expectations by giving information without authorised funding. Several participants mentioned that processes for DPs and contracted support were too complex to understand. One point of information contact was seen as ideal; eminently preferable would be another organisation sorting out PBs on their behalf.

**Self-directed support implementation process**

The AR project produced a number of tangible insights which informed the implementation of SDS, and was instrumental in identifying the context within the trust concerning preparedness for its implementation, particularly about outcome and needs assessment. The project also related the local context to national expectations to roll out a personalised service to all individuals requiring social care resources in mental health services, and was important in benchmarking where the trust’s position as first step in implementation.

The steering group, which included people with lived experience and carers indicated how to train the workforce and highlighted the cultural change required to foster new thinking concerning building services around the individual’s unique needs and preferences. The project included using focus groups to hear from carers and service-users what they thought of current services and the idea of having a more personalised approach from the trust, and trialling and rejecting tools for this as being unfit for purpose. The steering group was a pivotal decision making influence in this process, and all evidence and data was fed back there, discussed, and next steps agreed.

As the AR project ended, several recommendations were taken forward that have now been implemented. These included the decision to work with an external company to develop a resource allocation tool that was in use elsewhere to generate budgets, and this has now been implemented within the trust and is still under development in order to make it more accurate. The workforce is now trained and fully engaged in providing personalised services to their service-users and the culture has shifted significantly towards more person centred approaches. Additionally, issues and problems raised by the RCCOs provided learning for the trust in terms of improving and simplifying processes and information flows about SDS, which many found confusing. This information allowed for the re-design and contracting of more clearly accessible new services for people.

**Discussion**

The study’s aims were to implement SDS in mental health services, and as part of that process to understand from service-users’, carers’ and RCCOs’ perspectives what the benefits and obstacles were to implementation. In this AR study participants’ data produced themes and indicated several areas of commonality, as they both discussed Culture change, Outcomes, and Capability to manage, with RCCOs discussing an additional theme of Information and advice.

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Regarding Culture change, users and carers gave examples of poor practice and unsatisfactory attitudes, whilst RCCOs discussed how DPs could go some way to overcoming these attitudes by allowing services to be tailored to individuals’ needs and so foster recovery. These findings align with the need for a culture shift reported elsewhere (Coyle, 2011; Glendinning *et al.*, 2008; Manthorpe *et al.*, 2009; Newbronner *et al.*, 2011), moving from traditional, gift-bestowing to rights-based services with staff endorsing personalisation principles. Positive staff attitudes are crucial to promoting SDS (Newbigging & Lowe, 2005; Newbronner et al., 2011; Riddell et al., 2006; Spandler & Vick, 2004, 2005) but may be confounded where workers perceive themselves already overloaded and unable to keep up with new policies and innovations.

Similarly, Outcomes was a conjoint theme: carers believed DPs might help them improve people’s lives and RCCOs gave specific examples of purchased activities that had improved things for their clients. Although people’s wellbeing was not directly measured here, an improvement in the quality of health may have been assumed when recovery was discussed. Measured improvements in health and wellbeing have been shown where PBs are in place (Glendinning *et al.*, 2008; Rabiee *et al.,* 2009; Tyson *et al.*, 2010), and increased wellbeing reported in people with variable conditions having flexible support. Coyle’s (2011) study found PBs enhanced recovery amongst people with mental health problems from previous dependency on statutory services.

Improved quality of life is a key measurement outcome for SDS with Hatton *et al.* (2008) and Tyson *et al.* (2010) reporting higher levels of satisfaction across all areas of life. Elsewhere, little difference was found between control groups and PB holders except in mental health recipients where significant improvements were reported (Glendinning *et al.*, 2008), in quality of life (Mind, 2009), and in much fuller lives (Homer and Gilder, 2008).

Concerning Capability to manage, all focus group participants believed that service-users might suffer because of their additional responsibilities, and some might not be able to cope. This is noted in the Individual Budgets Evaluation alongside potentially greater risks for abuse and decreasing wellbeing, concerns about misspending of monies and fears that people will commit fraud more easily (Manthorpe *et al.*, 2009).

Lack of information about DPs for service-users and carers is a consistent theme in the literature (Brewis, 2007; Glendinning et al., 2008; Maglajlic *et al.*, 2000; Mind, 2009; Newbronner *et al.*, 2011; Ridley & Jones, 2002, 2003). In this study, RCCOs described themselves as information givers but struggled to keep up to date, wanting one Self-Directed Support information point, which is recommended elsewhere (Henwood &Hudson, 2007; Ridley *et al.*, 2011; Tyson *et al.*, 2010).

*Linking action research methodology and the development of personal budgets*

The iterative AR spirals of planning, action, evaluation, and reflection (McNiff and Whitehead 2002) informed all aspects of the study: the first spiral involved initial planning, adaptation, trialling and resultant discontinuation of the initial Resource Allocation System incorporating training sessions with staff. The second spiral involved planning and trialling a new Resource Allocation System, service-user and carer focus groups, and further workforce training. Thirdly the final spiral focussed on the preparing the organisation for the introduction of PBs by adapting existing systems including accrued learning from the study and from the RCCOs focus groups.

These outcomes illustrate a number of ways in which AR methodology directly influenced the implementation of personal budgets in this study. Firstly, AR focuses on research in action, rather than about action (Coughlan and Coghlan, 2002). The cyclical stepped AR process provided a high degree of flexibility to introduce change by internal participants, rather than by an external facilitator where the process is less likely to be favourably received. AR allowed greater ownership and made affecting change easier. An interactive research approach was sought, and AR encouraged people to speak, think and act for themselves and this resonated with her values of being person-centred and non-elitist.

SH wanted to explore and provide evidence to examine her 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, with a focus on differences for service-users rather than the considerations of a project management process. Shared concerns, critical examination of processes, tools, training, generated data and other aspects of PB implementation could thus be explored alongside the implementation process.

*Evaluative criteria and action research in this study.* This study also met the five evaluation criteria suggested by Williamson, Bellman, & Webster, (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 SDS in the 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 SH as lead researcher. Data analysis was also rigorous using intra-coder reliability (Miles and Huberman, 2014) and respondent validation (Silverman, 2006). Finally, Williamson (2012) suggests the AR needs to be transferable, and learning from this study may be useful to similar Trusts who are working with SDS 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 our recruitment process, learning around the steering group, and the findings from the co-researchers helpful when planning their studies.

**Conclusions**

The special contribution of this study is to detail how participation from the co-researcher service-users, carers and staff can influence the development of DPs in mental healthcare, and how their viewpoints overlapped as shown by the themes Capability to manage, Outcomes and Culture**.** This has an international dimension in mental health care and we have outlined a critical process by which, DPs offer the potential to improve outcomes and increase well-being for people receiving mental healthcare by offering flexibility and choice. However, concerns remain about these people’s ability to manage the additional responsibilities, especially when unwell. It is likely, as more countries move towards these types of arrangements (Carr & Fisher, 2010), that various models will be tested, researched and evaluated. If claims that DPs improve outcomes and increase well-being are to be substantiated, there is a need for large-scale studies that specifically quantify and measure such changes. This could fruitfully involve multi-national studies and comparisons.

**References**

Brewis, R. (2007). A voice and a choice: Self directed support by people with mental health problems. [Online] Available at: www.dhcarenetworks.org.uk/pageFinder.cfm?cid=2672. Accessed: 1.5.09.

Carr, S. and Dittrich, R. (2010). Personalisation a rough guide. London: Social Care Institute for Excellence.

Carr, S. and Fisher, M. (2010). *Personalization: Oxford Bibliographies Online Research Guide.* Oxford, Oxford University Press.

Clements, K. (2011). Participatory action research and photovoice in a psychiatric nursing/clubhouse collaboration exploring recovery narrative. *Journal of Psychiatric and Mental Health Nursing,* 19(9), 785–791.

Participatory action research to establish self-directed care for mental health recovery in Texas.

Cook, J., A., , Samuel, S., E., Burke-Miller, J.,K., Jonikas, J., A., Ferrara, M., Colegrove, S., Norris, W.,T., Ruckdeschel, B., Batteiger, A., P., Ohrtman, M., Grey, D., D. and Hicks, M., E. (2010). Participatory action research to establish self-directed care for mental health recovery in Texas. *Psychiatric Rehabilitation Journal*, 34(2),137-144. Coughlan, P., and Coghlan, D. (2002). Action research for operations management. *International Journal of Operations & Production Management,* 22(2), 220 – 240.

Coyle, D. (2011). Impact of person-centred thinking and personal budgets in mental health services: reporting a UK pilot. *Journal of Psychiatric and Mental Health Nursing*, 18, pp. 796-803.

Denscombe, M. (2007).*The Good Research Guide.* Maidenhead: Open University Press.

Department of Health. (2005). Independence, wellbeing and choice: Our vision for the future of social care for adults in England. London: Department of Health.

Department of Health. (2007). Putting people first: A shared vision and commitment to the transformation of adult social care. London: Department of Health.

Duffy, S. (2006). The implications of Individual Budgets. Journal of Integrated Care, 14(2), 3-10.

Duffy, S. (2007). The economics of self directed support. Journal of Integrated Care, 15(2), 26-37.

Fernandez, J.-L., Kendall, J., Davey, V., & Knapp, M. (2007). Direct Payments in England: Factors Linked to Variations in Local Provision. Journal of Social Policy, 36(1), 97-121.

Fieldhouse, J. (2012). Community participation and recovery for mental health service-users: an action research inquiry. *The British Journal of Occupational Therapy,* 75(9), 419-428.

Glendinning, C., Challis, D., Fernandez, J.-L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008). Evaluation of the Individual Budgets Programme: Final Report. Available at [On-line] www.york.ac.uk/spru . Accessed 3.6.2009.

Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O’Brien, J. and Towell, D. (2008). A report on in Control’s Second Phase. [Online] Available at: www.in-control.org.uk. Accessed: 5.6.2008.

Henwood, M. and Hudson, B. (2007). Here to Stay? Self Directed Support: Aspiration and Implementation, London, Department of Health.

Hitchen, S., Watkins, M., Williamson, G. R., Ambury, S., Bemrose, G., Cook, D. and Taylor, M. (2011). Lone voices have an emotional content: focussing on mental health service-user and carer involvement. International Journal of Health Care Quality Assurance. 24(2), 164-177.

Hitcvhen, S. and Williamson, G. R. (2014). A stronger voice: Action research in mental health services using carers and people with experience as co-researchers. Journal of International Health Care Quality Assurance. 28(2). *Accepted for publication:* *In press.*

Homer, T. and Gilder, P. (2008). A Review of Self-Directed Support in Scotland. The Scottish Government. [Online] Available at http://www.scotland.gov.uk/Publications/2008/05/30134050/15. Accessed: 14.3.12.

Hutchinson, A. and Lovell, A. (2013). Participatory action research: moving beyond the ‘service-user’ identity. *Journal of Psychiatric and Mental Health Nursing,* 20(7), 641–649.

Kreuger, R., A and Casey, M., A (2009).*Focus Groups- A Practical Guide for Applied Research.* Thousand Oaks CA: Sage.

Leighton. K. (2005). Action research: the revision of services at one mental health rehabilitation unit in the north of England. *Journal of Psychiatric and Mental Health Nursing.* 12(3), 372–379.

Maglajlic, R., Brandon, D. and Given, D. (2000). Making direct payments a choice: a report on the research findings. *Disability and Society* 15(1), pp. 99-113.

Manthorpe, J., Stevens, M., Rapaport, J., Harris, J., Jacobs, S., Challis, D., Netten, A., Knapp, M., Wilberforce, M. and Glendinning, C. (2009). Safeguarding and System Change: Early Perceptions of the Implications for Adult Protections Services of the English Individual Budgets Pilots - A Qualitative Study.*British Journal of Social Work*, 39(8), pp. 1465-1480.

Miles, M. and Huberman, A (2014). Qualitative Data Analysis. 3rd edition. Thousand Oaks, CA, Sage.

McKay, J. and Marshall, P. (2001). The dual imperatives of action research. *Information Technology and People.* 14(1), 46-59.

McNiff, J. and Whitehead, J. (2002) Action Research Principles and Practice. London, Routledge Falmer.

McNiff, J. and Whitehead, J. (2010). *You and your Action Research Project.* Abingdon, Routlege Falmer.

Mind (2009). Personalisation in mental health: Creating a vision. [On-line] Available at www.mind.org.uk/campaigns\_and\_issues/policy.../putting\_us\_first. Accessed 14/6/2009.

Newbigging, K. and Lowe, J. (2005). Direct Payments in Mental Health: new directions. [On-line] Available at [ http://www.jrf.org.uk/publications/implementing-direct-payments-mental-health. Accessed 3.2.10.

Newbronner, L., Chamberlain, R., Bosanquet, K., Batlett, C., Sass, B. and Glendinning, C. (2011). Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers. [On-line] Available at http://www.scie.org.uk/publications/reports/report40/index.asp. Accessed 3.4.12, Social Care Institute for Excellence.

Punch, K., F (2005). *Introduction to Social Research.* London: Sage.

Rabiee, P., Moran, N. and Glendinning, C. (2009). Individual Budgets: Lessons from Early Users Experiences. *British Journal of Social Work*, 39, pp. 918-935.

Reid Howie Associates. (2010). Study of the workforce and employment issues surrounding self-directed support. Edinburgh: Scottish Government Social Research.

Riddell, S., Priestley, M., Pearson, C., Mercer, G., Barnes, C., Jolly, D. and Williams, V. (2006). Disabled People and Direct Payments: A UK Comparative Study.

Ridley, J. and Jones, L. (2002). Direct What? A Study of Direct Payments to Mental Health Service-users. Scottish Executive Central Research Unit [On-line] Available at http://www.scotland.gov.uk/Resource/Doc/156674/0042103.pdf. Accessed 19.7.2009.

Ridley, J. and Jones, L. (2003). Direct What? The Untapped Potential of Direct Payments to Mental Health Service-users. *Disability and Society*, 18(5), pp. 643-658.

Ridley, J., Spandler, H., Rosengard, A., Little, S., Cornes, M., Manthorpe, J., Hunter, S., Kinder, T. and Gray, B. (2011). Evaluation of Self-Directed Support Test Sites in Scotland. [On-line] Available at [www.scotland.gov.uk/Resource/Doc/358197/0121078.pdf. Accessed 14.4.2012](http://www.scotland.gov.uk/Resource/Doc/358197/0121078.pdf.%20Accessed%2014.4.2012).

Silverman, D. (2006). Interpreting qualitative data: Methods for analysing talk, text and interaction. 3rd edition. London: Sage.

Spandler, H. and Vick, N. (2004).*Direct Payments, Independent Living and Mental Health: An Evaluation.*London: HASCAS.

Spandler, H. and Vick, N. (2005). Enabling Access to Direct Payments: an explanation of care coordinators decision making practices. *Journal of Mental Health*, 14(2), pp. 145-155.

Spandler, H. and Vick, N. (2006). Opportunities for independent living using direct payments in mental health. *Health & Social Care in the Community*, 14(2), pp. 107-115.

Staniszewska, S. (2009). Patient and public involvement in health services and health research: A brief overview of evidence, policy and activity. *Journal of Research in Nursing*, 14, 295-298.

Stevens, M., Glendinning, C., Jacobs, S., Moran, N., Challis, D., Manthorpe, J., Fernandez, J.-L., Jones, K., Knapp, M., Netten, A. and Wilberforce, M. (2011). Assessing the Role of Increasing Choice in English Social Care Services. *Journal of Social Policy*, 40(2), pp. 257-274.

Tyson, A., Brewis, R., Crosby, N., Hatton, C., Stansfiedl, J., Tomlinson, C., Waters, J. and Wood, A. (2010). A report on In Control’s Third Phase. [On-line] Available at www.in-control.org.uk. Accessed 13.9.2010.

Webber, M., Treacy, S., Carr, S., Clark, M., Parker, G. (2014). The effectiveness of personal budgets for people with mental health problems: a systematic review. *Journal of Mental Health,* 23(3),146–155.

Williamson, G., R, Bellman, L. and Webster, J. (2012). *Action Research in Nursing and Healthcare.* London: Sage.

Witcher, S., Stalker, K., Roadburg, M., & Jones, C. (2000). Direct Payments: the impact on choice and control for disabled people. [On-line] available at www.scotland.gov.uk/.../2f2d68f2-4138-417a-9755-17e1148928bc. Accessed 13.8.2008.

**Figures**

**Planning:**

Interviews with Co-researchers; Steering group nos. 1, 2 & 3

**Act and Observe:** Further collection of financial data; eight training sessions withRecovery coordinators

**Further Planning:**

Steering group 4 & 5; meetings in Trust

and Local Authority

Reporting and sharing progress to Local Authority planning group

Reporting and sharing progress with Local Authority planning group

**Acting**:

Adapting the Resource allocation System and collecting financial data for pilot; two Direct Payment workshops with Recovery Coordinators; meetings in Trust and Local Authority

**Reflection:**

Steering group meetings; debriefs, correspondence with Co-researcher; Lead Researcher’s diary

**Figure 1: Spiral One: First phase of project**

**Planning:**

Steering group 6, 7 & 8; meetings with Local Authority and Trust management.

**Further action and observations:** Presentation to Trust conference, two workshops with Recovery Coordinators and service-users, two further focus groups one each with service-users and carers.

Personal Budget Allocation planning group influence

**Action:**

Three training sessions; three provider workshops; Two focus groups (One each with service-users and carers); workshop with Recovery Coordinators

**Further Planning:**

Steering group nos. 8, 9 and 10; meetings with Local Authority and Trust management

**Reflection:**

Four meetings with co-researchers; steering group meetings and diary

Personal Budget Allocation planning group, Personal Budget Project Board and personalisation task group in Local Authority influence

**Figure 2: Spiral Two: Second phase of the project**

**Planning:**

Steering group nos. 11 and 12; meetings with Trust and Local Authority management

**Further Action and Observation**:

Further focus group with Recovery Coordinators; eleven training sessions to Recovery Coordinators; training feedback session.

Local Authority choice and control theme board and Trust Executive influence on planning

**Further Planning**:

Meetings with Trust and Local Authority management

Local Authority choice and control theme board and Trust Executive influence on planning

**Action:**

Focus groups with Recovery Coordinators

**Reflection:**

Steering groups, Lead Researcher diary

**Figure 3: Spiral Three: Third phase of the project**

**Tables**

|  |  |  |
| --- | --- | --- |
| Participant Representative | Number approached | Number attended |
| Service-users Focus Group 1 | 9 | 5 |
| Carers Focus Group 2 | 11 | 11 |
| Service-users Focus Group 3 | 7 | 6 |
| Carers Focus Group 4 | 10 | 10 |

**Table 1: User and carer participants at focus groups**

|  |  |  |
| --- | --- | --- |
| **Theme** | **Issues discussed by service-users and carers** | **Issues discussed by recovery co-ordinators**  |
| Capability to manage | Effect on healthReduced capability Funding misuse | Contracted support preferred by manyPeople unused to taking on required levels of responsibilityMoney management is problematicRoll out of Personal Budgets should increase people’s confidence Protection from risk |
| Outcomes | IndividualisationHealth and wellbeing RecoveryQuality of life | Produce positive recovery based outcomesDirect Payments for respite, personal care and activities beneficialRemoving Direct Payments can be difficult once set up |
| Culture | Requires change to be more person-centred | Changing commissioning contextDifficulties in embracing choice and control agenda |
| Information and advice  | [Not discussed by service-users and carers] | Recovery coordinators are seen as providing information but lack knowledgeConcerns about raising expectationsProcess simplification neededExternal provider of information, advice and support welcomed |

**Table 2: Themes and issues discussed in each theme from focus groups with service-users and carers and recovery co-ordinators**