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I was very happy to be asked to provide support for the production of the papers published here. My days as a researcher and teacher on issues about social care and health services are long behind me. Working with these papers particularly recalled my time at the School for Advanced Urban Studies at the University of Bristol. Much of our ‘bread and butter’ work there was the provision of short courses and practical research for local authorities and health authorities. But at the same time we developed a graduate course on policy studies and more ‘academic’ research on issues like policy implementation. The result was, for me, what often seemed a rather schizoid existence. The connections between detailed work on day to day practice issues and my aspiration to contribute to academic policy studies that could have international credibility were very often hard to make. That is still the case, though now the latter activities are much more salient in my life than the former.

It has therefore been particularly interesting to me to work with the authors of the studies reported here at the same time as I have been involved with colleagues from the Netherlands and Switzerland in editing a book of academic studies of the roles of street-level bureaucrats. All the studies reported here are about street-level activities in the broad sense of that term, that is about the realities of policy implementation. Of course they are very different from each other, and the professional concerns that are reflected in them are different and would be undervalued if they were just put together in an effort at overarching generalisation. Nevertheless there is something to be said about what they have in common, and it is very important for a wider debate – and not just an academic debate – about policy implementation.

That debate concerns the importance of discretion at the local level. In public policy implementation there is an inherent conflict between the case for top down regulation (responsive to political expectations and managerial expertise) and that for extensive discretion at the street level. The case for the former tends to be made very strongly these days. Responses to problems in policy delivery tend to involve arguments for tighter regulation and stricter inspection. It is important that this debate does not become a polarised one, there are things to be said for both perspectives and much depends upon issues and context. The work with my colleagues (Hupe, Hill & Buffat, 2015) has been particularly directed to the initiation of comparative exploration of the sources of differences in respect of the balance between rules and discretion. So there are important issues about how the ways in which specific tasks are performed, and about the inevitability of a measure of discretion in all tasks. But we must not lose sight of the underlying normative issues about how they should be performed. Baroness Neuberger said in respect of end of life care ‘caring for the dying must never again be practised as a tick box exercise’ (Independent Review of the Liverpool Care Pathway, 2013). I think the same should be said of many aspects of the caring tasks reported in these articles. Hence, to me, the common theme across these articles is the importance of having regard to the specific nature of the tasks involved, of recognising that they illustrate aspects of caring activities that cannot easily be routinised, and probably should not be routinised.

Phil Coady’s contribution is particularly relevant in providing an illustration of the complexity of residential care work, introducing the many sensitive issues that have to be addressed in the management of relationship between carers and children. Here there is a crucial balance that has to be found between minimising risk and maximising a caring relationship. In the current climate there must be a considerable temptation to maximise rules aimed at minimising risk, or at least the blame that follows when things go wrong. Yet his study shows wide variations in practice, governed by sensitivity to diverse situations. Individual, but of course professionally informed judgements, are essential.
This same theme comes up in a different way in Rhian Taylor’s article on supervision within a youth offending service. Here the concern is about a need for management styles that resist the pressures towards a ‘tick box’ approach. Rhian identifies a tradition of seeing supervision in social work as an activity which encourages practitioners to be reflective ‘at the process or critical level’ and explores ways in which this tradition may be keep alive. Here then the concern is with the preservation of a satisfactory level of autonomy both on part of both managers and those they manage.

The article by Naomi Clewett explores issues about the termination of personal budgets in mental health work and that by Lauren Chakkalackal on peer support of people with dementia may seem to have very different focuses from those mentioned so far, or indeed from each other. However, both echo aspects of the ‘personalisation’ theme in social care, which can only be developed effectively if the ‘persons’ are involved in a meaningful way. This implies that discretion in social care is about the relative autonomy of those receiving care as well as those giving it. A crucial issue for Naomi Clewett’s study is a need for those receiving time limited budgets to experience, and be involved with, goal-oriented progression in their care, not just the formal stopping of payments. Self evidently the ‘peer support’, shown by Lauren Chakkalackal to be beneficial for the care of people with dementia, cannot be the subject of formal regulation.

Finally, as a contrast to the previous two articles discussed here, Joy McLaggen takes us into an area of work that is clearly subject to regulation, the work of occupational therapists in the provision of equipment and adaptations for bathing and showering by handicapped people. What then is significant, from the point of view emphasised in this short note, is that this activity is most effective where decisions are negotiated with those to be helped, taking into account their needs and preferences.

Taken together these articles offer a presentation of the necessary diversity of care work, indicating implicitly the importance of discretion at the local level to adapt systems effectively to the needs of consumers.

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Over the last two decades the focus of activity related to getting research outputs used in practice, has evolved from simplistic two-way models of knowledge transfer to more holistic understandings of a knowledge ecosystem. Traditionally, two-way models saw a focus that relied on researchers ‘pushing out’ their knowledge through dissemination, or research users and practitioners ‘pulling it’ into their practice from sources they considered reliable. A decade or so ago a move was made towards the consideration of more complex relationship models as a focus on linkage and knowledge transfer as exchange emerged (Lomas, 2000; Lavis et al., 2002).

While exchange models are still the focus of scrutiny to understand the key characteristics at play (Pentland et al., 2011), they have tended to be replaced more recently by a focus on knowledge brokerage (Lomas, 2007), systems and processes decision-making (Mitton et al., 2007; Wilson et al., 2010) and knowledge mobilisation (Bennet & Bennet, 2007).

Despite their differences in focus, the commonality underpinning all of these approaches is the common emphasis on ensuring research is actually used in practice.

**Challenges and mechanisms**

If we were to conduct a straw poll of those reading this article, I have every confidence that the vast majority of you would agree that research should serve a purpose beyond creating or capturing new knowledge. To do so, to have a practical impact, this knowledge and research evidence needs to reach those who can use it. While this may feel a little obvious in principle, we are still far from reaching this reality in practice.

Lavis et al. (2006) identified four challenges to research being used in action:

1. Research is competing with other factors in the decision-making process.
2. Decision-makers do not always value research evidence.
3. The available research evidence may not be relevant for all audiences or decision-makers.
4. Research evidence is not always easy to access or use.

They then developed a much referenced framework to support the development of a knowledge exchange strategy that would address these factors. The framework consists of four methods that interplay to support the use of research in practice: developing a culture that supports research use; producing relevant research evidence; proactively acting to link research evidence to action; and evaluating these efforts. Of course we could argue that anyone who receives research funding should be routinely addressing each of these elements, as responsible researchers.
In the UK, Nutley et al. (2007) identified five prevalent strategies and mechanisms for effective research use:

1. Dissemination (circulating and presenting research findings).
2. Interaction (developing links between stakeholders and audiences).
3. Social influence (experts and peers informing and persuading on the value of research).
4. Facilitation (support to enable the use of research – this could be technical, financial, organisational or emotional).
5. Incentives and reinforcement (using rewards to reinforce desired behaviour).

Yet despite all of this awareness, we still appear to be no closer to the meaningful and routine use of evidence in practice. As Watson et al. (2012) reflect ‘in the complex world of social care, with its competing priorities and demands on resources, the process of getting research into practice remains fraught with difficulty’ (p.97).

**SCEiP project**

Back in 2012 a small team at LSE were awarded funding from LSE’s Higher Education Innovation Fund to explore practical approaches and ideas for getting social care research evidence into practice. The SCEiP (Social Care Evidence in Practice) project intended to explore ideas and give all interested parties the opportunity to ‘taste’ different approaches, regardless of their relationship to research and knowledge. The project started with an unconference (an event where the agenda is set in real time by participants attending on the day) open to anyone who was interested. The discussions held on this day set the agenda for the project moving forward. One of the more traditional approaches explored during the project were conferences and workshops. One of these conferences was JSWEC 2014 (Joint Social Work Education and Research Conference).

This commentary piece emerged out of the conversations and discussions had throughout the course of the SCEiP project and particularly one such discussion between workshop participants at the 2014 JSWEC Conference. This piece highlights some of the issues related to identity that have been raised to enable you (the reader) to consider them when planning or engaging in research about, or for, practice. In this instance practice refers to the daily undertakings of those working in adult social care or social work.

**JSWEC workshop**

Our workshop: *What’s the point of your research anyway? Exploring connections between research and practice* was intentionally designed to be interactive and provoke reflection on the challenges of getting research used in practice.

It was attended by a mixed group of 14 participants. The first exercise was a speed-networking task where participants introduced themselves to each other. This revealed a mixture of people who were social work practitioners, educators, and researchers (some a combination of more than one role). Participants then paired up and discussed what motivated them to conduct research, or work in practice or education, before sharing as a large group.

We then used small group activities to explore the barriers and facilitators to research being used in practice, and for researchers to engage practitioners in their work. The groups then mapped what they considered to be an idealised research process, considering different methods and ideas for breaking down barriers at each stage.

The workshop concluded with a discussion about how participants felt they could increase the use of research in practice, and what knowledge exchange methods produced the most impact for them.
Themes emerging from the workshop

One of the unexpected additions to the workshop was a cartoonist who was attending the conference, and joined us to capture any key points visually. He perfectly captured the initial discussion by sketching a person wearing three stacked hats; one labelled researcher, one academic, and one social worker. Sharing this image on social media with the question ‘does how you identify impact on practice?’ elicited similar responses to those in the room, about the complexity of balancing different roles.

Three key themes emerged through the workshop discussion: primary identity; confidence; and whether people felt they had sufficient knowledge.

Primary identity

The vast majority of participants strongly identified as social workers/social work students, or educators, first and foremost. Given the focus of the conference, and the delegates in attendance, this is not entirely surprising. We did not anticipate many researchers being in attendance, although several participants did identify as academics or researchers, but usually as an addition to some other primary identity. There was also a useful discussion about those who use services, and the interplay between many of us as professionals, while also service users, at some time of our lives.

Confidence

The strength with which most people identified as being in one field over another surprised one of the attendees who raised the issue of confidence in moving between roles. He felt that his strong identity meant he could cross boundaries and he expressed his surprise at what he considered to be others' construction of false dichotomies.

We also discussed how those receiving services have to quickly develop confidence and competence at navigating silos and ‘service land’.

Knowing enough

Confidence was also a discussion point raised by other participants, in relation to their relative experience and knowledge in their non-primary role. Participants talked about ‘not being experienced enough’ or ‘not knowing enough yet’ to consider themselves researchers or academics. There also appeared to be some distinction made between researchers (used interchangeably with the term academics) and those who viewed themselves as ‘educators’ who seemed to have non-research roles.

Identity within the research-practice literature

A quick scan of the literature in relation to researcher/practitioner identity raised a number of related factors to those that were explored in the workshop.

The role and status of practitioner research

A School for Social Care Research (SSCR) methods review by Shaw et al. (2014) explored the role of practitioner research in social care, considering its role as a source of knowledge for applying to practice, and as a method for how practitioners could conduct inquiry.

While they suggest that the practitioner/academic distinction makes less sense in some health or social care academic roles designed to cross traditional practice and academic boundaries, they acknowledge that ‘the person or people having a primarily practice identity did not hold the lead’ in many of the studies they reviewed (p.33).
They recommend that practitioner research is not seen as being a separate form of research, imploring readers to avoid ‘invidious distinctions of naïve versus mature, small versus large, and practitioner versus practitioner/academic models of practitioner research’. They go on to say that ‘these distinctions are premised on an unquestioning academisation of practitioner inquiry’ (p.37).

It may be that in focusing on developing practitioner-led research the distinction between researcher and practitioner has become amplified. It is also possible that the issues of confidence and ‘knowing enough’ raised by workshop participants actually emerge as a result of the low status, and incidence, of practitioner research in social care.

**Promoting social or political change**

Collinson (2004) in her research on the occupational identity of social science contract researchers in higher education, found those with professional experience in health, social work or law frequently entered contract research because they believed it was a good opportunity to promote social and political change, despite then ‘tolerating such a marginal status with all its attendant insecurities’ (p.317).

Contract researchers’ conceptions of identity were dependent on a number of factors including their biographical history, their academic capital, where they worked and prior research experience. Those with a social justice background had self-images still, at least partly, located in their earlier occupational experience and they viewed contract research as a practical tool to influence their fields and improve people’s life experiences.

This view of research as a lever for change is often proffered in relation to action research, where discussion of power dynamics at play are not unusual:

‘Empowering’ the women who take part is a primary aim of this kind of research, with fully participatory research involving participants in all stages of the research process, including the identification of the initial question or problem to be studied (Gillies & Alldred, 2012, p.51).

**Whether it’s possible to hold two, or more, separate identities**

It was clear in the workshop that most people had a primary identity that they related to. There was also discussion about whether it is possible, necessary, or indeed beneficial to differentiate between professional identities. Bell & Nutt (2012) discuss this issue in relation to Nutt’s dual roles of social worker and researcher:

*Before commencing this research she decided that she would not be a ‘social worker’ in the research interviews as she wanted to conduct them in a very different manner. For her this was new, less sure ground and she wanted to keep separate the two experiences of ‘doctoral researcher’ and ‘social work practitioner’* (p.82).

Despite Nutt’s best attempts to conceptualise the roles as separate identities, the overlaps were too great and she reflects that it was impossible to avoid wearing two ‘hats’ at the same time.

Anecdotally we know of career track researchers from the SCEiP project that started their careers in social care or social work practice, or have been involved in social care during their research careers (for example as carers to their own family members). Interestingly in those examples, it is only when looking at CVs or social conversations does this become evident. It is not an identity that these researchers put forward (even as secondary to their researcher role), yet it influences how they approach their research and their understanding of the practitioners they are engaging with or participants in their studies.
Implications of identity for getting evidence into practice

The workshop's discussions, and wider literature on professional identity, raise several considerations for the practice of getting evidence used in practice.

Three of the challenges that Lavis et al. (2006) identified were the competing priorities at play during the decision-making process, the lack of value placed on research, and the lack of relevance of research evidence.

Quite simply, if research is to be considered valuable and relevant by those who identify as practitioners first and foremost, it needs to be situated within the practice arena.

One potential avenue for the embedding of research evidence into social care practice, is to build relationships with existing groups, networks or professional bodies. It is clear from Collinson's work, and our workshop, albeit with a small group of participants, that most people had a primary identity that related to their professional training and practice. Therefore, connecting with the professional support systems for that identity is likely to lead to new audiences for that research, which in turn are likely to increase the chances of it being adopted into practice.

Action research, or practitioner-led research, are two approaches that are perhaps more likely to produce relevant and useful research. Clearly articulating how your research could be used to bring about practical changes, or increased social justice, is also likely to engage those from a social care or social work background.

Genuinely joint research, that involves practitioners (and/or other stakeholders and interested parties) at the start of the process, and on an equal footing throughout, is also likely to produce research that is successfully embedded in practice.

A truly co-produced, co-researched approach to knowledge generation would meet almost all of Nutley et al.'s mechanisms for research use. Interaction between all key stakeholders would guarantee social influence and dissemination, as participants share their experiences with colleagues. Actively engaging a range of stakeholders in the research process would also have the beneficial outcome of increasing their capacity for conducting, and understanding research. This in turn would increase people's confidence in research activity, and reduce any need for incentives or rewards.

Many of the implications above bring their own perceived barriers. Funding is, of course, at the top of the list. Ideally engagement takes place prior to the start of any research study, and preferably in designing research proposals. Yet we know from conversations throughout the SCEiP project that developing relationships and discussing priorities prior to research funding applications is seen to require resourcing not currently available, and requires a leap of faith that time spent on developing these relationships and identifying priorities will not be ‘wasted’. There is a role here for funders to make funding more accessible, and potentially introduce seed funding channels; however, arguably there is also a need to manage the expectations of all those involved, to understand the perspectives that people identify with, and for relationships developed in previous studies or through networking events to be built upon. In order to lead to a change in approach, we need to commit to building those relationships to utilise current evidence and expertise, which in due course may lead to action research or more representative research teams. This is particularly required when research funding calls have short timeframes for proposal submissions.

Another perceived barrier is the lack of information held by researchers about non-academic settings, practitioners and educators and their research interests. Discussions with academic researchers within the SCEiP project have repeatedly raised concerns about not knowing who
to approach, how to engage with the various professional networks and (for some newer researchers) generally where to start.

**Implications of identity for research**

Shaw and colleagues (2014) identified 72 relevant studies from their research on practitioner research. They noted that:

> **One of the more significant differences is associated with the professional and occupational roles of the authors and the relationships between joint authors. ...**[For those undertaken within a health context] those involved were not either practitioners or university-based researchers but occupied roles that included both service provision and scholarly activity... Single practitioner research was relatively unusual and was typically related to a study requirement for a university. Partnerships were more common, usually a practitioner and academic or specialist research role. There were also practitioner activities undertaken within larger group endeavours (p.5).

We know that those identifying predominantly as practitioners generally work within settings where research is not seen to be a priority, the time available is limited, as is support for research activities. There are also perceived to be limited research budgets available for practitioners to seek funding without some form of academic expertise within the proposal team. Where research is undertaken, it can be limited to internal knowledge sharing and only a ‘very small proportion of practitioner research studies... enter the public domain’ (Shaw et al., 2014, p.7). Producing journal papers, for example, is a priority for researchers based within academia but unlikely to happen for others. This in turn suggests there could be a wealth of evidence available within practice settings that we are just not aware of (Campbell et al., 2015).

A further activity the SCEiP project implemented was to seek professionals to support them to develop a journal article from research they had undertaken. The aim of this was two-fold: to support professionals to develop outputs – and open access peer-reviewed journal papers were chosen to do this – and secondly to encourage knowledge sharing from within practice organisations.

Applicants were offered academic mentoring support to develop their papers to a high quality standard. Once prepared they were submitted to the journal and subject to the journal’s external peer-review processes. No article was guaranteed acceptance but we did offer to support all the authors through peer-review and revisions until their article could be accepted. The mentoring support was made available not because there was a perceived lack of quality in the research itself that required addressing (although this has been raised as an issue in some SCEiP discussions), but to support practitioners to develop journal papers where this is not their immediate channel of communication.

Five were selected for mentoring support to develop their papers, as presented in this journal issue. Three were relatively new to research with the articles included in this issue being one of their first: one presents research as part of a Masters dissertation, a second covers findings from the first research study the author has undertaken (during her days off from her part-time position) and the third arose from a knowledge exchange initiative between a university and two local councils to support practitioner research. The remaining two authors are more experienced researchers working in non-profit organisations. As one noted in her application for support, this meant ‘an emphasis on quick and practical outputs’ where ‘opportunities for writing peer-reviewed papers have been limited’.

All five authors took up the opportunity of support from the academic mentor, as well as having access to additional support from the journal editors after submission, and developed their articles from reports previously written (and not all publicly available). These five identified as
social care professionals and responded to the call for applications addressed to professionals; two noted their titles as ‘Senior Researcher’ and ‘Research Officer’.

Alongside implications for evidence use in practice, there are implications for evidence generated within practice, and identity plays a significant role in both. There are improvements that are needed as to how knowledge is shared across social care research and practice; further breaking down barriers between identities is perhaps a first step.

**Conclusion**

Some of the issues emerging through the SCEiP project suggest that, perhaps not surprisingly, many people have more than one professional identity, although they seem to situate their self-concept within their primary role. The research-practice literature could benefit from a more holistic understanding and consideration of professional identity and its implication for engaging with, conducting or adopting research into practice. There are practical steps researchers, practitioners, educators, and those who support research and/or practice could take to enhance the type of evidence that is produced and the value it has for social care practice.

**References**


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Relationship boundaries in residential child care: connection and safety in group care relationships

A practitioner research study exploring boundary decisions of residential child care workers in their relationships with young people

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Abstract

Following a period in which the place of relationships in social care has been marginalised by an approach focusing on targets, outcomes, standards and regulation, there is a resurgence of interest in relationship-based approaches in both policy and practice arenas. However, it is not clear whether or not practices that have been influenced by prior policy positions and powerful discourses about the nature of professionalism will easily embrace this new position.

This practitioner research project was undertaken as part of a knowledge exchange project organised by University of Edinburgh in partnership with local authority children and families social work services to work towards reducing the gap between research and practice. This research project explores one aspect of the relationships between workers and young people in residential child care services – relationship boundary decisions of workers in a range of everyday situations, and the individual, organisational and contextual factors that appear to influence them.

A complex picture emerges, which suggests that relationship boundary decisions are influenced by a wide range of factors and does not support the idea that there are, or can be, clear boundary positions delineating the limits of professional behaviour.

Keywords: relationships, relationship boundaries, residential child care

Background

Engaging with people in helping relationships has traditionally been seen as a core function of social work and social care, and the relationship has been seen as a core element of the efforts of workers to offer help (O’Leary et al., 2013). In the late 20th century, the place of the helping relationship in social care became marginalised by the emergence of case management approaches focusing on standards, outcomes and targets. However, there has been a recent resurgence of interest in relationship-based working (Ruch, 2010; Smith, 2009). This interest is not confined to academic and practice settings. Government reports regarding child protection (Munro, 2011), youth justice (Youth Justice Board, 2008), family support and preventative services, (Ofsted, 2011) and residential and foster care (Scottish Government, 2013) have recognised the important influence of relationships on the effectiveness of interventions. This raises the question of whether conceptions of relationship boundaries that have been influenced by previous managerialist orientations towards social work and residential child care will be compatible with re-emerging relationship-based approaches.

Fewster (2004, p.11) defines a relationship boundary as ‘an imagined construct created by individuals to maintain a distinct and differentiated sense of self in their relationships with others’. Gharabaghi (2010) argues that, in care relationships, boundaries are relational, and points out that boundaries are an important feature of personal as well as professional relationships. Definitions of this kind suggest that, whilst relationship boundaries may be associated primarily with creating and protecting professional distance, there is necessarily a different emphasis in the way that boundaries are conceptualised in the care relationship; an
emphasis, not simply on distance, but also on connection. Doel et al. (2010) suggest that, while it is common for relationship boundaries to be conceptualised as lines representing clear demarcations between professional and unprofessional behaviour, in reality, boundary areas might more accurately be depicted as ‘the shadows’; contested areas over which competing claims might be made.

Just as social work, as a new profession, borrowed from more established professions, and in particular, medicine, leading to the development of boundaries prioritising professional distance (Alexander & Charles, 2009; Stuart, 2008), residential child care, in turn, has borrowed from social work in establishing its professional identity (Smith, 2003; 2009). Having become part of the new profession of social work in the U.K., it might be assumed that residential child care relationships, and relationship boundaries, should be similar to those in other areas of social work. However, Steckley and Smith (2011) argue that, due to the volume and intensity of time spent together in residential child care, these relationships are not comparable, and similar boundaries would not be appropriate. Ricks (1992) argues that, because of differences between care and other forms of professional relationship, there needs to be a different ethical basis for caring that recognises the personal and reciprocal nature of this type of relationship. However, in addition to the adoption of a ‘professional distance’ approach to boundaries in residential child care, the impact of a succession of high profile scandals relating to historic abuse has created significant professional anxiety, leading to the adoption of defensive boundary positions (Kendrick, 2013). These events have led to the development of a significant gap between the boundaries that might be considered theoretically and practically appropriate to the care relationship and the boundary positions that have developed in practice.

Views expressed by young people in research interviews about what they need from their care relationships with workers are remarkably consistent with regard to relationship boundary issues. A number of studies, including Cree & Davis (2006), Doel & Best (2008), Happer et al. (2006) and Richmond (2010) suggest that service users value skilful boundary crossing behaviour, including physical contact, sharing personal information, developing special relationships, offering additional or flexible contact outside of normal working hours, going ‘the extra mile’ beyond the strict confines of the worker role and keeping in contact after the end of the official service period. Kendrick (2013) also notes that young people often describe positive experiences in residential child care using a family metaphor, illustrating the intimacy and sense of connection that can exist in these relationships. These findings, and, in particular, the ways in which young people describe the role of boundary crossing behaviours in confirming the significance of their relationships, appear to demonstrate not just the practical value, but also the symbolic significance of skilful and well-judged boundary crossing behaviour. This highlights the potential for boundary crossing behaviour, as part of a relationship-based approach, to be a powerful means of meeting children’s needs.

However, as Stuart (2008) points out, the language commonly associated with boundary crossing behaviour illustrates a bias in favour of fixed, distant positions. Boundaries might be described favourably as ‘clear’ and ‘consistent’, or unfavourably as ‘blurred’, denying the validity of uncertainty, complexity, and flexibility in relation to boundary issues. She argues that language that is more positive, or at least neutral, than blurring, breaching or violating boundaries, such as boundary crossing, is needed to describe the process of deploying boundaries flexibly to take account of need and context.

Davidson (2004) argues, however, that boundary breaches can happen in either direction, and that an ideal position would not be a position of distance, but a position of balance between being too enmeshed or too rigid. It may be that any binary separation of personal and professional is inadequate to represent the complexity of care relationships and their boundaries. In social pedagogy, the 3Ps framework (Steckley & Smith, 2011; Thempra, 2013) offers a paradigm that allows for finer distinctions; professional, personal and private. It has also been suggested that in care relationships, a different view needs to be taken of the function of the relationship. Whilst in many helping professions, the relationship might assist the
Fewster (2004; 2005) also suggests that helping children to develop appropriate relationship boundaries is an important part of the residential child care task, as their previous attachment and relationship histories often lead to the development of boundaries that are either too rigid or too weak to facilitate the development of healthy relationships. This argument suggests both that workers need to be skilled in managing complex work in this area and that a rule-bound approach that presents the same boundaries to each young person cannot effectively facilitate this work. He suggests, therefore, that it is important to distinguish between boundaries, which are dynamic and can be deployed flexibly, and barriers, which are static and prioritise consistent application.

There is recognition in the academic literature that conceptions of professional boundaries in social work and social care have been significantly influenced by the professional distance model of more established professions and the impact of scandals relating to historic abuse. In spite of this, there is consensus suggesting that flexibility to act in ways appropriate to both the context and the needs of individuals is to be preferred to aiming for rigid consistency in boundary setting. Issues regarding relationship boundaries are of great interest to workers engaged in the care of young people. This is reflected in the regularity with which these issues appear in the online discussion group of the child and youth care organisation, cyc-net (www.cyc-net.org), and the large number of comments, expressing widely varying points of view, that are posted each time these issues emerge. However, in spite of this widespread academic and practice interest, very little research exists relating specifically to the views of workers in residential child care services. I was only able to find two studies, both from the United States, one involving eight care workers from four agencies and their administrators (Richmond & Padgett, 2002) and another focusing specifically on work in two agencies with young people at the ‘termination phase’ of the service (Zirkle et al., 2002). For this reason, I set out to explore the views and behaviours of residential child care workers in Scotland with regard to relationship boundaries, and hoped to attract responses from a wide range of agencies. The research project was undertaken as a practitioner research project. It was part of a knowledge exchange project organised by University of Edinburgh and funded, with the aim of ‘maximising the impact of social science research outside academia’ by the Economic and Social Research Council (ESRC) alongside matched funding from participating local authorities, including my own employing organisation, East Lothian Council.

Methods

Whilst a significant amount of support for flexibility in relationship boundaries can be found in both the academic literature and the views of service users, the degree to which this kind of flexibility is currently valued in practice settings is unclear. Given the current lack of information about workers’ relationship boundary decisions, I prioritised achieving a sample of reasonable size and diversity, and carried out a survey using an online questionnaire. Robson (2002) points out a number of advantages and drawbacks of self-administered surveys. Achieving a representative sample can be difficult, as the sample is, in some respects, self-selecting. Social desirability response bias can interfere with survey respondents representing their views accurately, although this effect may be reduced by the anonymity of self-administration. Response rates are often low, and ambiguity can be an issue when there is no opportunity for clarification. However, this method also allows relatively large amounts of data to be collected relatively quickly, and the data collected is highly standardised.

Ethical clearance was given by my employing organisation. The main ethical concerns were that, as is often the case in practitioner research (Costley et al., 2010), some of the participants would be known to me, and that the content of some of the questions might feel sensitive to some practitioners. However, the fact that participants would not be directly approached, and
that responses, or a decision not to participate, could be made anonymously, addressed these concerns sufficiently.

The survey used a questionnaire that asked respondents to choose multiple choice responses to questions about 20 common relationship boundary issues, and also asked 13 contextual questions about respondents and the care settings in which they worked. All of the questions relate to issues that were raised by service users in the interviews mentioned above (Cree & Davis, 2006; Doel & Best, 2008; Happer et al., 2006; Richmond, 2010), were discussed by care workers in the cyc-net online discussion group (cyc-net.org), or appeared in the two previously mentioned research projects specifically exploring residential child care (Richmond & Padgett, 2002; Zirkle et al., 2002).

The questions asked how often participants engaged in behaviours that might be seen as boundary-crossing, offering a choice between four responses; ‘routinely’, ‘frequently’, ‘occasionally’ or ‘never’. Questions focused on 8 areas of worker behaviour: physical contact, spending time alone with young people in their bedrooms, sharing personal information, lending and gifts, special relationships, contact via mobile technology and social media, extended contact with young people (outside working hours or after the end of the placement) and contact with the worker’s family and home.

The intended sample was a mixed group of female and male and more and less experienced participants working in worker, supervisor and manager roles in residential child care organisations representing different care settings, sectors, sizes, placement lengths and age ranges of young people. Residential child care is carried out in a range of settings, including small care homes, larger residential schools, secure settings and some that offer a mix of secure and residential school places. There is a mix of local authority, voluntary and private provision. The ideal for any survey is to have a sample that is numerically representative in every respect. However, as respondents in this online survey were, to a large extent, self-selecting, it would not have been possible, without rejecting many responses, to guarantee a representative sample. As these services are offered by a large number of organisations, and there is no single umbrella organisation representing all services, I used a range of organisations which represent or provide a service to large numbers of residential child care workers and their organisations, to make contact with prospective respondents. These were Education Through Care Scotland, the residential child care sub-group of Social Work Scotland, University of Strathclyde’s MSc in Advanced Residential Child Care programme and the social networking groups belonging to the Scottish Residential Child Care Workers Association and the Social Pedagogy Development Network. Comparison with the Scottish Social Services Council’s workforce data for 2013 (SSSC, 2014) indicated that this produced a sample that was representative of the whole workforce in terms of gender, but that managers and local authority workers were over-represented and care workers and voluntary sector workers were under-represented.

In addition to seeking a larger sample from a range of organisations, I arranged to ask workers in my own organisation to complete the same survey and to analyse their responses separately as a comparison group. There were two reasons for using my own organisation as a comparison group. Firstly, exploring the impact of both organisational culture and individual differences would be better facilitated by having a sample from within a single organisation to remove additional variables. Secondly, I was aware that the organisation has developed, over a period of nearly 20 years, a culture of flexibility in relationship boundaries within the context of accountability to the team. I was keen to test a hypothesis that this would lead to relationship boundary decisions within this organisation being different from other organisations, as this might suggest that it is possible to operate with greater flexibility than is currently the norm. In this sample, both gender and work roles were representative of the overall workforce, but the entire sample was from a local authority care home service.
In total, I received 86 responses from a range of care settings of different sizes and representing public, private and voluntary organisations, along with 20 comparison group responses from my own organisation. Although the workers and organisations in the main sample remained anonymous, the different combinations of setting, sector, size and age range represented, as shown in Table 1, suggest that responses were received from at least thirty different care settings.

Responses were analysed to explore variations in boundary crossing behaviour in relation to different activities and, using the biographical and workplace information provided as variables, the influence on boundary decisions of factors such as gender, work role and care setting. In addition to analyzing each question separately, a semantic differential scoring scale was also used, allocating 3, 2, 1 or 0 points for each of the four possible responses. This allowed for exploration of the question of whether workers tended to have relatively fixed levels of boundary flexibility across the range of questions and facilitated broad analysis of the main sample and comparison group.

Findings

Physical contact and physical intervention

Responses suggested that, for most workers (61%) physical contact with young people was seen as a frequent or routine occurrence. Participants from settings including younger children reported higher levels of routine physical contact than those with only older children (47% compared to 27%), and those offering mainly long-term placements also reported more routine or frequent levels of physical contact than short-term placements (65% compared to 38%). Male and female responses were broadly similar, although slightly higher numbers of female workers considered contact to be routine (35% compared to 31%) rather than occasional (35% compared to 41%). Nearly all respondents (98%) reported some involvement in physical intervention. For most (72%), it was seen as an occasional occurrence. However, for 26%, it was seen as either a routine or a frequent occurrence. The 12% who saw physical intervention as a routine occurrence represented only 4% of female responses, but 21% of male responses.
Spending time in young people’s bedrooms

Most participants (93%) reported spending time alone with young people in their bedrooms. Women tended to spend time in bedrooms more routinely or frequently than men (53% compared to 32%). It was also reported slightly more frequently by respondents in placements with mainly older children. More than a third of participants (35%) had shared bedroom (or caravan or tent) accommodation with young people, illustrating the intimate situations within which workers and young people sometimes build their relationships.

Sharing information

Most participants (90%) reported sharing some information about life events or family relationships with young people. For nearly a third (30%) this was either a routine or a frequent occurrence. Most respondents also reported sharing some personal information. Some (19%) appeared to be comfortable sharing information about life events but not personal information connected to where they live and who is in their family.

Lending and gifts

A majority of participants (59%) reported giving or receiving gifts. Women were more likely to give gifts than men (65% compared to 48%) and managers more likely than supervisors and workers (77% compared to 53%). Gifts appeared to be more likely to be given in placements including younger children (73% compared to 52%) and in settings offering mainly long-term placements (60% compared to 52%). The pattern of responses for giving gifts and lending were fairly similar. However, in general, lending appeared to be less problematic for workers than gift giving. Participation was slightly higher overall, with 74%, compared to 59%, participating. Again, women were more likely to report lending possessions either routinely or frequently (25% compared to 10%) and less likely never to lend (20% compared to 29%).

In relation to spending their own money on the group, a broadly similar pattern to giving gifts emerged. Although fairly equal numbers of men and women appeared to participate overall, more women participated either routinely or frequently (12% compared to 3%). Spending their money on an individual young person appeared to be a different prospect for some participants. As a result, only 45% reported spending money on an individual young person, compared to 62% who reported spending money on the group. It may be that this suggests that for some workers, treating everybody in the group in the same way is an important part of their concept of fairness. This possibility also arises in relation to other questions in the survey.

Special relationships

Nearly two thirds of participants (65%) reported never having relationships with a young person that are different from their relationships with others. Men were slightly more likely (44% compared to 35%) to report developing relationships of this kind, and managers and supervisors (50% compared to 28%) more likely than residential workers. Comments made by a few workers suggested that it was important to them to treat everybody the same. Avoiding treating a child unfavourably or creating a sense of unfairness without missing significant opportunities for a child to feel special to somebody is complicated in a group care setting. However, treating everybody the same may achieve the first at the expense of the second.

Extended contact with young people

A small majority (52%) reported having continuing contact with young people who had moved on. Managers were more likely than supervisors and workers to have contact of this kind (86% compared to 43%). Overall, only 9% of respondents reported having either frequent or routine contact. The fact that so few respondents reported having regular continuing contact with young people for whom they have provided care suggests that meaningful aftercare contact may still be far from being a well-established part of the care of young people in residential child care placements. Responses about contact with young people outside normal working hours were
mixed. A majority (59%) had no additional contact of this kind. Of the remaining 41%, almost all (38%) had this contact occasionally. Managers were more likely than supervisors and workers (60% compared to 35%) to have contact outside working hours.

**Contact with family, friends and home**

Contact with family and friends featured, mostly as an occasional occurrence, for 46% of respondents. It seems likely that almost all of this contact was with family members, as several comments mention family, but none mention friends. Managers were more likely than workers (73% compared to 35%) to report this kind of contact. It was significantly less likely that a young person would visit the home of a worker. For 85% of respondents, this had never happened. For those who had occasionally had a visit at home from a young person, a higher proportion were female (15% compared to 10%). However, the greatest differences in responses were between participants in different work roles. As for all forms of extended contact, managers were more likely to demonstrate flexibility in the boundary between work life and home life. Nearly a quarter (24%) of managers, compared with 9% of residential workers, had contact with a young person at home.

**Contact by mobile technology and social media**

Overall, use of mobile technology, including calls from mobiles, texts and social media, was the area in which most workers reported that they never engaged. Only 8% reported sharing their mobile number with a young person and having contact with a young person by text. Comments suggested that continuing contact with young people who had moved on appeared to be the most common situation in which this contact occurred. Contact through social media such as Facebook or Twitter was even less common than contact by text or mobile, and was the activity in which fewest workers in the sample (6%) engaged. Comments suggested that this contact, where it existed, also tended to focus on young people who had moved on, and focused on groups more than individuals.

**Comparison of responses from main sample and comparison group**

Comparison of overall responses between the main sample group and the comparison group from my own organisation reveals many differences in the proportionate use of the 4 available responses (routinely, frequently, occasionally and never). The comparison group, at least in some areas of the survey, seems to be an outlier. Responses to most questions (16 out of 20) were more flexible in relation to crossing boundaries than in the main sample. Using the semantic differential scoring system allocating 3, 2, 1 or 0 points to the four available responses to reflect overall boundary flexibility, the comparison group scores were, on average, over 50% higher (1.05 compared to 0.69) than the main sample. However, in spite of this, there are two important respects in which these differences cannot accurately be described simply as a generally greater level of boundary flexibility.

Firstly, the comparison group had a higher incidence of ‘frequently’ and ‘occasionally’ responses, but a lower proportion of both ‘routinely’ and ‘never’ responses, occupying the intermediate, rather than the extreme, positions more often. Secondly, there were areas in which the comparison group scores were similar or even slightly lower. It was within the areas in which the main sample scores were lowest, and in particular, in relation to additional, extended and home contact and contact via mobile technology that a chasm emerged between the two samples. Overall, average numbers who participated, to any degree, in the four extended contact activities were nearly twice as high in the comparison group (77.50% compared to 39.75%). In relation to mobile technology and social media, an even wider difference emerged (65% compared to 8%). This suggests that, in the main sample, strong taboos may exist in these areas, leading very high numbers of workers, many of whom were willing to cross boundaries in other areas, to completely avoid boundary crossings. In the comparison group, however, although there were areas where boundary crossing behaviour was less common, there was no evidence suggesting the existence of strong taboos.
Table 2. Questionnaire responses of main sample.

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Question</th>
<th>Routinely (=3)</th>
<th>Frequently (=2)</th>
<th>Occasionally (=1)</th>
<th>Never (=0)</th>
<th>Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Physical Contact (%)</td>
<td>34</td>
<td>27</td>
<td>35</td>
<td>5</td>
<td>1.92</td>
</tr>
<tr>
<td>2</td>
<td>Spending time in Young People’s Bedrooms (%)</td>
<td>20</td>
<td>27</td>
<td>47</td>
<td>7</td>
<td>1.58</td>
</tr>
<tr>
<td>3</td>
<td>Sharing Information about Life Events (%)</td>
<td>15</td>
<td>15</td>
<td>59</td>
<td>10</td>
<td>1.36</td>
</tr>
<tr>
<td>4</td>
<td>Physical Intervention (%)</td>
<td>12</td>
<td>14</td>
<td>72</td>
<td>2</td>
<td>1.34</td>
</tr>
<tr>
<td>5</td>
<td>Sharing Personal Information (%)</td>
<td>14</td>
<td>16</td>
<td>41</td>
<td>29</td>
<td>1.15</td>
</tr>
<tr>
<td>6</td>
<td>Lending Possessions (%)</td>
<td>7</td>
<td>10</td>
<td>57</td>
<td>26</td>
<td>1.00</td>
</tr>
<tr>
<td>7</td>
<td>Giving and Receiving Gifts (%)</td>
<td>5</td>
<td>7</td>
<td>48</td>
<td>41</td>
<td>0.77</td>
</tr>
<tr>
<td>8</td>
<td>Spending Money on the Group (%)</td>
<td>3</td>
<td>5</td>
<td>53</td>
<td>38</td>
<td>0.73</td>
</tr>
<tr>
<td>9</td>
<td>Aftercare Contact (%)</td>
<td>3</td>
<td>6</td>
<td>43</td>
<td>48</td>
<td>0.65</td>
</tr>
<tr>
<td>10</td>
<td>Spending Money on an Individual Young Person (%)</td>
<td>3</td>
<td>3</td>
<td>38</td>
<td>55</td>
<td>0.56</td>
</tr>
<tr>
<td>11</td>
<td>Contact with Worker’s Family and Friends (%)</td>
<td>1</td>
<td>3</td>
<td>42</td>
<td>53</td>
<td>0.53</td>
</tr>
<tr>
<td>12</td>
<td>Contact outside Working Hours (%)</td>
<td>1</td>
<td>2</td>
<td>37</td>
<td>59</td>
<td>0.47</td>
</tr>
<tr>
<td>13</td>
<td>Special Relationships (%)</td>
<td>2</td>
<td>5</td>
<td>28</td>
<td>65</td>
<td>0.44</td>
</tr>
<tr>
<td>14</td>
<td>Sharing Bedroom Accommodation (%)</td>
<td>2</td>
<td>3</td>
<td>30</td>
<td>64</td>
<td>0.43</td>
</tr>
<tr>
<td>15</td>
<td>Telephone Contact</td>
<td>1</td>
<td>2</td>
<td>26</td>
<td>71</td>
<td>0.34</td>
</tr>
<tr>
<td>16</td>
<td>Contact with Worker’s Home</td>
<td>0</td>
<td>1</td>
<td>14</td>
<td>85</td>
<td>0.17</td>
</tr>
<tr>
<td>17</td>
<td>Giving or Lending Money (%)</td>
<td>0</td>
<td>0</td>
<td>13</td>
<td>87</td>
<td>0.14</td>
</tr>
<tr>
<td>18</td>
<td>Giving Young Person Mobile Number (%)</td>
<td>1</td>
<td>0</td>
<td>6</td>
<td>93</td>
<td>0.10</td>
</tr>
<tr>
<td>18</td>
<td>Text Contact with Young Person outside Work (%)</td>
<td>0</td>
<td>1</td>
<td>7</td>
<td>92</td>
<td>0.10</td>
</tr>
<tr>
<td>20</td>
<td>Social Media Contact (%)</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>94</td>
<td>0.09</td>
</tr>
<tr>
<td>Overall Mean Score</td>
<td>6.20</td>
<td>7.45</td>
<td>34.95</td>
<td>51.20</td>
<td>0.69</td>
<td></td>
</tr>
</tbody>
</table>
The comparison group also helped to clarify that both individual differences in worker behaviours and organisational culture appear to influence boundary decisions. It was a notable feature, in the main sample, that there appeared to be workers who had an overall ‘style’ of flexibility or rigidity. More than a quarter of the group (29%) had scores of 0-9 on the semantic differential scoring system, indicating that they used the ‘never’ response for most questions, whilst another group (17%) had scores of 20 or higher, indicating much more infrequent use of this response. However, it also appeared that these individual differences were also mediated by culture, as the comparison group, although it still contained a range of responses (scores ranging from 12 to 36), had no scores in the 0-9 range.

Additional comments and issues

Participants were offered the opportunity to add further comments and raise further issues, and 35 respondents made a total of 62 comments. A wide range of issues emerged in these comments, about the needs of young people, the complexity of relationship boundary decisions and the group environment in which relationship boundary issues arise and are resolved. Comments were grouped into themes in which respondents made similar statements or commented on similar issues, and the following six areas emerged in which comments were made by at least 3 respondents.

The role of circumstance. Circumstances often played a part in the development of relationship boundary issues, and connections between personal life and work life were not always consciously chosen. Participants cited examples of working with young people who were connected to friends or family, or people with whom they went to school, and the impact of living and working in a small community, where dual relationships and unplanned contact with young people are regular occurrences.

Personal values and beliefs. The role of personal beliefs in shaping boundary decisions was evident in the number of comments that began with phrases such as ‘I believe’, ‘in my opinion’, ‘I feel’ and ‘I think’. These individual beliefs were also evident in the wide range of responses to the relationship boundary questions, even within the same setting.

The role of the team and the group. Discussing boundary issues as a team was seen as a key to safe decision-making. Comments about transparency and information-sharing also suggested a team decision-making approach. However, this was not always straightforward. One participant felt that making a decision to keep in touch with young people ‘seems to provoke anxiety in some staff’. Another suggested that managing relationship boundaries flexibly requires understanding and skill that not all workers have, and that it can be easier to ‘adopt a stand-offish position, seeking black and white rather than nuance when negotiating boundaries’.

A changing environment. For some participants, the environment in which they were making relationship boundary decisions had become more restrictive. One participant felt that ideas about ‘safe caring’ had brought about ‘major attitudinal changes’ regarding relationship boundaries. Others noted that ‘gift giving and physical contact are now frowned upon’ and that ‘policies about young people not ever going to your home’ had been introduced. For some, this diluted the effectiveness of their work. Workers suggested that these changes have ‘reduced the therapeutic aspect that young people need’ and that ‘the young people are cheated a little on the authenticity of our relationships by maintaining no-go areas’.

Responding to children’s needs. Some comments focused on what children need, and these suggested a need for emotional, as well as physical, involvement: ‘Children need to be nurtured and to feel loved’. One worker with experience as a foster carer was aware of the differences in how these needs might be met: ‘If I answered the same questions as a foster carer, they would be very different and reflect a more connected relationship’. Another worker commented on the emotional connections involved feeling like an ‘extended family’ and felt that caring for young
people ‘is more than a job, it’s a way of life’. It was also noted that young people might sometimes ‘become very attached to a worker’ or even ‘fixated on a particular staff member’ in a way that feels overwhelming.

**Managing anxiety and complexity.** For some, relationship boundary decisions could be a source of anxiety. One worker felt ‘anxiety about complaints being made or being falsely accused of something’. Another described a feeling of tension between meeting children’s needs and feeling safe: ‘there is a climate of staff being scared of touching the young people or spending time alone in a room with them, but these are needed things’. Other aspects of relationship boundaries also involved managing complexity. These included sensitively managing personal care for a doubly incontinent disabled young person, balancing making significant relationships with children with working to promote their attachments to parents, and managing the perceptions and misperceptions of young people who have been abused by parents or carers and might ‘mistake a caring relationship for attraction’.

**Implications for policy and practice**

Before considering possible implications, it is important to acknowledge the limitations of this study. As a small-scale practitioner research project, the study offers relatively modest sample sizes, and the samples used are, in many respects, not representative. Because of these limitations, it did not seem appropriate to carry out significance testing on these samples, and instead, it is necessary to accept that the study can only offer suggestive findings which reflect comments made by respondents and support arguments made and conclusions reached by other researchers and theorists. It is hoped that, in spite of these limitations, the study begins to shed some light on an area that has attracted very little previous research attention.

A number of issues arise from responses to the survey that suggest possible implications both for policy and practice and for our understanding of relationships and relationship boundaries in residential child care. The most obvious is the frequency with which variations in responses emerged, indicating that clear lines separating professional and unprofessional behaviour do not appear to exist. Instead, greater complexity is apparent, involving a range of considerations including need, relationship, culture, context, and professional identity.

It is not entirely clear how the differences between managers’ and workers’ responses in the sample should be interpreted, and, in particular, the fact that these became more pronounced where strong taboos appeared to exist. However, three observations can be made. The first is that additional experience alone did not appear to account for these differences. When experience was used as a variable, no differences emerged, other than a small difference in levels of contact with young people who have moved on. The second is that the increased level of professional education and more outward-looking focus of managers might increase their confidence to resist the dominant discourse about professional detachment and pressure to make risk-averse decisions, suggesting that increased educational opportunities for workers might have a similar impact. The third is that workers did not appear to automatically follow the more flexible lead of their managers, indicating that an explicit philosophy of care promoting such flexibility may also be required for this to become a team approach, rather than a course of action taken in isolation by particular managers. The differences in responses made by the comparison group suggest the potential for such philosophies and cultures to be developed and maintained.

Comments from participants about anxiety related to boundary crossing, and the emergence of a more restrictive environment around relationship boundaries, are linked to concerns about historic abuse. It was perhaps inevitable that the initial response to these concerns would be to prioritise regaining a sense of safety, even if this required sacrifices that restricted the development of significant relationships. However, it may be that an opportunity is now arising to develop a more balanced position that facilitates the development of significant and enduring relationships within the context of team safety and accountability.
In some areas of the survey it appeared that gaps exist between relationship boundary responses in practice and espoused values, theories and methods of work in residential child care. The clearest example of this related to continuing contact with young people who had moved on. In spite of consistent research evidence of its importance and significant political encouragement, this contact still appears to be minimal, suggesting that, even when care relationships are significant and positive, they are rarely enduring. Whilst it is true that most professional relationships are time-limited, the unique nature of the care relationship suggests that this is a situation in which a different boundary, reflecting the nature of this relationship, is required. It is worthwhile to consider whether these relationships might call for a different sense of professional identity to be developed more generally if residential child care is to become a more relationship-based service. There appears to be no reason why it might not be considered unprofessional, from a care perspective, to fail to provide children who grow up in our care with the significant, flexible and enduring care relationships that other children take for granted.

Conclusion

Theoretical discussion of relationship boundary issues frequently points out that professional identity in social work, and, by extension, residential child care, has been strongly influenced by the concerns of traditional professions. It is argued that, as a result of this, expectations about relationship boundaries in residential child care are based on notions of professional distance that are not appropriate to the caring role. Similarly, research exploring the views of service users suggests that flexibility regarding skilful and well-judged boundary crossing behaviour is often experienced powerfully as evidence of the commitment of the worker, the importance of the young person and the development of a significant relationship.

Responses to the questionnaire suggest that, in most situations, no clear lines exist separating behaviours that are always considered to fall within or outside acceptable boundaries. A small number of behaviours were generally seen as less controversial, and were widely practised. There were also two areas in which strong taboos existed that, in the main sample, appeared to influence all but a very small number of workers. However, most areas of the survey elicited a wide range of responses without a normative behaviour emerging. Boundary decisions appear to be influenced by a wide range of factors including the age of children and length of placements. Differences also emerged, with regard to some decisions, between women and men and, to an even greater degree, between managers and workers. Responses from the comparison group, in which greater flexibility was generally displayed, suggest that culture can play a very significant role in the development of norms regarding relationship boundary behaviour. Individual differences also appeared to influence responses, and, although to a reduced extent, even within the single organisation comparison group, a wide range of individual responses emerged.

A striking difference appeared to exist between the relatively low levels of flexibility in some areas of practice suggested by participants’ responses and the views expressed in research and theoretical writing, including the views of service users, in which greater flexibility is frequently advocated. It appears that a ‘professional distance’ stance, alongside concerns related to historic abuse, may exert a strong influence on boundary decisions, particularly in relation to activities involving contact outside the work setting and allocated hours of work. However, the more flexible behaviours reported in the comparison group may also indicate that, where a strong enough alternative culture develops, these influences can be overcome, and greater flexibility can develop.

Following a period in which both social work and residential child care have been influenced by target-driven and procedural responses, relationship-based work is regaining lost ground and receiving significant official recognition. These developments present an important opportunity for relationship-based approaches to flourish. The particular significance and potential of the relationship within the residential child care task suggest that residential child care should endeavour to play a leading role in exploring these possibilities. However, in order for these
possibilities to be fully realised, it will be necessary for the field to move beyond a professional identity based on the concerns of other professions and the difficulties of the past, and to address the task of developing its own unique ethical basis and clearly articulating the contribution that relationship-based care can offer. It is from this basis that relationships, and relationship boundaries, appropriate to the caring role can emerge.

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The death of reflective supervision? An exploration of the role of reflection within supervision in a Local Authority Youth Offending Service

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Abstract

Reflection within supervision has been identified as key to effective social work practice (Munro, 2011). However, despite the tradition of supervision being strongly embedded in youth justice practice, other imperatives, such as audit monitoring and the focus on inspection readiness, have impacted on the content of supervision and the degree of reflection which occurs. This article reports research that examined the experience of practitioners within a Local Authority Youth Offending Service, exploring the content and level of reflection within their supervision. The research found that whilst supervision is well embedded within the organisation, the content of supervision for practitioners largely focuses on the management function (Morrison, 2005). Whilst many participants thought that their supervision involved some reflection on further analysis, using Ruch’s (2005) levels of reflection model, much of the perceived reflection occurred at the ‘technical’ and ‘practical’ level rather than the ‘process’ or ‘critical’ level. The article explores the implications of the findings and the response of the author’s employing organisation to this research.

Keywords: supervision, reflection, youth justice

Introduction

Supervision is a well-embedded tradition in social work and within the Local Authority Youth Offending Service in which, until mid-2014, I worked as a Practice Manager and supervisor of staff. However, recent shifts in the organisational context led to my observing significant changes in the content and practice of supervision, especially with regard to reflection. A key driver to the shift in the organisational context was receiving an inspection report in 2011. The primary recommendations by the Inspectorate focused on improving the timeliness and quality of assessment documents, particularly identifying cases where these required documents were not in place, accompanied by a recommendation that there should be ‘more regular and effective oversight by managers, especially of screening decisions, that is clearly recorded on the case record, as appropriate to the specific case’ (Criminal Justice Joint Inspectorate, 2011). The Improvement Plan following this report focused upon the need to increase the level of management oversight on practice, particularly focusing on ensuring that documents and risk assessments were completed to a high standard and to specific deadlines. As a result of this, there was a shift in supervision practice. The use of computers to check on cases within supervision became commonplace and a spreadsheet was introduced on which supervisors needed to document the completion of core case and risk management processes.

As a manager implementing these new procedures, I was conscious of how my supervision practice and style changed from one where reflection was at the heart of this process, to one where I felt I was balancing my commitment to reflection with the requirement to complete a complex audit process and spreadsheet within supervision sessions. I found it challenging to negotiate this balance, noticing my own difficulty in maintaining reflective content whilst also undertaking audit tasks. I was also required to use a computer during my sessions.

To fully understand the implications of this shift in supervision practice, two years after the implementation of these new processes, I decided to investigate current supervision practice within the agency through undertaking a small qualitative research project. This involved interviewing Youth Offending Service (YOS) practitioners to understand how they experienced...
this change of emphasis. I was also interested in the context of these changes as social work research and academic writing documents a significant increase in audit processes as a result of neo-liberal policies in both bureaucracies generally, and the social work profession in particular (Power, 1997; Baldwin, 2004; Rogowski, 2011). However, Laming (2009), Munro (2011b) and The Social Work Reform Board (2010) all identify the importance of supervision, and the role of critical analysis and reflection within supervision, as significant to effective safeguarding and good practice.

**Theoretical framework**

Whilst there is a long tradition of supervision in social work (Tsui, 2005; O'Donoghue & Tsui, 2013), the first UK guide on supervision was published in 2007. It stated that:

*Effective supervision is one of the most important measures that organisations can put in place to ensure positive outcomes and quality services for the people who use social care and children’s services.* (Skills for Care/CWDC, 2007, p.10)

Their definition of supervision makes effective outcomes of work central to the purpose of the supervision task:

*Supervision is an accountable process which supports, assures and develops the knowledge, skills and values of an individual group or team. The purpose is to improve the quality of their work to achieve agreed objectives and outcomes.* (Skills for Care, op cit., p.5)

This focus on outcomes for service users reflects a more universal purpose of social work and something less susceptible to change as a result of cultural and organisational pressures, and this makes it a helpful working definition for the purpose of this article.

Wonnacott (2012, p.23) observes that definitions of supervision tend to be functional and depend on the specific functions or model of supervision being emphasised. Models of supervision have consequently been key in contributing to the debate around supervision. Kadushin et al. (1976) identified three main functional elements to supervision – education (the formative function), administration (the normative function) and support (the restorative function). These functions should not be seen as separate but are interrelated and fluid in nature. This model, although widely used, was also criticised for ignoring the increasing role of supervision as ‘mediation’; providing a forum for organisational negotiation between social work staff and their management (Richards et al., 1990). Morrison (2005) integrated this function into his model of supervision. He also indicated the importance of organisations being guided by a clear policy of supervision, and this four-pronged model was central to my agency’s supervision policy of January 2012, with each of Morrison’s functions being identified as important aspects of supervision in the organisation. Consequently, I have used this model with my research interviewees as a basis for exploring their supervision.

In addition to this, I wanted to specifically explore the role of reflection within supervision. Schön (1983) argued that the capacity to reflect in, and on, one’s action, and engage in continuous learning was a key ability of professional practice in a variety of disciplines. However, due to the complex and ambiguous nature of reflection, it has proved difficult within academic literature to unequivocally classify what precisely constitutes reflection (Ruch, 2005). Ixer (2010) argues that despite the concept of reflection having increasing prominence in a range of professions there is still no clear definition and common understanding as to what reflection is. Therefore, whilst acknowledging Ixer’s (1999) criticisms of the use of paradigms to underpin concepts of reflection, I found it helpful to utilise Ruch’s (2005) description of layers of reflection as the basis for my exploration. This provided a way to describe and discuss different components of reflection to my research participants. Ruch draws on the writings of Van Manen (1977) and Ward & McMahon (1998) who defined different levels of reflection. Van Manen identified three
different levels of reflection: technical, practical and critical. Ward and McMahon (1998) added a further level of reflection: process.

Using Ruch’s analysis, these levels can be summarised in the following ways. The technical level of reflection involves the comparison of performance in practice with standards, policies and procedures. The practical reflective level uses a practitioner’s experience as a source of self-evaluation, insight and learning. This involves moving from being able to reflect after the event to being able to reflect at the moment an incident is occurring. The third level of reflection is that of process. This level focuses on the interaction of thoughts and feelings and how these shape practitioners’ judgements and decisions. This level is rooted in psychodynamic theory. Finally, the critical level which assumes knowledge is socially constructed, and is therefore always evolving. It encourages the practitioners to question and challenge power relations and examine the worldview underpinning their interpretations (Ruch, 2005, p.172-176).

Methodology

This article reports on a small scale qualitative study of Youth Offending Service practitioners experiences of supervision. The study was designed to raise questions and provide indicators to areas for further research. A semi-structured interview format was used to enable some comparability while still providing space to investigate further than a structured interview would allow, and to encourage dialogue with interviewees. According to Yates (2004, p.156), such an interview enables participants to ‘develop a shared perspective and understanding between two or more people’.

It was important to ensure that there was no likelihood that participants would be negatively affected by their involvement, so full consideration was given to ensuring that they were clear about the confidentiality of the research and anonymity of my reporting. The study took place within a large Local Authority, where the author was a manager, and it was supported by senior managers. This may have had an impact on the responses of participants.

However, concepts of reflexivity in qualitative research recognise that the researcher affects all knowledge and that it is impossible to stay outside of the subject matter; furthermore, our presence will always have some kind of effect. Therefore, a commitment to the principle of reflexivity meant that the author used knowledge of the impact of her role and history within the data analysis.

The issue of confidentiality was addressed carefully with the interviewees. It was explained that the author worked part-time for the organisation, and also worked part-time as an academic. This research project was being undertaken in the author’s own time, and whilst permission had been granted by the Local Authority, this was an independent project, rather than a funded project. Permission for the research was sought and granted by the Research Governance Group of the Local Authority.

The sample was secured by sending out an email across the Youth Offending Service. This went to all youth offending practitioners currently working with young people outside of the author’s own team. Participants were given an information sheet about the research project, identifying key issues of confidentiality and data protection and a consent form was completed. Participants were given an opportunity to ask any questions and they were reminded that they could withdraw from the research at any time. Data was anonymised and arrangements were made to ensure compliance with the Data Protection Act. Participants were reassured that no information likely to identify them would appear in the research report.

Twenty-one participants volunteered to take part in the study. Nineteen of these were interviewed: the other two were unable to attend an interview and completed a written questionnaire. Nine respondents were social workers, two were probation officers, four were ‘youth offending service officers’ and six were support workers (with various job descriptions).
There was an almost equal representation of men and women. Ten had been in the organisation over five years; eight for between two and five years, and three had less than two years of service. None of the sample had supervisory responsibilities themselves. In total the sample represented approximately a fifth of the total number of practitioners in the agency. It was not possible to collect evidence of the extent to which this could be described as a representative sample.

The data was analysed by organising and coding the input from the interviews into specific areas. This enabled the identification of themes for analysis, drawing out common issues and meaning. Given the small scale of the study and the fact that the aim was to highlight issues about supervision rather than offer wider generalisations about practice, in the service studied and elsewhere, the findings are reported in qualitative terms using quotations from responses.

**Supervision – the current picture**

Overall findings indicated that practitioners valued reflection on their cases and were concerned and thoughtful about practice in the organisation. When asking my participants about their professional identity and what motivated them about their job, many participants talked about their desire to be more effective in their work with young people. Examples of typical responses were:

*I love working with young people. That’s where my passion is. It’s important to try and promote change and provide opportunities where I can... This is the main reason for my work.*

*It’s important that I’m good at my job – make a difference with young people – that I have an impact on the young people’s lives and the service too... At the moment I don’t feel my practice is as good as it should be but that is not because of my ability or my willingness it’s the impact of high caseloads, the complexity of caseloads and time.*

My initial questions asked participants to describe their supervision. All participants currently had regular supervision, although one participant described a period some years earlier when this wasn’t the case. All supervision sessions were recorded. Two participants reported the length of sessions as being around an hour, while the maximum length of supervision described was three hours in length. Most people said that the length of supervision varied depending on the particular circumstances of that session. These findings suggest there was a culture of regular supervision within the organisation.

In exploring whether staff found their supervision reflective, and with an awareness of the difficulties in conceptualising what reflection means, the levels of reflection described by Ruch (2005) were used as the basis for a series of open and closed questions exploring the reflective process. In describing their supervision the majority of respondents said they felt there was reflection within their supervision process. However, in some interviews respondents qualified this by describing barriers which they felt limited their experience of reflection in their supervision. These included the use of computers, a concentration on processes, the requirement to discuss each current case (sometimes this meant discussing as many as 20 young people), and the use within supervision of a spreadsheet for recording actions and processes. Comments from respondents included the following:

*I like to be able to talk through issues and ruminate with someone... The allotted supervision session tends to be more about the processes than the practice... I didn’t like using the computer, it felt that there was a third person in the room... after this stopped it became more intimate.*

*It’s more like line management where you go through your cases and see if everything is up to date.*
We sit at the computer and look at my caseload. We look at the comments from the previous supervision and see if there are any actions outstanding… I don’t mind this it is useful for the action side of things to know what you have and haven’t completed. The negative side is that it becomes process driven and it’s not sitting down and reflecting on actual feelings.

Analysing the responses using Ruch’s levels of reflection indicated that all participants described supervision which included the technical level of reflection, reporting a clear focus on the completion of tasks and procedures involved in their roles. Participants were asked questions about whether their supervisor regularly challenged their views and perceptions of their practice. Within the group of participants, 10 respondents said their supervision contained a degree of challenge about their views and perspectives, 6 said they were never challenged, whilst 5 participants said they were challenged over using correct processes and case management tasks only. One participant commented that she was “only challenged about documents being in place”.

It seems that for a number of participants in this sample supervision did not contain the kind of rigorous and robust challenge that would assist a more in-depth reflective process.

Participants were asked to what extent emotion was acknowledged in supervision. Munro (2008) highlights the danger of ignoring emotions in social work and argues that this leaves workers more vulnerable to the emotionally and occasionally dangerous impact of working with complex families. She argues that the emotions raised are themselves an important source of information in working out what is happening in a situation. Ignoring this level of reflection leaves the possibility of colluding with, or even increasing, dangerous dynamics in a family (Munro, 2011, p.51). It also seems unlikely that supervision will include Ruch’s third level of process in reflection without an exploration of emotions. When asked about the acknowledgement of emotion, six participants felt that emotions were always acknowledged and used in supervision, six respondents thought that there was occasional, but not consistent, acknowledgement of emotional processes, whilst nine participants felt that their emotions were never explored. One of the participants expressed their concern about the lack of emotional content saying:

There is no recognition of the role of emotion… if you don’t have discussion of emotion and how this affects judgements, and how it affects your position on a case, then you are not engaging in reflective practice… My peers protect me from dangerous practice rather than supervision.

Another respondent commented:

I will always say everything is ok – which it usually is, but would say it whether it was or not.

Ruch’s final level of reflection is described as the critical level. Functioning at this level would involve the ability to question and deconstruct knowledge, as well as applying an analytic approach to the socio-political context of the service users’ lives. Whilst it was difficult to find a way to fully explore with participants to what extent their reflection engaged with the various aspects of this level, it was explored in a limited way through asking participants about their engagement with the socio-political context of their service users’ lives. Some described acknowledgement of issues such as poverty and unemployment but a significant number of respondents (approximately half the sample) said there was no explicit discussion of these issues within supervision.

These findings suggest that the reflection that is occurring in supervision is predominantly at the first two levels of Ruch’s categorisation. Whilst some participants reached the second level of ‘practical reflection’, analysis of participant comments suggests that a relatively small proportion were engaged in the process or critical levels of reflection.
When participants were asked wider questions about reflective practice outside of supervision and in their teams more generally, a slightly different picture emerged. Nearly all participants reported that they received ‘ad hoc’ supervision in the form of discussion about their cases with their supervisors in between sessions. One participant stated that ad hoc discussions were ‘more reflective than supervision’. However, despite these discussions being significant to practitioners they were rarely being formally recorded, which raises issues of accountability. Interviewees also talked about the key importance of reflection within their team experience, and how reflection on cases often occurs between peers within a team rather than a supervisory setting. However, respondents reported an inconsistent picture of the potential for team reflection. It was especially difficult for people in areas where staff were working remotely, where they were performing the majority of their tasks away from their main office base. This is a concern given the increase in remote working occurring within social services departments.

The management function

The four functions of supervision (Management, Mediation, Development and Support) identified by Morrison (2005) were described to study participants who were asked to put the functions in order of how much priority was given to each within their supervision. Participants then allocated a percentage to how much focus was given to each function. All participants except one put management as the primary focus of their supervision. When the participants were asked to allocate a percentage to the degree of focus on management the percentages varied from thirty percent to ninety-eight percent. The average was sixty-seven percent. This high proportion of management focus indicates that there is very much less priority given to the other three aspects of this model. The average percentage given to the focus on support was fourteen percent, whilst development received ten percent. The mediation function was even lower at nine percent.

A concerning picture emerges from these figures. The basis of Morrison’s model is that all functions are important and interrelated, yet most respondents reported that the majority of their supervision was spent on management issues. Most participants with a high focus on the management tasks reported missing the development and support functions of supervision. One respondent said:

We never talked about my development; I just got offered some training courses occasionally.

The low percentage given to development is particularly at odds with the direction of the Social Work Professional Capabilities Framework, a set of overarching standards developed by the Social Work Reform Board and implemented by The College of Social Work with the aim of setting out consistent expectations for social workers throughout their careers. The relatively low level of priority given to the function of support also raises questions about how staff were assisted with the emotional impact of their work.

Interestingly, there was a sense of acceptance of the need for management accountability amongst respondents. One participant commented:

You have to start with management really, you have to start by looking at processes... Management has to be high doesn't it, because my role depends on me having appropriate caseloads and knowing what I am doing.

Nevertheless participants did express discontent about the consequences of the focus on management. Comments from participants included the following statements:

I used to dread supervision, as I knew it would just increase the things on my ‘to do’ list.
Discussion of cases can feel rushed, as it is left until last and my supervisor will often have another appointment to get to immediately after.

You are mainly making sure there is going to be no fall back on either of us... after we’ve done this, there might be time for the reflective bit... not a lot though.

Several participants said they thought the level of support would go up if it was specifically needed due to circumstances, and they thought there was some flexibility in the prioritisation of the different functions. A respondent who had recently completed the Assessed and Supported Year in Employment (ASYE) described how the input on her development had a far greater priority when she was completing this programme.

Although the need for a strong management focus in supervision was widely accepted by most respondents, many also expressed missing a stronger focus on their development and support, factors which contribute significantly to staff wellbeing and development. Beddoe comments on this aspect of supervision saying:

> The current preoccupation with oversight of practice has arguably strengthened the mandate for supervision; however, there is concern this might threaten its integrity as a learning-focused activity. (Beddoe, 2010, p.1280)

**Impact**

The final area of the research to highlight is that of the impact of supervision. If, as my definition suggests, outcomes for service users should be central to the value of supervision, was it possible to ascertain whether supervision in this Youth Offending Service was actively benefitting the young people and contributing to a reduction in their offending? Evaluating the impact of supervision on service users has traditionally been a difficult area to evaluate (Carpenter *et al.*, 2012) and identifying concrete evidence regarding improved outcomes for service users was beyond the scope of this study. However, the author did feel it was important to at least get a sense of participants’ perspective on whether they felt their supervision impacted positively on service users.

Respondents were asked to rate how their supervision changed their practice, on a scale from 1 to 10. Their answers spread across that scale from 0 to 8. It is not meaningful to explore the results in quantitative terms, but it is instructive to look briefly at comments made explaining high and low responses.

For those who scored more highly, there was reference to how problem solving was a useful task in supervision. One participant stated:

> Targets and practical ideas are useful.

One respondent who gave a low score for the potential impact of supervision said:

> There is not enough time to talk about direct work because of the concentration on paperwork.

Further respondents’ comments included the following:

> It doesn’t change how I work... discussion with colleagues is more effective than supervision.

> Supervision used to be important but now I have more experience I don’t need so much direction.
Interestingly, two participants commented that they felt the monitoring involved in supervision actually impeded their potential to intervene in a way they felt would be helpful for young people. This was expressed by one of these participants in the following way:

At times you think about going the extra mile for the young person – but then you think about what could go wrong and the fact you could get blamed.

Although this study was only able to explore a participant’s perception of the impact on their practice with service users, rather than any more objective measure, some of the participants’ comments raise concerns over how much positive impact supervision had on practice with service users. Though the needs of the organisation were being addressed through the priority given to the management function of supervision, the impact on the wellbeing of service users was less clear. Given this is an agency with a demonstrable commitment to the supervision process, it would be pertinent to explore this further and consider ways to improve the effectiveness of the supervisory relationship.

Conclusion

These findings indicate that within this Youth Offending Service there is a well-embedded culture of supervision. However, the degree to which reflective supervision occurs varies considerably. It appears that the strong priority given to the management function means that development and support are being given a diminishing priority. Although reflection occurs, it seems to be at the technical and practical level and not at the process or critical level that Ruch identifies as significant.

These findings should perhaps not come as a surprise: academics have been indicating for some time (see Howe, 1992, pp.492-508; Rogowski, 2011) that there is strong correlation between increased managerialism and the marginalisation of the service user and the social work relationship. Lawson warns that:

The proliferation of audit practices means service users' needs are no longer seen holistically. The effect on the social workers is that their professional identity is undermined as professional discretion, judgement and accountability is eroded. (Lawson, 2011, p.3)

Academic discussion in this area has been particularly focused around the issue of risk. In her article ‘Surveillance or Reflection’, Beddoe (2010) identifies two types of supervision emerging from relevant literature: a professional approach with a focus on learning and development; and an approach focused on risk management which includes micro-management and surveillance (p.1280). Findings from this study suggest that this Youth Offending Service was moving towards the second of these models, although it was notable that some practitioners described supervisors not using the computer, or completing the required checklists. It seemed that these supervisors were proactively choosing to keep a focus on the ‘professional approach’ and to maintain more reflection in their supervisory practice.

The changes in supervision in the service in the two years prior to this study were particularly focused around ensuring good risk assessment practice. It felt ironic, therefore, that the very procedures intended to improve practice might be working against effective risk management. Wilson (2013) comments on the danger that immersion in such cultures may lead to ‘ritualisation’ of reflective practice to the point at which it becomes, ironically, a ‘tick box exercise that is inimical to the development of critical thinking and undermines the learning process’ (p.168).

I would argue that it is critical thinking that leads to good professional judgement around risk, and critical thinking occurs most effectively in relationships of trust where emotions, intuition, uncertainty and different opinions can be safely voiced (Beddoe, 2010; Munro, 2011b). Whilst it often takes the tragedy of child deaths and learning from serious case reviews for the pendulum
of policy and practice to change, reports emphasising the need for in-depth reflection have been in the public domain for several years. Laming (2009), Munro (2011a) and the Social Work Task Force (2010), have been very clear in challenging the culture of task-centred supervision and advocating the necessity to put supervision and reflection at the heart of social work practice. However, despite this guidance, this study suggests that within this Youth Offending Service supervisory practice was moving in the opposite direction to these recommendations. It seems likely that the drive to perform well in inspections was a strong contributory factor to this trend. Munro warns in her interim report:

One way of summarising the problems identified in this review’s first report is that children’s social care departments are paying so much attention to complying with guidance and regulations from Government, and to meeting the criteria that they consider will produce a good rating from Ofsted, that they are paying insufficient attention to the children who need their help. (Munro, 2011a, p.51)

The reaction of the senior management of the Youth Offending Service to the research findings was encouraging. In response to preliminary findings, senior managers set up a working group of managers and practitioners to consider the development and implementation of a new and reflective model of supervision. The subsequent working group proposed the implementation of Wonnacott’s ‘4x4x4’ model of supervision throughout the service. This model recognises the importance of using all four functions of supervision defined by Morrison, and encourages the use of the processes of experience, reflection, analysis and action to underpin supervision (Wonnacott, 2012, p.53). Specific consideration was given to ways that the management function of supervision could be reduced, including no longer completing the audit spreadsheet within the supervision session, and reducing the number of cases that are discussed as this seemed crucial to freeing up time for more in-depth reflection. These recommendations have been integrated into a new supervision policy.

Whilst the current context might be challenging, it seems vital for social care organisations to heed the recommendations of government reviews and academic writers so that supervision policies and practice value and prioritise reflection, and work towards ensuring that supervision is an active contributor to ensuring effective practice with service users. In her 2013 lecture, Wonnacott says:

In this age of austerity we cannot afford not to supervise effectively. When we are struggling with scarce resources and dealing with ever more complex problems we need to foster resilience by providing frontline staff with the scaffolding they need to get out there and work with the most vulnerable members of our society with the emotional intelligence and compassion that will make a difference. (Wonnacott, 2013, p.15)

So is reflective supervision dead in a heavily regulated Local Authority context? Reflective supervision might not be dead but it needs prioritising at an organisational as well as individual level if it is to come off life support.

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How can the benefits of personal budgets for people with mental illness be sustained after the payments stop?

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Abstract

One aim of mental health social work is to promote recovery and independence for people accessing services. Personal budgets, which can now be requested by all mental health service users in England, can enable service users to achieve these outcomes. This paper addresses the lack of evidence on service user understandings of the purpose and duration of their personal budget, and their experiences of personal budgets ending. We draw on interviews with 53 mental health service users and 28 practitioners. We identify how different factors affect the sustainability of the outcome: the type of outcome identified, how far service user and practitioner understanding of outcomes are shared, and the ability to continue activities after the budget ends. We draw out learning for practitioners and policy makers on improving the sustainability of outcomes achieved through personal budgets, and improving service user experiences of their endings.

Keywords: personal budgets, mental health, outcomes, payment

Background

Evidence shows that the use of personal budgets in mental health social care may lead to positive outcomes for service users. The evaluation of the personal budget pilots in England found that personal budgets increased wellbeing for people using mental health services, but that the uptake among mental health service users was low compared to other groups (Glendinning et al., 2008). Similarly, a recent systematic review of personal budgets for mental health indicated potentially positive outcomes for choice and control, improved quality of life and reduced use of mental health services – although the quality of evidence was not strong (Webber et al., 2014). We have reported elsewhere the important role that personal budgets may play in improving outcomes within the context of fluctuating health and changing lives (Larsen et al., under review).

However, debate around personal budgets has largely focused on assessment, systems for allocating resource to individuals, and the choice of purchases made, while less attention has been paid to the process of ending personal budgets. The Care Act (2014) highlights the need for the review of personal budgets and for changes to budgets if individual circumstances change. The process of such reviews – particularly when it results in the withdrawal of support – is an important aspect of social care practice and the impact on the individual service user is largely unknown. Importantly, an outcomes-focused approach encourages both the individual and the funder to assess the effectiveness of the purchased support in meeting those outcomes. If the outcome is focused on change, once that change has been achieved, further support may or may not be required to sustain it. Equally, if a change outcome is not met, this may suggest that the support provided is not appropriate or effective and should be stopped or replaced by an alternative. However, if the outcome is to maintain wellbeing or participate in the decision-making process and management of care, meeting the outcome may be an indication that the support should continue. Nonetheless, the review process may result in stopping personal budgets that have been effective in maintaining good health.
The 2014 Care Act places a responsibility on English local authorities to prevent, delay and reduce the need for care and support of adults within their boundaries (Care Act, 2014). This provision has both an economic and a value based foundation; on the one hand there is a need to reduce the costs of providing social care support, on the other, there is recognition that health and social care agencies should promote independence and self-management. One important way that local authorities are permitted and now expected to meet adults’ social care needs is by allowing choice in their care through a personal budget. Personal budgets became government policy in 2007 (Department of Health, 2007) and are enshrined in the 2014 Care Act. The local authority calculates the amount of money that an eligible individual is entitled to in order to meet their assessed social care needs. Service users are then able to make decisions, alongside the local authority, about how to spend that money to best meet their needs. Depending on their circumstances and wishes, service users may receive the personal budget as a direct payment, through which they receive the money themselves to spend on support that they individually arrange or purchase. Alternatively, the money can be managed by the local authority but used to purchase support according to a plan agreed with the service user or by a proxy, such as a family carer. Much has been written about personal budgets (see Needham & Glasby, 2014, for an overview). This article addresses an under-reported area: what happens when a person’s personal budget funding stops.

There is increasing recognition that social care provision should not foster dependency on services, but rather should help individuals to set and reach goals that will allow them to live their lives and manage with as much independence as possible (Fine & Glendinning, 2005). This requires definable, personalised goals and measurable outcomes. Instead of being an ongoing means to address a care need, publicly funded social care support is increasingly intended to be a time-limited mechanism to recognise and build an individual’s skills and capacity to manage independently (Heginbotham & Newbigging, 2013). Because adult social care is based on models of shared decision making, and collaboration between practitioner and user (Needham & Carr, 2009), the practitioner clearly has an important role in setting these expectations.

The last decade saw a shift in policy attention from needs-based, to outcomes-focused assessment and services (Miller, 2010). Outcomes-focused services are closely associated with ‘personalised care’ through the move towards tailored packages of support based upon an individual’s own assessed needs and preferences, of which personal budgets are one important part. Glendinning et al. argued that ‘outcomes are by definition individualised, as they depend on the priorities and aspirations of individual people’ (Glendinning et al., 2006, p.v). However, they also made the point that outcomes do not necessarily need to be associated with a change in the individual’s needs or circumstances; they may be about maintaining a quality of life or levels of wellbeing and they may be about the process of deciding on and receiving support.

It is also important to acknowledge the impact of the reduction in available resources within local authorities that limits budget availability. It has been suggested that personal budgets may save money for local authorities (Leadbeater, 2008; Duffy et al., 2010; Needham, 2011), although this has been criticised (Beresford, 2011; Slasberg et al., 2012). However, the significance of potential cost-efficiencies in social care remains high as local authorities find themselves in ever tighter financial circumstances (Local Government Association, 2014). Whether or not these financial pressures influence individual assessments and decisions, they do provide a context for service users’ understandings of reductions to services.

In practice, the increased interest in change outcomes raises an important question for social care practitioners and policy-makers: how is the transition made from providing support to meet a person’s goals to withdrawing support because it is no longer needed? In this paper, we explore the experiences of people with a severe mental illness who had received, or were receiving social care support purchased through a personal budget, and the perceptions of practitioners who work with them. While other aspects of these experiences have been discussed elsewhere (Tew et al., under review; Hamilton et al., under review), here we focus
specifically on the factors that influence individuals' experience of personal budgets coming to an end: the understanding of the purpose of personal budgets, how far practitioners and service users share this understanding, and the process of ending a personal budget. Drawing on participants' experiences, we consider the impact of managing endings on the individuals, and look at how outcomes are sustained (or not) after a personal budget is no longer available.

Methods

This study took a longitudinal qualitative approach using repeated in-depth interviews with people who received a personal budget for mental health related social care needs and single interviews with mental health practitioners. Local research governance and national research ethics approvals were received for the study (Camberwell St Giles National Research Ethics Committee ref. 11/LO/0620).

Sites

Four English local authority sites were recruited to take part in the study. The sites were diverse and included two sites from the north and two from the south of England, two urban, one semi-urban and one rural site. One of these sites was unable to support recruitment within the time available due to delays in implementing personal budgets in mental health. As a result no data from this site is included. To protect participant confidentiality, sites are referred to as A, B and C in this paper.

Recruitment

Potential service user participants were identified through the local authorities or local voluntary sector organisations. In all cases care coordinators were contacted first to confirm eligibility and make the initial approach. If the service user agreed, their care coordinator passed on their contact details to the researcher who sent written information and spoke to the individual on the phone to explain the study. If they then agreed to take part, interviews were arranged at a time and location convenient to the individual and written consent was taken at that point. Mental health practitioners in all the sites were approached via email, phone and through researcher visits to team meetings. Practitioner interviews were conducted over the telephone to reduce their time commitment and maximise recruitment. Interviews were arranged at a time convenient for participants and consent was recorded both verbally and via email.

Participants

A total of 53 service users were interviewed. Participants were eligible if they had received mental health services for a severe mental illness and if they had experience of applying for or receiving a social care personal budget. Participants were defined as having a severe mental illness if their local authority social care team assessed them as having high needs. Service user participant characteristics are shown in Table 1. A total of 28 practitioners were interviewed. Practitioner characteristics are shown in Table 2. Where reference to individuals is made in the findings, pseudonyms are used.

Data collection

Where possible we interviewed service user participants twice (n=17) or three times (n=18) during 2012-13 allowing us to record how changes in their lives, their care and their mental health were interrelated. Practitioners were interviewed once. Topic guides were developed with input from a group of service user advisors (people with mental health problems and carers), who were recruited through service user-led organisations in each of the study sites. All interviews were conducted using a semi-structured topic guide (see Appendix 1, 2 and 3) that was flexible in allowing the interviewer to respond to the participant's account. With consent, interviews were audio recorded and transcribed verbatim. Where consent to record was not given, detailed notes were taken during the interview.
Table 1. Participant characteristics – people accessing mental health services.

<table>
<thead>
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<td>B</td>
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</tr>
<tr>
<td>C</td>
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Table 2. Participant characteristics – Mental Health Practitioners.

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<td>Local Authority B</td>
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</tr>
<tr>
<td>Local Authority C</td>
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Analysis

The analysis was conducted using an Interpretive Framework Approach (Ritchie & Spencer, 1994) as it allows for simultaneous analysis across both themes and cases to identify patterns and retrieve data easily. This approach provides a method for systematic thematic coding, using a matrix to provide transparency and to make gaps in the data apparent. Four members of the research team familiarised themselves with the data and established an initial framework designed around research questions and emerging themes. Service user advisors independently coded example transcripts and following a consultation meeting the coding framework was revised. Transcripts were divided between the researchers for systematic coding which was reviewed again to ensure consistency and to check whether themes had changed or new themes developed. Having agreed a final framework, transcripts were coded, collated and summarised using the software NVivo 9. A matrix containing summaries of each coded quote provided transparency in the representation of agreements and contrasts within data.

In this paper we focus on the service user experiences of endings, and how these related to influencing factors. Practitioner data are drawn up on where they provide further insights and explanations for local practices. Data addressing themes around understandings of the purpose of personal budgets, anticipating endings, and experiences after endings were extracted and analysed within each theme to identify sub-themes and links between data. Findings are drawn from analysis across all 53 service user interviews and 28 practitioner interviews in the discussion of the understanding of personal budgets and perceptions of endings. Only 13 service users interviewed had experienced a personal budget ending, and this data was analysed alongside practitioner data to investigate their experience of endings. We have provided three illustrative case studies (see boxes) which demonstrate how the combination of the understanding of personal budgets and the personal budget process may impact upon the experience of endings within an individual's life context. Whilst acknowledging that the term is problematic for some (Dickens & Picchioni, 2012), we use ‘service user’ here to refer to the participants in the study who had used or were using mental health services.

Findings

How far the benefits gained from personal budgets were sustainable after the payments were stopped was influenced by a) the extent to which personal budgets were initially presented and understood as outcomes focused – including whether specific outcomes were identified and whether these were change outcomes – and b) the extent to which there was agreement between the practitioner and service user about whether they had achieved their outcome and whether a personal budget was still required.

How far are personal budgets understood to be outcomes-focused?

In data from practitioners and all 53 service user participants we found considerable variation in both service users' and practitioners' explanations of the general purpose of personal budgets. Some practitioners described them in relation to addressing an ‘unmet need’ (Community Practice Nurse (CPN), Site B). Many, however, talked about personal budgets as a means of achieving a goal or outcome. While a few identified maintenance outcomes as being an acceptable use – i.e. to sustain an individual’s wellbeing ‘for life’ (Social Worker, Site A), most practitioners emphasised the need to address change outcomes. Often this was associated with a commitment to recovery-focused practice:

*It's also about enabling us to put a package together with all concerned to best enable [service users] to move on, support them in their recovery, in their rehabilitation in the community, preventing relapse.* (CPN, Site D)
A few practitioners suggested there had been a shift in the local authorities’ approach to personal budgets to emphasise the need to focus on change outcomes:

*I think there were various different phases of direct payments. One which was: ‘hey, there’s this money, go and spend it’ [...] And then other workers were being told to go out and say: ‘actually, no, [...] this has to be attached to the recovery plan, it has to be showing clear goals and change’. (Social Worker, Site A)*

It was widely understood among practitioners that to get a package of support approved by the local authority, clear links had to be made between how a personal budget is spent and individual goals in the user’s plan. Moreover, depending on the perception of financial pressures, practitioners were also likely to believe that costly or long-term budgets would not be approved and that goals should be achievable within a relatively short time. In some cases practitioners fully supported the local authority stance, while in others they aligned themselves with the service user in supporting them to get the most out of the system by tailoring plans towards these types of outcomes. Several practitioners stated their assumption that when budgets were reviewed they would most likely be reduced and eventually ended once outcomes had been achieved.

This understanding was shared by some service users who saw their personal budget as a way to increase their independence and reduce their need for support. Those who fell into this group often described a clear and measurable change outcome which they felt could be achieved through the support they purchased with their personal budget. Anne’s case *(Box 1)* is an example of this approach.

Sixteen participants identified goals intended to increase independence, for example, learning to cook, driving lessons and confidence to go out independently:

*I wanted to go out more on public transport that was one thing I wanted to do, to walk on my own from one place to back home or one place to another. (Service User 5, Site C)*

*The end goal is to stand up on my own two feet, mentally and emotionally, for the first time in my life. (Service User 16, Site B)*

For others, the personal budget allowed them to address areas that they struggled with by employing others to do this, including through Personal Assistants (PAs) and cleaners, and through hobbies or social activities. Rather than seeking change in the individual’s circumstances, this addresses a maintenance outcome, through which the person’s quality of life is maintained as long as that support is available.

A small number did not identify outcomes at all but perceived the personal budget as additional income which they were entitled to as a result of their mental health problem, without linking this to an identified goal.

*There won’t be any revelations or anything new to my life. I’ll be in a better financial position, but that’s about it. (Service User 14, Site B)*

Practitioners recognised the difficulty some faced in understanding personal budgets as outcomes-focused and time limited.

*I think often clients think it’s for life. I can think of one, maybe two [...] clients in the team that have that expectation, and it’s been quite difficult to say to them that that’s not the case: it’s to bring about some goal or aim, and then once that’s been achieved to then... that it needs to be stopped. (Occupational Therapist, Site A)*
Some practitioners thought that personal budgets should not be used for ongoing activities because they ‘created a dependency’ (CPN, Site B) when it was not feasible to fund them indefinitely. Indeed, both service users and practitioners agreed that where ongoing activities are paid for with no sense of change being achieved, benefits were much less likely to be sustained after the payments stopped.

*Because you can see how it benefits them at the time, something like horse-riding lessons, but it's that worry that when it stops, what do they do then? They've not got the money to carry on themselves, so they're a little bit back to where they were before.*

(Social Worker, Site B)

### Ending types

Drawing on data from 13 service users who experienced personal budgets ending, and practitioner experiences, three types of ending were identified:

1. **Personal budget not renewed following a review** – frequently the personal budget was reviewed after a period (often, but not always one year). For some, the result of the review was that a personal budget was no longer needed or that the person’s needs had changed and they were no longer eligible. This sometimes happened over a number of reviews through which the budget was reduced to create a tapered ending. This was the most common anticipated and actual ending of a personal budget for our participants. Nine service user participants experienced this type of ending.

2. **Service user chooses to end their personal budget or not to re-apply following review** – this was not common, but occurred for several reasons: the budget was no longer benefitting them, they had outgrown the need for this support, they preferred traditional mechanisms of support, or they were too unwell to continue using the budget as intended. Three service user participants experienced this type of ending.

3. **Personal budget stopped early due to misuse of funds** – only one service user participant experienced this in our study, and another had their budget reduced. Although rare, this was experienced by service users as a punishment.

The type of ending was characterised by the relative power and control of three key agents in decision making: the service user, the practitioner, and local authority managers.

When choosing to end their own budget, clearly the service user takes control of decision making, albeit within the limitations of their own capacity and knowledge about the possibilities of personal budgets. One service user ended their personal budget as they felt they no longer had a need for it, two others were not happy with the care they were receiving. In the latter cases there was evidence that their decision might be different had they been aware of the option to change their provider. In contrast, budgets stopped early were being reduced/ended in line with local authority rules about restrictions on budgets. However, how far the service user had understood and agreed to the rules about spending was unclear given apparent levels of confusion and disagreement with the decision.

When personal budgets are reduced or ceased following a review (the most common type of ending), control over the decision is less clear. Although the review process is intended to be person-centred, both service users and practitioners were aware of the power held by the practitioner as gatekeeper of funds (see Hamilton et al., 2015, for a full discussion on choice and control with personal budgets), and the restrictions in place through local authority policies. Anne’s case study (see Box 1) may be seen as a positive example of this type of ending; following a review, Anne and her practitioner agreed that the personal budget was no longer needed. This agreement was facilitated by earlier explicit conversations about the personal budget ending. However, in several instances service users did not agree with the decision that
their personal budget was no longer needed to achieve their goals. They perceived that the real reason for ending the personal budget was the local authority’s need to make financial savings. This was often associated with a broader impression that support and benefits were being cut. Some, like Arthur (see Box 2), felt ‘resigned’ to the idea that due to ‘austerity in cuts in the NHS, […] funding for me had to stop’ while others felt angry and de-valued.

Many practitioners voiced similar concerns about local authority cuts, citing reductions in the size and number of personal budgets being approved in response to tightening local finances. Some reported being under pressure to reduce or end personal budgets:

*I mean, the impact is that they’ll get less, get a smaller budget ultimately. I think we are starting to be more targeted […] we are in the world we’re in, which is one of budgets and shrinking resources, so, yes, I think we have got a responsibility to govern those resources and try and target those resources.* (CPN, Site B)

Within the context of perceived and real pressure from the local authority, practitioners and service users negotiated the process of endings.

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### Box 1. Anne (Site A) – A positive move to independence

At the time of applying for a personal budget Anne had four children and was feeling very low. With her practitioner, she identified a need for therapy but was unable to attend appointments because of childcare needs. They agreed to apply for a direct payment to pay for childcare to enable her to attend therapy. Anne had a very clearly defined understanding of what the purpose of the budget was, and when it would end, from the outset:

*I only wanted it for a specific purpose. I do know of other people that have used it for other things, but I wanted it for a specific purpose, to pay for childcare so I could go to my therapy […] I just took it that, if I got better, when my therapy was finished it would stop, because I would stop needing to go and that would be that.*

The identified change outcome was to manage her mental health through the benefits gained through therapy and the link from her use of the personal budget to this outcome was explicitly drawn.

*I was on the verge of getting sectioned, so if I hadn’t had the direct payment and been able to access my therapy, nobody knows what would have happened.*

The point at which the personal budget would end was openly discussed from the initial application.

*We were talking about when we should let them know to finish it, when I was going to be finishing [the therapy] and all that kind of thing, and I didn’t need it any more.*

At the point of our last interview with Anne, she was working part-time and studying. She continued to draw on techniques from her therapy to help her with negative thoughts. The ending of the budget coincided with the ending of her therapy, which, although daunting for her, was viewed as a positive move to independence.
Change outcomes and endings

The most positive endings were found amongst service users who shared an understanding of change outcomes with their practitioner, and were able to achieve their outcomes during the time they received their personal budget, and therefore continued to benefit from the budget after it ended. This occurred in four cases out of the 13 participants whose budgets ended. Changes that could be sustained without support tended to involve change in relation to skills, confidence or qualifications.

So, it was a very good thing in my life but I feel now that I’ve moved on from it, that I am back to, not wholly back to my old self. But my point was that I don’t feel like the sort of person that needs [a personal] budget at the taxpayers’ expense anymore.

(Service User 19, Site B)

In Anne’s case (Box 1), she identified a clear purpose for the personal budget with a natural end point when her goal of developing self-management techniques through therapy had been reached.

Maintenance outcomes and endings

For service users who had identified maintenance outcomes, sustaining change after the budget ended was more difficult. As the benefit of the budget was in the ongoing activities it funded, the emphasis for these service users was on finding a way to continue activities and maintain this outcome, rather than moving on.

Arthur had little information about personal budgets before beginning to receive one, and was led by his social worker, deciding to ‘go with the flow’. He understood that the payment was meant ‘to cover activities which we deemed would be very therapeutic for my mental health’, including yoga, Tai Chi and art classes. He found this ‘incredibly therapeutic’ saying it brought his symptoms under control as well as ‘[keeping] myself occupied’ and ‘allow[ing] me to reduce my weight’. During the period of receiving a personal budget he ‘wasn’t quite sure when it would end, quite how much longer I had’.

Arthur understood that the personal budget was to be used ‘as kind of a stepping stone, into sort of being able to earn my own money from it’. He remembers that he was told ‘we’d like you to think about trying to provide these activities under your own steam, possibly by looking for work’. Arthur did not feel, however, that working was a realistic prospect for him at that time and he therefore struggled to continue to fund the activities. He described the ways he found to manage using his social security benefits to pay, including pooling funds with friends to save on food bills, using savings and receiving a discounted price from his yoga teacher. He said that ‘I quite desperately want to be able to keep these activities going’ but was ‘having to tighten my belt quite a lot’. At the same time Arthur worried that his income would be cut further by changes to his benefits and he would no longer be able to do these activities at all.

By the time of the final interview Arthur was more hopeful that he would be able to cope with some part-time work or make some money by selling some of his art work.

Box 2. Arthur* (Site A) – A struggle to maintain benefits after the personal budget ended

Arthur had little information about personal budgets before beginning to receive one, and was led by his social worker, deciding to ‘go with the flow’. He understood that the payment was meant ‘to cover activities which we deemed would be very therapeutic for my mental health’, including yoga, Tai Chi and art classes. He found this ‘incredibly therapeutic’ saying it brought his symptoms under control as well as ‘[keeping] myself occupied’ and ‘allow[ing] me to reduce my weight’. During the period of receiving a personal budget he ‘wasn’t quite sure when it would end, quite how much longer I had’.

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By the time of the final interview Arthur was more hopeful that he would be able to cope with some part-time work or make some money by selling some of his art work.
Several service users sought to fund activities themselves. For some, this became possible because of the benefits of the personal budget itself, for instance getting the person back into work and earning. This enabled them to continue with activities to support their day-to-day wellbeing that were previously covered by their personal budget.

Arthur’s experience (see Box 2), however, demonstrates the difficulties that some faced in attempting to fund activities themselves. In this case, maintaining activities was possible only through compromising on other areas of spending.

For others, who could not afford to continue chosen activities, the only solution was to reduce or stop activities altogether. When activities were relied upon for daily wellbeing, it was difficult to sustain the same level of wellbeing once these activities were removed from an individual’s life:

So we still did some of it, we just did less of it, because I couldn’t... I can’t afford to do it all the time. And it’s funny, there was definitely a noticeable slowing of my improvement, because I couldn’t practice quite so often. (Service User 6, Site A)

In these cases, the end of a budget was often associated with a great sense of loss, and frustration that something helpful that they relied upon was being withdrawn. In Helen’s case (see Box 3) her understanding was of a maintenance outcome, she had not planned or agreed to an ending, and therefore could not see how her wellbeing could be maintained once the budget was withdrawn.

### Box 3. Helen* (Site B) – Deterioration of mood following the end of personal budgets

Helen received a personal budget for about 2 years and was interviewed before and after it ended. On the one hand she saw it as a way to improve her social inclusion and quality of life, using the money to fund trips to visit relatives, alternative therapies and home improvements. She described how having the personal budget made her feel good as she was going out to see people again. However, she did not have a clear goal articulated and did not have a plan for sustaining these benefits beyond the personal budget; receiving the money in itself made her feel ‘cared for’.

Helen linked her ongoing wellbeing with the activities funded by her personal budget. Consequently, the 6 monthly reviews prompted considerable anxiety as she was worried that the support would stop. Helen said that after her last review the money stopped coming into her account, and shortly afterwards she was also discharged from the secondary care mental health team.

Following the end of her personal budget, Helen was not able to visit family as often as she used to and said that she ‘felt a bit depressed and down again. It’s back to I can’t go out again [...] I just feel fed up [...]. I cannot afford mentally to stay like that’. She attributed the deterioration in her mood with her inability to continue activities that maintain her wellbeing. Helen could not understand the reason for her personal budget ending, particularly as she felt that it was actually saving the NHS money.
Ending personal budgets

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Generally maintenance outcomes required resources from the service user if they were to be sustainable after budget ending, however, there were some exceptions. In areas where there is a good variety of free or accessible local resources, practitioners may be able to find alternative means of support for service users to fill the gap after a budget is withdrawn. In reality, there was little evidence of this happening within our sample. There was, however, evidence that some one-off payments were being made to support long-term maintenance outcomes. For example, one service user purchased a laptop to contact family and friends abroad, reducing their social isolation. However, some who made this type of purchase were concerned about what would happen if the item broke or needed replacing.

Discussion and recommendations for practice

Our findings and the case studies presented here illustrate the variation in approach to personal budgets and to managing their ending. In mental health at least, our data shows that for some, personal budgets are increasingly used as short- or medium-term interventions, not as indefinite sources of support. How this is explained to service users and the management of the transition from personal budgets may affect the ability to sustain any benefits achieved through this support.

Many service user participants were unclear about the purpose of personal budgets and did not understand them to be outcomes-focused. This was further reflected in the accounts of some practitioners who described that the emphasis had changed over time. This was compounded by a belief that support was being withdrawn as a result of government cuts.

Accounts in our data suggest that the outcomes debate has prioritised change outcomes over maintenance outcomes for people with severe mental illness. While participants felt that personal budgets were effective in maintaining mental health and wellbeing, these benefits were generally not sustained after the money ended, nor were alternative sources of this support provided. Moreover, a long-term goal taking years to achieve may be viewed as a less efficient use of local authority funds and terminated early.

Given this emphasis in practice on relatively short-term change outcomes goals, our findings suggest that greater attention needs to be paid not only to the benefits to be achieved through a personal budget but also to how these can be sustained after the money is no longer provided. Characteristics of the most effective ongoing budgets identified in our study are that: a) the service user and practitioner both understand the personal budget is to be used to meet an agreed goal or outcome; b) both understand that the personal budget will be reduced or ended once/if that goal is met; c) both agree that the goal has been met at the point when the personal budget ends; and d) some plan is in place for sustaining any benefits before the budget is ended. When communication between the local authority and the individual was good, and both parties agreed on their goals and how to measure success, endings were viewed as a positive step towards independence. Where these were not in place, the loss of support through a personal budget often meant that benefits were not sustained and even caused people additional difficulties and distress.

Our findings also contribute to the debate around whether social care should be needs-based or goal-led (Foster et al., 2006; Trevillion, 2007). Participants who used personal budgets to maintain their wellbeing and who experienced an improvement in their mental health as a result found themselves no longer eligible for support. Cases like that of Helen show how this mechanism may contribute to a ‘revolving-door’ effect in which people’s health declines, increasing the need for further intensive support again. In order to prevent people repeatedly re-entering the system, this study shows that either there should be resources allocated to continually fund support that maintains mental health, or that other, more sustainable sources of support are found – either through mainstream free and affordable local services, or through a different kind of purchase from a personal budget. The purchases made through personal budgets in this study demonstrate how, for some, they may be used as a preventative tool and
reduce the demand on health services in the future. To achieve this, attention should be paid to how this kind of support can be maintained longer term, in line with the commitments in the Care Act 2014 to ‘prevent, delay and reduce needs’.

The strength of our study is the longitudinal, qualitative approach enabling us to capture not only the use of personal budgets but also the impact on the service user after the personal budget ceased. We drew on data from both service users and practitioners. However, this study is limited by the sample size, in terms of the number of local authorities and the number of participants. While drawing on 53 accounts of personal budgets and service users’ beliefs about their purpose and feelings about ending, only 13 of these actually finished using a personal budget within the data collection period. Furthermore, local authorities are constantly revising their implementation of personal budgets in response to financial and other pressures. As a result, caution is needed about generalising this study to wider social care practice. Despite this, the findings reported have potential value for both policy and practice.

**Conclusion**

The implementation of personal budgets in mental health comes at a time of increased focus on outcomes in social care and of tightening local authority budgets (Heginbotham & Newbigging, 2013; Local Government Association, 2014). This study demonstrates that sustainable outcomes from personal budgets are possible after the payments end if both service user and practitioner have a shared understanding of the outcome and a) it is a change outcome AND this outcome is achieved through the personal budget, or b) it is a maintenance outcome AND the personal budget can be replaced by other forms of finance or free local services or resources after it ends.

Our findings contain messages for both practitioners and policy makers around the purpose of personal budgets in mental health social care support, and the process of ending these. This includes the importance of clear guidance on the purpose of personal budgets for mental health teams, including the short- or long-term scope of personal budgets and the types of outcome considered appropriate. A more sophisticated understanding of the link between personalised care and outcomes-focused care, and between outcomes-focused and needs-driven support, is also called for. If personal budgets are intended to facilitate change outcomes and the aim is to end support after a specific goal is met, their use for long-term maintenance of mental health may be questioned. Alternatively, if maintaining mental health and wellbeing is considered a legitimate use of personal budgets, longer-term commitments to personal budgets for individual service users could reduce anxiety and support sustained wellbeing. Regular reassessment may mean that people who are benefiting from personal budgets to improve their mental health no longer receive them. In these cases, plans for sustaining outcomes beyond the provision of a personal budget, whether through self-funding, alternative (free) provision or reducing need should be a policy priority to ensure that personal budgets represent good value long-term.

For practitioners, these findings emphasise the importance of clarity about the purpose and duration of personal budgets in initial and subsequent discussions with service users. This should lead to a discussion of realistic goals and an agreement of what progress and achievement will look like. In this way, personal outcomes can be framed positively and the end of the personal budget may be more likely to be experienced as an achievement. Where personal budgets are funding ongoing activities, planning for the ending should include discussions about either how activities will continue, or how the benefits of these activities might be maintained after the payments stop. This may include signposting to alternative and free of charge community resources.
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Appendix 1: Service user topic guide – Time 1

1. What is your current situation with receiving Personalised care?
   a. Are you receiving/attempting to receive Personalised care at the moment? Could you elaborate?
   b. And how long have you previously been in contact with services for?
   c. What types of care and/or services do you access at the moment?
   d. [If interviewee is accessing Personalised care] How was your care organised before you accessed Personalised services?
   e. In what way does the care which you receive support your mental wellbeing?
   f. How satisfied are you with your current support package?

2. What was your situation before you were offered Personalised care?
   a. Living circumstances?
   b. Social wellbeing and quality of life, including relationships?
   c. Health status?
   d. How did the services which you were receiving meet your needs?

   a. Who referred you [Care coordinator? Social worker?] and what information did they provide?
   b. How long did you have to wait for your referral to be dealt with?
   c. Have you been kept informed about the status of your application?
   d. What did you expect in terms of the referral process?
   e. How in control did you feel?

And now we’re going to move on and talk about the support planning process. If the interviewee is not yet in receipt of Personalised care, move to qu. 9.

4. Could you describe the process of being assessed for Personalised care?
   a. Which practitioners and services did you work with? In what ways did they guide you through the process?
   b. Who else supported you [family, friends, peers]? And in what ways?
   c. How long was the process?
   d. How was your relationship with your support planner?
   e. Were you offered a choice in terms of who conducted the planning?
   f. How did you reach a sense of what your needs or outcomes were?
   g. How did you feel about the process?
   h. What could have been done better?
   i. Were you offered choice/given options?
j. Were possible changes in your health or mental wellbeing considered in the planning process?
k. Was a broker involved in the process? If so, what role did they take?
l. Were you made aware of how funding for your direct payment/personal budget would be calculated?
m. Could I possibly see your care plan?

5. How do you manage and spend your budget?

a. Were you given a figure for how much money you would receive? How accurate was this?
b. Was there any negotiation around that? If so, could you explain?
c. Were you satisfied with the amount of money budgeted? How did it fit with your expectations?
d. Did somebody help you with the accounting process?
e. How much choice were you given in how, and where you spent your money? [i.e. if you have a PA, were you given the opportunity to choose who you wanted to employ?]
f. In terms of holding your own budget, what worked well, and what could have been organised better?

6. Have you had a review since you have been accessing Personalised care?

a. How frequently does this take place?
b. Have you considered asking for an early review?
c. If you haven’t had a review, do you know why?
d. How do you find the process of being reviewed?
e. Who is involved in the reviewing process, and what role are you yourself given?
f. What seemed to be the main conclusions or changes about how you should manage your Personalised care?
g. How did you feel about this?
h. Were there any needs you felt you had, which were not addressed?

7. What affect has personalised care and support had on your life?

a. What does Personalised care mean to you?
b. What specific impacts has Personalised care had on your life circumstances?
c. Has your access to Personalised care impacted on other people in your life?

8. How do you see your future, and the influence which Personalised care might have on your life?

a. How do you think your life will look like in 6 months time? And beyond this?
b. What are your aspirations?
c. How will your support enable you to achieve these things?
d. What might get in the way of achieving these things?
9. If you are not yet accessing Personalised care:

a. What stage in the application process are you? [Have you just heard about Personalisation? Have you been referred? Is your application being processed?]

b. To what extent do you feel that you have been kept informed about what will happen next, and at which point in time?

c. How have you found the process so far? What are the positives and what are the negatives? Is the process what you were expecting?

d. In what ways do you think that Personalisation could help you to achieve your goals?

e. In what ways do you think that accessing Personalised care, rather than the current system of care which you use, would benefit you?

f. If you were given a personal budget/direct payment, how would you like to use it to change your life?
Appendix 2: Service user topic guide – Time 2/3

1. How have you been in the last 6 months?

2. Have there been any changes in your circumstances since Interview 1?

   Have there been any changes in your life since we last met?
   
   If yes – have they made you reconsider your personal goals and support needs?

   How has your health been in the past 6 months?

   Have there been any changes to your social care? (Identify causes, explore the effects)
   
   If yes – has your personal budget been affected?

3. How would you describe the progress with personal budget?

   Specific questions regarding personal circumstances, based on T1 interview

   How do you feel about your progress in working towards your goals?

4. How have you been using your personal budget? (Identify currently used support and services to compare with T1)

   Have you been accessing any new services?

   Have you stopped using any services?

   Have there been any things that you haven’t been able to do or achieve?

   What aspect of your budget have you been enjoying the most?

   How satisfied are you with the support you are receiving?

   In what way does the care which you receive support your mental wellbeing?

   How much in control have you felt?

5. How would you describe your relationship with your care coordinator?

6. How would you describe your social wellbeing and quality of life, including relationships and social networks?
7. Have there been any changes in the way you manage your budget (accounting process)?

8. Have you had a review since our last meeting?
   - How do you find the process of being reviewed?
   - Who is involved in the reviewing process, and what role are you yourself given?
   - What seemed to be the main conclusions or changes about how you should manage your Personalised care?
   - How did you feel about this?
   - Were there any needs you felt you had, which were not addressed?

9. What impact has Personalised care and support had on your life?
   - What specific impacts has Personalised care had on your life circumstances?
   - Has your access to Personalised care impacted on other people in your life?

10. How do you see your future, and the influence which Personalised care might have on your life?
    - How do you think your life will look like in 6 months’ time? And beyond this?
    - What are your aspirations?
    - How will your support enable you to achieve these things?
    - What might get in the way of achieving these things?
Appendix 3: Interview topic guide – key worker interview

Introduction

Thank you for agreeing to speak to me today. The purpose of the interview is to explore your experiences of ‘personalisation’ as a care coordinator.

With your permission I will turn the recorder on now. You may wish to use examples from your work and if any names are mentioned, we will ensure these remain anonymous in our data. The recordings will only be listened to by our research staff.

Do you have any questions before we start?

Confirm the interviewee read and understood the consent form provided prior to the interview.

1. ‘Personalisation’ is a contested term and we are interested in how different people perceive it. What do you understand by ‘Personalisation’?
   Probes:
   • How does ‘Personalisation’ change the way social care is delivered?
     (If budgets not mentioned – introduce)

2. When did you first start hearing the term ‘Personalisation’ used?
   Probes:
   • How was it introduced? In what circumstances (training, guidance received)?
     How long ago?
   • What impact did you expect Personalisation to have?

3. Has the way you work with clients been impacted by ‘Personalisation’?
   Probes:
   • Has this changed over time since the introduction of personalisation?
   • How? Describe impact.
   • Changes in relationships with clients?
   • Decision-making process around care planning?
   • Identifying needs/solutions.
   • Assessment/support planning.
   • Managing support.
   • Finance/resource changes.

a) Do you have clients on PBs etc.?
   Probes:
   • How many, how long?
   • How did clients come to access it? (Did you introduce the idea to client, or did they ask for it etc?)
   • Why are some clients accessing PBs while others are not?
   • Are there clients who would have benefitted from PBs but don’t access them? Why?
• How long do you expect your clients to remain on a budget?
• Have you had any clients who have come off a budget? How were they affected by this?

b) Can you think of an example where Personalisation works well and not?
Probes:
• Why?
• Severity of SMI?
• Outcomes?
• Identification, assessment?
• Risk?
• Area?

c) Have you had any requests for PBs to be spent on inappropriate things?
• What makes some things inappropriate and others not?
• How far do you think clients understand what is appropriate and not?

d) How confident do you feel around ‘Personalisation’?
Probes:
• What is difficult? (Decisions you found hard, how do you manage risk e.g. safeguarding?)
• Need for support? (Specific support around working with people with SMI/ fluctuating conditions?)

4. What do you think about Personalisation?
What do you think is the future for Personalisation?
(integration)

5. What would you have found useful in your role in Personalisation?
What do you think other care coordinators would have found useful in their role?

6. Is there anything else you would like to tell me?

Thank you!
The value of peer support on cognitive improvement amongst older people living with dementia

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Abstract

Peer support can play a critical role in improving the wellbeing, social support and practical coping strategies of older people living with dementia. This paper describes selected findings from the Mental Health Foundation’s evaluation of three peer support groups for people living with dementia in extra-care housing schemes. It highlights the groups as a promising approach for maintaining cognitive faculties, reducing social isolation, increasing social networks and improving overall wellbeing. A mixed-method study design examined the impact of the groups on participants’ wellbeing, managing memory, independent living skills and social support. Participants reported positive impact from taking part in the support groups for wellbeing, social support and practical coping strategies. Participants also reported positive benefits of the groups on communication abilities, managing memory and managing their lives. Peer support groups in extra-care housing schemes address the psychological, social and emotional needs of people with dementia. This evaluation adds to the literature on the effectiveness of these interventions for those with cognitive impairment.

Keywords: peer support, self-management, community services for older people, people living with dementia, extra-care housing schemes

Background

More than 800,000 people in the UK live with dementia (Alzheimer’s Society, 2014a). One in fourteen people over the age of 65 experience the condition, which increases to 1 in 6 over the age of 80 and to one third of all people over the age of 95 (Alzheimer’s Society, 2012). By 2021, it is estimated that there will be one million people in the UK living with dementia (Alzheimer’s Society, 2013). In spite of the increasingly large numbers of people living with dementia, less than half (44%) of people with dementia in England, Wales and Northern Ireland have a formal diagnosis and as a result may not be receiving appropriate treatment and care for their condition (Alzheimer’s Society, 2013).

As age is a risk factor for dementia, and as an ageing society witnessing significant increases in the number of people moving into later life, the UK economy is also witnessing a significant rise in the cost of care for people with dementia. Older people make up the biggest group whom social care services provide care for; accordingly, older people with dementia will also be frequent service users. The total cost of dementia to society in the UK is £26 billion a year with more than £10 billion of that spent on social care (Alzheimer’s Society, 2014b).

Continued cuts in social care funding has meant many services, such as day centres or community support and activities may no longer exist and changes in eligibility for publicly funded social care may impact on support available for people with dementia. Funding spend in social care in parts of the UK is decreasing as demand for these services is rising (ADASS, 2014). Simultaneously, there has been a shift in social care practice to personalising support for people to enable them to live in their homes for longer (DH, 2012).

Risk factors for loneliness

It is estimated that one third of people living with dementia live in care homes (Alzheimer’s Society, 2007), and more than 80% of care home residents in the UK have dementia or
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significant memory problems (Alzheimer’s Society, 2013). Living in residential care is a factor associated with loneliness (The Residents and Relatives Association, 2010), as is poor health (Victor et al., 2005), reduced mobility (Tijhuis et al., 1999) and cognitive impairment (Victor et al., 2005): all of which are factors common to people with dementia and increase a person’s chances of being lonely. Dementia 2014 (Alzheimer’s Society, 2014a) reported that 42% of respondents from their survey said that they were not living well with their dementia, 61% felt anxious or depressed recently and 40% felt lonely.

**Impact of social support, cognitive stimulation and peer support approaches**

One study examining social engagement amongst older people living in the community found those without social interactions, either through social connections or activities, had an increased risk for cognitive impairment (Bassuk et al., 1999). It is less clear, however, how these findings affect those who already have some level of cognitive impairment, such as the case of people with dementia. Having larger social networks is associated with reduced cognitive decline in the general older population (Barnes et al., 2004) and requires further validation amongst people with dementia. Social and leisure activities are shown to have beneficial effects on maintaining functional cognitive abilities and lowering risk of dementia (Wang et al., 2002), but the impact of these activities on the cognitive abilities of people who already have dementia has not been formally evaluated.

A national inquiry into the mental health of people in later life, including people with dementia, reported that social relationships and meaningful activity positively affected the mental health of older people (Age Concern & the Mental Health Foundation, 2006). In addition, a number of reports by the Joseph Rowntree Foundation (JRF, 2009; 2013) have also highlighted the importance of social wellbeing and promoting the social needs of individuals in planning purpose-built accommodation.

‘Alzheimer’s Cafés’, originally a model from the Netherlands, have established roots in the UK in the last ten years. These cafés typically take place on a weekly basis in community settings and serve to provide practical support and advice to people with dementia (usually in the mild to moderate stages of the condition) and their families and friends. While these cafés are informal and don’t provide clinical interventions or services, sessions are structured and can involve talks or films that are associated with living with dementia. Several organisations have adapted the model of Alzheimer’s Cafés for use in sheltered housing: one, a partnership between the Sanctuary Group and the Cambridge branch of the Alzheimer’s Society (Moore, 2009) and another project, a collaboration between four organisations: the South London Family Housing Association, Alzheimer’s Society Southwark, South London and Maudsley NHS Trust (SLAM) and Outreach and Support in South London (OASIS) (Hough & Brims, 2009). While both sheltered housing projects have been described in the literature, neither have been formally evaluated regarding the impact of the groups on people with dementia.

A Cochrane review (Woods et al., 2012) evaluating the effectiveness of cognitive stimulation interventions for people with dementia found these interventions to be beneficial to cognitive functioning, quality of life and wellbeing for people with dementia. These interventions were defined as offering a range of enjoyable activities for people with dementia that provide general stimulation for thinking, concentration and memory and typically take place in social settings and small groups.

Peer support can be defined as the help and support people with lived experience of a mental illness, learning disability or physical health condition provide to one another (Mental Health Foundation, 2014). This support can be social, emotional or practical in nature. However, key to the approach is that support is reciprocal and mutually provided. It differs from self-help approaches where individuals manage themselves by employing skills, strategies and methods to control symptoms (Crepaz-Keay & Cyhlarova, 2012).
Studies evaluating peer support methods to improve self-management of chronic conditions such as diabetes, cardiovascular disease and arthritis have examined their efficacy and effectiveness (Fisher *et al.*, 2012; Harvey *et al.*, 2008). Recently, an evaluation of a peer-led self-management training for mental health service users has shown lasting positive change in wellbeing and health-promoting lifestyle behaviours (Cyhlarova *et al.*, 2014). Two key aspects that contributed to the participants’ improved outcomes were the facilitators who shared a lived experience of a mental health problem and who were also former participants of the training.

The Department of Health’s Healthbridge evaluation (DH, 2013) assessed 40 services for people with dementia and their carers, including programmes modelled around peer support. The authors reported the value of peer support networks in increasing confidence for people with dementia and decreasing isolation. These networks also played a critical role with receiving a diagnosis and tackling stigma. A qualitative study conducted in 8 of the 40 services from the Healthbridge evaluation (Keyes *et al.*, 2014) showed the positive emotional and social impact of peer support for people living with dementia. A self-management programme for people in the early stages of dementia was qualitatively evaluated. The programme was attended by 6 participants and addressed wellbeing and coping strategies for handling memory changes. Participants reported enjoyment and benefits from the intervention which included spending time with others who shared a similar experience to them (Martin *et al.*, 2013).

**Mental Health Foundation evaluation**

The evaluation of peer support groups for people with dementia examined the impact of the groups on participants’ wellbeing and learnt coping strategies to manage memory.

The aims of the peer support groups were to:

- improve people with dementia’s understanding of memory loss and other issues associated with dementia;
- enable participants to learn simple, practical coping strategies to deal with memory loss and other issues associated with dementia.

It was also hoped that the groups might:

- help participants maintain or even reduce the level of care needs as practical coping improved;
- reduce social isolation and feelings of loneliness among participants by increasing social networks and interaction;
- be sustained beyond the lifetime of the project itself and become an intrinsic part of the housing provision where they were located.

The groups were modelled on a peer support approach with each group running once a week for six months and led by an experienced facilitator. The facilitator was a trained occupational therapist who did not have dementia and previously facilitated groups in the community for older people and their carers. The groups were comprised of peers, people living with dementia or those who had memory difficulties living in extra-care housing schemes. Each group also had a co-facilitator, these were: a resident living in the housing scheme who did not have dementia, the housing provider staff member and two volunteers from the Recovery Enablers programme at South London and Maudsley NHS Trust. The co-facilitators supported the role of the facilitator in leading, observing, reflecting and helping other group members to participate.

The role of the facilitator involved engaging participants to share their opinions and ideas and to draw out common issues or problems shared among members. The facilitator enabled the group to work cohesively and encouraged members to make decisions in their life.
After six months, when the facilitator left the groups, it was hoped that the groups would become self-sustaining or be sustained through local support. Each week there was a different focus or activity, with the aim that people would learn to support themselves and one another through the challenges of living with dementia while also having fun and enjoying themselves. Group members participated in activities that included: creative writing, learning strategies to remember names and numbers, healthy living to keep minds active, preparing to go into hospital, stress and relaxation, and using technology to help.

This article draws on the selected findings from the evaluation of peer support groups for people with dementia (Chakkalackal & Kalathil, 2014), and reports on the positive benefit of the groups on participants’ memory recall, orientation in time, concentration abilities and communication.

**Evaluation design and methods**

The evaluation was based on a mixed-methods design; both quantitative and qualitative data were collected.

**Selection of participants**

Participants were pre-selected by the group facilitator and assessed as suitable for the group’s activities based on their cognitive and physical functioning. The group facilitator interviewed residents living in the schemes whom housing staff had indicated had a formal diagnosis of dementia or who had memory difficulties. The facilitator used an informal assessment of cognitive functioning and asked each resident whether they felt they had memory difficulties, if they had a formal diagnosis of dementia or whether they had been assessed for memory difficulties or dementia by a GP. Those who had significant physical frailty or physical disability or severe dementia were excluded from participating in the groups as there were insufficient housing and care staff to support their involvement. Participation in the group was voluntary.

**Consent**

All group members assessed by the facilitator were deemed to have capacity and the ability to give informed consent. Group members were introduced to the researcher by the facilitator prior to start of the groups. The researcher asked members whether they would like to participate in the evaluation using easy-read information sheets and consent forms.

**Quantitative data collection**

Quantitative data were collected at three time points: baseline (T1), at 6 months (T2) and at 9 months (T3). At 6 months the group facilitator withdrew; at this point, it was hoped the groups would become self-sustaining.

Quantitative data collected included measures on participants’ physical functioning, social relationships, wellbeing and orientation in time. The following scales were employed:

1. The Lawton-Brody International Activities of Daily Living Scale (IADL; Lawton & Brody, 1969) to assess practical coping skills associated with independent living. The IADL is a validated instrument in the assessment of independent living skills in older adults. It is used to identify how a person is functioning at the present time across eight domains (such as food preparation, housekeeping, laundering etc.). Summary scores range from zero (low function, dependent) to eight (high function, independent). The outcomes evaluation team slightly adapted the measure to provide more complex detail about participant ability; however, the form of the scale was maintained for analysis purposes.
2. The Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS; Stewart-Brown et al., 2009), a measure of positive mental wellbeing. Higher scores on the SWEMWBS indicate positive wellbeing and greater psychological functioning. The SWEMWBS is a 7-item measure created from the original 14-item Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS). There is high correlation between the SWEMWBS and the WEMWBS. Normative data for SWEMWBS was calculated by halving the mean WEMWBS score.

3. A participant expectations questionnaire developed by the evaluation team to collect information on participants’ perception of the impact of the group on social support, loneliness, understanding memory loss and initiating new activities. Each item was ranked on a three point Likert type scale (e.g. not much, somewhat, a great deal).

4. A social relationships questionnaire developed for the purposes of the evaluation to ascertain the level of social support and social networks of participants (see Appendix 1).

5. A measure of orientation in time, assessed by asking participants: time, day of the week, date and season.

**Qualitative data collection**

Qualitative data were collected in the form of semi-structured interviews that explored topics including: strategies or approaches learnt to manage memory or memory loss; use of memory aids in daily life; and new behaviours and activities as a result of coming along to the group (see Appendix 1).

**Ethics**

Ethical approval for the study was obtained from the Social Care Research Ethics Committee (ref no: 12/1EC08/0012).

**Analysis**

Quantitative and qualitative data were analysed using SPSS statistical software and Excel. The Friedman test was performed on participants who completed all surveys on measures of wellbeing (SWEMWBS) and activity of daily living scores (IADL) in order to compare means of the same group of participants across the three time points. Non-parametric Wilcoxon Signed Rank Tests were performed for all group participants on wellbeing (SWEMWBS) and activity of daily living scores (IADL) given the small numbers of participants and non-normal distribution of the sample.

**Findings**

The small-group approach of the peer support model meant participants were divided into three groups based on the housing scheme in which they resided. The findings here, however, are presented for the sample as a whole. While there was some variation in group composition and activities in which each group engaged, which may be responsible for some differences in the findings, the small numbers of participants meant it was not possible to make comparisons of this kind.

**Characteristics of the participants**

A total of 21 participants agreed to take part in the evaluation. Their mean age was 83 years (SD=9.56) with the youngest aged 66 years and the oldest aged 97 years. There were 9 participants in the first group, 6 in the second group and 6 in the third group. Across all groups, 13 females and 8 males participated.
Ethnic makeup of the groups

Based on facilitator reports, one third of (8 out of 21) participants were non-UK born. Place of ethnic origin for group attendees included: Caribbean (5), Ireland (1), South Africa (1), Nigeria (1), France (1) and India (1).

Figure 1 illustrates the high level of disability amongst participants, based on the group facilitator and researcher’s reports. As can be seen from Figure 1, nearly half of the participants (48%) had more than one impairment (i.e. hearing and vision impairment, physical mobility issue and hearing and vision impairment, speech impairment and physical mobility issue, etc) prior to participating in the groups. Almost a quarter (24%) of participants had reduced mobility due to a physical impairment. Just over a quarter of participants (28%) had no physical impairment or disability. All participants had significant memory problems or a formal diagnosis of dementia.

Numbers of participants and attrition

Some attrition occurred over the course of the evaluation due to the following factors: participants becoming unwell; going into hospital; moving away; death; or no longer coming to the group. At baseline, there were 21 group members participating in the evaluation, 15 at T2 and 11 at T3.

Wellbeing

As can be seen from Figure 2, following participation in the groups (n=10), there was a minor increase in the mean wellbeing scores as measured by the SWEMWBS from T1 to T3.

The mean SWEMWBS score at T1 was 22.10 (n=10, SD=5.087) and at T3 was 22.90 (SD=3.414), though the non-parametric Wilcoxon Signed Ranks Test across all participants showed that the change was not significant (Z=-1.80, p=0.857). The mean wellbeing score increased from T2 to T3 which would indicate that there was a small benefit of the groups to members after participation which continued to increase after the facilitator departed at T2.

Figure 1. Level of disability and physical frailty of participants (n=21).
**Figure 2.** Mean wellbeing scores (SWEMWBS) over three time points.

<table>
<thead>
<tr>
<th>Wellbeing Score (SWEMWBS)</th>
<th>SWEMWBS T1 (n=10)</th>
<th>SWEMWBS T2 (n=10)</th>
<th>SWEMWBS T3 (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>22.10</td>
<td>22.20</td>
<td>22.90</td>
</tr>
</tbody>
</table>

**Independent living skills**

From the findings on the IADL (n=10), physical functioning of participants deteriorated slightly at T2, and stayed around this level at T3 (Figure 3).

The mean IADL score at T1 was 3.00 (SD=2.31) and at T2 it was 1.80 (SD=1.81); the non-parametric Wilcoxon Signed Ranks Test across all participants showed this change was significant (Z=-2.99, p=0.003). One possibility for the deterioration may be explained by pre-existing high levels of physical frailty among participants, which was unlikely to improve over time, although the mean IADL score stayed roughly the same between T2 and T3.

**Participants’ orientation in time**

Figure 4 shows the numbers of participants at T1 and T3 who gave correct responses when asked questions on orientation in time.

Following participation in the groups (n=11), participants at T3 improved on most measures of orientation in time (e.g. time, month, season and date) compared with responses at T1. The same numbers of participants at T1 and T3 (n=8) were using aids (e.g. clock, watch, calendar) to keep them orientated in time, indicating there was a positive change on measures of orientation in time as a result of participation in the groups.

**Memory recall and perceived social support**

Although memory recall was not directly tested in this evaluation, participants were asked how many tenants they knew in the housing scheme where they lived and how many friends they had outside the scheme, to gauge their level of social support.

Equal numbers of participants recalled names of tenants at T1 and T2, however, participants at T2 could recall *more names* of people living in their scheme, and in particular they recalled more names of group members including the facilitator. Participants also reported noticing improvements in recall after participation in the groups. One participant reported using the photo book album, an item created in the group, to help them remember names. From these findings it would appear that participants were more cognisant of others and reported better recall of others as a result of participation in the group.
Figure 3. Participants’ change in IADL scores over time.

![Figure 3](image)

<table>
<thead>
<tr>
<th></th>
<th>IADL T1 (n=10)</th>
<th>IADL T2 (n=10)</th>
<th>IADL T3 (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>3.00</td>
<td>1.80</td>
<td>2.00</td>
</tr>
</tbody>
</table>

Figure 4. Number of participants with correct response on measures of orientation in time at T1 and T3.

![Figure 4](image)
Qualitative interviews with participants provided additional findings indicating improved memory recall. Interviewees spoke of how participation in the groups had helped them understand more about the brain and increased their understanding of memory and memory loss. Members spoke about using different cognitive strategies, which they had learnt through taking part in their support group, to help them remember things such as names, dates and numbers.

You learn more through association. Like the telephone, if you want to remember numbers like the pin number, you make a number on the telephone keyboard like the L shape on the left or right. (Participant #7)

I’m remembering more things now because I’m thinking more about it. What I’m doing at the time and what I should say. (Participant #8)

Participants spoke of realising from strategies learnt during the group, the importance of keeping the brain ‘active’ to keep the mind alert and to improve their concentration abilities. They spoke of doing activities such as Sudoku puzzles, word searches and reading books to help keep their mind sharp.

Certainly keeping the brain active, I’m a great word searcher, learning to keep your brain much more active. (Participant #3)

Improvements in perceived social support was also seen when comparing participants’ experiences following participation in the group, with their initial expectations as reported on the participants’ expectations form. When asked whether the groups would help members support each other (item 1) or feel less lonely (item 2), participants reported they had benefitted more than they expected. The mean difference in expectations between T2 and T1 on the item of supporting one another was 0.36 and for feeling less lonely 0.15. A positive integer reflects on average participants benefitted more from the group (T2) than they expected to at T1. This illustrates how the groups helped to alleviate isolation for people with dementia in the scheme and reduce loneliness.

Confidence to do new things

Many participants reported increased confidence and a greater sense of self as a result of participation in the groups. The group setting, based on supportive relationships, set the foundation for group members to try to plan to do new things, such as talking to more people, going out on their own and using the communal tenants’ room where previously some had been afraid to use on their own.

I’m feeling much more determined with how I want to do things. Before I went to the group I always thought I was going to have an addled brain, but it’s not like that at all. Going to the group and listening and learning, they’ve shown me how to point myself to the future. (Participant #3)

I never used to go downstairs till the group started. (Participant #21)

Coping skills and self-management

Group members spoke about learning practical coping strategies, which helped them improve their communication with others. These included:

- allowing people to finish when they are speaking and minimising interruptions;
- patience;
- listening to one another;
- accepting that all people are different and behave differently.
Group members also spoke of learning methods, skills and strategies to manage their memory. Other specific learning during the groups included sessions on relaxation techniques, and planning and preparing for end of life issues, such as going into hospital. This helped ease participants’ anxieties and gave them a greater sense of control over their lives.

[The group] seemed like nothing at all, but in the last few meetings I noticed how useful the group could be in getting things done, teaching people how to manage themselves [their memory]. (Participant #18)

Relaxation was so useful. We had a lady come in to teach us relaxation and breathing techniques, I found that very useful. (Participant #3)

Going into hospital with a picture board with your name on it, with what you like and what you want to be called as, and what your favourite food is. That was excellent, that was a good idea. (Participant #3)

**Positive supportive relationships**

Participants reported meeting and interacting with others who shared a similar experience to them to be the most important and meaningful aspect of the groups. Participants spoke about how much they enjoyed going to the group each week and how supported they felt by one another.

Oh yeah, I get along with the group. ‘Cause it helps, you know, and you’re not lonely and you listen to them and it’s very nice. It’s nice being talked to. (Participant #4)

It [the group] livens you up. (Participant #6)

I remember the most the talking and the friends I’ve made. As it is going now, it’s lovely. I want that to continue, it keeps us all together. (Participant #9)

**Meaningful activity**

It was also extremely important for participants, that the group activities reflected things that were of interest and had meaning to them.

I thoroughly enjoyed the film we had, it was to do with the Old Kent Road and life in the 1900s, it’s called ‘Say it With Flowers’. ‘X’ (participant’s name) was brought up on the Old Kent Road and she was singing away with gusto and she really enjoyed it. (Participant #3)

[Facilitator] would always ask what you would like to happen in the group; all that was put down by us. (Participant #12)

**Discussion and conclusions**

The trend in health and social care services has been towards person-centred care and personalisation since the 1990 NHS and Community Care Act (DH, 1990). In recent years, the value of peer support and self-management programmes has garnered interest from health and social care commissioners who are keen to invest in interventions which support people living independently longer. Despite interest, however, there is relatively little research examining the effectiveness of these interventions and none that has been applied within supported accommodation such as in extra-care housing schemes. Studies that have evaluated programmes have tended to focus on chronic physical health conditions, for example, cancer, diabetes, chronic pain and arthritis (Harvey et al., 2008). More recently, peer-led self-management programmes for people with serious mental illness have been evaluated (Druss et al., 2012; Cyhlarova et al., 2014) and have shown positive improvements in patient self-efficacy, emotional wellbeing and healthy living.
The aim of this paper has been to describe the effectiveness of peer support groups for people with dementia living in supported housing. This article offers additional evidence to support claims about the value of peer support and self-management among older people with dementia. The paper suggests that peer support can have a positive benefit on the cognitive functioning of people living with dementia.

The study examined the impact of the groups on: managing memory and memory loss; wellbeing; learning practical coping strategies; maintaining or reducing care needs; and reducing social isolation. Positive findings were reported in wellbeing, memory recall, time orientation, concentration abilities and communication from qualitative interviews following participation in the groups.

The mean SWEMWBS score of our sample at T1 was 22.10. Participants reported minor improvements in wellbeing after the groups, despite the change not being statistically significant. These findings are consistent with improved wellbeing reported from participation in cognitive stimulation interventions for people with dementia and participation in peer-led self-management programmes (Woods et al., 2012; Cyhlarova et al., 2014).

There was some deterioration in the independent living skills over time of participants, as measured on the IADL scale. It may be that the high level of physical frailty and impairment in the sample made it unlikely that practical coping would improve. This is consistent with findings from the English Longitudinal Study of Ageing which found that prevalence in reporting one or more limitations in activities of daily living increased with age (Zaninotto & Steptoe, 2012).

Qualitative feedback at T2 and T3 suggested that participants are more cognisant of each other and had improved memory recall, possibly as a consequence of the increased socialisation opportunities and the cognitive activities they completed in the group. Certainly one of the greatest reported positive benefits were the opportunities to socialise and interact with others with a shared experience. While studies have looked at the relationship between social activities and social engagement and cognitive decline/impairment and dementia, results are mixed (Wang et al., 2011).

The study had several limitations. The small sample size of the groups meant findings from quantitative measures were limited and therefore overall findings must be treated with caution. Drop out was high in the groups as many participants became unwell, went into hospital or passed away during the evaluation. Another limitation was the study did not use a control group of residents living in the housing scheme who were not participating in the groups and who did not have dementia. Though this was planned, through the housing provider’s care databases, obtaining data on changes in resident care or wellbeing was not possible during the timeframe of the study.

The value of peer support and self-help approaches in housing schemes should be encouraged by housing providers as interventions like these address the psychological, social and emotional needs of residents living in these schemes. These approaches also support a shift from a supported housing culture that focuses on maintaining individual independence to one which supports individuals’ inter-dependence, by encouraging mutual support and sharing coping strategies among people using social care services. A culture of inter-dependence supports community engagement, meaningful activity and supportive relationships, which increases an individual’s social support, positively impacts on their wellbeing and reduces isolation and feelings of loneliness.

The findings from this study offer support for claims about the value of peer support groups for people with mild to moderate dementia in supported housing. The evaluation reported improvements in wellbeing, concentration, memory recall, orientation in time and communication abilities following participation in the support groups. The study adds to the research on peer support and self-management programmes and suggests interventions like
these are meaningful and beneficial for people with dementia in extra-care housing settings. Future research is needed to address the impact of these groups on formal measures of cognitive functioning.

Acknowledgements

Thank you to group participants from Housing & Care 21’s extra-care sheltered housing schemes for their participation in the evaluation and to Toby Williamson and Yulia Kartalova O’Doherty for their support. The study described in this paper was funded by The Joseph Rowntree Foundation.

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**Notes on Contributor**

Lauren Chakkalackal is an experienced research scientist with over five years’ mental health experience in the UK and Canada. Her research includes evaluations both in the public and voluntary sector working with vulnerable and excluded groups, including: people with dementia, veterans, and gang affected youth. Her research interests lie in examining self-management and peer support interventions for improving wellbeing and resilience. She is a Yoga Alliance Accredited yoga teacher leading workplace yoga sessions with interests in mind body approaches in mental health. She holds an MSc in Mental Health Studies from King’s College London and a BSc in Psychology from McGill University.

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Appendix 1: Social relationships questionnaire

1. If you are really worried about something do you have someone you can call/contact/talk to?
   - A relative? A staff member? A friend? Anyone inside the home? Anyone outside the home?

2. How many people do you know living here?
   - Can you name them?
   - Do you consider any of them to be your friends?

3. How many people in the home would you feel comfortable to speak to if something was bothering you?

4. Do you do an activity outside the home? Inside the home?
   - If yes, what and how often?

6 month (T2) interview schedule

   - What strategies/approaches have you learnt in the group that would help them to manage their memory or memory loss? *Ask them to specify*

   - Were you given any equipment from Cindy? – (Date clock, photo book of names, magnifier, calendar, hospital bag, preference sheets, information on planning for the future... power of attorney) Do you use any of the new equipment? Has it made a difference in your day-to-day life? How?

   - Have you started doing new things as a result of coming to the group? If so, what things have you started doing?

9 month (T3) interview schedule

   - Are you doing anything differently since starting the group? *Prompt: think back to a year ago and now*

   - Have things changed over the last three months? (Since facilitator left) *Prompts: socializing more, interacting with others in the home, started any new activities, feeling more content with themselves*

   - What do you remember MOST from the group?

   - Do you use any memory strategies in your day-to-day life that you learnt in the group?
Decisions about equipment and adaptations used for bathing and showering

Joy McLaggan¹

¹Adult Services, Hampshire County Council

Abstract
Bathing and showering equipment and adaptations are commonly prescribed by Occupational Therapists in Adult Services. Despite this very little is known about what affects whether or not these items are used by individuals. With demands increasing it is essential that the experiences, preferences and needs of users are better understood in order that the equipment and adaptations provided are fully utilised and the need of the user met in a client-centred approach.

This article details the research ‘Equipment and Adaptations used for Bathing and Showering: Views of Individuals on their Use’ (McLaggan, 2011) which examined:
- What equipment and/or adaptations do people use for bathing and showering?
- Do people utilise all the equipment and/or adaptations they possess?
- What affects whether or not people use equipment and/or adaptations?

The article will consider the findings from this research in relation to existing research in this field.

Keywords: bathing, showering, equipment, adaptations

Background

Occupational Therapists (OTs) facilitate occupational performance of individuals by removing barriers, adapting or modifying physical environments; promoting function and independence and offering support, guidance and education for individuals and carers (Creek, 2003).

In 2009/2010 over half a million people in England received equipment and minor adaptations from councils with adult social services responsibilities at a cost of over £233 million (The Information Centre for Health and Social Care, 2010). Additionally many Housing Associations provide minor adaptations for their tenants. During the same time period, 127,070 Disabled Facilities Grants were provided under the Housing Grants and Regeneration Act (1996) at a cost of over £232 million (Department of Communities and Local Government, 2010).

Findings from studies conducted by Riley et al. (2008) found that over 33% of referrals to councils with adult social services responsibilities were for OT services, although OTs only make up 1.9% of the Social Care workforce (Local Authority Workforce Intelligence Group, 2007). There are 10 million people in the United Kingdom (UK) with a disability (Department for Work and Pensions, 2011) and councils with adult social services responsibilities are struggling with demand and thus waiting lists for equipment and adaptations (College of Occupational Therapists, 2008a) and this will continue to increase in an ageing population. There is strong evidence to suggest that equipment and adaptation usage increases with age (Kaye et al., 2008; Pressler & Ferraro, 2010), therefore effective provision of services is vital.

OTs in Adult Services are at the heart of the personalisation agenda (Department of Health, 2007; Riley et al., 2008), providing preventative and reablement services along with enabling those with complex needs to remain living in the community in their own homes for longer (College of Occupational Therapists, 2008b). Equipment and adaptations have the capacity to produce cost savings (Mann et al., 1999; Heywood et al., 2005), especially to the costs of residential care and intensive home-care services (Heywood & Turner, 2007).
OT includes working with people to encourage them to select, try and use equipment and adaptations (Schemm & Gitlin, 1998), with the simplest and most cost effective solutions such as equipment and minor adaptations being considered first (Dean, 1999a).

Demand for bathing and showering related assessment is high because this is one of the first activities of daily living with which people with deteriorating functional abilities experience difficulties. This is because these activities are energetic; requiring a high degree of strength, balance (including the ability to stand on one leg), coordination and tolerance to temperature change (Foster, 2002; Mackey & Nanocarrow, 2006). Bathing is a complex activity (Naik et al., 2004) which involves a range of sensorimotor and cognitive skills (Dean, 1999b). Bathing difficulties have been found to be a strong predictor of disability within other activity of daily living areas (Jaggar et al., 2001; Gill et al., 2006a). Gill et al. (2006b) demonstrated that bathing difficulties are strongly associated with the risk of admission into a nursing home and to receiving help in the home (LaPlante et al., 2002).

**Literature search**

The main literature searches were conducted in 2011 and updated in August 2015. Electronic databases were searched to identify general equipment and/or adaptation studies using the search terms ‘adults’, ‘equipment or ‘adaptations’ and ‘experiences’, and specific bathing or showering equipment and/or adaptations studies by using the search terms ‘adults’, ‘bathing’ and ‘equipment or ‘adaptations’. Table 1 shows the search terms used.

Additional searches included the reference lists of relevant articles and grey literature including unpublished dissertations and local authority service evaluations, which were obtained through the College of Occupational Therapists and the Local Authority where the research took place.

International literature was included, however literature written in another language was excluded. The database searches excluded work published prior to 2000, however this restriction did not apply to the other searches. Figure 1 shows the process by which information was screened for inclusion or exclusion and number of studies at each stage.

**Table 1. Literature search: search terms and alternative terms.**

<table>
<thead>
<tr>
<th>Search Term</th>
<th>Alternative Terms</th>
<th>Search Term</th>
<th>Alternative Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Equipment’</td>
<td>• Adaptive equipment</td>
<td>‘Experience’</td>
<td>• Attitudes</td>
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<tr>
<td></td>
<td>• Disability equipment</td>
<td></td>
<td>• Feelings</td>
</tr>
<tr>
<td></td>
<td>• Assistive technology</td>
<td></td>
<td>• Opinions</td>
</tr>
<tr>
<td></td>
<td>• Assistive devices</td>
<td></td>
<td>• Views</td>
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<tr>
<td></td>
<td>• Aids (not HIV)</td>
<td></td>
<td>• Satisfaction</td>
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<td></td>
<td></td>
<td></td>
<td>• Experiences</td>
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<tr>
<td>‘Adaptations’</td>
<td>• Housing adaptation</td>
<td>‘Bathing’</td>
<td>• Bathing</td>
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<td></td>
<td>• Home modification</td>
<td></td>
<td>• Showering</td>
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<td></td>
<td>• Minor adaptation</td>
<td></td>
<td>• Washing</td>
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<tr>
<td></td>
<td>• Major adaptation</td>
<td></td>
<td>• Personal care</td>
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<td></td>
<td>• Home alteration</td>
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<tr>
<td>‘Adults’</td>
<td>• Older people</td>
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<td></td>
<td>• Elderly</td>
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<td></td>
<td>• Physical disability</td>
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<tr>
<td></td>
<td>• User</td>
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</table>
Studies were screened through reading of titles and abstracts, if these seemed relevant the full texts were obtained. Any which made explicit reference to the inclusion of bathing or showering equipment and/or adaptations were critically appraised and included in this article.

Methods

The research used mixed methods and the research design used a ‘sequential explanatory strategy’ characterised by the collection and analysis of quantitative data which used a postal questionnaire in the initial phase followed by collection and analysis of qualitative data using semi-structured interviews in the second phase (Creswell, 2009).

Participants who were invited to take part in this research lived within a Borough Council in the Southwest of Hampshire and were contacted following involvement from the Adult Services OT Team between January and March 2011. Inclusion criteria were: being over 18 years of age, living in the community, having a physical disability and having equipment and/or adaptations for bathing or showering. People previously known to the researcher, known to have a terminal illness or a cognitive impairment were excluded.

The purpose of the questionnaire was to investigate the equipment and/or adaptations used for bathing and showering, whether there was a difference between what people owned and what they used and to find out what possible factors affect whether or not people use equipment and/or adaptations.
Figure 2. Questionnaire sample: age and gender.

Questionnaires (40 related to shower equipment and adaptations and 17 for bathing equipment and adaptations) were posted in May 2011 to the 57 people who met the inclusion criteria. Figure 2 shows the distribution of age ranges and gender.

There was an overall response rate of 42%, 14 showering and 10 bathing questionnaires were returned.

Some basic descriptive statistics were computed and content analysis was used to analyse the free text responses in the questionnaires; the categories that were identified went on to inform the topics that were covered in the face-to-face semi structured interviews. These included how, why and what equipment and/or adaptations were being used, how interviewees felt about this and how satisfied they were with their current routine and equipment and/or adaptation usage, the appearance and physical features of their equipment and/or adaptations and whether these were important. They were also asked about the role of their equipment and/or adaptations in relation to falls.

In-depth interviews were carried out with four participants chosen to reflect users of a variety of types of equipment and adaptations, who had provided interesting views and, in particular, had identified any equipment or adaptations not being used which merited further exploration.

Limitations

The study has a number of limitations:

- Questionnaire sample did not equally represent the views of men and people under 75 years old.
- Questionnaire target sample size was small so not clear whether the views obtained are representative of all users.
- Interviewee sample unlikely to be representative of the whole questionnaire sample in their views due to self-selection and small sample size.
- Interviewee sample over-represented the viewpoints of elderly women who used equipment or adaptations without carer assistance.
- In some cases the equipment and adaptations had only been used by participants for a short length of time.
These limitations mean that the results of this study cannot be generalised, but may be useful to accentuate our understanding that people’s usage of equipment and/or adaptations is a complex topic.

Findings

Variety of equipment and adaptations used

The most commonly prescribed equipment and adaptations were documented in the questionnaires with the anticipation that all of these would be in use, therefore it was a surprise that no wheeled shower chairs or swivel bathers were in use. Figure 3 shows the usage of each equipment and adaptation.

There are many more types of equipment and adaptations that are available such as hoists over the bath, shower-loos, specialist baths and shower benches which were not explored in this study. Perhaps if these had been included in the questionnaire they would have evoked different, perhaps more extreme responses from participants, given that one of the interviewees talked of the humiliation if she were ever to need a hoist to assist with getting in/out of the bath.

Comparing these current findings to other research is problematic, particularly with international studies (Schemm & Gitlin, 1998; Wielandt et al., 2001; Gill et al., 2007), as they include many items that in the UK would either not be classed as specialist OT equipment, such as non-slip mats, or users would be expected to provide for themselves, for example handheld shower sprays, wash mitts and long-handled brushes.

By focusing on the most popular types of equipment and adaptations in the UK, it was hoped that the findings from this study would be more capable of generalisation to other areas. Making comparisons between studies as to what equipment and adaptations are least and most popular is difficult because each study focuses on different items.

Figure 3. Number of people using each equipment and adaptation.
Three of the five common types of shower seats were not used by any of the participants. Most other studies do not break down the types of shower seats used and categorise them only as wall-mounted or free-standing: however the Medical Devices Agency (2002) did report on usage rates of the wheeled shower chair (13%) being much higher than this study which found none being used. As was found with the current study, other studies have also found the use of grab rails (De Craen et al., 2006; Häggblov-Kronlōf & Sonn, 2007) and level access showers (Medical Devices Agency, 2002) most popular for assisting with bathing and showering.

**Reasons for non-use**

Six items were reported to be owned but not used; Table 2 gives details of these.

According to the existing evidence from other studies, the majority of reasons for non-use of equipment and minor adaptations have related to users’ needs changing through a deterioration or improvement in their condition. The majority of studies which have explored item non-use have done so following hospital discharge or rehabilitation, where a commonly cited reason for non-use and abandonment includes users improving and the items becoming redundant (Wielandt et al., 2001, 2006; Steel & Gray, 2009). In these settings rates of non-use can be quite high as items are often provided for short-term use. These studies usually only review equipment or grab rails, as more complex and costly adaptations are usually only provided by OTs working for councils with adult social services responsibilities where there is a long-term need.

The sample in this study differs to those discharged from hospital or undergoing rehabilitation as Adult Services users tend to be people with long-term and chronic conditions in which their functional abilities are unlikely to improve. Also since provision had only been made a few months previous to taking part in the study, it was unlikely their needs would have changed during this time. This may explain the low rates of non-use found in this study.

A variety of items were not being used. These included two grab rails, a wall fixed shower seat with arms, a bath seat, a bath board and an over-bath shower. Other studies which have itemised items not in use (Pendleton, 1985; Clemson & Martin, 1996; Chamberlain et al., 2001; Hoffmann & McKenna, 2004) do not identify any specific types of items which are more likely to be abandoned.

Whilst the number of equipment and adaptations found to be unused was small, these findings are limited because of the short timescale in the study. Abandonment rates vary (De Craen et al., 2006) according to the sample studied (rehabilitation, hospital or community) and methods used, which make the results hard to compare. Shower seats are commonly provided as part of level access shower installations (Kimbell, 1999) and it is important that the height of these allow users’ feet to be supported to prevent users sliding forwards in the seat (Disabled Living Foundation, 2007). A wall-fixed shower seat provided with a level access shower adaptation was not being used, mainly because the interviewee felt she was going to slip off the seat, which she had attributed to it being too high. Heywood (2001) found seat surfaces can become slippery when wet.

Other studies have also found shower seats to be unused, with reasons for non-use also including safety concerns (Clemson & Martin, 1996; Hoffmann & McKenna, 2004; Medical Devices Agency, 2002). These studies, except for Medical Devices Agency (2002) study, do not, however, make any differentiation between the types of shower seats which are not being used or what the nature of the reported safety concerns are. In the Medical Devices Agency (2002) study one reason for non-use was due to the user feeling as if they were slipping off the seat, as was found in this study.
Table 2. Reasons given for equipment or adaptations not being used.

<table>
<thead>
<tr>
<th>Item</th>
<th>Reason for non-use</th>
</tr>
</thead>
</table>
| Fixed shower seat     | ‘When it is wet I feel that I am going to slip off’  
                        | *(Respondent 10)*                                                                 |
| Bath seat             | ‘Disadvantage to using the seat is that I can’t immerse myself in the water this way, keeping warm is difficult even with the heating on’  
                        | *(Respondent 48)*                                                                 |
| Bath board            | ‘Sitting on this to bath is all wrong, you wash the floor more’                    |
                        | *(Respondent 50)*                                                                 |
| Over-bath shower      | ‘I prefer a bath – I feel more secure’                                             |
                        | *(Respondent 44)*                                                                 |
| Grab rail             | ‘Reason – poorly positioned’                                                       |
                        | *(In-depth respondent 1)*                                                          |
| Grab rail             | ‘Used as towel rail’                                                               |
                        | *(In-depth respondent 2)*                                                          |

Two grab rails were not being used, both of which were provided as part of two separate level access shower adaptations provided by Disabled Facilities Grants. In the first example the user had two grab rails fitted as part of her shower adaptation. The user had requested one grab rail only, but as two rails had been specified on the builder’s schedule of work the surplus rail was fitted as a towel rail as neither the builder nor user could find a suitable position to install it. In the second example the grab rail was installed without consultation with the user, and was fixed in an impractical position.

Other studies have found non-use of grab rails to be a problem and have provided some reasons for this (Pendleton, 1985; Clemson & Martin, 1996; Hoffmann & McKenna, 2004). Findings by Hoffmann & McKenna (2004) found that grab rails were not used because they had been provided but were never required by the user. This suggests that perhaps grab rails are provided based on the assumption that if they are fitted then the user will automatically use them. A study by Sveistrup et al. (2006) found that even if grab rails are provided, if the user doesn’t perceive that they need them they will not use them.

Bath and shower boards help people to get in and out of the bath and can be used to sit on for washing or showering (Mackey & Nanocarrow, 2006). Their use, however, can make it more likely that water spills over the edge of the bath (Pain, 2003) because the shower curtain cannot be tucked inside the bath so easily. One participant did not use their bath board because of the volume of water ending up on the floor. This may be difficult for the user to clean up and if the flooring becomes slippery when wet, this obviously increases the risk of slips, trips and falls for the user (Hall, 2003). Not being able to cope with water spillage was noted by Medical Devices Agency (2002) in relation to shower facilities, which may prevent their use.

Other studies have found non-use of bath boards to be a problem (Pendleton, 1985; Wielandt et al., 2001; Hoffmann & McKenna, 2004). In particular Pendleton (1985) found high numbers of bath boards not being used, of which 72% of these were never used. The author, however, does not elaborate further on possible reasons for their non-use.
The importance of training so that equipment is used safely and effectively has been highlighted in the literature (Schemm & Gitlin, 1998; Eldar & Iwarsson, 2001). The lack of training on how to use the equipment was found to be a reason for non-use of bath boards in a study by Wielandt et al. (2001). Whilst one of the interviewees in this study was using a bath board as a seat for showering, she was having difficulty transferring in and out of the bath as she had not been shown how to use the bath board for this. This example illustrates the importance of providing users with some form of practical training in how to make the most of the equipment, findings confirmed by Chiu & Man (2004), in which training in the use of bathing equipment improved usage rates.

One bath seat was not being used because the user could not immerse themselves fully in the bath and therefore felt cold. This type of problem may not be confined to this type of equipment, as showering without adequate heating, either in a stand-alone facility or over the bath, can be problematic because of the cold (Medical Devices Agency, 2002).

There appears to be very little literature which relates to the use of bath seats, mainly because the term is used ambiguously (Clemson & Martin, 1996; Mann et al., 1996). Therefore it is not clear whether these results can be drawn upon. Pendleton (1985) found that non-use of bath seats was a particular issue and those that were not being used were due to the user’s needs changing.

One participant reported that she was not using her over-bath shower as she was washing using an alternative piece of equipment (bathlift). In this case the over-bath shower was already in the property prior to the interviewee moving in.

With the exception of Bowring (2007) non-use of over-bath showers is not reported in the literature. This may be due to few being fitted by the Disabled Facilities Grants (Pain, 2003). For many older people bathing is a preferred option. Parkes (1993, cited in Pain et al., 2003) found that 62-71% of older people preferred to bathe, therefore this reason for non-use of the over-bath shower is not an uncommon one. However, trends are changing as people are recognising that showers can offer a quicker and safer alternative for many (Hill, 1996; Kimbell, 1999; Medical Devices Agency, 2002) and in this study 18 of the participants were showering rather than bathing.

Two items were not being used for their intended purpose, one was a bath seat being used as a stool and the other a grab rail being used as a towel rail. This suggests that the items were deemed unsuitable by the user for their intended purpose.

**Factors supporting use**

The majority of studies generalise their findings across a range of ‘bathing’ or ‘showering’ equipment or adaptations. There are only a handful of studies which focus on use of specific items such as showers (Pain, 2003), grab rails (Lockett et al., 2002) or even long-handled sponges (Rogers et al., 2002) and which detail the reasons for their use. The most commonly used items in this study were the fixed shower seats with arms, grab rails and level access showers.

This study identified a variety of reasons for use of a fixed shower seat with arms, shown in Table 3.

There were 10 respondents who provided reasons for using level access showers; all these reasons related to its ease of use since there was no step into the shower, therefore nothing to trip over. These findings were similar to the users of level access showers studies by Pain (2003) and Adams & Grisbrooke (1998).
Table 3. Reasons provided for use of fixed shower seat with arms.

<table>
<thead>
<tr>
<th>Reason for use</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase safety</td>
<td>3</td>
</tr>
<tr>
<td>Support</td>
<td>2</td>
</tr>
<tr>
<td>Helpful</td>
<td>1</td>
</tr>
<tr>
<td>Aid washing</td>
<td>2</td>
</tr>
<tr>
<td>Practical reasons</td>
<td>2</td>
</tr>
</tbody>
</table>

I wouldn’t feel safe [referring to a shower stool without a back rest].

(Respondent 1)

Table 4. Reasons provided for use of grab rails.

<table>
<thead>
<tr>
<th>Reason for use</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support to stand or get into shower</td>
<td>6</td>
</tr>
<tr>
<td>Aid getting up from seat</td>
<td>1</td>
</tr>
<tr>
<td>Reduce risk of falling/ slipping</td>
<td>5</td>
</tr>
<tr>
<td>Transferring into the bath</td>
<td>1</td>
</tr>
<tr>
<td>Support</td>
<td>3</td>
</tr>
</tbody>
</table>

They [grab rails] help steady me, I am reassured that I won’t slip.

(Respondent 27)

Grab rails were used by those who showered and those who bathed; Table 4 shows the reasons for use.

Other studies have found that positioning of grab rails is an important determinant in their use (Clemson & Martin, 1996; Heywood, 2001; Sveistrup et al., 2006). Sveistrup et al. (2006) explored the optimum positioning and numbers of grab rails required to assist with getting in/out of the bath and concluded that the ideal number of grab rails required was two. There is no similar data on use of stand-alone showers and this study found that of the two interviewees using shower adaptations, both used grab rails located very differently. The Medical Devices Agency (2002) suggest that a combination of an oblique rail beside a seat, a vertical rail beside the shower head riser and a horizontal rail for holding whilst standing are common locations for grab rails in showers.

Clemson & Martin (1996) found that satisfaction was determined with the positioning of the participants’ grab rails according to their height, angle and position. Satisfaction was high, ranging between 93-100% for bath rails and 82-98% for shower rails. These high satisfaction rates accorded with those found in this study.
In order to speed up delivery of services and manage demands many councils with adult social services responsibilities and Housing Associations are offering ‘fast-track’ services for items such as grab rails where users can arrange to have these fitted without a visit from an OT (Hampshire County Council, 2010; College of Occupational Therapists, 2006). This idea of self-assessment may work for the majority of individuals, but not for all. Sveistrup et al. (2006) found 14% of their participants were unable to visualise or place where they needed their grab rails. This supports the findings of this study which suggest that there are still large numbers of users who find difficulty pinpointing where their grab rails are needed.

A number of elements are of importance in determining whether equipment and/or adaptations are used and ultimately how satisfied the user is with them. Figure 4 illustrates how these elements might link together as a process.

Should this ‘process’ be interrupted because a particular aspect cannot be met or overcome then the equipment and/or adaptation risks not being used and the user may experience dissatisfaction, as use and satisfaction appear to be closely related.

Discussion and conclusions

Endorsement

Awareness and availability of equipment and adaptations is increasing, however some service users do not feel in a position to articulate their preferences and exercise their choices - a key aspect of personalisation (Foster et al., 2006). For many people recommendations and practical expertise offered to them by professionals are of utmost importance (Steel & Gray, 2009), especially when this is considered along with the sense of powerlessness which can result from complex and confusing processes (Hardy et al., 1999), which are well documented in relation to
the Disabled Facilities Grant process (Carlton et al., 2001; Awang, 2002; Nord et al., 2009). Adams & Grisbrooke (1998) noted willingness of builders to provide choice when installing shower adaptations. Tanner et al. (2008) found that as long as the users had perceived an active role in important aspects to them, then this contributed towards their satisfaction with their adaptations.

**Task enabling**

All participants viewed using their equipment and adaptations positively, enabling them to carry out the tasks of bathing or showering that they would otherwise be unable to do (task-enablers) and were necessities, views shared by the participants of Pettersson et al. (2007) study. It was important that the items they were provided with met the need for which they were originally intended; this was also an important factor in other studies (Clemson & Martin, 1996; Wielandt et al., 2006). Equipment and adaptations are also commonly used to overcome functional limitations (Wielandt et al., 2006; Häggblom-Kronlöf & Sonn, 2007) and to overcome difficulties experienced as a result of arthritic conditions.

**Usability**

Comments (n=5) were made relating to not having enough space for items or preferring items which could be folded up in the instance of shower seats or the practicality of cleaning and comfort. Other research has found that durability is an important factor in determining usage (Clemson & Martin, 1996; Wielandt et al., 2006).

Häggblom-Kronlöf & Sonn (2007) described the practical aspects of people’s experiences of using equipment and adaptations on another continuum, with experiences ranging from usable to inappropriate and essential to cumbersome. Most of the interviewees felt that having enough space was important which supports findings by Tanner et al. (2008). Space was an issue for one of the interviewees using a bathlift who found it cumbersome and bulky in the bathroom. However, this was outweighed by being able to keep clean and soak in the bath, suggesting her viewpoint would have been more towards the cumbersome end of Häggblom-Kronlöf & Sonn’s (2007) continuum.

Another important factor was ease of use of items, a finding also reported by Clemson & Martin (1996) and Wielandt et al. (2006). Seale et al. (2002) recommended the importance of user involvement within the design and development of equipment and adaptations to maximise effectiveness and usability.

Two comments were made about the aesthetics, by people pleased with the appearance of their adaptations which demonstrated that adaptations do not need to look clinical (Kimbell, 1999). Other studies have found that pleasing aesthetics are important (Tanner et al., 2008) and aesthetic appeal influences use (Wielandt et al., 2006). In contrast, the findings of this study, particularly in relation to the shower adaptations, mirrored results from Steel & Gray (2009) in which it was found that aesthetics did not influence usage. Adams & Grisbrooke (1998) also reported on satisfaction towards the appearance of level access showers and Heywood (2001) reported that 95% of participants were satisfied with the way their minor adaptations looked. The results from this study found that all the interviewees were happy with the basic equipment and adaptations which were provided for them.

**Safety**

Increased safety was the most frequently reported reason for using equipment and adaptations, making them feel more secure and reducing their risk of falling.

In contrast a small number of respondents felt that if the equipment or adaptations made the task unsafe, this could result in the item not being used.
It is common for some elderly and disabled people to worry about falling (Legters, 2002) with the prevalence and risk of falls being well documented (Department of Health, 2009). Three of the interviewees had reported having a fall in the past. Whilst some participants were not worried about falls, others were clearly concerned about falling and subsequent injuries and so had implemented several strategies to prevent falls including the use of equipment, adaptations and behavioural adaptation such as ‘taking care’ (Kruse et al., 2010) or placing towels on the floor or seat surfaces. All acknowledged the role that equipment and adaptations could play in the prevention of falls, even if they were not directly concerned themselves. The preventative function of equipment and adaptations within OT interventions is documented in the literature (Cumming et al., 1999; Clemson et al., 2008; Monaco et al., 2008) with commonly cited reasons for using equipment and adaptations including feeling secure, 56%, (Häggblom-Kronlöf & Sonn, 2007), 62% (Heywood, 2001) and 97% feeling safe (Medical Devices Agency, 2002).

Acceptance

Research has confirmed that users are receptive to equipment and adaptations (McCreadie & Tinker, 2005), particularly where they can see it improves quality of life and alleviates safety problems (Heywood, 2001; Roelands et al., 2002). Therefore they may alter their routine to showering from bathing (Pain, 2003). Adaptation to or acceptance of disability plays a major role in the determination of equipment and adaptation use (Pape et al., 2002). Therefore this could suggest that the interviewees had accepted their need for help from equipment and adaptations. For some it enabled them to exert some control over or a way of coping with their situation and condition (Hill et al., 2009), although some were grateful to receive any help at all (Heywood, 2001) and felt lucky and happy to use them which represented the ‘pleasant’ end in a continuum of people’s experiences of using equipment and adaptations, developed by Häggblom-Kronlöf & Sonn (2007).

Lund & Nygård (2003) identified that types of users could be defined according to the weighting they place on the desirable and undesirable consequences of using equipment and adaptations. They found that some users were more likely to find fault with things than others and end up discarding items.

Summary

It is hoped this article has raised awareness regarding the broad range of meaning and experiences users have towards their use of equipment and/or adaptations for bathing or showering and of the complexity of the issues which surround their use.

OTs have an important role in the successful uptake of equipment and adaptations by providing choice, sharing expertise and problem-solving skills to enable users to find the right equipment and/or adaptations which supports their bathing or showering needs. This research suggests that equipment and adaptations need to be practical, fit for purpose, simple to use and safe for them to be accepted, but, ultimately the user needs to be receptive to task modification and equipment and/or adaptation use.

This study along with other studies (Sainty et al., 2009; Chamberlain et al., 2001) recommends that equipment and adaptations are followed up with users to identify items not being used, whether alternative equipment and/or adaptations are needed and to address any difficulties or concerns that have become apparent after their use for a period of time.

Future research would be useful in this field to test the proposed ‘Factors that Influence Equipment and/or Adaptation Use and Satisfaction’ model.
References


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Housing Grants Construction and Regeneration Act 1996 (c.53), London: HMSO.


**Notes on Contributor**

Joy McLaggan is an Occupational Therapist who has been qualified and working for Adult Services in Hampshire for over 10 years. Her research was conducted under the supervision of Dr Jani Grisbrooke whilst studying at the University of Southampton for a Masters in Clinical Research, which was funded by the NIHR Clinical Academic Training Pathway. In 2012 she was awarded a Distinction and after a short break from practice to have twins, she is now establishing a research career alongside her clinical practice. She has recently joined the *Research Development and Governance Panel* in Hampshire and this will be her first journal publication. Her research interests are in occupational therapy, equipment, adaptations, housing and social care.
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- to provide a network of mutual support and a forum for the exchange of ideas and information on social and health care services;
- to promote high standards in social and health care services research, information, planning and evaluation;
- encourage collaboration in social, housing and health services activities;
- to develop an informed body of opinion on social and health care services activities;
- to provide a channel of communication for the collective views of the Group to central and local government, other professional bodies and the public;
- to sponsor relevant research and identify neglected areas of research;
- to encourage and, where appropriate, sponsor high quality training in research techniques.

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How is it organised?
SSRG is run by an ‘Executive Committee’ (EC) which comprises elected and selected officers, elected members, co-opted members and representatives from SSRG Scotland, whose principal tasks are to promote the objectives of the group and to co-ordinate its activities.

What does it do?
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