



Open Research Online

Citation

Larkin, Mary and Dickinson, Helen (2011). Personalisation: what will the impacts be for carers? TSRC, Birmingham.

URL

<https://oro.open.ac.uk/41088/>

License

(CC-BY-NC-ND 3.0)Creative Commons: Attribution-Noncommercial-No Derivative Works 3.0

Policy

This document has been downloaded from Open Research Online, The Open University's repository of research publications. This version is being made available in accordance with Open Research Online policies available from [Open Research Online \(ORO\) Policies](#)

Versions

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding

Third Sector Research Centre

Working Paper 64

Personalisation: what will the impacts be for carers?

Dr Mary Larkin and Dr Helen Dickinson

July 2011

Abstract

Much has been written about personalisation and the potential that this agenda holds for change within welfare services. Although carers have been identified as an important group in translating personalisation into practice we know very little about how the third sector might support carers in order to make personalisation effective. In this paper we examine the literature to identify the existing evidence base available to examine the impact of personalisation on carers. We find that this evidence is limited at best and therefore set out those areas of further research which we argue are required to inform third sector practice. We illustrate these areas of further research via some real-life case studies in order to root these examples in everyday practice.

Keywords

Personalisation; carers; impact; evidence.

Acknowledgements

The authors would like to thank the Carers Federation and the Princess Royal Trust for Carers for all their support for the development of the evidence base about carers within the personalisation agenda.

Contents

- Introduction..... 3**
- The personalisation agenda..... 4**
- What do we know about the impact of personalisation on carers?..... 5**
- Evidence required by third sector organisations to support carers as personalisation**
 - progresses 9**
 - Skills 9
 - Service design 10
 - Emotional impacts..... 11
 - Ways of supporting carers 11
 - Policy development..... 12
- Taking this agenda forward..... 12**
- Conclusions 13**
- References 14**

Introduction

The delivery of adult social care without the 6.4 million people who are carers is unsustainable; not only are they central in delivering good outcomes for those for whom they care but it is also estimated that they save the United Kingdom £119 billion a year (Buckner and Yeandle, 2011). Personalisation is associated with the potential for many changes which could have profound implications for a wide range of individuals, groups and organisations, including carers. Despite recognition that the successful implementation of personalisation is very much dependent on the vast number of carers in our society and their invaluable yet unpaid contributions to social care, they have received less attention than other groups in research carried out into the changes taking place as a result of the personalisation agenda (Glendinning *et al.*, 2009). Moreover, the main focus of TSRC's work on this agenda to date has been in relation to service users and providers (see TSRC Working Paper 30, Dickinson and Glasby, 2010). Consequently, there is a lack of knowledge in general about the personalisation agenda and its outcomes for carers, and more specifically the evidence base on which the third sector can draw when addressing carers' needs is limited.

The complexity of personalisation is widely acknowledged and research shows that third sector organisations are still not fully aware of its implications yet (Dickinson and Glasby, 2010). Thus, responding appropriately to personalisation is challenging for the third sector, and responding to those groups about which there is an insubstantial evidence base, such as carers, is even more problematic. As a result, the third sector is currently less able to support carers than other groups as the current transformation of health and social care increasingly gathers momentum (Larkin, 2011). Yet, the Coalition government sees the role of carers as a vital component of the Big Society (Department of Health, 2010b). It is therefore essential that a body of research is developed to help the third sector understand the implications of the changes that are taking place so that they can respond to carers more appropriately. The need for such research is compounded by that fact that moves towards mainstream operation of personalisation are set to continue.

Against this background, this paper aims to:

- review the existing evidence base available to the third sector about the impact of personalisation on carers;
- identify those areas of further research required to inform practice across the third sector;
- identify issues that local and national policy makers will need to consider in relation to service delivery as personalisation evolves.

In addressing these aims the paper starts by providing an overview of the major features of the personalisation agenda in order to contextualise the debate to come. We do not go into great depth about the history of and drivers for personalisation as this has been set out in a previous TSRC publication (Dickinson and Glasby, 2010). We would recommend that any readers not familiar with this context might benefit from reading TSRC Working Paper 30 before this document. The paper then moves on to review the evidence base on the impact of personalisation on carers. We find that the evidence base for traditional research is limited, with very few studies focusing exclusively on carers.

The majority of findings about carers and personalisation have emerged from studies into different forms of self-directed support, which in addition to individual budgets also include direct payments and personal budgets. We then move on to set out what evidence we believe is required by the third sector in order to support carers as the personalisation agenda progresses. These issues are set out according to the themes of skills, service design, emotional impacts, ways of supporting carers, and policy development and are illustrated by way of case studies which seek to embed these within everyday practice. The paper ends with a reflection on gathering the evidence identified and the implications for the next stage in the TSRC's research programme into personalisation.

The personalisation agenda

Needham (2011: pg. 54) describes personalisation as having 'become a unifying theme and a dominant narrative across public services in England'. Although the original policy interest in this agenda came about under the New Labour governments, personalisation has caught the attention of the Conservative party and remains a crucial policy lever under the Coalition government. The cross party support for its underlying principles also indicates it will retain political currency for the next few years, regardless of who is in government (Hiscock and Stirling, 2009). At a meta-level, personalisation is essentially concerned with thinking about public services from the perspective of the person, rather than from the starting point of what services are currently delivered. However, beyond these rather broad aims, there is little more specificity about what personalisation means precisely (for some selected examples see Leadbeater, 2004; Cutler *et al.*, 2007; Glasby and Littlechild, 2009). Indeed, one of the very complexities of a personalised system is that it is difficult to predict in advance what this might look like: in a truly personalised system individuals would shape their services around their personal needs and wishes and it is difficult to predict the desires of service users in advance within a system in which this is currently not often taken into consideration.

TSRC has already published a Working Paper that sets out the history, policy drivers and wider features of the personalisation agenda (Dickinson and Glasby, 2010), so in this paper we do not intend to rehearse these issues again. It is sufficient to note that personalisation has a more significant history than simply recent political interventions and the concept of personalisation in its broadest sense is linked to notions of improved outcomes for service users, rather than simply the technical levers available to try and bring about personalised services which it is often conflated with (such as direct payments, personal budgets, individual budgets). Personalisation is therefore broadly the ways in which services are tailored to the needs and preferences of citizens (HM Government Policy Review, 2007) and is set against a background of the public becoming increasingly demanding about the types of services that they receive as individuals demand more empowered care and to establish different types of less passive relationships with providers and professionals involved in the design and delivery of their care. Those advocating personalisation often highlight it as a way of developing a citizenship agenda and moving from a gift-based welfare system to one of empowerment (e.g. Glasby and Littlechild, 2009). Personalisation is on the agenda across health and social care (which this paper is primarily concerned with) but is also a central theme in education, children's services and social security (for example, Department for Education and Skills, 2005; Department for Children,

2008; Office for Public Management, 2008; Cabinet Office, 2009). Further, this is an international phenomenon, with interest in shifting models of care across all the UK governments, in addition to Canada, New Zealand, USA, Australia, France, South Africa and other national contexts.

Yet, despite this groundswell of interest in this agenda, as Harlock (2009: pg. 8) notes, 'personalisation is still evolving in terms of policy implementation and practice and how we can turn the rhetoric of personalisation into an effective reality is as yet unclear'. Similarly, Needham (2011: pg. 56) observes, personalisation is not policy programme with a fixed content but instead can be characterised as a 'story line'. What is being argued here is that the search for a clear and consistent policy programme - and by implication an evidence-base underpinning this agenda - may not be entirely fruitful. In our previous working paper on personalisation and the implications for the third sector (Dickinson and Glasby, 2010) we argued that whilst personalisation potentially fulfils many of the types of things which third sector organisations have been arguing for some time, it could also mean significant changes for providers involved in the delivery of services. Further, it is important that third sector bodies understand these implications and are able to respond to these appropriately or else risk losing out in this change process.

Personalisation has risen as an area of interest as it is the means through which a number of debates over the relationship between citizen and state have been conducted in recent times. Although there is some evidence from the national IBSEN review (Glendinning *et al.*, 2008) and from the In Control programme (Poll *et al.*, 2006; Hatton, 2008), the traditional evidence base to support personalisation is far from compelling. Whether personalisation proves to deliver a step-change in the types of services delivered and outcomes of individuals largely depends on the ways in which this agenda goes on to be implemented in practice. Arguably at this still early stage there is a risk that personalisation could be seen to be implemented or achieved, but in reality little may have changed for those individuals using services. With this in mind, one group that are crucial in terms of the efficacy and effectiveness of personalisation are carers. However, as we will go on to argue in the next section, little is known about the impact of personalisation on carers. In this paper we set out what we already know about these issues and where the gaps in the evidence lie. We argue that thinking through these gaps and the implications for research, policy and practice are crucial in this agenda proving effective in the longer term.

What do we know about the impact of personalisation on carers?

The transformation of the social care system that is currently taking place as a result of the personalisation agenda requires complex cultural, structural and procedural adjustments which impact at organisational and personal levels. Studies have identified issues for many of the main participants. For instance, local authorities face challenges such as developing procedures, and integrating separate income streams (Browning, 2007; Hudson and Henwood, 2009). Other studies have highlighted some of the implications for the social care workforce. For instance with reference to social workers, it is predicted that there will be a 'significant shift in culture for them as professionals' (Cunningham and Nickson, 2011: pg. 7). This is because their jobs are likely to be redesigned to include further use of para-professionals and more prevention, brokerage and risk assessment work

(Carr, 2009; Cunningham and Nickson, 2011). Other frontline social care staff will experience a move towards more casualised work, a requirement to acquire new skills and the potential fragmentation of their pay and conditions away from collective agreements (Cunningham and Nickson, 2011). Several studies have also focused on service users, exploring the impact on different groups of service users across a number of life domains. Examples of outcomes for users are feelings of being in more control of their lives and improvements in health, quality of life, and levels of community participation. However, outcomes do vary between user groups and depend on factors such as the nature of their support planning and on their support networks. Furthermore, responding effectively to some groups, such those with complex needs, has proved to be more problematic (Glendinning *et al.*, 2008; Carr, 2009; Glasby and Littlechild, 2009; Chester *et al.*, 2010).

The importance of carers to the successful implementation of the personalisation agenda is consistently acknowledged in the literature. Briefing documents have examined the way carers have a greater responsibility for ensuring the quality of the support provided to some groups of service users within the personalisation agenda (Social Care Institute for Excellence in conjunction with Carers UK, 2009; Social Care Institute for Excellence, 2010). With reference to personal budgets specifically, a recent document stated that 'carers play a central role in helping many personal budget holders to take up and manage their budgets', and that 'carers should be involved on all stages of the personal budget process' (Newbronner *et al.*, 2011: pg. 66). Therefore carers are important as they often provide a degree of continuity in terms of care and play an important role in the caring process. If Third Sector organisations want to understand the full implications of the personalisation agenda then having a sense of where carers fit and the sorts of needs they may have is crucial. Third sector organisations have many potential roles in relation to this agenda (service provider, advocate, campaigner etc), but what is common across these functions is that having a more comprehensive understanding of the role that carers play and the implications of personalisation for this group is important.

However, carers have received relatively little attention compared to other groups affected by what are regarded as the biggest changes since the introduction of community care (Hatton *et al.*, 2008; Hiscock and Stirling, 2009). Existing findings about carers are incidental to or only part of the main study in most of the research that has been carried out (Flynn, 2005; Glendinning *et al.*, 2008; Glynn *et al.*, 2008; Commission for Social Care Inspection, 2009; Pitts *et al.*, 2009; Duncan-Turnbull, 2010; Waters and Hay, 2009). There has been just one study that has focused exclusively on carers but this addressed the impact of individual budgets only on carers of older people and carers of people with learning difficulties (Glendinning *et al.*, 2009). Indeed the majority of the findings about carers and personalisation have emerged from studies into the different forms of self-directed support which, in addition to individual budgets, also include direct payments and personal budgets. Self-directed support involves the allocation of resources to service users to use for the support of their choice. Service users, or their representatives where appropriate, control these resources, directly or indirectly depending on the form the self-directed support takes. Following a separate assessment of their carer-related needs, carers can also receive self-directed support, such as direct payments, in their own right (Department of Health, 2009; Glendinning *et al.*, 2009). In a review of the UK and international

literature on consumer-directed payments, SCIE (2007) found that where direct-payment type initiatives were introduced there is a significant increase in the demand for personal assistants (PAs) in all countries. Many countries (e.g. Luxembourg, Sweden, Norway, Austria and Germany) also often allow direct payment recipients to employ relatives and debates over low wages for PAs and unregulated markets are also common.

The evidence to date suggests that overall, self-directed support has resulted in improved outcomes for carers. Examples of positive outcomes that have been identified are being more of an equal partner in planning support for the person for whom they care, and having the opportunity to secure the type of support that benefits and relieves them, more free time and increased choice and control over their lives. Carers have also reported improvements in their quality of life, health and well being, and relationship with the service user. However, the extent to which carers experience these more positive outcomes can depend on the nature of the needs of the person they are supporting. Less positive outcomes have been identified too, such as the fact that carers' capacity to undertake paid work does not increase (Waters and Hay, 2009; Duncan-Turnbull, 2010; Tyson *et al.*, 2010) they spend more time on 'managerial care' as opposed to 'direct 'hands-on' care', perceive the administrative and managerially responsibilities involved as additional burdens and feel higher levels of support should be provided (Rosenthal *et al.*, 2007: pg. 756; Glendinning *et al.*, 2009; Duncan-Turnbull, 2010; Moran *et al.*, 2011). In addition, findings indicate that self-directed support means carers can be faced with having to cope with several changes in their caring role. These changes include the service user making more of the decisions about their own care, having to make different contributions to the provision of care which may involve carers in new tasks as well as new roles. With reference to the latter, in some cases, there may be a contractual relationship with the service user (Rosenthal *et al.*, 2007: pg. 756; Glendinning *et al.*, 2009; Duncan-Turnbull, 2010).

In relation to these types of contractual relationships, there is a stream of research which has focused on PAs and who it is that are employed in these roles and the impact that this type of employment has on these individuals. Glasby and Littlechild (2009: pg. 156) suggest that 'it seems likely that the majority of PAs employed will be women' and ask whether this could lead to the greater exploitation of women. Ungerson (1997; 2003; 2004; 2007) has researched and written extensively on just this topic. She argues that direct payment arrangements might lead to those who are the worst off being further exploited by being paid low wages and not being able to access holiday or sick pay and potentially being exposed to unsafe work practices. She terms this the 'commodification of care' and essentially what Ungerson draws attention to are the changes in boundaries between work and care and the resulting shift in relationships between people with disabilities and their families and PAs. There is some research which suggests that most PAs are highly satisfied with their work (see Glasby and Littlechild, 2009 for a summary of this evidence) and the issue of whether PAs are exploited or not is less than clear cut. However, what is clear is that direct payments and other cash for care systems have the potential to fundamentally change the nature of relationships between service users and those who care for them.

A review of recently commissioned studies shows that the need to explore the impact of personalisation on carers further is being recognised. For instance, a study being funded at the moment by the National Institute for Health Research School for Social Care Research (NIHR SSCR) is focusing on the roles of carers in assessment, support planning and managing personal budgets. This study aims to examine how far current practice in social care recognises and balances the needs and interests of service users and informal carers, and how far this practice is consistent with what service users and carers actually want. Another study being carried out by the Carers Federation and De Montfort University is exploring changes that occur in the carer-service user relationship as a result of the service user becoming a personal budget holder. Nonetheless, although some research has been carried out and there is the promise of productive studies in the immediate future, there is still a distinct lack of knowledge about the outcomes of the personalisation agenda for carers.

This apparent marginalisation of carers within the research to date concerning the implications of personalisation is at odds with policy trends within social care; over the past ten years, there has been a series of initiatives which have raised the profile and recognition of carers, their needs and their levels of support. These include the Carers (Equal Opportunities) Act (2004) which extended carers statutory rights to assessment of their own needs under the Carers Recognition and Services Act (1995), the introduction of further measures following the National Strategy for Carers (1999) to support carers and safeguard their health and well-being while they carry out their caring responsibilities in the Carers and Disabled Children's Act, (2000) and the acknowledgment that they should be treated with dignity and respect as 'expert care partners' in the National Carers Strategy (2008). The Coalition government has also signalled its commitment to the continued support of carers and recognition of their role as partners in the planning and delivery of services (Department of Health, 2010c). In addition, it runs counter to other social care policy initiatives, such as user led organisations, where both service users and carers are defined as inter-dependent and important stakeholders (Office for Disability Issues, 2007).

Furthermore, the lack of knowledge about personalisation in relation to carers conflicts with other developments within the personalisation agenda. One of these is the policy commitment to optimising the outcomes of personalisation for carers, as illustrated in the quotation below:

Personalisation means that all services and support available to carers should be tailored to their specific needs as far as possible: for example, that advice and information should be inclusive of all, including disabled carers, young and older carers, inter-generational carers and carers from ethnic minority groups, and that universally available services should be flexible in their approaches in order to respond to the variety of ways in which those with caring responsibilities can be supported (Department of Health, 2010c: pg. 19).

In the absence of a substantial body of research, translating such objectives for carers into reality will be problematic. Therefore, to conclude, not only is there a general need for a more comprehensive evidence base about the impact of personalisation on carers, such a body of knowledge is also required in order to ensure that personalisation progresses as promised within policy initiatives.

Evidence required by third sector organisations to support carers as personalisation progresses

As discussed above, studies into self-directed support have produced most of the findings to date about the impact of personalisation on carers. These studies also demonstrate that, because of the mutually dependent nature of the relationship between carer and service user, it is self-directed support initiatives that are likely to have the most significant implications for carers within personalisation. The use of self-directed support is set to increase as a result of the drive to ensure that all those receiving adult social care will receive a personal budget by 2013 (Department of Health, 2010a). In addition, personal health budgets are now being used in mental health. These changes have many potential implications for third sector organisations whether this is as a campaigning or support organisation or as a service provider. There is the potential for a range of changes to both who delivers health and social care services, who supports service users and carers in accessing and navigating the welfare system and potentially the relationship between individuals, their families and the state. Third sector organisations play important roles in all of these functions so thinking through the types of implications for carers is crucial.

The evidence identified below is that required by the third sector in general to provide carers with the support they need in order to maximise the benefits of personalisation as it progresses self-directed support, and more specifically personal budgets. Whilst a series of themes are used to indicate those areas in which evidence is needed, this is not an exhaustive account and inevitably some issues will cut across the different themes. However, we hope it sets out some of the main areas in which there is still a need for evidence and starts a debate around these themes. We have also tried to illustrate these themes in everyday practice by presenting these in relation to case studies based on carers' stories that have emerged from the study mentioned above that is currently being carried out by the Carers Federation and De Montfort University. Although these stories might not be considered strong evidence in the traditional hierarchy of knowledge, as Glasby and Beresford (2006) argue such stories are still valid forms of evidence. In the absence of more traditional sources of evidence we use these stories to illustrate the types of evidence that we need to generate and that can be used to support carers in relation to personalisation.

Skills

The existing and emerging studies indicate that self-directed support results in many carers undertaking certain roles to assist the service user. Examples are that of an employer where carers are required to work with service users to oversee the employment of individuals and therefore undertake all the tasks that this entails. Such roles simultaneously require skills which carers may not have in their existing skill sets, for instance, management and administration skills. As employers they are required to deal with various tax and national insurance issues and may also be required to consider issues related to insurance and employment law. The case study below highlights some of the implications of undertaking the role of employer for carers of service users who are personal budget holders. As this demonstrates, there is a need for more evidence about the types of roles carers carry out within self-directed support and the demands these roles place on carers in terms of

their skills. Furthermore, we need evidence about the ways in which third sector organisations might then be able to support these types of activities and who it is that might pay for the provision of this support.

Case study: Susan's story

Susan cares for husband Bill who is a stroke victim. He has been a personal budget holder for five years and has used his money to enable him to pursue his interests and maintain his friendships. As such he has a personal assistant to take him bird watching three times a week and someone to accompany him on bus trips to visit friends. When invited to describe the implications of these support arrangements for her as a carer, Susan described how it involves her in being a “personnel officer” because she has to draw up job descriptions and contracts, recruit staff, train them, complete timesheets and deal with any staff performance issues. Although she had a background in management, she found it all “very daunting at first” and at times it is still “incredibly stressful”.

Service design

Carers of service users in receipt of self-directed support may also have to access the knowledge and information necessary to engage in service design with the service user. Service provision within personalisation to date has included a range of fluid responses to market forces which makes acquiring such knowledge and information complex. This indicates that it is important for third sector organisations to establish the most effective ways of equipping themselves to support carers with service design. Examples include identifying mechanisms for providing carers with sources of up-to-date information about the full range of specialist support services within their locality, together with an assessment of their quality, reliability, eligibility requirements and the rates they charge. The following case study illustrates this theme.

Case study: Mike's story

Mike has been a widower for the past ten years and cares for his 30 year old son Dennis who has learning difficulties. Dennis also lives with Mike and has recently been assessed as being eligible for self-directed support. He has several ideas about the ways he wants to use this to make a difference to his life. These include going to a photography class, having someone help him with his stamp collection each week, and having a personal assistant to take him to events on the local steam railway. Dennis's particular needs mean that anyone assisting him with these activities would need to help him with personal care. He is very shy and also, because his father has cared for him so long, he does not like women or young people to help him with these needs. Therefore, he only wants to have middle-aged male assistants. Mike has heard that there are specialist agencies in the area that do provide services to meet such individual support needs but does not know how to access information about them and the costs involved. He feels he cannot help Dennis progress his preferred service design without further advice.

Emotional impacts

Inevitably, carrying out the aforementioned roles and tasks will be stressful for carers at times. For many carers this is nothing new as caring is an inherently stressful task and this is starting to be acknowledged by health and social care organisations. However, it is important that increased choice for service users as a result of personalisation does not increase carers' stress levels. For those carers of service users who make the transition to self-directed support from other support arrangements, there will be role changes which can mean that they also have to make adjustments to their lifestyles and self-identity. Nor is the adoption of new roles within personalisation restricted to carers; as self-directed support means that service users have more choice and control, their role may also change. Hence the move to self-directed support has the potential to alter the dynamics of existing caring relationships. As the third and final case study below shows, the effects of these sorts of role changes can also be compounded by any misalignments between the needs of carers and service users. Consequently, evidence about the emotional impact of self-directed support on carers and their relationship with service users is required in order to support carers through any emotional issues they have to address as a result of self-directed support.

Case study: Gordon and Kate

Gordon has multiple health problems as a result of a brain injury in 2000. These include epilepsy, memory loss and no sense of smell. He also has diabetes. His partner, Kate gave up a her career to care for him 8 years ago to enable him, in her words, "to have a better life" because "he wasn't coping with the way that the state was doing things for him." He has had a personal budget since 2008 and wanted to use this for different activities such as attending a computing course at the local college and employing someone in to help him to work on landscaping their garden. However, Kate says he often does "things that he knows he hasn't go to, that'll be a danger to him" and that others do not anticipate his behaviour in the same way as she does. She worries about the consequences and hence has insisted on Gordon spending the money available to employ her as his personal assistant, only using other people when she has been ill. The fact that Kate will not relinquish her role as his full-time carer has led to tension between the couple; whilst she feels she is acting in his best interests he wants to have more choice now that he is in the role of 'employer' and use the personal budget to have a more varied lifestyle. Kate finds this situation very stressful and does not know how to address these tensions in their relationship.

Ways of supporting carers

The three themes above all emphasise the importance of support for carers about different issues in relation to personalisation. Central to the provision of such support is careful consideration of evidence about approaches that work best for carers. A key area for exploration already identified in the existing literature is the delivery of the support, namely whether one or more of the following are used - online, face-to-face, group, peer or practical support. Other topics include the timing of the availability of the support, the resources used, as well as the extent to which it supplements and/compliments that given

by Local Authorities and other agencies. Acknowledgement of the impact of the specific needs of the service users for whom they are caring or the support carers require is also essential. Last but not least, simple toolkits for assessing carers' wellbeing and support needs for use by third sector organisations would help to ensure any support provided matches these needs. Hence, there are many reasons why it is necessary to establish a body of evidence about ways of delivering support to carers which is relevant to their particular circumstances within personalisation.

Policy development

The role of the third sector in policy development is well established. Furthermore, part of the Coalition government's vision of the Big Society is an expansion of the role of third sector organisations, Department of Health, 2010a). It is therefore important that any evidence gathered must be able to be used to inform policy to ensure future policies are true to the ethos of personalisation. Given that personalisation can be implemented in such a wide range of different ways then it is important that feedback is provided about the ways in which personalisation is working out in practice and the impact that this is having on service users and carers. Third sector organisations have long played a role in the support of carers and a number of groups have often advocated on behalf of service users and carers. It follows that there is a role for some third sector organisations to become involved in feeding back into policy about the impacts that these types of changes are producing in practice.

Taking this agenda forward

In the previous section there was much reference to gathering evidence about the issues raised and in this paper we have argued that there is a general lack of evidence concerning the impacts of personalisation on carers. However, this may not simply be because there is a lack of interest in this area or there is not the will to bring together such an evidence case. Obtaining evidence in the areas identified raises methodological and ethical dilemmas. For example, developing samples of carers for research purposes can be problematic. This is because many carers do not self-identify as such, and there is a range of types of self-directed support which not only have been introduced progressively but have also been subject to changes. As a result, developing a sample of carers using the same form of self-directed support in order to make any comparisons with those, say, who are not in receipt of such support poses considerable and often insurmountable challenges. Furthermore, the transition to self-directed support can be a long process and consequently the stage at which research takes place is critical to its outcomes.

As scholars such as Ungerson illustrate, researching initiatives such as personalisation is highly complex as it has the potential to change a range of factors from how services are delivered to the relationships between individuals and their families. Such pieces of research almost always involve significant value judgements and what are positive developments for some are not always for all. Hence, establishing how to conduct efficacious research into the issues about carers and personalisation needs to be prioritised. In order to address the gaps in existing knowledge, as indicated above, such research also needs to focus centrally on carers and their relationships with other key stakeholders (users, providers, support organisations) and make use of methodologies that

produce real understandings of carers' views about and experiences of the different forms of self-directed support, particularly those which are most likely to become universal.

As a next stage in our research programme into personalisation TSRC would like to bring together a range of stakeholders to discuss the issues we have set out here. We plan to use this event to bring together key individuals and groups who have an interest in carers and helping to provide a more robust evidence base concerning the impacts that personalisation might have on carers. The event will also be used to form coalitions of interested parties around these key issues and help us set our research agenda for this area going forward.

Conclusions

What is clear from the personalisation literature is that carers are absolutely crucial to the effective implementation of these changes. Yet we know very little about the evidence concerning how the third sector might most effectively work with carers to support individuals and groups within the context of the personalisation agenda. Existing findings about carers are incidental to or only part of the main study in most of the research that has been carried out. We argue that in the absence of a substantial body of research, translating the objectives of personalisation into reality will be problematic, particularly in relation to carers. There is not only a general need for a more comprehensive evidence base about the impact of personalisation on carers, but this is also required in order to ensure that personalisation progresses as promised within policy initiatives.

In this paper we have outlined a number of areas where we believe that further evidence is needed so that carers can continue to provide high quality support and so that third sector organisations can best focus their efforts to offer support to carers and service users. We have illustrated these by case studies in order to firmly anchor these within everyday practice. Carers play a crucial role within our society and within the support of individuals with care needs and ultimately any changes that come about under the umbrella of personalisation should seek to work with and support carers and not work against them.

References

- Browning D. (2007) Evaluation of the self-directed support network. A review of progress up to 31st March 2007. in Control Publications, London.
- Buckner L. and Yeandle S. (2011) Valuing carers 2001. Calculating the value of carers' support. University of Leeds and Carers UK, London.
- Cabinet Office (2009) Building Britain's Future. London.
- Carr S. (2009) The implementation of individual budget schemes in adult social care. Social Care Institute for Excellence, London.
- Chester H., Hughes J., and Challis D. (2010) Patterns of commissioning, contracting and care management in social care service for older people in England. *British Journal of Social Work* 40, 2523-2537.
- Commission for Social Care Inspection (2009) The state of social care in England 2007-08. CSCI, London.
- Cunningham I. and Nickson D. (2011) Personlisation and its implications for work and employment in the voluntary sector. Voluntary Sector Social Services Workforce Unit, Glasgow.
- Cutler T., Waive B., and Brehony K. (2007) A new epoch of individualization? Problems with the 'personalization' of public sector services. *Public Administration* 85, 847-855.
- Department for Children Schools and Families (DCSF) (2008) Personalised learning - a practical guide. DCSF, London.
- Department for Education and Skills (2005) Higher standards, better schools for all: more choice for parents and pupils. HMSO, London.
- Department of Health (2009) A guide to getting direct payments from your council: a route to independent living. Department of Health, London.
- Department of Health (2010a) A vision for adult social care: capable communities active citizens. Department of Health, London.
- Department of Health (2010b) Carers and personalisation: improving outcomes. HMSO, London.
- Department of Health (2010c) Recognised, valued and supported: next steps for the Carers Strategy. HMSO, London.
- Dickinson H. and Glasby J. (2010) The personalisation agenda: implications for the Third Sector. Third Sector Research Centre, Birmingham.
- Duncan-Turnbull H. (2010) It's your life, take control: Evaluating self-directed support in Hertfordshire. *Journal of Care Services Management* 4, 250-258.
- Flynn M. (2005) Developing the role of personal assistants. Skills for Care, Leeds.
- Glasby J. and Beresford P. (2006) Who knows best? Evidence-based practice and the service user contribution. *Critical Social Policy* 26, 268-284.
- Glasby J. and Littlechild R. (2009) Direct payments and personal budgets: putting personalisation into practice. The Policy Press, Bristol.

- Glendinning C., Arksey H., Jon K., Moran N., Netten A. and Rabiee P. (2009) The individual budgets pilot projects: impact and outcomes for carers. Social Policy Research Unit, York.
- Glendinning C., Challis D., Fernandez J., Jacobs S., Jones K., Knapp M., Manthorpe J., Moran N., Netten A., Stevens M., and Wilberforce M. (2008) Evaluation of the individual budgets pilot programme: final report. IBSEN, York.
- Glynn M., Beresford P., Bewley C., Branfield F., Butt J., Croft S., Dattani Pitt K., Fleming J., Flynn R., Parmore C., Postle K., and Turner M. (2008) Person-centred support: what service users and practitioners say. Joseph Rowntree Foundation, York.
- Harlock J. (2009) Personalisation: rhetoric to reality. NCVO, London.
- Hatton C. (2008) A report on in Control's second phase: evaluation and learning 2005-2007. in Control Publications, London.
- Hatton C., Duffy S., Waters J., Senker J., Crosby N., Poll C., Tyson A., Towell D., and O'Brien J. (2008) An evaluation of, and report on, in Control's work 2005-2007. in Control Publications, London.
- Hiscock D. and Stirling S. (2009) Prospects for more local, more personalised public services: A North East perspective. accessed 18th March 2011, Available from: <http://www.ippr.org.uk/publicationsandreports/publication.asp?id=642>.
- HM Government Policy Review (2007) Building on progress: Public Services. Prime Minister's Strategy Unit, London.
- Hudson M. and Henwood M. (2009) Working for people: the workforce implications of putting People first - a report for the Department of Health. Melanie Henwood Associates, Towcester.
- Larkin M. (2011) What about the carers? In T.D.Heller and C.E.Lloyd (Eds) Long Term Conditions: Challenges in Health and Social Care practice. Sage Publications, London.
- Leadbeater C. (2004) Personalisation through participation: a new script for public services. Demos, London.
- Moran N., Arksey H., Glendinning C., Jones K., Netten A., and Rabiee P. (2011) Personalisation and carers: whose rights? Whose benefits? *British Journal of Social Work* 10.1093/bjsw/bcr075.
- Needham C. (2011) Personalization: from story-line to practice. *Social Policy and Administration* 45, 54-68.
- Newbrunner L., Chamberlain R., Bosanquet K., Bartlett C., Sass B., and Glendinning C. (2011) Keeping personal budgets personal: learning from the experience of older people, people with mental health problems and their carers. Social Care Institute for Excellence, London.
- Office for Disability Issues (2007) Annual Report. Office for Disability Issues, London.
- Office for Public Management (2008) Budget-holding lead professional pilots: final report. OPM, London.
- Pitts J., Soave V., and Waters J. (2009) Doing it your way: the story of self-directed support in Worcestershire. Worcestershire County Council and in Control partnerships, Worcestershire.
- Poll C., Duffy S., Hatton C., Sanderson H., and Routledge M. (2006) A report on in Control's first phase, 2003-2005. in Control Publications, London.

- Rosenthal C. J., Martin-Matthews A., and Keefe J.M. (2007) Care management and care provision for older relatives amongst employed informal care-givers. *Ageing and Society* 27, 755-778.
- Social Care Institute for Excellence (SCIE) (2007) Choice, control and individual budgets: emerging themes. SCIE, London.
- Social Care Institute for Excellence (2010) At a glance 21: Personalisation briefing: Implications for people with autistic spectrum conditions and their family carers. Social Care Institute for Excellence, London.
- Social Care Institute for Excellence in conjunction with Carers UK (2009) Personalisation briefing: implications for carers. Social Care Institute for Excellence, London.
- Tyson A., Brewis R., Crosby N., Hatton C., Stansfield J., Tomlinson C., Waters J., and Wood A. (2010) A report on In Control's Third Phase - Evaluation and learning 2008-2009. In Control Publications, London.
- Ungerson C. (1997) Give them the money: is cash a route to empowerment? *Social Policy and Administration* 31, 45-53.
- Ungerson C. (2003) Commodified care work in European labour markets. *European Societies* 5, 377-396.
- Ungerson C. (2004) Whose empowerment and independence? A cross-national perspective on "cash for care" schemes. *Ageing and Society* 24, 189-212.
- Ungerson C. and Yeandle S. (2007) Cash for care systems in developed welfare states. Palgrave Macmillan, Basingstoke.
- Waters J. and Hay M. (2009) Steering my own course. The introduction of self-directed support in Cambridgeshire. Cambridgeshire County Council and in Control Partnerships, Cambridgeshire.

About the Centre

The third sector provides support and services to millions of people. Whether providing front-line services, making policy or campaigning for change, good quality research is vital for organisations to achieve the best possible impact. The Third Sector Research Centre exists to develop the evidence base on, for and with the third sector in the UK. Working closely with practitioners, policy-makers and other academics, TSRC is undertaking and reviewing research, and making this research widely available. The Centre works in collaboration with the third sector, ensuring its research reflects the realities of those working within it, and helping to build the sector's capacity to use and conduct research.

Third Sector Research Centre, Park House, 40 Edgbaston Park Road,
University of Birmingham, Birmingham, B15 2RT

Tel: 0121 414 3086

Email: info@tsrc.ac.uk

www.tsrc.ac.uk

Service Delivery

From housing, to health, social care or criminal justice, third sector organisations provide an increasing number of public services. Working with policy makers and practitioners to identify key priorities, this work will cut across a number of research streams and cover a series of key issues.

Critical understanding service delivery by the third sector is important to policy making as the third sector now provides a major - and very different - option for public services, which may be more responsive to the needs of citizens and service users. At the same time, there are dangers inherent in the third sector becoming over-dependent on funding from service contracts – particularly in terms of a potential loss of its independence. The centre's research will help to inform the debate on the way in which service delivery is developing, the potential role of the third sector in commissioning as well as contracting, and the implications of different approaches to service delivery on the overall impact of the third sector.

Contact the author

Mary Larkin

mlarkin@dmu.ac.uk

0116 257 7985

Helen Dickinson

h.dickinson@tsrc.ac.uk

0121 414 7069

The support of the Economic and Social Research Council (ESRC), the Office for Civil Society (OCS) and the Barrow Cadbury UK Trust is gratefully acknowledged. The work was part of the programme of the joint ESRC, OCS Barrow Cadbury Third Sector Research Centre.