

Third Sector Research Centre

Working Paper 104

Personalisation: a new dawn or the end of the road for third sector support for carers?

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July 2013

Abstract

Personalisation is the latest dynamic in the long and complex relationship between the third and public sectors who work within the field of social care. It has been seen as both an opportunity for third sector organisations (TSOs) to have the freedom to deliver the more flexible and holistic support that they aspire to, but also a potential financial challenge due to the need to compete for more individualised purchasing of care. In this paper we respond to calls to move beyond seeing personalisation as a 'blanket' approach and experience, through exploring the impacts within the particular field of carer support. Building on a literature review and a stakeholder event, semi-structured interviews were undertaken with those working in the third sector, and those in related policy and commissioning roles within the public sector. These interviews highlighted the fact that despite different perspectives on the scale and nature of change required, the move towards more personalised support was seen as a positive development for carers. Benefits that were reported included opportunities to pursue personal interests, to have regular breaks from caring and to improve the relationship with the 'cared for'. However, such impacts were seen to be reduced through lack of public sector funding, complicated and lengthy assessment and financial procedures, and carers' personal ability and capacity to take up the potential opportunities. The aspiration of personalisation (that is, more individualised and flexible support determined and led by the recipients) was seen by most interviewees as being in line with the values of TSOs who work in this sector. In principle this would mean that TSOs are well placed to respond to carers through a personalised model of care which would therefore be of benefit to carers and TSOs. However, there were also concerns that through their emphasis on quality and fair wages for staff, TSOs may struggle to compete with other providers if carers act as 'individual consumers' seeking to get the most service possible from their personal budget allocation. Other interviewees viewed many TSOs as having become complacent and no longer responsive to the changing needs and aspirations of carers, and for them these competitive pressures would either force the existing organisations to change or lead to their decline.

Personalised support for carers reflects debates in broader public policy regarding the distinctiveness (or not) of the third sector, and the most beneficial approach through which the public sector should engage with and provide funding to TSOs. Furthermore the connected market pressures will arguably test out in practice if carers do value and will therefore pay for services provided by TSOs. Ultimately though, if personalised support for carers relies on discrete public sector funding, then the chances of significant progress being made in a time of austerity seems unlikely. Success will depend on TSOs being able to identify and draw upon other funding routes (including carers purchasing services out of their own resources) and mainstream services embracing the needs of carers alongside that of the cared-for.

Keywords

Third sector, personalisation, carers, commissioners, adult social care.

Acknowledgements

This paper arises from a programme of activities completed by the Third Sector Research Centre and the Health Services Management Centre. Dr Helen Dickinson and Professor Jon Glasby have made considerable contributions to this, as did the academic, third and public sector colleagues who participated in the workshop and interviews. Particular thanks are also due to our reviewers whose insightful comments considerably sharpened our analysis and discussion.

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Introduction

In recent years collaborative relationships between the third and public sectors have been portrayed by English governments as an opportunity for shared innovation and benefits to both sectors and the people that they support (for example, OTS 2006, OCS 2010). However, the relationship is also a source of much angst through the perceived risk that it will result in a loss of autonomy and independence of the third sector and undermine the very distinctiveness that the public sector appears to value (for example, Macmillan 2010, Carmel and Harlock 2008, Baring Foundation 2012). These two sets of diverse and changing organisations have existed alongside each other, at times working collaboratively to achieve common goals whilst at others expressing frustration and acrimony at the others' perceived lack of understanding and responsiveness. There are general trends in this relationship, for instance in the centralisation of power and resources within the public sector in the early 20th century, the interest in the 1980s and onwards in the third sector being deliverers of publically-funded services, and the continued role of parts of the third sector in championing the needs of groups within society who have been disadvantaged by policy failure or neglect (Harris 2010). Whilst there remains considerable confusion and distrust about what the 'big society' concept and policy actually means, the current government does appear to see a role within this for TSOs and/or activities often associated with them (such as volunteering) (Macmillan 2013). Within these general trends, a combination of demographic demands, perceived voter interest, professional cultures and prevailing civil service departmental ideologies mean that the story and experience of this relationship is different within each area of public service. Furthermore local interactions between each third sector and public sector organisation are unique as they build on the particular histories, priorities and visions of the individual entities and the key people within them. These personal and organisational nuances feed into debates over the extent to which it is possible to band such a diverse range of legal forms, income generation models and delivery approaches within a common 'third' sector (Alcock 2010, Carmel and Harlock 2008).

The rise to prominence of 'personalisation' within adult social care and other areas of the public sector is a contemporary example of the complexity of this relationship. Its roots (see Needham 2011 and Glasby and Littlechild 2009) have been traced back to disability and mental health rights organisations campaigning in the 1980s and 1990s for their members and fellow disabled people to have the opportunity to have more independence and control over their lives. This lobbying resulted in a number of disabled people being given direct allocations of cash through the Independent Living Fund and in conjunction with a shift in public policy to more individual approaches to assessment and care planning to the steady introduction of Direct Payments as a mainstream option available to all adult social care user groups, including carers. Third Sector advocacy organisations also had a major influence in the centrality of 'person centred planning' within the Valuing People White Paper in 2001, and in 2003 a charitable organisation (In Control) worked with a sample of local authorities in piloting individual budgets as a means to achieve the principles of this policy. TSOs were co-signatories with public and private organisations to the 2007 People First concordant which set out a ten year vision for

the development of a 'personalised' adults social care system and to the subsequent 'Think Local Act Personal' agreement which sought in 2010 to provide a framework for further action. Alongside this lobbying and development role, TSOs have expanded their role as deliverers of adult social care services so that they now deliver over £7 billion of services (IFF 2007) and account for 17% of all services registered with the Care Quality Commission (Dickinson et al. 2012). Social service organisations are the largest sub-sector within the third sector in the UK, with over 30,000 TSOs involved in related activities (NCVO 2013). Direct payments and/or personal budgets are becoming the norm for allocating and distributing adult social care funding in England and this means that TSOs' public sector income streams are increasingly moving to individual purchasing arrangements.

Thus in relation to 'personalisation', TSOs can be seen as instigators, advocates, providers, and co-producers of policy. It is less certain however what the purpose and outcome of all this activity will be. Needham (2011) highlights that there are a number of key 'storylines' that are commonly used by different stakeholders to explain and promote personalisation. This leads to multiple, fluid and to some extent conflicting interpretations of its purpose and meaning (Needham 2011). In terms of impact, there is evidence that individual funding arrangements have led to positive impacts for some recipients (Hatton et al. 2013) but concerns have also been raised. These include its potential: to increase inequality of experiences of social care services as more informed and able families may take better advantage of its flexibilities; to negatively affect the employment conditions of already low paid workers; to result in decreased efficiency through increasing transactional costs; to 'de-professionalise' social work through opening up the brokerage role to family and friends; and to introduce a whole scale 'marketisation' of adult social care services (for example, Needham 2010, Ferguson 2007, Netten et al. 2012). These lead Spicker (2012) to wonder if there has been the 'over-selling of personalisation' to achieve more preventative, flexible and joined-up services – 'this is a leap of faith; there is no basis of evidence on which to evaluate the argument' (p. 4). The negatives outlined above are interpreted by others as giving the opportunity for more positive change, and as often is the case with forecasting of policy impact 'beauty is in the eye of the beholder'. Dickinson and Glasby (2010) argue that we need to move beyond general discussions of the rights and wrongs of the concept and to develop a more sophisticated and robust evidence base that explores how personalisation works for whom and within what contexts. This includes an understanding of the implications of personalisation on TSOs working in different service areas and localities, and their relationship with the public sector.

In pursuit of such a 'realistic' approach, this working paper seeks to add to the current knowledge base regarding TSOs and personalisation through exploring it specifically within the context of support for carers. Carers are recognised as providing a vital contribution to the meeting of adult social care needs and support for them has been an expressed priority within previous, current and future social care policy (Buckner and Yeandle 2011). Despite these expressions of intent however, there is evidence that their needs are still largely unmet and in this regard they can be viewed as a disadvantaged and neglected group within society and adult social care funding allocation (Larkin and Milne 2013). Thus they provide a case study through which to investigate a specialist area of provision

and policy in its own right and as an example of how personalisation is impacting on TSOs working in social care in general.

TSRC's work in this area began with a review of evidence and opinion regarding third sector and personalisation in general (Dickinson and Glasby 2010). This was followed by a more focused review regarding services for carers which identified key areas for development regarding the role for TSOs in supporting carers and the skills that they would require to fulfil these roles (Larkin and Dickinson 2011). Stakeholders representing the third sector, local authorities, national policy makers and academia were then brought together for a workshop to reflect on the themes from the carers review and to consider priorities for future research. Collectively these activities highlighted the fact that although there are emerging knowledge bases regarding 'personalisation and carers' and 'the third sector and personalisation' there is no specific research at present focusing on TSOs working with carers. As a consequence, whilst the literature review and stakeholder discussions could suggest a range of potential issues, there was no formally gathered empirical evidence to support or refute these. This study therefore sought to address this knowledge gap in relation to both the impact of personalisation on TSOs as organisations and on the carers they support.

The specific research questions we sought to explore were:

1. How is personalisation interpreted by those working within carers services?
2. Are TSOs uniquely placed to provide personalised support to carers?
3. What have been the impacts of personalisation on carers?
4. What have been the impacts on TSOs who work with carers?

Before discussing the research methodology and findings we will begin with overviews of the current knowledge and commentaries regarding 'TSOs', 'carers' and personalisation.

Personalisation and the third sector

As outlined above, social care policy in England has sought to frame personalisation as a broader initiative than simply the introduction of individual budgets that are held and /or controlled by service users and their families. This has been reflected in the interpretation provided by third sector representative bodies, such as the National Council for Voluntary Organisations (NCVO) and the Association of Chief Executives of Voluntary Organisations (ACEVO). NCVO defines personalisation as:

'a way of thinking and working that puts the service user at the centre of public services. It means operating from a bottom-up approach to understand the needs, preferences and aspirations of service users and developing services and solutions around those needs, rather than the needs and preferences of commissioners and providers' (Harlock 2009, p. 6).

Achieving a personalised approach has been seen as requiring significant change within social care provider organisations, including those from the third sector. The Social Care Institute for Excellence (SCIE 2012a) and Stirk and Sanderson (2012) provide practical examples in which TSOs have sought to develop their cultures, processes and structures through staff training, management approaches

and engagement of service users in organisational and individual planning. The ACEVO (2009) commission recommended that personalisation would entail a 'whole systems' approach beyond that of change within individual provider organisation. This should incorporate not only delivery and payment mechanisms but also the basic principles on which services were planned, funded and developed, a holistic view of the aspirations of and expectations on service users, and radically different organisational cultures (see Box 1).

Box 1: A 'whole systems' approach to personalisation

1. Devolving financial control: control over how money is spent on services should be devolved down to a level as close as possible to the service user. There are a wide variety of tools that can be used to achieve this.
2. Self-help and mutual aid: the service-centric model of 'public services' should be turned inside-out, with self-help and mutual aid (in other words, community) placed firmly at its heart. We should see people not as 'service users' but as 'service helpers' and change agents.
3. Building 'can do' assets: personalisation should be accompanied by a renewed focus on building up the emotional, financial and intellectual assets of service users in a risk-smart and preventative way.
4. Culture change: personalisation should inspire a revolution on the supply side of public services, a revolution that sees far-reaching culture change throughout the system, that frees up public service professionals and that creates an environment in which innovation flourishes.
5. Social markets: a new generation of genuine social markets should be created, in which power shifts from commissioner and provider to service users, and in which good performance is rewarded and invested in and poor performance is driven out (ACEVO 2009).

In line with the current debates regarding the increasing role of the third sector as a provider of services on behalf of the public sector (see, for example, Macmillan 2010) there has been a particular focus on implications for the current and future incomes of TSOs within social care. The extent to which TSOs experience personalisation as a positive or negative influence on their income was described by Dayson (2011) as being dependant on both *internal* factors (such as their capacity and capability to adapt to the changes) and their *external* environments (most notably the market shaping undertaken or not by the commissioners). Building on the internal factors, Dickinson and Glasby (2010) highlight key organisational challenges that TSOs will face through personalisation. These are:

- responding to the change in level of demand, the types of services bought and different expectations in relation to flexibility and quality;
- developing financial models that can provide an affordable but realistic unit cost and cope with variations in service delivery;

- ensuring that they have sufficient administration support whilst not increasing their unit charge beyond what will be seen as affordable – potentially through sharing backroom functions with other TSOs;
- employing staff on flexible contracts that will reflect the potential variation in demand;
- marketing to service users and families rather than/alongside local authority commissioners;
- partnering with other TSOs who could be seen as collaborators and/or competitors.

In 2008 Bartlett and Leadbeater highlighted that perhaps the greatest obstacle to meeting such challenges was that many TSOs were not sufficiently aware of personalisation and the major role that it would play in future. This was in the (relatively) early days of personalisation, however Dayson (2011) subsequently mirrored this finding in his work with infrastructure support organisations when he described three ‘types’ of TSOs in relation to their readiness to respond to personalisation. Whilst two of these ‘types’ were not in a good position to exploit the potential for increased levels and security of income, those who were not currently majorly reliant on local authority funding were less at risk of collapsing altogether. Those who were best placed were often larger TSOs with mixed income streams – reflecting concerns and/or evidence that dependency on local authority funding in general may lead to increased domination by such TSOs and loss of smaller more community based entities whose work is taken over by those who are more proficient at contracting processes (Buckingham 2010, Baring Foundation 2012).

Beyond direct service delivery, personalisation was initially viewed and indeed experienced by TSOs as an opportunity to extend their advocacy and guidance work into being commissioned to support service users manage their direct payments. User-led organisations have been seen as having particular strengths in this regard, with their independence from statutory services enabling them to ‘secure creative support arrangements’ (SCIE 2010). A recent study reports though that many local authorities are now ‘re-colonising’ support services in an attempt to save money, this denying the TSOs concerned the opportunity to expand their advocacy and guidance roles and to attract the connected funding (Williams et al. 2013).

Personalisation and carers

As Larkin and Dickinson (2011) explain in their aforementioned review of the existing literature about carers, TSOs and personalisation, although the importance and centrality of carers to the successful implementation of the personalisation agenda has been consistently acknowledged, until recently, they have received relatively little attention compared to other groups affected by the changes. The majority of the findings about carers and personalisation to date have emerged from studies into the different forms of self-directed support. Furthermore, several of these studies have been carried out within a limited number of case study local authorities and few have focused exclusively on carers and hence the findings about them tend to be incidental to or only part of the main study. From the evidence available though it appears that self-directed support has resulted in improved outcomes for carers. Examples of positive outcomes identified are that carers are more likely to be undertaking activities of their choice, have more time for themselves and for other family members, have a social

life and feel in control of their daily lives. They are also more likely to enjoy caring and have a better relationship with the person for whom they care. In addition to their higher quality of life, carers' health and wellbeing improve with self-directed support.

Positive outcomes were found to vary with the nature of the needs of the person they are supporting, the amount and quality of the eligibility information available to carers and ways in which different local authorities implement self-directed support. Less positive outcomes emerged from the review too; carers have to take on additional responsibilities, such as administrative and managerial tasks, which can be a burdensome, particularly at the beginning of the process of setting up personal budgets and for those carers without previous experience of such tasks. Self-directed support means carers face having to cope with several changes in their caring role which they may find challenging. These changes include the service user making more of the decisions about their own care and entering into a contractual relationship with the service user. The latter has the potential to fundamentally change the nature of relationships between service users and those who care for them.

Studies carried out subsequent to the review have reinforced and extended these conclusions. For example, carers in the main report being highly positive about the impact of personal budgets on their quality of life and their physical and mental wellbeing. They also comment on the way that personal budgets have increased their choice, control and use of time, particularly the time they have to spend with other family members. However their opportunities to undertake paid employment do not seem to have improved. In addition, they are negative about all aspects of the personal budget process and, unsurprisingly, the stress and worry they associated with personal budgets for the person they were caring for (Hatton et al. 2013: 9) (Carers Trust 2012, Jones et al. 2012, Moran et al. 2012, SCIE 2012b). Personal health budgets have also been found to have positive impacts on carers, in that they were more likely to report a better quality of life and perceived health than carers of people who were in receipt of conventional service delivery. They also had lower instances of having their health affected by their caring role and felt that other family members benefited (Forder et al. 2012).

Methods

At the stakeholder workshop the role and types of TSO that work with carers and therefore which should be represented in the research was identified. Building on this, a purposive sample was developed to incorporate the following variables:

- experiences of working with all adult service user groups (that is, older people, mental health, learning and/ or physical disability);
- the different roles commonly undertaken by TSOs in relation to carers (see Table 1);
- smaller TSOs which worked within a defined locality, and those which worked on a national basis.

It was intended that those providing support to carers regarding the management of direct payments would also be included but the organisations concerned withdrew due to lack of capacity and other pressures. Individuals within local commissioning and/or national policy roles were also interviewed to provide a statutory sector perspective. A semi-structured interview schedule was drawn up to ensure

that the main issues were explored and provide sufficient flexibility for respondents to raise other points that they thought were important. Prearranged telephone interviews were conducted by the two authors. These interviews were recorded, transcribed and thematically analysed in relation to the research questions. It is acknowledged that whilst this methodology was productive in terms of in-depth discussion of the issues, there was a danger that respondents would say what they thought was the 'right' answer and the interviewers did not have as many opportunities to prompt and probe as in face-to-face interviews. Furthermore the number of interviews completed was limited (fifteen in total) – broadening the number and range may have provided additional data and responses to the themes. That said, there were recurrent and common themes identified by the interviewees.

Table 1: Roles undertaken by TSOs within sample

- provider of care services to person cared for, including short break in their home;
- provider of general advice and guidance to family carers;
- researching needs of family carers and opportunities to change to more personalised services;
- providing specialist advice and guidance to care managers, commissioners and/or policy makers;
- developing networks of TSOs in relation to the opportunities and challenges of personalisation.

Findings

Interpretations of personalisation

The respondents' interpretations of personalisation were wide ranging; at one end of the continuum there were those who saw it as "a complete overhaul of the system". In contrast, those at the other end of the continuum said that it had resulted in very little change because personalisation already features in many of our everyday encounters, such as those that take place in a commercial context. The middle ground was occupied by those who argued it is a "combination of new and existing practice". Similarly, there were differences in the views expressed about the relationship between personalisation and self-directed support; some argued that these were independent variables whilst others saw personalisation solely in terms of self-directed support.

Despite such nuances in their conceptualisations of personalisation, there were commonalities in the interviewees' responses. Many agreed with personalisation in principle and welcomed its potential to improve the lives of those receiving care:

'the patient or service user at the centre of identifying what their needs were and how they can best be met which gives people independence, choice and control over their own care and who provides it' (TSO)

Some also mentioned that it gives particular groups of carers, such as parent carers, more choice. In addition, the impact on the care market of such choice and control was seen as resulting in positive outcomes, most notably in relation to the way it increases competitiveness between providers and

improves quality. Other empowering elements of personalisation that were identified included how it represents both a move away from the:

‘professional gift model and dependency to a shift in the balance of power from the professional to the individual.’ (Commissioner)

However the point was made that this recalibration of power may lead to valuable contributions made by trained professionals not being taken into consideration with the result that some individuals make inappropriate decisions. As one respondent remarked, this meant there was a risk of throwing the “baby out with the bathwater”.

Public sector spending cuts were perceived as a threat to personalisation because of the limitations they impose on choice and control. This concern was linked to the more negative aspects of personalisation that emerged, which centred on the mismatch between the aspirations of personalisation and its reality in practice. For instance personalisation was reported to be leading to traditional services being wound down and no suitable alternatives being put in place. In this respect personalisation was seen as a money-saving exercise and that whilst the “rhetoric has been about choice and control... the subtext is saving money”. Others highlighted considerable local variation in the way personalisation is implemented and a general reluctance of local authorities to address perceived differences in the level of support provided to different user groups:

‘The discrimination against older people in the provision of care services is still rife and you’ve got these massive disparities between what certain people can get because they’re in one eligibility box, and what other people can get because they’re older.’ (TSO)

There was unanimous agreement that further work was required to ensure that personalisation results in successful outcomes. Suggestions made included a whole systems adjustment to the concept of personalisation by commissioners and service providers as well as taking into account:

‘individuals’ abilities and disabilities, and the needs of those around them, such as their family...and the nature of local communities.’

Ability of TSOs to support carers through personalisation

The majority of interviewees from both the third and public sectors highlighted a number of features which they saw as being common to the third sector which acted as enablers to responding positively to the needs of carers. TSOs were seen as being more dedicated than other types of organisations to tailoring their services to respond to the needs of carers, as supporting a particular cohort of parents/carers was often at the heart of their initial development as an organisation. This was then reported to be translated into their fundamental missions being to provide benefit for carers and/or carers and the person cared for, and to the development of governance structures which underlined their primary accountability to carers. Most of the TSOs interviewed had carers on their governing boards, and in some cases carers were the majority of board members:

‘This organisation was set up all those years ago to give parents a break – it wasn’t really about the child or the adult with the learning disability. And that’s why I think it works – because the parents we have on the committee are firm believers in having some respite and being able to carry on caring.’ (TSO)

This primary dedication to serving carers was compared favourably with the private sector, as it was thought that private organisations may be distracted by a need to make profit for owners and/or shareholders, and the public sector, which was seen to be compromised through a need to balance the needs of carers with the finances available and respond to broader statutory responsibilities. The long term relationship with carers that arose from their mission was seen as enabling TSOs to develop specialist knowledge and skills in how best to respond to carers' needs, and these were associated with a willingness to be flexible around different needs and circumstances. Furthermore TSOs were described as having unique local intelligence about who carers were and what they wanted, and the local organisations, resources and networks that could support them. The accumulated sense of most interviewees was that the third sector had strong foundations to provide personalised support:

'I think that had the right ingredients for personalisation because we were already set up as a family support service. And, because we've always had that embedded in what we do and we've always kept... you know, working with the whole family.' (TSO)

However there were interviewees from both third and public sector organisations that either saw TSOs as either not having a common distinctiveness and advantage over organisational forms, or who perceived a negative rather than positive commonality. For instance one commissioner was frustrated with their experience of a shared unwillingness of existing TSOs to embrace the requirements and opportunities of the new system. For these interviewees the way to achieve personalisation across the system was not through fostering the third sector in particular but by developing a diverse market in which carers could choose the organisation from any sector that they thought would most appropriately meet their needs:

'my approach is it doesn't necessarily matter whether it's the third sector provides it or whether it's the local authority directly or any other kind of provider – I think it's more about what the service is that they're offering.' (TSO)

From this perspective, the test of TSOs' distinctiveness in practice was if carers choose to invest their limited personal budgets with them – if not then the attractiveness and uniqueness of their offer can be questioned.

All TSOs and a number of public sector interviewees reported that local authorities were imposing a number of barriers to the ability of TSOs to provide a more personalised service to carers. Causing particular problems were new care management and purchasing systems which combined the introduction of personal budgets with a more adversarial approach to procurement. This was seen to have introduced considerable bureaucracy with little advantage for carers, and had led ironically to the financial aspects of the care system being less, rather than more, personalised:

'It now has to go through a process of a panel meeting to procurement. We're not allowed to give any care until procurement send us something in writing...but how do you tell Joe Blogg's mum that they can't go and get their plane to wherever because procurement haven't sent us the paperwork. Life's become much more difficult from that side of things. And I think, from a local authority's point of view, it certainly isn't as personal as it used to be.' (TSO)

Care managers within local authorities were seen as struggling with these new systems, either because they were concerned that transferring existing services onto a direct payment may lead to this funding subsequently being withdrawn and/or because they were confused about how the new processes would operate:

‘care coordinators are saying to us, “We don’t know how this process works anymore” – and we’ve stopped, really, asking.’ (TSO)

This was thought to result in care managers becoming sceptical about the potential of personalisation and to their enthusiasm for facilitating more creative responses to carers being lost. In turn this led to the ‘status quo’ being maintained and TSOs being prevented from developing more innovative packages to meet individual carer’s needs. For TSOs who worked in more than one locality there was the added complexity of local authorities having different processes and systems, meaning that they had to spend time and resources understanding these and responding appropriately. It was also reported that social care commissioners were unable and/or unwilling to develop the local market to ensure that it had the capacity and diversity to respond to carers’ requirements:

‘one of the effects has been a complete abdication on the part of commissioners in terms of managing the market. I mean it’s all nonsense this bit about that it would pre-empt choice and control; the reason they’re doing it is to save money.’ (TSO)

Impacts of personalisation on carers

Reference was made above to some of the implications of personalisation for service users and carers. Many respondents focused on the advantages and disadvantages for *both* service users and carers. Amongst the advantages that were identified were the flexibility and choice it gives service users and carers in terms of tailoring support to their particular circumstances. When care and support is well-organised and runs smoothly, personalisation can provide both with opportunities to undertake activities they want to do either separately or together that were previously not an option. Whilst this can be beneficial for the carer-service user relationship, other aspects of personalisation are less so; conflict engendered by disagreements over support packages were frequently mentioned. As one respondent said:

‘if you’ve got a carer who wants to make certain choices and you’ve got the person that they look after wants to make certain choices, one of the major problems is reconciling the two so that if you give someone the chance to live the life they choose you then find that that means that someone else can’t.’ (Commissioner)

The lack of suitable services for service users and carers in some areas was another feature of personalisation that had negative effects on both service users and carers. Some attributed this to local variations in the implementation of personalisation. Others argued that:

‘the role of commissioners in diversifying local markets has just not really evolved... I mean there was a lot of talk about commissioners making sure there were enough local services that were suitable and diverse enough to meet local needs, and it rarely happens that commissioners ensure that support or local authorities take it upon themselves to ensure that that’s available.’ (TSO)

Distinctions were also made between the effects on service users and the effects on carers. With reference to service users, there was an acknowledgment that it could potentially give them more control and choice which meant that they could have “a life rather than having to depend on services”. However, the extent to which these outcomes were achieved depended on a number of variables. One of these was the nature of service users’ needs and therefore the user group that they were assigned to by local authorities. For example, those with learning difficulties were commonly seen to benefit more than older people, with older people being less likely than other groups to be aware that they are even in receipt of self-directed support. Cultural and language barriers mean that black and minority ethnic service users have a greater risk of being disadvantaged by personalisation. The general shortfall in service capacity and range was seen as imposing limitations on service users’ choice. The adequacy of the safeguarding procedures adopted by some services was also questioned. One respondent went as far as arguing that services can undermine the principles of personalisation. This was because, to ensure their viability, service providers:

‘tend to shunt some of the risk onto the service user, so they say...You’ve got to sign up for thirteen weeks ..., but what if you’re sick? What if you’re in hospital? What if you’re dead? I mean where do you draw the line in terms of saying “You’ve got to pay regardless”? So what that’s doing is shunting the risk onto the vulnerable service user, which is a travesty of personalisation; it’s the opposite of what personalisation ought to be about, but it’s one of the things that’s happened.’ (TSO)

Therefore, personalisation was seen as not empowering all service users and in some circumstances, having harmful consequences.

Although some respondents made the point that the understanding of personalisation in relation to carers is still limited, the interviews were highly productive in terms of the insights they provided about the effects of personalisation on carers. Inevitably these can be categorised into positive and more negative effects. The positive effects included the increased flexibility, choice and control already mentioned which were seen as life enhancing; respondents talked about how personal budgets allow carers to have regular respite during the day and find more fulfilment from their other roles, for example to “just be a mum”. Another positive effect derives from the fact that if personalisation results in the cared-for person being happier, the carer is happier. In addition, personalisation means that there is now the opportunity for carers to be paid as a Personal Assistant for carrying out their caring role.

Alongside these improvements for carers were several significant problematic issues. The most prominent of these was the management of the personalised care for the person they care for. This necessitates them employing, managing and supervising staff, which requires expertise in areas such as health and safety, employment law and budget management. Undertaking such managerial roles can put more pressure on carers and as one respondent said:

‘My worry is that we’re dumping a lot of that onto carers and goodness knows carer’s stress is high enough anyway without that sort of stuff. So I think there may be circumstances in which some carers are actually doing less hands-on care but the managerial stuff they’re doing, the personnel management type stuff they’re doing, is actually more stressful than the caring they used to do... they might do less in the way of

hands-on caring, but they might spend all their bloody time doing paperwork'
(Commissioner)

These pressures may be compounded by the protracted and complicated processes involved in accessing self-directed support, a lack of bespoke quality services, funding cuts and arbitrary regulations about the use of budgets. An example of such regulations was described by one of the interviewees:

'one carer told me that her husband needs to go swimming and he needs two people to help him to go swimming, ...But they insisted that she had to be one of the people that went, it had to be a family carer that went, and she doesn't want to go swimming. And she's like "How is this choice? I don't want to do that. I want someone else to do that". But they were adamant that either she had to go or he didn't get to go swimming.' (TSO)

It was also reported that some carers feel excluded from the planning process and may end up "unhappy with the support packages", preferring previous care arrangements to those now in place. Furthermore, the emphasis on choice and control for service users means that many carers experience a change in their relationship with the person they care for and a loss of control over their care. This is most likely to occur when they have been providing intensive care for a long time. As one respondent remarked:

'a carer's own feeling of self-worth can be affected if no longer 'in control'...where a carer, for instance, has been used to making all of the decisions and then all of a sudden someone else comes in and says "Well no, they could decide these things for themselves."' (Commissioner)

However, some carers do find it easier to adjust to having less control than others, for instance:

'younger carers are very happy to accept it; you find the older carers just really don't want to know.. older carers see that more of a risk.' (TSO)

These findings clearly demonstrate that personalisation generates additional support needs for carers. Two of the respondents felt that carers who are middle class, educated and whose first language is English cope better with personalisation in general than others. Nonetheless, the majority readily suggested ways in which carers need to be supported. Several argued that the first step in supporting carers is to fully involve them in support planning for the cared-for person and ensuring that their needs are not overlooked. More information and advice for carers plus peer support and befriending services should also be provided so that they can be supported in making informed choices. Others identified carers' training needs within personalisation:

'training around how to manage employees....training in actually dealing with the personal budgets.....and advocating as well' (Commissioner)

Help with overcoming any fears they had about changes that personalisation brings and adjusting to their new roles within personalisation and was considered important too. Reasons given for this included so "that they don't feel that they've been doing it wrong all of these years" and "can let go". Sources of such support were seen as being carers support groups, resource packs and toolkits.

Impact of personalisation on TSOs

For those TSOs that provided direct support to carers the most common impact raised was the financial uncertainty that resulted from the move from block contractual arrangements to those based on individual packages. These were seen to be transferring risk from the local authority to the TSO and generating considerable financial uncertainty for the organisations. To mitigate these risks TSOs were introducing 'zero hour contracts' in which staff had no security of income and/or closing down more congregate facilities such as day-services which have relatively high fixed costs regardless of uptake. Thus these financial changes connected with personalisation were seen to be directly impacting previously important aspects of the TSOs way of doing business (that is, positively rewarding staff) and the support they could provide to their beneficiaries (and which seemed to be welcomed by those who attended). Furthermore it was reported that applying for external funds to develop new services was more difficult as the TSOs were less able to provide evidence that they were financially sound. This led to them being excluded or disadvantaged within the application process. In contrast to the positive features regarding their potential to deliver personalised care, TSOs were generally seen as being in a worse position than other organisations to pro-actively respond to the financial opportunities that personalisation could bring. This was due to the view of many trustees that their roles were to be 'careful stewards' of charitable funds and avoid risks to the organisations, and/or because trustees saw charging carers as clashing with their overall mission:

'And they're charities; you're not allowed to do highly financially risky things, I mean apart from the fact you'd probably come unstuck if you did, but as a charity you're not allowed to take big risky punts with things' (TSO)

'You've still got groups of trustees, for example, who have got this "Well I give my free time to do this and I'm not comfortable with charging people" and things like this.' (Commissioner)

Alongside these limitations on entrepreneurial activity were concerns that TSOs would not be able to compete in an open market with private providers due to their commitment to providing excellent rather than minimum standards, investment in staff training and development, and greater overheads connected with maintaining a central infrastructure and wider charitable activities. There were similar concerns regarding the financial attractiveness for carers of employing their own staff rather than purchasing from a TSO. From a commissioner's perspective however there was a sense that a number of TSOs had become somewhat complacent in their approaches, and increased competition was just what was needed to force them to become more dynamic. This included carers setting up new TSOs rather than accessing the existing organisations:

'They were very inflexible and only did three hour shifts. They didn't do weekends and they didn't deal with people with... We've actually got this budget now and we've found this woman down the road who used to work for the local authority who has now registered herself as a self-employed personal assistant, and she's willing to do this, this, this, this, and this. And she doesn't mind doing weekends. It makes much more sense to have her.' (Commissioner)

Respondents varied in their opinions of which parts of the third sector were more at risk of these negative financial impacts – for most it was the smaller organisations who did not have the resources

or capacity to make the necessary changes. However representatives of the larger TSOs thought that their bigger infrastructures would result in their unit costs being seen as unaffordable. It appears therefore that there is a general anxiety across TSOs who work in the adult social care system regarding how personalisation will play out in practice. It was reflected that there was potential for TSOs to collaborate better as a means to mitigate against the financial difficulties, but equally the complexity of developing these partnerships may prevent this in practice. Furthermore reflecting broader tensions described above the threats on smaller TSOs were at times ascribed to larger TSOs as they were better able to prepare for competitive tenders and to market more effectively to carers:

‘a number of smaller voluntary sector organisations...were tendering for services they’d been providing for ten or fifteen years and providing them really well and actually lost out to a very big national charity who, you know, basically could put in a very strong bright shiny bid’ (TSO)

Despite these concerns most of the TSOs interviewed had not experienced lower demand for their services. Indeed they had found that they had maintained the majority of the clients who had previously been funded through block arrangements and added new clients who were choosing to spend their personal budgets with the TSO:

‘I have to say I don’t expect it to because we’ve got a good reputation and it is word of mouth and that sort of thing. I don’t expect us to have a problem – we haven’t so far’ (TSO)

Furthermore those who had a role in advising central government, carrying out research and /or supporting other TSOs with adapting to new policies had found personalisation to be an opportunity to attract new funding and so grow the organisation:

‘we’ve got that very strong link to organisations across, you know, England and some very big organisations, some very small, but also, you know, we have that dialogue, if you like, so we can then feed that up in our strategic partner role,... I think we are pretty essential to their thinking and I think, you know, the sort of current policy, certainly in terms of the reforms that are coming through’ (TSO)

Moving on from issues relating to funding to those of practice, the impact of personalisation was reported to be seen as being relatively minor. This was commonly due to the perception of the TSOs that they had always tried to provide ‘personalised’ support, and a belief that the services they provided were still of value even if local authority commissioners did not want to grant fund them:

‘We still hold our coffee mornings, we still have an open-door policy, we still speak to families on the phone. And, no, I don’t think that’s changed for us.’ (TSO)

Finally there were also reports that the influence of personalisation was declining over time and other policy initiatives were being prioritised by commissioners. This was particularly the case within mental health services:

‘I think there was a time, a couple of years ago, when it became a real focus for the organisation – and gearing up to this new model of service and looking at how we would provide those services. And, to be honest, a lot of that has started to dissipate because, in mental health, at least, the actual implementation has been so slow that has been a real challenge.’ (TSO)

Discussion

The number of carers is predicted to expand rapidly in line with demographic changes and medical advances. In response to this increase, and in recognition that support for carers has not always been holistic and responsive, a drive towards more personalised support for carers is embedded within current policy intentions. There is commitment by the Coalition Government to improving the outcomes of personalisation for *all* carers with an emphasis on tailoring services to *their* needs (Department of Health 2010a and 2010b). Personal budgets for service users and their carers are to be a mandatory part of all care plans (HM Government 2012) and from April 2014 people who are already receiving NHS Continuing Healthcare will have a right to ask for a personal health budget (Department of Health 2012). Consequently, more carers will directly experience a personal budget of some sort, either as a result of the person they care for being in receipt of one or in their own right. The Common Resource Allocation System Framework developed by the Association of Directors of Adult Social Services (ADASS, 2009) “explicitly states that councils must take full account of the role of carers in providing on-going support, and that the assessment process should include (or lead to) a full carer’s assessment (unless this is refused)” (Moran et al. 2012: 476).

There still remain though different narratives regarding the purpose of and rationale for personalisation. The interviewees within this study reflected the range of interpretations described by Needham (2011) and demonstrated considerable variation in their estimations of the scale of change that it has and will entail. It was telling though that all, even those who began by giving a broader view of personalisation, progressively focused their attention within their interview on the financial aspects of personalisation. This included the individual allocation and payment systems that it has introduced and the extent to which these have enabled local authorities to reduce their level of support. Those who were more cynical about the underlying motivations saw the deployment of personalisation initiatives as cost savings mechanisms. For all, including the more hopeful, the current austerity measures were seen as a major risk and there was unilateral disquiet about the positives of personalisation being hijacked by the all-prevailing need to protect depleted and stretched public sector funds.

Hence, whilst the interviewees expressed a common hope that personalisation (however it is defined) could be an opportunity to improve the lives of carers, their acknowledgment of its implementation in reality invariably meant that they saw public sector funding cuts as being a highly significant threat to such improvements. Their perceived improvements for carers were in line with existing findings and included more flexibility, choice and control. This in turn could lead to carers having more freedom to pursue their own activities and other roles, as well as individualised and better quality care for those for whom they cared. However, the extent to which these could occur was shaped by a number of countervailing variables many of which provided new insights into the constraints on the extent to which personalisation can lead to improved outcomes for carers. Examples of these are local variations in the availability of suitable services, inequalities within the social care system between service user groups, class and language barriers, the paperwork and managerial responsibilities that inevitably accompany self-directed support, carers exclusion from the

planning process, loss of identity as a carer, tensions in the carer-cared-for person relationship and lack of support. Funding cuts were seen as not only compounding the negative effects of such variables but also increasing their number, thereby further reducing the realisation of the potential advantages of personalisation.

The study also highlighted key support and training needs for carers within personalisation – advice and guidance during the process of setting up a personal budget, personal budget management, and adapting to their new role and relationship with the person they care for. Such findings require more exploration in order to increase knowledge of exactly *how* TSOs can effectively respond to the growing numbers of carers who are at the core of their business and potentially those who can determine the survival of their business. Hence, although in reality the picture is probably more complex, as carers will of course vary in their use of TSOs, one way forward is to increase TSOs responsiveness to carers through further research. Effecting the changes in TSO service required may necessitate reviewing existing philosophies, approaches and structures. However, as personalisation has been described as the biggest change to the social care system since the introduction of community care, it will inevitably simultaneously generate major changes within the third sector

The growing numbers of carers affected by personalisation as it evolves together with requirements to address carers' needs therefore points to an ongoing need for *more* knowledge and further research about personalisation and carers. Nonetheless, it is important to acknowledge that studies carried out should not focus solely on '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)' (Larkin and Dickinson 2011: 4). In order to gain comprehensive understandings, research must also address personalisation in its broadest sense and its implementation at both local and national levels.

In contrast to the findings of Bartlett and Leadbeater (2008) all of the TSOs interviewed were all aware of personalisation. As they were involved in the social care sector in which personalisation has been trialled and the policy is now five years further in its implementation this is perhaps unsurprising. Furthermore, they had all taken steps to respond internally to the new funding arrangements and potential user expectations that arise out of the broad personalisation related reforms. There was a sense though in some user groups, particularly mental health, that its importance was waning. Whilst the TSOs shared concerns regarding the loss of block funding arrangements, the overall financial impact was more complex. For example, whilst some had lost, other TSOs had gained funding connected with the provision of direct services. There were also opportunities for growth in relation to ancillary work around the development, implementation and evaluation of personalisation.

The majority of interviewees from the public and third sectors saw the third sector as well placed to provide 'personalised support'. Reflecting the distinctive features commonly ascribed to the third sector (Macmillan 2012), this was on the basis of the centrality of carers within their mission, specialist skills, involvement of carers within their governance, and freedom from the pressure to maximise profit or respond to statutory duties. They also recognised the potential financial challenges for TSOs, especially in regard to achieving competitive unit costs and moving to more innovative funding models. However wider stakeholders did not unanimously see TSOs as having a right to be providers within a

personalised social care market place, and for them the priority was for carers to be able to choose the right provider from any sector. There were also some expressions of cynicism and frustration regarding the willingness and ability of TSOs to respond to the new requirements and expectations of carers.

In relation to the broader theme of the roles and relationships of TSOs in the current policy environment a number of noteworthy issues emerged:

The impact of policy on the third sector

The TSOs largely saw themselves as already providing flexible, carer-centred care that would be in tune with the broad aspirations of personalisation and so did not identify a great need to change what they provided, and a number were trying to maintain their previous provision despite the changes. However, the individual payment mechanisms and connected competition with other providers were seen to be driving changes to their approach to employing staff and restricting their ability to continue with more communal provision such as day services. Arguably then personalisation was not consistently leading to positive changes such as a modernisation of service offer (which commissioners did perceive was required even if the TSOs did not always do so) but was resulting in more negative impacts such as loss of service options and employment of low-paid workers.

Reliance on public sector funding

Within social care in particular there has been an encouragement from central and local government for TSOs to take on contracts for direct delivery. Having generated this resource dependency (and in doing so potentially reducing TSOs expertise in gathering revenue from other sources) the public sector is now reducing the overall level and unit cost of funding that it can provide. TSOs are expected to develop new, more 'entrepreneurial' business models that will enable their services to continue without this contractual income, with the move by many to adopt a 'social enterprise' persona as a whole or partial identity part of this trend. However many TSOs within social care had been developed or expanded on the basis of public sector grants or contracts and are less skilled and confident in generating other income opportunities. This highlights the dangers of the third sector (or indeed any organisations) becoming too reliant on a single funding stream. It also raises the possibility that if alternative funding streams are now found TSOs will be in a stronger position to be less sensitive to changes in public policy trends and more able to advocate and lobby on behalf of their beneficiaries.

Impact of market mechanisms on TSOs

The loss of financial certainty, closure of types of provision and indeed the collapse of smaller TSOs can be seen as a quasi-market approach preventing TSOs from providing what they know carers need. However, an alternative view is if carers choose not to purchase support from TSOs then perhaps these organisations were not in fact in touch with carers' demands and expectations. Extending this argument could suggest that TSOs who lose business have had a greater focus on what *they thought* was in the best interest of the carer, rather than responding to what carers actually required. This in turn questions the impact of carers within TSOs' governance and the expectation that this would result in greater responsiveness and flexibility. In reality the picture is probably more complex, as carers will of course vary in both their willingness and ability to get involved in TSOs and

will also want different types of support, although again these could be seen to question a congregate rather than an individual organisation of service delivery.

Conclusion

Personalisation looks set to provide the binding narrative for social care services in England for the foreseeable future. This study reveals that there is a general consensus across the public and third sectors regarding the basic principles that lie behind personalisation, their potential to be a force for improvement within carers' services, and the need for a whole systems change. Where consensus ends is in the parts of the system which are most in need of change and who should be trusted with the limited resources available to achieve personalisation. Put simply, is it local authorities that are out of step and therefore should trust the third sector to use its carer-centric values and governance arrangements to determine what support is required and how best to deliver this? Or are some parts of the third sector only responding to a small proportion of the current carer population through traditional services and therefore a consumer led approach is required to incentivise them to demonstrate innovation and efficiency?

These debates reflect those underway more broadly regarding the relationship between the public and third sectors (a partnership of equals or that of purchaser-supplier) and the emphasis of personalisation (a user-led grassroots movement or a market reform). They highlight that such differences in a strategic alliance can only be accommodated on a temporary basis before they surface and cause tension. Arguably though, neither of these paradigms of personalisation will enable the radical improvement in carers' support that is required. The realities of the current financial environment and increasing numbers of carers means that any model that is reliant on significant discrete funding from the public sector is doomed to fail. The fundamental question therefore is not how to ensure that the third sector is able to access the available funding from the public sector or if the third sector is using this funding wisely. It is rather, how do we achieve the aspirations of personalisation for carers without additional public sector funding and who will shape and lead this change? And whilst it will not be easy, there is an argument that the third sector, with its long-term relationships, values and commitment to carers is uniquely placed to take on this role. However this will require a willingness to be more entrepreneurial in relation to funding (including charging carers and working with private business) and in policy development (to be ready to agitate and lobby as well as partner and support). This will require existing TSOs to take an honest look at their current approaches and be ready to break with established cultures, practices and processes. If not, there is a real danger that for a number of TSOs working with carers, personalisation will be end of the road rather than a new dawn.

Recommendations for research

- To compare the outcomes experienced by carers between block and individualised funding approaches to carers' support.
- To explore carers' perspectives on support they need from TSOs, including those whose family members have different types of need.
- To investigate local authority and GP commissioners' perspectives of TSOs role in supporting carers in more depth.

Recommendations for practice

- To pilot models for carer support based on minimal or no public funding.
- Local authorities to engage with TSOs regarding their financial and procurement processes connected with personalisation.
- TSOs to undertake independent review of their governance arrangements in relation to the engagement of the carer community that they seek to serve and the impact on the running of the organisation.
- TSOs to be clearer regarding the added value that they bring over organisations from other sectors.
- Health and Wellbeing Boards to consider the needs of carers and engage TSOs in the development of their Health and Wellbeing strategy.

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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.

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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.

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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.