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Carers, Choice and Personalisation: What do we know?

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Despite the long-term strategic shift to personalisation, with its emphasis on choice and control for those who use public services, there has been relatively little policy consideration of family carers' choice within personalisation. The relationship between carers and personalisation also remains under-researched. This article is based on a review of existing knowledge around personalisation. It shows that carer choice is highly complex, not least because of the multifaceted and paradoxical nature of the concept of choice itself. The review demonstrates that choice for carers within personalisation is no less complex and is subject to new and overlapping variables which do not necessarily lead to improved choice for carers. In light of the limited empirical evidence about carers, choice and personalisation, the introduction of the Care Act 2014 and the importance of frontline practice in securing choice for carers, recommendations are made for future research and social work policy and practice.

Key words: choice, carers, carer choice, personalisation, adult social care

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Carers, Choice and Personalisation: What do we know?

Introduction

This paper is based on a literature review of existing knowledge around personalisation and family carers, with particular reference to personalisation's emphasis on greater choice and control for people who use public services (DH, 2007; DH 2010a). The aim is to stimulate further debate and research about the hitherto underexplored issue of family carers' choice in England within personalisation - a policy agenda that has been actively promoted since the beginning of the 21st century in the UK and which has been a significant driver of change in health and social care (Dickinson and Glasby, 2010; Lymbery 2012). The discussions also have wider relevance; personalisation is an international phenomenon shaping approaches across many policy areas (e.g. education, children's services, employment, criminal justice and housing) and in many countries (e.g. Canada, New Zealand, USA, Australia, France, and South Africa (Authors No.1, 2011; Needham, 2011).

Choice for carers and its ensuing complexities are contextualised before moving onto the issue of carer choice in relation to personalisation. Underlying tensions in late modern society between competing discourses, such as individualism and familialism and, debates about

empowerment and active citizenship are simultaneously explored. In light of the conclusions that emerge, suggestions are made about ways of ensuring that the personalisation of services and accompanying support really do promote “choice, control and independence for carers” (DH, 2010a:5), a policy directive also recently enshrined in the Care Act 2014.

The review carried out involved a comprehensive search of relevant databases. These included Social Care Online, Social Policy and Research, Scopus, PsychINFO, HMIC, ASSIA, MEDLINE, Embase, CINAHL Plus and AMED. The key search terms used were: choice, carers, caregiver, carer choice, personalisation and self-directed support. Further studies and grey literature were identified via related articles and article reference lists. The main time period covered was 2000-2014 in order to reflect the contemporary nature of this knowledge base, but a few highly relevant earlier items were also reviewed. Non-English language articles were excluded from the review. The search yielded 54 items, including previous reviews. Each item was read and critically appraised using Critical Appraisal Skills Programme tools (CASP www.casp-uk.net). The results were recorded on an excel spreadsheet together with a brief synopsis of each item. The findings were then thematically analysed. Six themes emerged: the concept of choice; the complexity of choice for carers; choice for carers in late modern society; personalisation and choice; existing knowledge about carers, personalisation and choice; and

factors influencing carer choice. These themes are used to structure the arguments about choice and carers that follow.

Choice and Carers

The concept of choice

Whilst the literature surrounding the concept of choice is diverse, two broad camps can be identified. There are those who argue that 'choice' is intrinsically positive; it is a 'good thing', central to personal independence and individual physical and mental well-being (Rabiee and Glendinning, 2010). Choice is also frequently closely associated with principles of citizenship and human rights (Glendinning, 2008; Rabiee and Glendinning, 2010). In addition, choice can be viewed as having positive instrumental value as it provides the means for individuals to acquire greater personal independence and control (Morris, 2006). However, others are more cautionary, emphasising that choice can lead to anxiety, stress and regret (Arksey and Glendinning, 2007; Winter *et al*., 2010; Schulz *et al*., 2012; Daly, 2012; Longacre *et al*., 2013). Indeed, it is argued that choice may be avoided due to fears of potential or anticipated negative consequences (Baxter and Glendinning, 2013).

Within these contrasting approaches, choice is often presented as the outcome of processes involving assessment and judgement, evaluating different options and making a decision about which option to choose (Beresford and Sloper, 2008). Certain preconditions for choice are noted, such as having accessible information and an opportunity to choose between at least two positively viewed alternatives (Arksey and Glendinning, 2007; Schulz *et al*., 2012). Absence of positively valued alternatives represents an absence of 'true choice' (Beresford and Sloper, 2008). There is also a vast psychological literature around descriptive theories of choice-making - how people actually make choices and the underlying cognitive processes. Different choice theories draw and/or emphasise different factors and processes. Some of the most common involve the number of alternatives individuals have to choose from, time pressures, personal differences (values, beliefs and experiences), the use of heuristics to help find 'good enough' solutions and, the use of 'framing'. How an individual chooses (often unconsciously) to frame alternatives can influence perceptions of choice and options chosen (see Beresford and Sloper's 2008 review).

In the context of social policy, especially with respect to policies around personalisation, developing markets and extending service choice for individuals is often viewed positively. Such developments are perceived as leading to improved service quality with more efficient services,

responsive to consumers' needs and wishes (Clarke *et al*., 2007; Le Grand, 2007). For some, this focus on services, consumers and choice is narrow and partial (Lent and Arend, 2004; Burchardt *et al*., 2014) and raises questions whether social care and health services can or should be left to market forces and consumer choice. (Clarke et al., 2005; Beresford, 2008; Daly, 2012). Focusing on individualisation and taking more control and responsibility has led to concerns that individualisation and privatisation marginalises the importance of citizens' social rights and the collective community (Daly, 2012).

Indeed, when choice and citizenship are linked together deeper questions emerge about outcomes of choice for individuals, particularly, in relation to achieving personal control and well-being. Schwartz (2004) in particular has highlighted the paradoxical nature of choice in relation to citizenship ; increased choice accentuates emotional anxiety and time burdens, thereby disempowering rather than empowering individuals, (see also Daly, 2012; Sandel, 2012).

Furthermore increased choice does not necessarily reduce inequalities (Clarke et al., 2005; Daly, 2012). Drawing on Bourdieu's concepts of cultural and symbolic capital, Greener (2002) argues that because wider socio-economic inequalities and barriers continue to influence how choice is exercised by individuals and groups of service users, not all people

experience choice and autonomy equitably. Similarly Pickard (2010) maintains that those with access to more social and material resources are frequently able to make better use of choices and choice-making opportunities. Hence, having choice, making a choice and realising/achieving personal choice can be separate processes, not necessarily leading on from one another (Burchardt *et al*., 2014).

The complexity of choice for carers

Although the body of literature, particularly empirically-based research, about carers and choice is relatively limited, it does highlight the multidimensional nature of choice for carers. For example, it may involve the choice over whether to care or not to care, which care related tasks to undertake or pass on to others and/or how to spend any 'free' time carers may have; carers can experience all or only some of these choices (Arksey and Glendinning, 2007). Exploration of the nuances of these different, but often interrelated dimensions provides compelling evidence of the complexity of choice for carers.

Literature reviews of informal caring provide insights into carers' feelings about choices available to them, especially over whether to care or not. Carers who feel they have little choice tend to experience poorer outcomes; they report more emotional stress, negative health and reduced

levels of adjustment to their caregiving role. Those perceiving more choice have higher levels of life satisfaction, emotional and physical well-being and personal adjustment to their caregiving role (Winter *et al*., 2010; Schulz *et al*., 2012; Longacre *et al*., 2013; Zegwaard *et al*., 2013). However, personal perceptions of choice are not static; carers' experiences of and attitudes to choice can change over the course of their caregiving journey (Burridge *et al*., 2007; Bowlby *et al*., 2010). Similarly, the very act of caring can simultaneously be experienced positively (e.g. as personally satisfying) and negatively (e.g. as demanding on personal time) (Pratesi, 2011). Interestingly, increased state service provision is not necessarily correlated with reduced levels of informal care and hence, more choice for carers (Oudijk *et al*., 2011).

A key literature review of informal caring was that conducted by Arksey and Glendinning in 2007. They reviewed the literature about carer choice situations from 1985 - 2006. This review not only highlighted that choice for carers is complicated but also potentially problematic because carers do not make choices in a vacuum. Choice-making within caring is not an individualised activity as it involves weighing up options with other people, including, service users, carers and service providers (Author No.2, 2012). This demands, as Arksey and Glendinning suggest, awareness of the nature of caregiving relationships alongside wider organisational and contextual factors which may be beyond the control of carers.

Work that has been carried out since Arksey and Glendinning's (2007) review has both supported and developed their suggestion about the need for awareness of the nature of caregiving relationships. For example, others have emphasised the importance of acknowledging that carers and those they support may differ in their views and expectations about each other's needs and the caring role (Dunér, 2008; Kuşçu *et al*.; 2009; Oudijk *et al*., 2011; Shulz *et al*., 2012; Longacre *et al*., 2013).

Arksey and Glendinning (2007) also reported that carers' interpretations draw on a myriad of personal motives and life history experiences spanning social, moral and cultural spheres. They specifically identified the importance of carer emotions, such as altruism, obligation and reciprocity and the way these are simultaneously bound up with kinship ties and feelings of 'love' for the person they support. Feelings of altruism and obligation, often epitomised by the 'dutiful wife' and the 'loving daughter/son' - with the subtext that caring is the 'right' or 'proper' thing to do - have been reiterated in other work (Dunér, 2008; Kuşçu *et al*., 2009; Lyon, 2010; Shulz *et al*., 2012).

However, the strength of perceived obligations can vary, as different cultures have different social norms (Oudijk *et al*., 2011). Recent research has considered cultural acceptability because, as Gysels and Higginson

(2009) and Burridge *et al*. (2007) argue, the dearth of research around carer choice, especially carers choosing not to care, may be due to pressures of social acceptability and associated moral imperatives to care. Feelings of reciprocity between carers and the person they support can also be multi-directional (Winter *et al*., 2010).

Furthermore, subsequent studies have continued to indicate that organisational and contextual factors constrain carer choices and that many carers feel they have little real alternative to caring (Schulz *et al*., 2012, Dunér, 2008; Kuşçu *et al*., 2009). Such factors include professional attitudes and practices. Professionals have been found to hold different caring expectations and/or assumptions about different types of relationships which frequently mirror wider social norms and values, for example, spousal caring as a normal extension of love within marriage (Twigg and Atkin, 1995). Wider issues of class, race and gender can also interact with professionals' assumptions - especially caring as 'natural' for women – to shape levels of support and/or services offered to individual carers (Twigg, 1982; Twigg and Aktin, 1994; Hockey and James, 2002). This, in turn, can impact on the level of choice carers feel they have/do not have.

The growing body of literature around the geography of caregiving, especially, spatial contexts of care, also provides insights into the role of

normative assumptions in shaping carer choice. This work focuses on how both professionals and carers differentiate between public and private caregiving spaces, with care in the home viewed as private, based on personal relationships and negotiations between individuals Such perceptions of public/private spaces can impact on professionals' attitudes and influence their actions, for example, professionals willingness to enter areas defined as private and to affect changes in them and their corresponding carer/cared for relationships. As these actions have leverage within the home and within spousal relationships, they can structure carers' own perceptions of the role they have/should have and the care choices open to them (Miligan and Wiles, 2010; Egdell, 2013).

Choice for carers in late modern society

Choice for carers will continue to be no less problematic; the family care gap is imminent (predicted from 2017) when the number of older people needing care in the UK will outstrip the number of adult children able to provide care (McNeil and Hunter, 2014). The raising of important policy questions around future state service provision and requirements is concurrent with an increased onus on those available to perform a caring role. There are also potential theoretical conflicts around choice for carers in late modern society. This is due to two competing discourses, namely individualism and familialism (Pickard, 2010; Cash *et al*., 2013; Fine,

2013; Grootegoed, 2013). Individualism is premised on personal fulfilment and self-actualisation (i.e. autonomous identity and agency for both carers and the cared for person). The continuing emphasis within more traditional familialism is on family care obligations – pitted alongside the rise of active citizenship with its emphasis on the collective and citizens caring for fellow citizens, ideally facilitating increased social cohesion in society. Negotiating both discourses is viewed as increasingly difficult.

Whilst acknowledging the role of these challenges in late modern society, a significant, if not the most significant factor for carer choice in England is the long-term strategic shift to 'personalisation'. This is not only because of its centrality to social care and extension beyond social care (as signaled by the introduction of personal health budgets in England) (DH, 2009) but because it also reflects ongoing tensions between individuals and the collective and more specifically, individualism and familialism for carers.

Personalisation and Choice

Although there are multiple, fluid and often conflicting interpretations of its purpose, meaning and dimensions, personalisation is broadly defined as 'the way in which services start with and are tailored to the needs and preferences of individual service users (DH, 2007). It is frequently

associated with enhancing choice and control for people who use public services. Other key themes include transforming people's lives for the better and that service users are 'experts on their own lives' (Poll, 2007 :53) and therefore, best placed to know their own needs.

The personalisation policy agenda is set against a background of changing public expectations and service demands, integral to which is the public becoming increasingly demanding about the type of services they receive as individuals - expecting more empowered care and relationships with professionals and service providers that are involved in the design and delivery of their care (Author No.1, 2011; Needham, 2011, 2014; Moran *et al*., 2012). Personalisation has subsequently given rise to debates around empowerment and relationships between citizens and the state (Glasby and Littlechild, 2009); within the empowerment discourse, empowered individuals and groups gain or increase choice and control over key aspects of their lives in order to maximise their quality of life. However, evidence about increasingly limited resources, structural constraints and the nature of professional power challenges whether people *can* have control over their lives and care decisions (Authors No.1, 2014)

As mentioned above, personalisation has become a driver of change within health and social care. This is reflected in the move away from

traditional ‘one-size-fits-all’ approaches to a more ‘personalised’ approach, within which individuals who receive support are offered ‘choice and control’ and empowered “to shape their own lives and the services they receive in all care settings” (DH, 2007 :5). A consequence of adopting this approach has been the introduction of a range of models and initiatives to enable service users to determine their own priorities and preferences. These include the different forms of self-directed support, such as individual budgets, direct payments and personal budgets. In England, with reference specifically to personal budgets, these are now a mandatory part of all care plans and involve a needs-based sum of money being directly paid to individuals or managed by the Local Authority (DH, 2010b). Although such self-directed models are only the technical levers to bring about personalised services, their visibility means that they are often mistakenly conflated with personalisation in its broader sense (Author No.1, 2015).

In contrast to the emphasis on choice and control for service users, there has been relatively little policy consideration of choice and control in relation to carers, particularly family carers, within personalisation in England. This lack of consideration appears inconsistent with public recognition and English policy initiatives raising the profile of carers and their needs over the past 15 years (e.g. HM Government, 2008). This can, in part, be attributed to the problematic nature of separate user and carer

legislation (Authors No.2, 2014b). Other contributory factors include the absence of a clear carer/cared-for dichotomy because of the interdependent and reciprocal nature of caregiving relationships (Fine and Glendinning, 2005; Authors No.1, 2014). In addition, there are unresolved debates about whether policies that support carers perpetuate disabled and older people's dependence (Shakespeare, 2000; Morris, 2001). Nonetheless, government good practice guidance in England (DH, 2010a) does make recommendations which, in theory, should have increased choice and control for carers. For example, to not assume carers' willingness and ability to continue caring; to offer separate assessments to carers; to allocate resources to carers in their own right through a transparent and equitable system (DH, 2010a). The Care Act 2014 also strengthens carers' rights in relation to social care and reiterates the importance of outcomes carers wish to achieve in their daily lives as well as their willingness to continue to choose to care.

Existing Knowledge about Carers, Personalisation and Choice

Whilst the impact of personalisation within health and social care has been recognised and researched for a number of years at a range of organisational and personal levels (Dickinson and Glasby, 2010, Author No.1, 2014), carers are still marginalised in this growing body of personalisation research (Flynn, 2005; Jones *et al*., 2012; Moran *et al*.,

2012). Although the majority of findings about carers and personalisation to date are quite specific and have emerged from studies into the various forms of self-directed support, the evidence from these studies provides insights into choice for carers within personalisation (especially in relation to increased flexibility for carers) and the range of factors influencing the level of choice carers experience in their everyday lives. These two issues are addressed below.

More choice for carers?

There is evidence that self-directed support (in its various forms) allows carers flexibility around the amount of caring they provide (Rummery, 2011; Jones *et al*., 2012; Moran *et al*., 2012). In some cases, this may not be immediate because many carers have concerns about accessing suitable services for the person they support and being less involved in providing care themselves. For example, Author No.1 (2015) found that carers were anxious about the recruitment and training of personal assistants, commenting on the difficulties of 'finding the right people' and then teaching them about the care required, particularly when the service user had complex needs. This study also showed that whilst such anxieties can ease with time, especially if carers develop confidence in the quality of the replacement care provided/available, carers are frequently unsupported in achieving such flexibility.

When personalisation does result in increased flexibility, carers are more likely to choose how they spend their 'non-caring' time (this can be alone, without the person they care for and/or with the person they care for) and to report feeling more in control of their daily lives (Hatton and Waters, 2011; Jones *et al*., 2012; Moran *et al*., 2012). Examples of choices carers have made about this time include pursuing their own interests (e.g. voluntary work or an interest in sport), having a social life and creating more time for both themselves and other family members. These outcomes are significant for several reasons, especially because of their centrality to the Carers (Equal Opportunities) Act 2004 and its associated statutory duty on practitioners to consider carers' aspirations for employment, learning and leisure in carer assessments. Importantly, these outcomes can also lead to carers experiencing a better quality of life and happier relationship with the person for whom they care. Consequently, carers report enjoying caring and their caring role much more (Hatton & Waters, 2011; Office for Public Management, 2011; Carers Trust, 2012; Forder *et al*., 2012: Jones *et al*. 2012; Moran *et al*., 2012; Hatton *et al.,* 2013; Author No.1, 2014).

Although personalisation can potentially increase carers' choices, studies have also demonstrated that some of these choices may not be life enhancing. For example, carers still bear the burden of caring when they

become a paid personal assistant to the relative for whom they care. This can adversely impact on other aspects of their lives, such as limiting their social and working lives (Breda *et al*., 2006). In relation to carers' employment, there is evidence that personal budgets do not improve carers' opportunities to undertake paid employment (Hatton *et al*., 2013; Pickard and King, 2013). Concerns have been raised about carers' low market rates of pay and ongoing financial dependence which, in turn, results in poverty, post caring (especially, in older age) (Keefe and Rajnovich, 2007).

A cause for further unease around carers becoming paid personal assistants is the accompanying move to a contractual relationship with the person for whom they care for (Rosenthal *et al*., 2007; Glendinning *et al*., 2009; Duncan-Turnbull, 2010). Some carers, particularly those in long-standing care relationships – most notably spousal and/or family relationships - may struggle with the monetarisation of this relationship (Kremer, 2006). A formalised personal assistant contract can also paradoxically loosen carers' rights. This is because family carers (in contrast to non-familial/friend carers) may find it harder to exercise their own employment rights when acting in a paid caring capacity due to wider relationships issues and/or considerations between carers and those they care for. As Kremer (2006:397) concludes, 'moral obligations feel stronger when they are formalised'. Moreover, formalised personal assistant

contracts can reinforce traditional gender roles with women as primary carers in the family by virtue of the fact that most carers are women. Hence, this gender role reinforcement can lead to a re-familiarisation of care (Kremer, 2006). This illustrates how carers' experience of choice in relation to personal budgets reflects, as noted above, the inherent tensions between individualism and familialism.

Factors influencing carer choice

It is clear there are limitations to carer choice over caregiving (including particularly, the choice not to care) that are inadvertently intrinsic to the operation of personalisation. The existing literature also identifies a number of variables which constrain the extent to which carers *do* have more choice and control within personalisation.

Information and organisational factors

Many carers say that they do not have sufficient information to make informed choices (Carers UK, 2013). Another key variable is the nature of the needs of the person they are supporting; self-directed support (at its broadest level) lends itself to meeting the needs of some service users (such as younger working age people) more than others (such as those with complex needs and multiple disabilities). This is due mainly to the availability and flexibility of appropriate services in local care markets

(Glendinning *et al.,* 2009: Hatton and Waters, 2011; Office for Public Management, 2011; Woolham and Benton, 2012) compounded by the fact that the development of social care markets in England remains unequal with more limited choice for some service users and their carers than others (Spicker, 2012; Rodrigues and Glendinning, 2014). Furthermore, inequalities in the capacity of some citizens 'to navigate complex care systems' has led to relatively low take-up of self-directed support by some more marginalized groups, for instance, 'older people, people with mental health problems, and people from ethnic minorities' (Needham, 2013 :8). Carers of people in these groups therefore do not stand to benefit from choices that personalisation potentially offers. For example, the opportunity - as seen in good practice guidance in England for carers of disabled and/or older people (DH, 2010a) - to feed their own views and/or support preferences into the social care assessments and support planning processes of the person they support.

The availability of support, especially, in the context of financial capping, alongside local authority regulations around the use of resources in relation to carers' choices (for example, payments as only one-off block grants to carers) are also important as they can restrict the flexible and creative tailoring of individual support (Authors No.2, 2015b). This flexibility and creativity provides carers with options and thus, potentially, more choice. Regulations can also determine the extent to which carers

have to ‘pick-up’ caring responsibilities because of shortfalls in services (Rabiee, 2013).

Studies have also shown that the management of personalisation (e.g. the paper work and staff recruitment associated with direct payments) can place additional demands on carers’ time, particularly at the ‘setting-up’ stage (Rosenthal *et al*. 2007; Grootegoed *et al*., 2010; Callaghan *et al*., 2011; Routledge and Lewis, 2011; Author No.1, 2014; Ritters *et al*., 2014). Whilst those carers with previous administrative and managerial experience (paid and unpaid) cope better (Grootegoed *et al*., 2010; Brookes *et al*., 2013), the importance of independent advice and practical support for carers has been acknowledged. However, there are few services available to carers to support them with problems they experience (Manthorpe *et al*., 2011).

Homecare provider failure further increases the pressure on carers as they are left with the responsibility of providing necessary care themselves (frequently at short notice or in emergency situations) or having to renegotiate care provision. This often involves lengthy processes of finding replacement homecare providers (Fotaki *et al.,* 2013; Authors No.2, 2015a). Such demands on carers’ time represent yet more constraints on them and any freedom to make choices about their daily lives that they may have (or have hoped for).

In addition, practitioners can inadvertently shape carer choices. For example, in a recent study of English social care, Authors No.2 (2014a) report that during service user assessments practitioners were often unsure what services and/or support they could offer carers in their own right (Authors No.2, 2013), especially, support around leisure, employment and training, as outlined in the Carers (Equal Opportunities) Act 2004. A lack of transparency surrounding what help can be offered to carers has also been highlighted by Rand and Malley (2014).

Frontline practice

Although local authorities in England have duties to involve carers in service user assessments and undertake separate carer assessments, the reality of frontline practice means that it can impose restrictions on opportunities for carers to express their own wishes and/preferences and for them to be taken into account. Authors' No.2 (2014a) argue that this is partly the result of practitioners focusing on service user assessments (or joint service user and carer assessments) with limited use of separate assessments for carers. Whilst carers are frequently asked about their willingness and ability to continue caring during service user assessments, attention to their *own* care and support related needs - especially wider objectives around leisure, employment and training - often remain marginal. This is because practitioners do not routinely incorporate carer

preferences into service user personalisation processes. For example, Authors No.2 (2014a; 2014b) found little evidence that service user support planning processes take account of carer views and support preferences expressed via carer assessments. This is despite, as noted earlier, good practice guidance advocating that information from carer assessments should 'feed into' and hence inform service user support planning (DH, 2010a). The problem of uncoordinated service user and carer assessments (Authors No.2, 2014a) supports findings from previous research reporting low take-up of separate carer assessments (Seddon, *et al*,. 2007).

Carers' personal experiences of personalisation

Studies also show that personalisation means carers may have to cope with several changes to their caring role which can be experienced as both challenging and conflictual. For instance, increasingly having to make decisions on behalf of the person they are caring for (e.g. for service users with dementia or other progressive conditions) and service users making more decisions about their own care which may be hard for carers to accept, especially, carers that have been used to having overall control of caring and support provision (Rosenthal *et al.* 2007; Glendinning *et al.* 2009; Duncan-Turnbull 2010). These changes can alter the dynamics of carer and service user relationships and may lead to tensions. There is also recent evidence that carers worry about the effects of continuing local

authority budget cuts on personal budget allocations (Gardam, 2014; Author No.1, 2015). Findings about such stressful and challenging experiences indicate that instead of giving carers more freedom to make choices and improve the quality of their lives, personalisation processes can paradoxically impose additional stresses (Schwartz, 2004; Daly, 2012).

Discussion

The evidence base: choice and constraint?

The review of the existing literature that forms the basis for this paper indicates that whilst personalisation does afford opportunities for increased carer choice – around who, when and how alternative support is provided to the cared for person - improvements to carers' lives are also constrained by a range of factors. Burchardt *et al.*'s (2014) distinctions between the processes (referred to earlier) of having choice, making a choice and realising/achieving personal choice is also reflected in the existing knowledge. See for example, longitudinal research about health and social care choice-making processes as experienced by service users and their carers (Author No.2, 2012; Baxter and Glendinning, 2013; Rabiee, 2013). Participants in these studies did not always progress to or

achieve all three of these choice-related stages as complex individual and wider socio-economic factors influenced choice-making processes.

Furthermore, there is evidence that the aforementioned tensions for carers between discourses of individualism and familialism are far from eclipsed by personalisation. Policy makers fear that the anticipated 'family care gap', may heighten these and other discourse tensions, for example, between individual and state, and individual and collective (Clarke et al. 2005, Daly, 2012). This may result in carers increasingly facing the demands of negotiating and seeking personal self-actualisation, whilst also meeting policy proclamations around the importance of the family and being active citizens (Pickard, 2010; Cash *et al*., 2013; Grootegoed, 2013; McNeil and Hunter, 2014). Negotiating these ideologies raises complex questions for carers, particularly with the extension of personalisation beyond social care into health care.

Reviewing the literature has highlighted that some of the constraints on carer choice relate to unanticipated consequences of the very measures introduced to enhance carers' level of choice, such as those carers who become paid assistants to the person for whom they support, hence formalising caring relationships. Previous work on carer choice (Arksey and Glendinning, 2007) highlighted the important role of the nature of caregiving relationships and complex life-histories, particularly, kinship ties

and interdependencies between partners alongside wider organisational and contextual factors.

Whilst aspects of both of these influences feature in the reported findings around carers, personalisation and choice, different dimensions also emerge as having significance. For instance, in caregiving relationships, the needs and capacity of the person receiving care can limit carers' choices. Examples of wider organisational and contextual factors specifically relevant to carer choice in personalisation include the way local authority regulations and practices shape personalisation processes with the result that carers do not always benefit from intended personalisation outcomes. This is particularly apparent in English social care when carer assessments and service user assessments are uncoordinated with the consequence that carer information is potentially marginalized (Authors, 2014a, 2014b, 2015a). Further marginalisation can occur during carer assessments when carers' wider personal outcomes (around leisure, employment and training) are not considered (Seddon and Robinson, 2015). Although not all carers want or choose to have a carer assessment, eligibility for these assessments and any ensuing local authority support may be increasingly reduced (despite formalisation of greater carer rights in England with the Care Act 2014) as eligibility thresholds are re-assessed and/or raised (Glasby, 2014). This, in turn, may limit the discussion of carer choice and the scope of any such

discussions, including future development of carer support services, especially services beyond traditional support (see Seddon and Robinson, 2015).

Another key theme to emerge is the need for more support to facilitate carer choice. Studies show that advice and guidance as well as emotional and practical support are required by carers to help them manage and cope with changes that the move to personalisation can entail (Manthorpe *et al.*, 2011).

Closer examination of the nature of the evidence about carers and personalisation demonstrates that it is weakened by the fact that the majority of findings reported are derived from studies exploring specific forms of self-directed support. The fact that the focus of studies to date has largely been on the technical levers which bring about personalised services, as opposed to the adoption of a personalised approach and ethos to public service provision limits their contribution to our knowledge of carers and personalisation. There are also other features of the studies reported that restrict their scope. Amongst the most significant is the way that, until most recently, studies lacked generalisability because they have been carried out within particular authorities. In addition, and more importantly, apart from one or two small scale studies which have focused exclusively on carers, findings are based primarily on studies within which

carers are incidental to or, only part of the main study (Authors No.1, 2011; Jones *et al*., 2012; Moran *et al*., 2012; Authors No.2, 2013).

Next steps – further research

Further research is therefore required not only to extend knowledge and understanding of carers, personalisation and choice but is essential to improving support for carers. Building on the strengths and tackling the deficits of the existing literature could also help facilitate greater carer choice. For instance, concentrating less on the technical levers of personalised services, adopting a holistic approach to personalisation and conducting studies which focus exclusively on carers', particularly around carers' hitherto unmet needs that have emerged (such as their need for more support and advice with managing and adapting to personalisation). Research drawing on larger samples of carers across a range of authorities could extend the knowledge base. However, as with any research exploring carers needs and wishes it is important to recognise their heterogeneity. This highlights the exigency of research with different groups of carers, for instance, carers of older people and people with mental health conditions because, as noted earlier, personalisation can be experienced differently by different groups of service users (Needham, 2013). This, in turn, can impact on carers' experiences of personalisation processes and within this, choice and choice-making opportunities.

Next steps – social work policy and practice

It is also clear from the review that those carers who feel they have more choice and control (including the choice not to care) experience better outcomes (Winter et al., 2010; Schulz et al., 2012; Longacre et al., 2013; Zegwaard et al., 2013). This underscores the importance of facilitating greater choice for carers. Whilst recognising that choice for carers is complex, change in social work practice is one way forward. The attitudes and knowledge of practitioners, especially social workers, is known to influence users' experiences of personal budgets (Glasby, 2014). A number of commentators have argued that the introduction of personalisation policies has led to a re-assessment and re-definition of the role of social work and social workers (Leece and Leece, 2011; Lymbery, 2012; Needham, 2014), Changing social work practice therefore appears both pertinent and opportune. Approaches that have been suggested to help service users achieve greater control and independence are equally relevant to carers and could therefore be adapted by social workers when working with carers. For example, Rabiee (2013) argues that social work practice needs to be underpinned by a more in-depth understanding of the complexity and multi-dimensionality of choice-making. She places

particular emphasis on the way that choice-making is relative, is subject to a variety of individual interpretations and, can be temporal with short- and long-term goals. Hence, there is a need within social work practice to acknowledge that people seek different goals and make different choices at different times. Rabiee (2013) also notes the importance of holistic family practice with practitioners taking account of different family members care choice preferences and this is reinforced in the Care Act 2014.

Concluding comments

The review of existing knowledge around personalisation and family carers presented in this paper shows that although the potential for greater choice for carers certainly exists within personalisation, there are a number of constraining variables. Further research and consideration of frontline practice can both play a role in improving choices for carers. The Care Act 2014 also promises more choice for carers; it extends their rights, introduces parity between service users and carers' rights, focuses on carers' willingness and ability to continue providing care and obliges local authorities to provide services/support to those carers meeting eligibility criteria. Nonetheless, the delivery of these developments is potentially problematic, particularly in the context of the ongoing local authority budget cuts and increasing service rationing (Glasby, 2014; Rand and Malley, 2014; Pickard et al., 2015). Such challenges lead to

questions around local authorities' ability to offer carers *real* choice around, for example, offering carers personal budgets or support services and the choice to accept (or reject) this support.

In addition to its more explicit findings, this review highlights some of the problems of appealing to existing evidence. Glasby (2014) argues that 'evidence' can be viewed positively or negatively, depending on different definitions of what constitutes 'evidence' and individual attitudes to personalisation and the state. He also maintains that a lack of evidence can lead to either pre or post-personalisation idealisations. Therefore, when identifying ways of improving choice for carers as personalisation becomes more embedded within health and social care, it is important to acknowledge that carers' personal choice accounts may not always apply the same degree of proof when comparing the 'old system' of state service provision and the 'new system' of personalisation and social care markets. Acknowledging the more opaque complexities such as these can productively inform much needed future research and social care practice development around carers, choice and personalisation.

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