University of Dundee

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Mladenov, T.; Owens, John; Cribb, A.

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Personalisation in disability services and healthcare: a critical comparative analysis

Teodor Mladenov, John Owens and Alan Cribb

Centre for Public Policy Research, King's College London, UK

Abstract

Personalisation is a key term in contemporary British social policy. This paper conceptualises personalisation as embodying two aspects – marketisation and social justice – and explores their interaction in discourses and practices of personalisation in disability services and healthcare. Comparing the application and reception of personalisation in these two social policy domains, the paper identifies a tendency of marketisation to override social justice and highlights the negative implications of this tendency. The analysis is further contextualised by looking at the uses of personalisation to legitimise retrenchment of public provision in the context of post-2008 austerity. In conclusion, the paper calls for a critical engagement with the dominant interpretations of personalisation in order to prevent its reduction to a vehicle for unchecked marketisation of social policy.

Introduction

This paper examines the personalisation of disability services and healthcare in the United Kingdom but its conclusions are applicable to other social policy contexts as well. The analysis aims to unpack the different and sometimes conflicting meanings of personalisation, the ways in which they play out in the two domains of disability services and healthcare, and the relation of these diverging or converging articulations of personalisation to the more general process of restructuring the welfare state over the last decade, with a special focus on post-2008 austerity. It is hoped that the comparative perspective, by bringing together two distinct but intrinsically related social policy areas, will add fresh insights into the ongoing debate about the mantra of present-day reform of public services in the UK.

Personalisation is a hybrid concept. It is prescribed in the name of economic efficiency, but also as a means for achieving social justice, mainly in terms of greater autonomy and choice for service users. In the context of social policy, personalisation means that social services are designed to fit their users, instead of users having to adapt to the services. New personalised solutions are opposed to traditional, one-size-fits-all, standardised service schemes (Leadbeater, 2004). With personalisation, the focus is on individuals and their idiosyncratic needs, values and preferences rather than on groups and their common needs. Accordingly, the autonomy of the user is promoted as the highest value, in opposition to 'top-down', paternalistic arrangements that allow the interests and decisions of service providers to take precedence over those of service users.

A number of scholars have pointed out that personalisation is a concept without a clear meaning. The term has even been regarded as an 'empty signifier' (West, 2013) because it is

not firmly attached to any particular signified element – it may refer to cost-effectiveness, privatisation, marketisation, consumer satisfaction, choice, autonomy, empowerment, user involvement, or democratisation of expertise (Cribb and Owens, 2010). This lack of semantic clarity allows personalisation to obscure the ideological 'antinomies' (Ferguson, 2007) underlying specific policy reforms and to create the illusion of a post-ideological consensus in order to accommodate conflicting agendas. As Needham (2011: 55) puts it, '[t]he elasticity of personalization ensures that a wide range of divergent interests have been able to sign up to and advance it, without needing to reconcile internal tensions'.

On the one hand, personalisation promises economic efficiency through marketisation. The claims that personalisation saves money is often regarded as self-evidential (Needham, 2011: 59-60). The underlying assumption is that the introduction of market mechanisms such as consumer choice and competition between service providers will increase the efficiency of personalised social services. This aspect of personalisation has appealed to the advocates of the free market. On the other hand, personalisation promises social justice by liberating service users from top-down, paternalistic control, transforming them from passive recipients of 'care' into active agents of their own wellbeing. In this way personalisation might address patterns of subordination and 'misrecognition' (Fraser, 2013) that have been perpetuated by 'experts' in healthcare, disability services, education, etc. (medical professionals, rehabilitators, social workers, teachers and so forth). These professionals have been empowered by a hierarchical, bureaucratic, centralised and over-controlling welfare state (Rose, 1996: 54). Personalisation challenges these hierarchical structures by acknowledging 'lay' forms of knowledge and expertise, as well as by promoting greater autonomy for service users through the redistribution of power and the democratisation of choice and decision-making. An important corollary is the promotion of equity by making choice available for all service users and not

simply for those who are able to manipulate the system. Accordingly, personalisation has resonated with patients' groups, disability campaigners and other groups concerned with issues of social justice in public services.

Over the past decade, though, concerns have been raised that the two aspects of personalisation do not enjoy equal standing. Critics of the concept and its application in social policy have argued that, whenever personalisation is implemented, the agenda of marketisation tends to override that of social justice (Beresford, 2009; Ferguson, 2007; Needham, 2011; West, 2013). This argument echoes the broader point that in contemporary Britain, social democratic values and policies have been systematically subordinated to neoliberal ones even by those ostensibly on the Left (Hall, 2005: 329). What is more, whereas personalisation is represented as a mechanism that will revive the welfare state in the 21st century in a non-paternalistic, non-hierarchical, less interventionist form, in actuality it seems to be used as an instrument for welfare state retrenchment through privatisation of services and responsibilisation of service users. On this view, 'personalisation amounts to nothing more than a covert strategy for importing market techniques into public services' (Owens, 2010: 42).

The aim of this paper is to explore these claims by discussing personalisation in disability services and in healthcare, making recourse to reports and analyses from the UK. We assume that personalisation concerns users with all kinds of impairments, including mental and psychosocial ones, because we understand autonomy in relational rather than purely cognitive terms – i.e., as an ability to make independent decisions that emerges within and is maintained by appropriate infrastructures of support (Mladenov, 2012). In addition, we prefer the more neutral term 'disability services' to the more conventional 'adult social care services' because the word 'care', when applied to disabled people, carries a heavy historical burden of

consistently associating disability with passivity, deficiency and, ultimately, dependency (a nuanced discussion is provided by Hughes *et al*, 2005). The reference to 'care' in the domain of health policy has been less controversial and so we opt for preserving the term 'healthcare'.

The intersection of disability services and healthcare around direct payments and personal budgets provides the most advanced example of personalisation, although the concept gets applied in education and a range of other service areas as well. This reflects the elasticity of the term, but also the variety of domains it is used in, which points towards the need to analyse personalisation in a cross-sectoral, comparative perspective. Yet so far, individual accounts of personalisation have tended to focus on a single area of social policy, in isolation from others. Thus analyses which deal with disability services have disregarded healthcare, while those which deal with healthcare have hardly looked at disability services.

The two social policy areas reviewed here provide usefully contrasting cases as regards their surrounding policy 'climates'. Whereas mainstream debates about disability services have long had to engage with identity politics, including issues of recognition, inclusion and voice, mainstream debates around healthcare have, by contrast, come to these concerns about identity, power and inclusion later and less visibly, and are still substantially dominated by professional agendas, especially biomedical ones. Indeed, the role of the biomedical model in the two areas provides another important axis of contrast, which is also reflected in the aforementioned difference in the attitude towards the term 'care' in the two domains. Some of the calls for personalisation in healthcare are based on the notion that the 'persons' who are the objects of, and potentially participants in, healthcare should not be thought of wholly in terms of biomedical categories but as embodying other characteristics – subjectivity, agency, biography, etc. However, despite this broadening lens it has proved very hard to shake off the

incredible structural and discursive dominance of biomedical categories in health policy contexts. By contrast, it is presently commonplace for those who use and analyse disability services to define disability outside, and in many respects in terms that are oppositional to, the reductionist categories of biomedicine – i.e., by treating disability as a social rather than a medical category (Barnes, 2007).

Such comparisons are crucial for understanding the reception of personalisation across policy domains. The present paper initiates such a cross-sectoral discussion by bringing together expertise from authors who have studied personalisation in healthcare (Owens, 2010, 2012a, 2012b; Cribb and Owens, 2010) and disability policy (Mladenov, 2012). The questions that will be addressed on the following pages are: How are the two major aspects of personalisation – marketisation, on the one hand, and social justice, on the other – realised in the context of social services for disabled people and of healthcare? What attempts are made at overcoming, integrating or reconciling the ensuing contradictions? How are these contradictions differently manifested in the two policy areas? More generally, how does the dynamic of the contradictions reflect the broader context of post-2008 austerity? It is envisioned that the answers to these questions will constitute a critical comparative analysis of the concept and practices of personalisation that will be of interest to social policy analysts and practitioners alike.

Personalisation and disability services

Disability scholars and activists have regarded personalisation with unease (Beresford, 2009; Morris, 2014). Despite being billed as 'person-centred' and oppositional to 'top-down' approaches, personalisation has been seen as alien, articulated not by service users but by

professionals and, accordingly, driven by values and interests that are at odds with those of disabled people. The top-down genealogy of personalisation and its embrace by politicians of all persuasions (Left and Right) has made it suspect from the perspective of disabled people's movement. Indeed, in the context of a neoliberal political culture in which popular rhetoric is routinely employed to mask the twin goals of marketisation and austerity (Hall, 2005), the stated aim of personalisation to provide disabled people with greater voice and choice has, at times, appeared to be more of an appropriation of the movement's goals for reasons of political expediency than a sincere attempt to help meet these goals.

Personalisation has therefore tended to be viewed with suspicion from within the disabled people's movement. However, within the broad discourse of personalisation, the mechanism of 'direct payments' has enjoyed widespread acclaim among disability scholars and activists. Direct payments involve diverting money from institutions, projects or facilities to which disabled people might be entitled access as part of their 'care', and channelling a proportion of this money directly to individuals to spend on the support they need as they see fit. Studies of actually existing direct payment schemes in the UK have shown that, for the users, the most beneficial aspects of such schemes – and the ones that sharply distinguish direct payments from traditional forms of disability support – are the ability to choose one's personal assistant(s) and to control the timing and content of the assistance (Stainton and Boyce, 2004: 449-50). In effect, users have reported deeply transformative experiences: 'I have got freedom now which I felt for years I didn't have. I have got control. I can control my own life now.' (Stainton and Boyce, 2004: 453)

Unlike the genealogy of personalisation, the genealogy of direct payments has been a bottom-up one – the emergence of the mechanism is located in the Independent Living philosophy and

the social model of disability, as formulated and promoted by the disabled people's movement (Barnes, 2007; Spandler, 2004). And while some social policy analysts have regarded direct payments as a form of personalisation that embodies the latter's shortcomings (e.g., Ferguson, 2007), others have insisted on making a distinction between the values and ideologies underpinning the two concepts (e.g., Morris, 2014).

Those wishing to distinguish personalisation from direct payments have regarded the marketisation aspect of personalisation as particularly troublesome (Morris, 2011: 12-13). The reason is that marketisation tends to overemphasise economic efficiency, which often translates into welfare cuts, especially in times of austerity. Furthermore, marketisation routinely crowds out non-market values such as solidarity, erodes collective forms of support, boosts inequality, privatises risk and responsibilises service users. This creates tensions between the principles of marketisation and those of social justice, even in the liberal version of the latter that reduces justice to non-interference and negative liberty (Berlin, 1969). Accordingly, attempts have been made to disengage direct payments from marketisation. To give but one example, Beresford (2009: 4) has argued that the model of direct payments 'was far from being a consumerist model. On the contrary, direct payments were a collectively inspired means of supporting the rights and liberation of service users.'

And yet, the tension between marketisation and social justice seems intrinsic to the principles and practices of direct payments in the same way in which it is intrinsic to personalisation. Thus Pearson (2000: 463) claims that 'the move to direct payments has been justified by market and social justice discourses', and Spandler (2004: 190-1) points out that market consumerism and social justice were two conflicting motivations for direct payments. In the same study, Spandler (2004: 202) also notes that 'it is not clear how far [direct payments] can

cultivate welfare relationships outside and against the trend of market capitalism'. On the basis of such a suspicion, some commentators have regarded direct payments as 'a Trojan horse for the introduction of even greater privatization and penetration of market forces into the welfare state' (Ferguson, 2007: 398).

Furthermore, Mladenov (2012) has shown that in their advocacy for direct payments, prominent disability activists such as Ratzka (2004; 1993) have made recourse to market principles (competition, consumer sovereignty) *in order to* advance the cause of social justice for disabled people. In this regard, Ratzka (1993: n.p.) recounts how in the 1980s in Sweden, Right-wing politicians were more sympathetic to disabled people's demands for direct payments than Left-wing ones:

> The conservative parties who had been propagating 'freedom of choice under own responsibility' for decades embraced [our demands] wholeheartedly. The Social-democratic and Communist parties, both at that time in the government, reacted mainly negatively interpreting the demand for alternative solutions as a right-wing attack on the public sector. The unions, in particular, opposed this 'privatization' move on the grounds that it would put their members right back to the last century where the upper class kept maids and other subordinates for menial and underpaid jobs.

This picture is not clear-cut though, for even in Ratzka's strong version of marketisation discourse, the individualism of the disabled 'customer' in receipt of direct payments is actually underpinned by the collectivism of peer-to-peer training and support (Mladenov, 2012). A number of disability scholars have highlighted this collective aspect of direct payment schemes as a fundamental condition for their proper functioning. For example, Beresford (2009: 4) makes clear that effective direct payments schemes require '[a] network of local

user-controlled organisations, or "centres for independent living", [to be] developed to provide the necessary infrastructure to support people in operating the payments schemes, and to offer a valued source of collective services and good quality personal assistants'. A study conducted by Stainton and Boyce (2004) looked at an 'Independent Living Scheme' jointly funded by two Welsh local authorities, but initiated, developed and managed by a local disabled people's organisation in order to aid people in using their direct payments. The support provided by the scheme included information about direct payments, help with recruiting personal assistants, training on how to be an employer, and a payroll service (Stainton and Boyce, 2004: 445). Most users in Stainton and Boyce's (2004: 447) study regarded this peer support as a crucial factor for the success of the service.

To recapitulate, the tension between the two aspects of personalisation – that of marketisation and that of social justice – has shaped the attitudes towards the concept in the area of disability thought and activism. There have been different strategies for resolving this tension. Left-leaning disability scholars and activists have tried to dissociate the visions and aspirations of the disabled people's movement from marketisation. Instead, they have emphasised the social justice aspect as the authentic motivation and principle of direct payments. However, this strategy has been problematic from the perspective of those social policy analyses that have regarded the contradiction as intrinsic to the mechanism of direct payments. Unlike their colleagues on the Left, Right-leaning disability thinkers and activists have promoted marketisation as the only mechanism that could bring about social justice to disabled users of social services. And yet, the strong individualism of this position has been undermined by an equally strong emphasis on the collective infrastructures of peer support needed to facilitate self-determination. It seems that for both groups peer support (including counselling, advocacy, watchdog, administrative support, and training activities) is absolutely essential for

the genuine personalisation of disability services. From the perspective of the disabled people's movement, the collective dimension is irreducible and provides the foundation for individual independence.

Personalisation and healthcare

As in disability services, personalisation has been deployed within healthcare policy with a significant degree of elasticity, encompassing proposals which range from superficial rebranding to radical restructuring. Personalisation of the NHS has promised to deliver 'patient-led' services which are responsive to the unique (biomedical) needs as well as (subjective) preferences of individuals. For instance, the Darzi review (2008) announced that delivering a personalised, patient-centred NHS meant focusing on both the quality of care and the experiences of patients. Accordingly, a system of Patient Reported Outcome Measures which records patient experiences was introduced across the NHS, extending to the introduction of 'Amazon-style' feedback forms which link institutional funding to patient evaluation of the care they have received. Many healthcare services are now participating in the 'Friends and Family Test', a national scheme whereby feedback information is gathered from patients about whether they would recommend the service to friends and family if they required similar treatment.

Attention to patient experiences has been accompanied by the introduction of greater levels of choice for patients, typically over the 'who, when and where' of healthcare services. For example, allowing patients greater choice over which doctor they see and offering them a more convenient range of appointment times has been described as a means of personalising general practice around the preferences of individual patients. Similarly, the personalisation agenda

contributed to the decision to allow patients to choose which hospital they attend for elective surgery with the publication of data describing hospital performance and patient feedback providing a basis for the patient's selection. Here, the introduction of performance league tables has been billed as a means of stimulating competition expected to drive up standards of care while providing patients with a transparent and flexible service catered to their choices. Although such practices could be seen as contributing to the social justice aspect of personalisation by empowering patients as equal partners in treatment, their main impact consists in advancing the marketisation of healthcare.

A potentially more significant contribution of personalisation towards enhancing social justice can be seen in measures that allow patients greater say over the 'what' of healthcare. Thus, moves towards personalised care plans, shared decision-making, increased patient self-management and the introduction of the Expert Patients Programme have provided patients with far greater opportunity to decide upon and enact the means and ends of their treatment (Department of Health, 2001, 2005, 2007; Donaldson, 2003). Indeed, following the lead of disability services, personal budgets and direct payments have been introduced to many patients suffering long-term and chronic conditions, allowing them to select and purchase their care directly. In practice, this makes personal budgets more focused on the health outcomes achieved through money spent than on the types of goods and services that are purchased. This means restrictions are lifted on what can be funded, as Duffy *et al* (2010: 5) describe:

> Where outcomes are clearly defined upfront the local authority can agree a plan to use public money on things well outside of the traditional service scope, including: Air conditioning for someone with breathing problems; Electric wheelchairs for someone with mobility problems; A caravan for a family needing respite; A holiday for someone with mental health problems.

Personalisation of this sort has far more radical implications for the evolution of practices, roles and values that govern healthcare. As well as introducing a more overtly consumerist model of healthcare interaction in which the professional's role increasingly resembles that of an advisor, gatekeeper and/or facilitator of services, deeper forms of personalisation which encourage patients to take a lead in decision-making have been presented as a means of moving away from traditional top-down, paternalistic care rooted in the biomedical model and assuming deferential patients complying with authoritative health professionals. As within disability services, by providing opportunities for patients to contribute to decision-making processes, personalisation has been seen as enhancing social justice by creating more just forms of healthcare practice which respect and promote patient autonomy (Duffy, 2010; Owens, 2012a). Indeed, Duffy *et al* (2010: 3) emphasise that 'the only valid way of meeting a need is in a way that respects the individual's autonomy'.

While these measures may bring some positive outcomes for patients, the personalisation of healthcare services has not escaped criticism. Firstly, some authors have been suspicious of policies which have professed a desire to foster patient autonomy through the introduction of collaborative and concordant forms of professional-patient interaction. For example, Iona Heath (2003) has expressed concern that personalised healthcare services will retain paternalistic structures of power despite their stated interest in supporting greater patient autonomy. Heath likens 'concordant' professional-patient relationships to a 'wolf in sheep's clothing': While overtly extolling the importance of patient autonomy, Heath claims professionals are likely to employ forms of soft power which aim to get patients to comply with their prescriptions. Similarly, Scambler and Britten (2001) have described how professionals may use concealed strategic action to persuade patients to conform to their

values and agendas. Though it may appear neutral, the content and presentation of information that is given to patients about their therapeutic options – in a policy environment shaped by 'evidence based medicine' – is likely to reflect professional and institutional values and agendas creating a climate in which patients are free to choose as they wish as long as it is in line with what the professional would recommend. These tendencies are reinforced by models of 'personalised medicine' (e.g., Ginsburg and Willard, 2009 – a distinct variant of personalisation in healthcare) that can be seen as an extension and intensification of the biomedical model because of its concern with customising interventions in response to the molecular biology of individuals. Such re-assertions of the biomedical model cannot be read as merely about the distribution of power and control – they also reflect a reluctance to consider patient autonomy as being more important than competing values such as concerns for patient safety, clinical effectiveness and accountability or fair resource allocation.

Secondly, as Owens and Cribb (2013) point out, providing patients with a greater degree of choice over their treatment does not typically mean that they will be able to actually achieve better health in the way that the literature which presents personalisation typically suggests. This is because, in healthcare as in disability services, empowering people to take control of their lives is not simply a matter of coming up with policies which will enable individuals to exercise choice. Rather, creating the conditions for empowerment requires policies that address the wider structural circumstances which enable or constrain personal autonomy. Therefore, attention to the material, socio-economic, cultural and political environments in which patients are situated is key for the empowerment agenda, and it is not clear how the individualising focus of personalisation – that becomes pivotal when personalisation is reduced to a form of marketisation – is able to contribute to addressing such structural issues.

Thirdly, there are concerns that personalisation may diminish the scope and quality of healthcare relationships by introducing market-based norms and practices which may erode qualities like trust and intimacy that have traditionally been particularly important within healthcare settings (Owens, 2012a). While personalisation may be formulated in a way which supports such qualities (for instance, through patients choosing to form or continue within close relationships with the professionals responsible for helping them to plan their care), personalisation's casting of the patient as a 'consumer' who can select the services of healthcare providers risks the commodification of healthcare. Commodification of the professional-patient relationship itself carries with it the danger that care may become reduced from a complex process characterised by empathy and honesty in conditions of vulnerability and uncertainty to a transactional product in which these important qualities become crowded out by demands for efficiency, utility and uniformity. Furthermore, if the relationship between patient and professional is reduced to that of consumer and provider of services, there may be little to stop patients from chopping and changing their provider in search of better results, which may lead to a breakdown in the continuity of care. So, while personalisation may support patient autonomy and may also lead to higher standards of care, there is a risk that it comes with a price of eroding much that is of value within the professional-patient relationship.

Finally, while personalisation may be thought to support social justice by bolstering resistance to medical paternalism, there is some concern about the effect that it may have upon distributive social justice, particularly social inequalities. While some claim that personalisation can serve to create more equal access to choice within healthcare services (Reid, 2003), critics suggest that opportunities to make choices within the NHS are more likely to be taken up by the articulate, sharp-elbowed middle classes who feel more comfortable

asserting their demands than disadvantaged groups. Similar issue is highlighted with regard to direct payments for disabled people (e.g., Spandler, 2004: 195). In the context of healthcare, this concern is supported by a phenomenon known as the 'inverse care law' (Crinson, 2005; Tudor Hart, 1971) which suggests that citizens from lower socio-economic backgrounds use fewer healthcare resources relative to their needs than their more affluent co-citizens. Unless the myriad causes of the inverse care law are addressed, there is a danger that personalisation may actually deepen inequality of access to healthcare in a way that increases inequalities across society.

In summary, the tension between marketisation and social justice characterises the introduction of personalisation in healthcare in ways that echo the analogous contradiction within disability services. In cases when it is effective (rather than just the 'sheep's clothing' covering up the 'wolf' of professional power), the undermining of paternalism through market mechanisms risks disregarding the structures that support individual autonomy, commodifying important norms and relationships, overvaluing economic efficiency, and privileging those who are already empowered. As will be explained in the next section, all this makes personalisation in disability services and healthcare amenable to uses that support the retrenchment of public provision in times of austerity. The limited differences between the two domains can be seen as reflecting their respective policy histories and trajectories, providing subtly different 'centres of gravity' for debate. In particular, there are some stronger 'bottom up' elements in disability services policy – especially around direct payments – and a more visible politicised debate about the contradictions of personalisation, with disability activists and scholars explicitly addressing some of the relevant contests. In addition, the powerful biologically reductionist currents embedded in healthcare through biomedicine seem to systematically circumscribe and frame interpretations and applications of personalisation in

healthcare, whilst prominent debates within disability scholarship and policy are framed by at least an implicit recognition of the importance of non-reductionist and collectivist thinking for genuine personalisation.

Personalisation and austerity

In the aftermath of the financial crisis of 2007-2008, both disability services and healthcare in the UK have been subjected to austerity measures. The reduction of disability services has been epitomised by the closure of the Independent Living Fund (ILF), a public body responsible for providing money directly to disabled people with high-support needs in order to enable them to employ personal assistants (either directly or through an agency). The ILF has been closed to new applicants since December 2010 and, at the time of writing this text, its closure to existing users is scheduled for 30 June 2015 (https://www.gov.uk/government/organisations/independent-living-fund/about). In addition, funds available for disability services at the local level have also declined significantly since 2010, notwithstanding that the number of people in need has increased:

> Local government has faced unprecedented cuts over the last four years that have impacted dramatically on adult social care and its capacity to deliver. The impact is ultimately felt by people who use social care services. (LGA/ADASS, 2014)

Since the end of the 2000s, the move towards personalised disability provision has coincided with this wave of austerity measures, which raises the question about the relationship between personalisation in disability services and the agenda of reducing costs and rolling back of support. As already pointed out, personalisation promises to enhance the economic efficiency of welfare provision by way of marketisation. When left unchecked, this aspect quickly

overshadows the concern for social justice, especially in a situation of ubiquitous pressures to reduce welfare expenses.

While the NHS has been supposedly 'ring-fenced' from austerity savings, rising inflation and a need to implement efficiency savings of 4% year on year has meant that funding has been effectively frozen in real terms. This has happened at a time when further financial pressure is being exerted on the NHS by the twin challenges of an aging population and a changing illness demographic. A number of reports (Barker, 2014; Coulter *et al*, 2013; Department of Health, 2010; NHS England, 2014; Wanless, 2004) find that the proliferation of chronic diseases and long term conditions will require the NHS to meet the expenses of caring for people with multiple long-term health conditions as the population ages, requiring either massive additional funding or radical changes to policy and practice. Whatever the arguments about social justice, a key reason behind the traction that personalisation has gained within the evolution of NHS policy is its potential to disrupt existing policies, practices and expectations in a way which can ease financial burdens. Thus, personalisation within the NHS is viewed as a means of achieving more with less, an opportunity to introduce market efficiencies and, through movements towards self-management practices, to capitalise on an under-used resource, patients themselves. Given these financial constraints, and the NHS's obligation to provide patients with free care to all at the point of use (an obligation which is not shared in the context of disability services) it is difficult to see how personalisation within the NHS could ever be delivered in a way that does not limit patient demands, regardless of however loudly the rhetoric of patient choice and empowerment is broadcast.

A number of recent reports provide evidence in support of the argument that in both disability services and healthcare, personalisation is used to advance an agenda of financial restraint and

austerity. Thus, in her study of personalisation in one local authority in England, West (2013: 643) highlights 'the way in which the Council sought to pass the "new offer" off [i.e., the one advancing austerity] as part of a transformation programme, strongly connoted with personalization as liberation and empowerment and signifying dignity and self-actualization for social care users'. In general, the closure of standardised disability services such as day centres has been justified with the move towards personalisation, while the reforms have actually been motivated by the pressure to reduce public expenditure (Morris, 2014; Roulstone and Morgan, 2009). At that, the language of personalisation has been used to mask austerity as 'improvement', thus providing an 'ideological cover for the most draconian of austerity measures' (West, 2013: 646). A study done by Needham (2011: 64) presents similar concerns: 'There was a sense in the interviews that the popularity of personalization as a policy approach was being used to offer political cover for service changes which were more about cutting budgets than about enhancing choice and control.'

Similarly, the personalisation agenda has been used to justify the changes to the commissioning structure in the NHS within the 2012 Health and Social Care Act. A key reason given for replacing Primary Care Trusts (PCTs) with Clinical Commissioning Groups (CCGs) was that the creation of CCGs would allow General Practitioners – who understand the particular needs and desires of their patients in a way PCT staff do not – to use market mechanisms to create innovative and personalised solutions. As Owens (2012b: 140) states, 'proposed reform of the NHS's commissioning structure, from a centralised model run by primary care trusts to one based on GP-led commissioning groups appears to be in part motivated by a desire to bring the decision-making process closer to patients, allowing them, through dialogue with their physician, greater influence over the way the money is spent'. Accompanied as this was by legislation that opened up the bidding process for NHS contracts

to private healthcare companies, the reforms to commissioning introduced in the 2012 Health and Social Care Act has done more to advance the process of marketisation within the NHS than any other reform in its sixty year history. Given the twin goals of implementing 'top-down' institutional changes and meeting the financial challenges associated with rising long-term and chronic conditions and an aging population, personalisation appears to be more a justification for efficiency savings though market-based policy reform than an effective means of empowering patients to better health.

Besides presenting cuts and the spread of marketisation as policy improvements, there is yet another way in which personalisation facilitates austerity measures. In agreement with the doctrine of neoliberalism, personalisation promotes a reduction of the role of the state in the provision of services (Ferguson, 2007). On the one hand, the external (paternalistic) interference in the lives of the users is to be minimised. Yet on the other hand, the (autonomous) life choices of the users are to be channelled into what is considered responsible behaviour. In the context of austerity, the responsible behaviour is either to take one's 'care' in one's own hands, or to enter the labour market, whatever the disadvantages for the worker. This technology for governing individuals through freedom is characteristic of advanced liberal societies (Rose, 1996). In the aftermath of the social struggles and the rise of neoliberal politics in the 1980s, the power of welfare experts was challenged. Yet instead of (or, in some cases, together with) bringing about more liberty, this brought about new techniques of government. Top-down, expert control was substituted (or, in some cases, merely supplemented) by self-discipline guided by economic imperatives:

> Welfare paternalism – a 'state knows what's best' approach, against which the disabled people's movement campaigned so effectively during the 1980s and 1990s – meant that disabled people were identified as objects of pity and charity. It has now been

replaced by liberal paternalism – where the state aims to 'help people to help themselves' – which applies more malicious stereotypes to people who are not economically productive. (Morris, 2011: 10)

By internalising norms such as productivity, efficiency, self-care and maximisaiton of one's potential, individuals take on themselves the task of regulating their own conduct. According to Rose (1996: 58-9), 'such lifestyle maximization entails a relation to authority in the very moment as it pronounces itself the outcome of free choice'. In accord with this mode of government, personalisation substitutes (external) discipline with (internal) self-discipline that subtly makes people responsible for their own support and/or pushes them into employment under unfavourable conditions. From this perspective, the empowerment of personalisation 'is deployed in such a way as to make the user behave more responsibly, cleaving to a broader neo-liberal agenda' (Needham, 2011: 63). Such a technology of responsibilisation advances the agenda of austerity in the context of healthcare as well, where personalisation encourages 'a culture of greater patient responsibility for their health which it is argued will save money and make the NHS more sustainable' (Owens, 2010: 213). In clinical settings, especially the long-term care for patients with chronic conditions, personalisation's reconstruction of the role of the patient as an active decision-maker and actor capable of self-managing their condition involves a redistribution of responsibility and accountability away from the professionals and towards individual patients. The corollary is the proliferation of victim-blaming narratives which treat ill health as an outcome of irresponsible personal choices.

This brings us to a final point: Personalisation could serve the agenda of austerity by individualising social support and diverting attention from structural problems rooted in 'maldistribution' (Fraser, 2013). Critics of direct payments have pointed out that the focus of

direct payments schemes on individual empowerment discourages engagement with the mechanisms of social oppression (Spandler, 2004: 195). Lyon (2005: 249) has highlighted the risk that 'individual solutions to social exclusion via direct payments could distort the general picture allowing the general public to believe that social exclusion is not a significant problem'. Similar concerns have been raised in the context of healthcare, where it has been argued that 'personalisation concentrates too closely on the promotion of patient choice and not enough on the structures that create the context in which choices must be made' (Owens, 2010: 185). Data from public health research demonstrates that many health problems are caused by the structural circumstances in which people live (Dorling, 2013; Marmot, 2010; Marmot and Wilkinson, 2006). For instance, factors like poverty, poor housing, environmental pollution, poor diet, social isolation play a clear role in the onset of many chronic and long term conditions including asthma, depression, diabetes, hypertension and obesity. While attention to individual decisions and appropriate clinical measures are clearly important for the prevention and alleviation of such conditions, attention to the structural factors that causes them is equally important if people are to be empowered to better health (Owens and Cribb, 2013). As such, it is crucial that individualising agendas do not come to eclipse the structural focus of public health and that institutions oriented towards public health are not simply replaced by market-based policy mechanisms.

Conclusions

The foregoing discussion of personalisation in disability services and healthcare suggests several conclusions that concern the genealogy, the meaning and the politics of the concept.

In terms of genealogy, personalisation was first elaborated in the context of disability services (Needham, 2011: 54-5) and subsequently applied to healthcare. The general discourse of personalisation that emerged in the first half of the 2000s built on and subsumed the more specific discourse of direct payments. Indeed, disabled people have been entitled to direct payments since the adoption of the Community Care (Direct Payments) Act in 1996, while the advocacy for direct payments in the UK dates back to the 1980s (Evans, 2002). Yet whereas the mechanism of direct payments has been developed and promoted in a bottom-up manner by the disabled people's movement, the subsequent elaboration of the principles and policies of personalisation has been associated with top-down policy making and calculations of political expediency. Despite interest in the concept from patients groups and health networks, the relationship between personalisation and the grassroots of healthcare is even less discernible, where it lacks the social base provided by direct payments in disability policy. This engagement has also been suppressed by the (still all too) powerful biomedical model in healthcare. Considering the key role of disabled people's movement in promoting the social justice agenda within disability services, it seems that the disconnectedness between the grassroots and personalisation has made the concept amenable to rhetorical misuses in the service of neoliberal social policy reforms.

This point leads directly to the issue of meaning. In disability services as well as in healthcare, personalisation has incorporated the tension between marketisation and social justice. There have been attempts to reconcile these two aspects of personalisation – some disability scholars/activists have considered marketisation as a prerequisite for achieving social justice for disabled people, while the empowerment of patients as 'consumers' has been promoted by healthcare analysts and policy makers as a major condition for equalising doctor-patient relationships. More broadly, some advocates of personalisation have felt able to argue –

against much previous policy orthodoxy – that greater personal choice can coincide with and help produce greater equity of provision. Yet it has proved difficult to achieve such satisfactory reconciliations in practice. One of the main reasons is that the contradiction runs deeper, cutting through each of the opposing terms. The emancipatory potential of marketisation – its ability to dismantle paternalistic arrangements or to challenge the top-down power of professionals – is in tension with its intrinsic drive towards efficiency. Sometimes, emancipation costs more, not less. Similarly, the redistributive understanding of social justice (linked to a positive conception of liberty) is in tension with its liberal understanding as freedom from interference (linked to a negative conception of liberty). Rather than being resolved or at least addressed, these contradictions have been displaced by the semblance of consensus provided by the prevailing discourse of personalisation. And yet, they have shaped the actual translation of the principles of personalisation into social policy initiatives, creating more problems than solutions in disability services and healthcare.

Finally, in terms of politics, the discourse of personalisation has provided an ideological cover for austerity measures in both social policy domains. Concerns with social justice have been routinely subordinated to structures and processes of marketisation. The witting or unwitting corollary of the market-based undermining of paternalism has included: disregarding the structural dimensions of autonomy, support, exclusion, and ill-health; commodification of processes and relationships of support and healing; crowding out of non-market values such as solidarity, trust and intimacy; and victim-blaming of service users and patients by way of systematic responsibilisation. These adverse effects have been covered up by presenting personalisation as an unequivocal improvement of disability and healthcare services. In reality, personalisation often gets reduced to a means for achieving more with less, which greatly undermines its usefulness for improving social justice. Without throwing the baby of

autonomy out with the bathwater of unchecked marketisation, it is important to critically address personalisation by highlighting the problems that dominant interpretations of it produce in all areas of social policy where it is currently prescribed as a panacea.

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