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What Justice, What Autonomy? The Ethical Constraints Upon

Personalisation

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<u>Abstract</u>

This article considers the ethical dimensions of attempts to 'personalise' health and social care services in the UK. Personalisation is identified as closely related to efforts to introduce elements of neoliberal marketisation into public service provision, particularly through the introduction of consumer choice for services users. We consider two areas of ethical concern surrounding personalisation: its contribution to social justice agendas and the enhancement of service users' autonomy. While personalisation in general, and consumer choice in particular, has been presented as positively contributing to both social justice and autonomy, we critically revaluate these claims. We draw on the work of Nancy Fraser and relational theories of autonomy to highlight the ethical complexities of personalisation and the potentially negative effects that the extension of consumer choice may have on promoting social justice and supporting substantive forms of autonomy. We suggest that understanding and negotiating these complexities imposes ethical constraints on the ways in which, and extent to which, health and social care services can be defensibly personalised.

Introduction

Personalisation is a key idea driving contemporary reform of public services both in the United Kingdom and internationally. Across much of the developed world, including Australia, Canada, the USA, and Europe, the principle that services ought to become more personalised and sensitive to the demands of individual service users has driven innovation within health and social care services (Bonfils and Askheim, 2014; European Commission; Gooding, 2016; Lord and Hutchinson, 2003; Ungerson and Yeandle, 2007). Advocates of personalisation often characterise it not merely as a strategy for creating more efficient, higher quality services but also as a means of achieving ethically important goals (Mladenov et al 2015). Specifically, personalisation is presented as a way of enhancing service users' autonomy and contributing positively to social justice agendas. We examine the ethical credentials of personalisation in this paper, using these same two dimensions of ethical concern to problematise aspects of, and versions of, the personalisation of health and social care services. Whilst accepting that there are many positive features of personalisation, we argue that the ethical impact of personalisation is more complex than is often suggested by its advocates and that these two dimensions should be seen as capable of providing ethical constraints on the advocacy for, and implementation of, personalisation.

Before we begin, it is worth briefly highlighting what we mean by 'ethical constraints', especially as it may not be obvious how or why ethical concerns could place limits on public policy at all. Perhaps the most prominent type of constraints imposed on policy makers seeking to implement reform agendas are economic and political. For instance, budgetary limitations may make the implementation of certain policy aspirations difficult or impossible. Likewise, policy agendas may be stifled by an absence of political will, or from insufficient support from governments, institutions, and/or the stakeholders responsible for enacting the policy.

Similarly, ethical concerns are a salient factor influencing the policy-making process, albeit one that tends to receive relatively less attention. One reason for this is because normative considerations can be seen as already incorporated into political positions. For instance, liberal politics may be taken to inherently presuppose adherence to underlying ethical principles (such as respect for property ownership or certain civil liberties) such that there seems to be no need for separate recourse to ethical considerations. Alternatively, ethical concerns might be relatively neglected where they are considered to be so well-established that there is little need to do any serious thinking in this area. For example, at least in the current political environment within the UK, it is highly unlikely that corporal punishment in schools could be plausibly reintroduced primarily because of pervasive beliefs that it is ethically unacceptable.

There are numerous other clear-cut examples where ethical beliefs are so well-established that they set boundaries that limit the nature and scope of policy agendas. However, there are many occasions where ethical considerations are less 'visible' and thus appear to present less of a constraint to policy-makers. This may be the case where ethical concerns are obscured or marginalized by competing considerations (such as economic or political agendas) or because the ethical issues themselves have received relatively little, or at least selective, attention and are therefore not well understood. In such cases deficits in our understanding do not, of course, indicate that the ethical issues are unimportant; rather significant moral transgressions, harms or injustices may be at stake.

The personalisation of health and social care services in the UK provides an example of a policy agenda where the ethical dimensions of social justice and autonomy are relatively poorly understood; and thus after briefly introducing 'personalisation' in the next section, we aim to contribute to the ethical scrutiny of personalisation policies. Personalisation is often presented, at least within the policy literature, as an unqualified good with positive implications for both social justice and the autonomy of service users (Cribb and Owens 2010; Leadbeater 2004; HM Government 2011, 2014). By contrast, we argue that personalisation, especially when reduced to market-based consumer choice, risks negatively impacting on both social justice agendas and the autonomy of service users. We regard many personalisation policies as intrinsically related to the neoliberal political project of marketisation and seek to show how this

relationship potentially undermines respect for social justice and autonomy concerns. We suggest that proper attention to these issues highlights ethical constraints that alter the nature and scope of the personalisation agenda within health and social care services. We thus see our argument as contributing to the existing scholarship that critiques the neoliberal marketisation of public services (e.g., Ferguson 2007, 2012; Roulstone and Morgan 2009).

Personalisation as an organising principle for health and social care services

'Personalisation' refers to the process of replacing traditional models of centralised, provider-led public services with decentralised, market-based, user-led services (Cribb and Owens 2010). Advocates of personalised public services often present them as 'tailoring' of services so that they are designed to fit (or even designed by) their users according to their own specifications (Needham and Tizard 2010). Personalised services are thus contrasted with old-style 'one size fits all' services, where users have to passively take what is on offer (HM Government 2014). In contrast to old fashioned 'top-down' models of service delivery, personalised public services are organised and delivered from the 'bottom-up' in order to meet the specific needs, desires and expectations of individuals (Leadbeater 2004; Mladenov et al 2015).

Granting users greater choice over services has been a key means of promoting personalisation. The centrality of choice to the reform agenda was spelt out explicitly in the Coalition government's *Open Public Services* white paper:

> 'Wherever possible, people should have the power of choice about what services they receive... Choice is about empowering people. And just as importantly, it's a crucial lever in improving the quality of public service delivery, incentivising providers to deliver the services that people want and choose for themselves and their families. Choice also recognises that people's needs don't come in neat bundles. Whether we are talking about an older person with dementia or a child in one of the most socio-economically disadvantaged families in the country, individuals have complex sets of needs which inflexible, one-size-fits-all public services cannot meet'. (HM Government 2011: 1)

This quotation captures much of which is thought to be valuable about personalisation: it is a means of improving quality and (by implication) efficiency, creating services that are more sensitive to users' needs, circumstances and expectations, and empowering users by granting them more control.

Personalisation has been applied across a wide variety of service areas, from health and social care and beyond to employment, education and rehabilitation (HM Government 2011: 8). As such, personalisation is an elastic term, capable of bearing a number of different meanings and strategies (Cribb and Owens 2010; Needham 2011; West 2013). It provides an agenda that can be realised in more or less radical terms, ranging from granting service users greater flexibility and convenience in accessing services to more 'disruptive' changes that redistribute funds and resources directly to service users (Leadbeater 2004). For example, since the mid 2000s, outpatients requiring care have had the opportunity to choose which hospital they are referred to by their GP. This was extended through the introduction of the NHS's *Choose and Book* service across a range of NHS services (Muir and Quilter-Pinner 2015: 13-14), including the ability for patients accessing General Practitioner services to register outside of their traditional boundary areas. Likewise, in mental health services and elective surgery, patients now have the chance to choose who provides their care, as well as its time and location. More radically, in England and Wales, personalisation has prompted the introduction of 'personal budgets' to those entitled to health and social care services (Leadbeater 2004; McDonald 2014; Muir and Quilter-Pinner 2015; NHS England 2014). Personal budgets involve transferring funds to those entitled to care, in some cases via a 'direct' payment to the beneficiary. Recipients can then use these funds to design their own service packages or purchase the services they require directly. Personal budgets thus enable service users to choose not just the time, place and provider of their services,

but also to have greater influence over the aims, means and substantive contents of services too.[1]

As well as being a means of lowering costs and increasing efficiency, personalisation has also been presented as a way of attending to ethical concerns within the care services. For instance, it has been suggested that providing greater choice is a means of putting service users in control of their care (Duffy et al 2010; Mladenov et al 2015; Muir and Quilter-Pinner 2015). Consequently, personalisation has been billed as a means of moving beyond the paternalistic practices associated with the traditional 'top-down' service model and empowering service users by putting them in decision-making roles (McDonald 2014). Advocates of personalisation have thus been able to claim that part of the value of personalisation is its potential to enhance both social justice and service users' autonomy. In what follows we will analyse the ethical credentials of personalisation in more detail, looking at its potential impact first on social justice and then on the autonomy of service users. In so doing we will also begin to open up the relationships between these two dimensions of ethical concern and to follow up and fill out our suggestion that these ethical considerations should provide constraints on the personalisation of health and social care services.

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[1] When discussing personal budgets in the UK context it is important to remember that although healthcare is free-at-the-point-of-use, social care is not. This difference is significant because users of healthcare services know that the NHS *will* pay for their care, while social care users are used to contributing themselves, both in financial terms, and perhaps also in terms of decision-making. A personal budget thus provides healthcare users with choice where previously it was absent, while social care users are granted some peace of mind that they know what their local authority will pay for concerning at least part of their care needs.

Personalisation, marketisation and social justice

The argument that personalisation should be normatively assessed with reference to its impact on social justice has been made by a variety of academics, critics and campaigners (Duffy 2010; Ferguson, 2012). Iain Ferguson (2012: 57) argues that the theory of justice elaborated by Nancy Fraser provides a strong theoretical basis for the normative evaluation of personalisation. We follow him in using Fraser's (1995, 1996, 2013) theory of justice to examine questions concerning personalisation and its impact on economic redistribution and cultural recognition.

According to Fraser's initial formulation (1995; 1996), social justice ought to be understood in relation to both economic and cultural mechanisms rather than being reduced to one or the other. Fraser later (2013) added a third dimension to her initially two-dimensional conception of justice – political representation. The confines of the present discussion do not allow us to expand on the intersection between personalisation and participation in democratic deliberation, although we acknowledge its theoretical and practical significance in at least two major respects – first, concerning the content of personalisation reforms, where specific 'personalisation technologies' (Duffy 2011) have emerged out of collective struggles of service users for inclusion in decision-making and where user-led organising has always been an

essential condition for the successful personalisation of services (see

Mladenov 2012); and second, concerning the implementation of

personalisation reforms, where democratic deficits have been reported as

jeopardising the whole process (Beresford 2009). Fraser (2005) distinguishes

three levels of political injustice or 'misrepresentation': (i) ordinary-political

misrepresentation – when members of a political community are denied full

participation in deliberation and decision-making concerning policies of

redistribution and recognition that affect them; (ii) misframing – when affected

people are denied membership in the political community that deliberates and

makes decisions about redistribution and recognition; and (iii) meta-political

misrepresentation – when affected people are excluded from processes of

frame-setting, i.e., from deliberation and decision-making that determines the

criteria for political membership. Beresford (2009: 2) has observed that

'service users and their organisations generally feel they have had little say in

[personalisation's] shaping or development', and that 'face-to-face

practitioners… are at best anxious about "personalisation", and at worst see it

as another top-down policy to restrict their practice and independence'. These

observations link personalisation to ordinary-political misrepresentation

because those most affected by the reform (i.e., service users and

practitioners providing services) have been denied full participation or

effective 'voice' in deliberations and decision-making concerning

personalisation policy. With this preliminary consideration in mind, we now

turn towards Fraser's originally 'bivalent' theory of justice in order to apply it to

personalisation.

As suggested above, developing an understanding of the 'real world' impact that personalisation has for social justice will require a closer look at neoliberal processes of marketisation of public provision and the general 'rolling back' of the welfare state. In addition, the context of post-2008 austerity has created an increasingly pressing need to consider distributive issues when evaluating strategies for public sector reform.

From the perspective of redistribution, Fraser suggests that socioeconomic mechanisms that (re)produce exploitation, economic marginalisation and material deprivation are socially unjust (Fraser 1996: 7). Accordingly, social justice requires economic equality and demands measures that span from surface-level, affirmative interventions (for example, actions which improve pay and benefits), to deep-level, transformative interventions across society (for example, actions that alter the relations of production or the division of labour). Reforms of welfare programmes, although usually regarded as affirmative rather than transformative, may also be effective in the second, more profound sense. For example, Fraser (Fraser and Honneth 2003: 78) considers Unconditional Basic Income as a social security scheme that could potentially have far-reaching structural effects, including shifts in the 'balance of power between capital and labor' and decommodification of labour. As we will see, similar considerations apply to personalisation, where a reform of the principles of allocation of public funding for social support is summoned to alter the balance of power between service users and providers.

From the perspective of recognition, Fraser suggests that social injustice is generated by cultural mechanisms that (re)produce forms of cultural domination, non-recognition and disrespect (1996: 7). Accordingly, social justice requires status equality that could be pursued by interventions on different levels – from upward revaluation of previously disparaged or disregarded differences, through recognition of erased or undermined commonalities, to deconstruction of the key terms in which differences are articulated. Within her conceptualisation of social justice Fraser proposes a 'status model' of recognition, according to which misrecognition is understood as a cause of injustice insofar as it impairs the social standing of people and prevents them from participating fully in public life. This consideration suggests that in our assessment of personalisation's impact on social justice we should focus on its impact on people's status as participants in social life.

Fraser's two-dimensional framework implies that personalisation's potential for contributing towards social justice depends on its ability to bring together redistribution and recognition in ways that, first, guarantee the economic resources needed by service users for equal participation in social life (thus satisfying concerns about redistribution), and second, institutionalise patterns of cultural interpretation that equalise the status of service users in social interaction (thus satisfying the principle of recognition).

Historically, public services characteristic of the welfare-state capitalism of the 1950s and 1960s failed to secure the autonomy of the users due to their failure to wed redistribution with recognition. Here we see the way in which a concern to address social justice can coincide with a concern to promote service users' autonomy. In the UK at least, enhanced redistribution ensured that people gained improved access to healthcare, social care, social security, and education. Yet public services were organised and provided in such ways that deprived their users of 'voice' and undermined their status: although widely accessible, 'one size fits all' solutions (e.g., residential institutions for social care) dominated by over-powerful experts (e.g., medical professionals) created deficits in terms of service users' autonomy (Evans 2002; Morris 2011).

It was in response to such restrictions of autonomy and voice that social movements such as the Independent Living movement emerged in the 1970s (Evans 2002). Independent Living advocates demanded a greater say in the care they received, campaigning for the deinstitutionalisation of public services through mechanisms such as direct payments that work by transferring funds directly to the users in order to enable them to have full control over their assistance. Direct payments schemes have been regarded as bringing about empowerment and emancipation to their recipients because through them disabled people become 'employers/contractors' (Stainton and Boice 2004: 443) who either directly recruit, hire and manage their personal assistants or do so through the mediation of independent service providers

(agencies). Prominent campaigners have argued that the mechanism is supposed to create a market where providers and other support structures compete among themselves in order to attract the users who now sovereignly wield the purchasing power (Ratzka 2004).

Direct payments have been a key member of a family of innovative mechanisms for enhancing users' autonomy that emerged more or less simultaneously and included peer support, individual/personal budgets, person-centred planning, supported employment and supported living (Duffy 2011). These mechanisms were subsumed in the 2000s under the general heading of 'personalisation' (Leadbeater 2004; Duffy 2010, 2011). Personalisation was thus able to be presented as an overarching strategy for providing autonomy that had been denied to services users by the institutions of the welfare state. As Duffy describes:

> 'personalisation is the fruit of the long-standing effort of disabled people, and many other excluded groups, together with their allies, to achieve social justice from within a broken welfare system' (2011: 11).

We suggest that the scope for personalisation reform to undermine economic redistribution has been covered up by the emphasis it places on a consumerist version of recognition. Our argument hinges on understanding the place of personalisation within wider agenda to reform the welfare state in

line with the neoliberal processes of radical marketisation and the 'rolling back'

of the state. In a previous paper (Mladenov et al 2015) we regarded

personalisation as encompassing two aspects – marketisation and social

justice, and characterised the former as tending to overshadow the latter,

especially in the context of post-2008 austerity in the UK. We argued that the

ways in which personalisation seeks to undermine paternalism by recruiting

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'

(Mladenov et al 2015: 11). In the remainder of this section, we elaborate on

these claims by using Fraser's bivalent theory of social justice to consider the

extent to which an overemphasis on consumerist recognition masks the

potential of personalisation reforms to undermine redistribution.

Personalisation might be thought to contribute to both dimensions if it is taken

to be concerned with improving the extant mechanisms of redistribution *in*

order to redress misrecognition. In its 'deep' forms (Leadbeater 2004)

epitomised by direct payments and personal budgets, the strategy amounts to

redirecting public funds from institutionalised care to user-led support that is

expected to enhance the autonomy of users and their status within

interactions with services providers and professionals by providing the users

with the prospect of exercising greater influence in decision-making processes.

Providing service users with more opportunities for 'choice and control' over

processes of procurement, delivery and evaluation, including over the content

of services, creates possibilities for service users to participate as peers in the

wider cultural and economic life of their communities as well. For example, by

providing disabled people with control over the nature and timing of their

personal assistance, direct payments enable users to (re)engage in gainful

employment, which could alleviate their economic marginalisation and

decrease their material deprivation, redressing two of the instances of

maldistribution highlighted by Fraser (1996: 7).

However, a more detailed analysis of the wider context in which

personalisation is implemented reveals problems with regards to distributive

justice. Currently in the UK, the allocation of personalised funding for social

support through personal budgets (that could then be taken either as direct

payments or as services in kind) is determined through a process that utilises

a combination of preliminary 'upfront allocation' and subsequent actual

allocation achieved through needs assessment and support planning

(Slasberg, Beresford and Schofield 2012). The idea is that potential users will

be in a better position to articulate and negotiate their needs during the

support planning if they know in advance, through an indicative upfront

allocation, how much money they will get for covering their social support

expenses. Yet critics have argued that the indicative component of the

process is redundant and misleading because in majority of the cases, the

actual budgets are significantly smaller than the indicative ones (Slasberg,

Beresford and Schofield 2012, 2013). In addition, the system for upfront

allocation, being extremely complex and bureaucratised, tends to

disempowers users (Slasberg, Beresford and Schofield 2012, 2013). In 2012, Simon Duffy, the chief architect and promoter of this mechanism, issued a public apology in which he described the extant system as a 'disaster area', noting that the problems brought about by it were 'further accelerated in 2010, as the new government imposed its 25% cut on social care, and as authorities began to use any tool possible to make these unfair cuts' (Duffy 2012: n.p.). In this way, personalisation can be viewed as an effective means of masking the realities of the diminishing allocation of resources being directed towards users of health and social care services.

As far as recognition is concerned, personalisation promises to enhance the status of service users as equal partners in social interaction by valorising the users' perspectives that have traditionally been submerged under the perspectives of welfare experts. And yet, personalisation's upward revaluation of users' perspectives is not straightforward, and it seems unlikely that its complexity can be fully accounted for within the narrow discourse of consumerism – the emphasis on turning service users into consumers of services whose preferences can then be satisfied through market transactions tends to promote a limited version of recognition. For example, simply granting a person with one or more long-term chronic health conditions greater choice over who provides the clinical support she is entitled to would, on its own, appear to do very little to actually recognise her perspective on her illness or to properly respect her beliefs about what form the treatment ought to take. As Mol (2008) suggests, a more substantive engagement with

patients' beliefs and values requires the development of longstanding, caring relationships between patients and professionals, a measure that the imposition of market mechanisms promoting consumer choice can impede (see also Owens 2012).

Without additional provision of peer support, personalisation tends to favour people who already enjoy relatively high social standing due to their privileged positions along intersecting axes of difference including class, gender and ethnicity. In healthcare, the 'inverse care law' (Tudor Hart 1971) suggests that the patients with least resources are likely to benefit least from personalised provision (Mladenov et al 2015: 11; Boyle 2013). Similarly, in disability policy, the advantages offered by direct payments and personal budgets have been more readily available to the more educated and articulate middle-class users (Slasberg et al 2013: 101; Ferguson 2007: 398). As Beresford has suggested (Beresford and Stansfield 2013), such inequalities present a challenge to government to provide additional redistributive mechanisms necessary for ensuring the level of peer and other additional support required by the users of personalised services for successful equalisation of their status in social interaction.

Concerns about potentially negative implications for social justice should constrain the scope and course of personalisation reforms. Advocates of personalisation must be ready to measure their hopes against both broadly based theoretical accounts of social justice and challenges arising from the

operationalisation of conceptions of justice in practical contexts, given that the latter are frequently shaped by other values and imperatives. At least they must be able to respond to the twin challenges of economic redistribution and cultural recognition: To address the distributive dimension of justice, personalisation must support (rather than undermine) a wider vision of, and strategy for, redressing maldistribution. Similarly, to address cultural injustice, mechanisms of support that exceed the narrow understanding of autonomy as 'consumer choice' are needed. We shall develop this argument about the limits and burdens of choice further in the next section which focuses expressly on the autonomy and empowerment of service users.

Personalisation, autonomy and empowerment

Concerns about the contribution of personalisation to social justice are closely related to overlapping questions about its potentially negative impact on the autonomy of service users. As with social justice it is important to recognise that 'autonomy' can be approached through different conceptions and with emphases placed on different facets; for example, as we will shortly come on to illustrate, an important distinction can be drawn between autonomy in relation to decisions and autonomy in relation to action more broadly construed. A core consideration here is the way in which autonomy is frequently narrowly constructed within the literature as being constituted by extended opportunities for individual services users to exercise 'choice and

voice' (Mladenov et al 2015).[2] This is well illustrated by McDonald's

characterisation of the autonomous users of personalised healthcare services

as having the means to 'influence and control decisions that affect them' and

of empowered patients as having their 'views heard, through the choices they

make and the feedback they give' (2014: 12-13). We are concerned that the

pervasive ideas and influences of neoliberalism – particularly its core

commitment to promoting forms of market-based choice for individuals – have

led to a hollowing out of autonomy and empowerment within policy discourses

and practices of personalisation in ways that may limit the potential for service

users to actually achieve valuable goals.

We should make clear at this point that we agree that additional recognition

and respect for the choice and voice of service users does have the potential

to deliver significant benefits. This will be particularly true where

personalisation enables service users to gain the sort of status-enhancing

recognition outlined above with reference to Fraser's theory of social justice.

However, we question the extent to which the mechanisms of feedback and

consumer choice can actually deliver meaningful and substantive forms of

autonomy. Here we have in mind two broad areas of concern – first, the

concern that implementing 'more (consumer) choice' as a means of promoting

autonomy carries risks as well as benefits; and second, the concern that this

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[2] The characterisation of 'choice and voice' in much of the policy literature is based upon a consumerist motif that either explicitly refers to or implies an atomistic, self-maximising and calculative behaviour on the part of individual services users. This formulation bears little resemblance to more profound, collectively sustained forms of 'choice and voice' that have been envisioned by the campaigners for user autonomy (for example, within the disabled people's movement) in their critique of old-style welfare-state institutions (see Roulstone and Morgan 2009).

conception of autonomy is inherently limited in ethically important respects. We will discuss each of these in turn.

Firstly, consideration of personal budgets highlights some potential problems with providing service users with greater consumer choice. Framing autonomy in terms of health and/or social care service users managing a personal budget will not be appropriate if people either do not wish to take up a personal budget, or if they lack the additional support (e.g. peer support) needed to effectively cope with the demands of managing a personal budget. Though personal budgets are presented as optional, many service users may feel that there is an expectation that they take this option. This may result in 'enforced individualism' as a substitute for the 'enforced collectivity' of traditional provision (Lloyd, 2010; Roulstone and Morgan 2009). For example, service users may feel pressured to accept a personal budget if, whether in conversation with service providers or through exposure to the policy literature, they detect an inherent normative presumption in favour of personal budgets and against traditional methods. In many contexts, it may be hard to resist the presumption that services users *ought* to be engaged in the processes of planning, procuring and evaluating their care because they *will* be empowered if they do so. This pressure may be compounded if services users feel that by not accepting a personal budget they would be failing to meet the conduct and expectations required of an 'empowered' and 'autonomous' service user.

Should service users take up a personal budget where this is against their wishes any associated gains to their autonomy will be accompanied by the added anxieties it generates. This burden may be faced more generally by all recipients of personal budgets who are made responsible for planning and procuring their care and managing the entailed financial and legal obligations. As Schwartz (2005) argues, choosing is frequently accompanied by considerable anxieties, and it is often the case that living with the consequences of our choices means facing an added burden of responsibility, especially if users feel they have been 'abandoned' to their choice by those who formerly provided their care (Calne et al 2009; Loewy 2005: 445). While many services users may be happy to live with these extra responsibilities, it should not be assumed that providing opportunities for service users to make choices and engage in decision-making processes can be delivered without potential sacrifices. Risk of harm may be particularly acute for service users who either decide not to take up a personal budget or lack the additional support to do so if their only alternative is to accept top-down and paternalistic forms of care. As Marion Barnes notes, '"Care and protection" is the booby prize if people can't exercise "choice and control"' (2011: 160). This proposition grows increasingly alarming if a combination of market-based competition and austerity leads to a significant reduction in available care services.[3] In such cases there is a danger that constructing the autonomous and empowered service user as the manager of a personal budget will

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[3] One consequence of introducing a competitive market model that diverts funding directly to service users is that more or less 'traditional' health and social care services may face reduction or closure if they prove 'unpopular' with holders of personal budgets and in times of austerity such services may not be replaced by alternative forms of support.

exclude those who either cannot or will not take on this role, and in so doing

fail to respect and respond to other forms of autonomous expression.

Secondly, we question the extent to which providing individuals with greater

consumer choice and voice actually delivers autonomy in a meaningful sense.

This argument is based on two concerns: i) personalisation is often

accompanied by measures that seek to influence service users' choices; ii)

providing service users with market-based choice is not sufficient for

delivering autonomy and empowering people in the way that is suggested

within the literature which promotes personalisation.

To take the former point, the personalisation agenda has often been

accompanied by the introduction of measures that seek to bring service users'

decisions into line with the agendas of policy makers and services providers.

While personalisation has generally sought to replace policies and practices

which exert 'hard power' directly on service users with measures that

encourage them to engage in decision-making, this has been accompanied by

an increasing use of what Joseph Nye has described as 'soft co-optive' forms

of power (1990: 167). For instance, public health strategy in the UK has

recently shifted away from enacting structural, top-down strategies in favour of

strategies that seek to promote healthier decision-making amongst the public

through encouraging us to make healthier choices and adopt forms of

behaviour change. In 2010 the *Behavioural Insights Team* was set up by the

UK government in order to find ways of 'enabling people to make better

choices for themselves and society' (HM Government 2011: 9). At the same time we have seen the emergence of 'nudge' strategies that involve creating environmental conditions that seek to influence the decisions that people make (Thaler and Sunstein 2008). So-called 'choice architecture' approaches supply policy-makers and service providers with a covert means of 'nudging' service users into making choices that align with their own agendas. Using behavioural psychology with the precise intent of shaping the choices and decisions of service users undermines claims that providing greater choice is a means of respecting service users' autonomy and delivering genuine empowerment.

The latter point is based on more fundamental doubts that introducing greater choice and voice will actually put services users in the position of autonomy in the way that is often suggested. The rhetoric promoting personalisation derives much of its moral and political appeal from the suggestion that providing services users with choices will grant them the freedom to *act* and *achieve* valuable outcomes. Yet, however valuable the choices offered to service users may be, providing users with opportunities to engage in evaluation and decision-making does not necessarily mean that service users will be in a position to *act on* these decisions and *achieve* the object of their choices.[4] For example, taking up a personal budget for social care needs may enable a person to choose who provides their care services as well as the

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[4] This argument is based on a distinction that can be drawn between the capacity for autonomous *deliberation* and the capacity for autonomous *action*, a distinction that is routinely ignored by those who suggest that greater choice will deliver substantive autonomy to service users (see Owens and Cribb 2013).

goals that these services are directed towards, but they may remain incapable of not only actually achieving these goals but also of meaningfully pursuing them because of circumstantial factors which fall outside the scope of their choice-making. This may be especially true of services users who occupy positions of significant material, socio-cultural, political and/or economic disadvantage.

This argument amounts to the claim that advocates of personalisation need to understand autonomy in *relational* terms. Relational theorists describe a person's freedom to deliberate and act as partially dependent on the myriad material and social relationships in which they are situated (Clifford 2013; Mackenzie and Stoljar 2000; Owens and Cribb 2013). Before concluding we can briefly sketch two illustrative examples of the way in which a relational understanding of autonomy is important for understanding personalisation. These indicate, in a way that both interlinks with and parallels the points made about social justice, the broad base of normative considerations which are relevant to evaluating the impacts of personalisation and, more substantively, the wider social conditions that need to be in place if policies are to actually, and not just rhetorically, serve the ends of social justice and personal autonomy.

First, even with personalised support, most disabled people would still be employed in low-paying, precarious jobs in the absence of high-paying and secure employment opportunities and 'reasonable accommodation'

arrangements for disabled employees (on the employment problems experienced by disabled people under conditions of contemporary capitalism see Russell, 2002). This highlights the limitations of approaches to autonomy that focus narrowly on providing individuals with choice and ignore the wider structural circumstances in which individuals make choices (Owens and Cribb, 2013). We suggest that if personalisation is to genuinely enable services users to *act* on their decisions and *achieve* their goals it needs to be integrated into broader strategies for reforming the structural conditions in which service users are positioned (in the case of disability this could include reforms to the labour market, the accessibility of public infrastructure, socio-cultural attitudes towards disability, the presence of supportive personal and professional relationships, etc.). This critique is particularly important given the propensity for reforms based on personalisation to allow concerns with the private to eclipse the public, reducing or even closing the services, facilities and public institutions that support and maintain permissive structural conditions across society. Moreover, it is doubly important in times of austerity, when cuts in public services threaten to reduce personalisation to a cost-saving instrument that legitimises maldistribution instead of redressing it (Ferguson 2012; Needham 2011).

Secondly, it is also important to recognise the impact that specific practices of personalisation may have on the relationships and interactions between service providers and service users, including the potential for negative, as well as positive, effects on the autonomy of both groups. In many instances

the opportunities open to service users to decide and act freely will depend on the breadth of possibilities that service providers themselves have to decide and act. Service providers clearly have to adapt to new roles and relationships to fully embrace and enact personalisation, but they are themselves positioned within structural conditions that shape the possibilities of adaptation and personalisation. Regimes of increasing managerialism and ever tighter auditing and accountability frameworks which have accompanied the personalisation agenda have squeezed the autonomy of health and social care professionals, affecting their practice and the freedom they have to interact with patients (Clarke and Newman 1997; Cribb 2008; Department of Health 2008). In this context the welcome recognition of, and respect for, the expertise and judgment of patients has the potential to further limit the potentially open-ended caring and advising roles of healthcare professionals, replacing them with needlessly circumscribed roles directed towards managing care-plans, acting as a gate-keeper of resources and/or a facilitator of patients choices (Glendinning et al, 2015; Mladenov et al 2015; Mol 2008; Owens 2012). If, for instance, GPs feel less able to freely interact with their patients because they are required to meet a set of performance indicators and work towards a specified set of outcomes, or because they work in a normative climate that equates all expressions of opinion, however supportive or skilfully accomplished, with an imposition of values on patients, this may end up restricting the quality and freedom of clinical relationships. If personalisation is to be realised in practice the autonomy of service providers may sometimes need to be moderated to enable greater autonomy for service

users; but there need be no assumption that autonomy gains for users must equate to autonomy losses for providers. Indeed the benefits that personalisation can bring to service users will depend upon addressing and supporting the relational autonomy of both users and providers.

<u>Conclusion</u>

Personalisation has the potential to deliver significant benefits to users of health and social care services, but in this paper we have argued that the ethics of personalisation is more complicated than it is often suggested. Whilst advocates of personalisation are right to place emphasis on the promotion of social justice and service user autonomy as ethically relevant considerations, we have suggested that these considerations point in more than one direction. These complexities arise, as we have shown, both because of the need to theoretically 'unpack' the values of social justice and autonomy into different conceptions and aspects, and because of the move from an abstract 'in principle' defence of personalisation to a real world enactment of personalisation policies that often assume marketised and consumerist forms. We argue that understanding and negotiating these complexities imposes ethical constraints on the ways and extent to which health and social care services can be defensibly personalised.

Further research that illuminates the ethical impact of personalisation for users and providers of public services is needed, especially as more radical forms of personalisation are introduced and as the spending constraints of austerity cut deeper. We suggest that Nancy Fraser's approach to social justice is an invaluable tool for such research, providing a platform for considering the impact of personalisation on economic distribution and cultural recognition across society and the potential effects in terms of inequality and disadvantage. Likewise, relational approaches to autonomy, which help to highlight the gulf between shallow choice-making options and the underlying social conditions needed for autonomous action, will be invaluable for generating critical understanding of the various positive and negative implications that personalisation has for the autonomy of service users. These perspectives, and the ethical challenges they reveal, provide an opportunity to cut through the rhetoric surrounding personalisation and to motivate both more theoretically informed and more grounded evaluations of the potential benefits and harms of the proposed reforms.

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