

Social care, personalisation and service users: addressing the ambiguities

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Abstract

This article explores current moves to 'personalisation' in English adult social care. It sets out the government commitment to 'transform' social care, focusing on the contrasting perceptions of reform between policymakers, service users and service workers. While personalisation and 'self-directed support' have been advanced as progressive ways to reform social care, strong suspicions and concerns about it continue to exist among the stakeholders most crucially involved: service users, practitioners and carers.

In the light of the recent publication of a Government Green Paper on the future funding of adult social care, this article explores the relationship between funding proposals and the progressive and regressive potential of social care reform. It explores two key questions. Will social care be equipped to throw off its Poor Law inheritance to provide a needs and rights based service, and are proposals likely to provide the basis for reducing the current gap between the aspirations and claims of policymakers and the lived experience of the large and growing numbers of people requiring support from social care and related policy and services.

Keywords: Transformation, personalisation, self-directed support, social care Green Paper, service users, practitioners, ambiguity

The commitment to transform

In 2007, David Behan, the Department of Health's Director General of Social Care, at a national conference bringing together policymakers and service users, spelled out the Government's plans for the future of adult social care. He said:

The current system of social care needs to be transformed, to a new set of arrangements. This is what we are setting out in our vision. It is a transformation in the way that services are commissioned, developed and delivered. This needs to be based on services being 'personalised' around individual needs, so they are tailored to people's particular circumstances and requirements. (Beresford & Hasler, 2009, p.45)

This vision was officially announced that same year in a short document published by the Government, which it called a 'concordat' and which others have since called a 'manifesto', *Putting People First* (HM Government, 2007; Glasby & Littlechild, 2009, p.82). This document was signed by six Government departments and a series of national health, social care and local government organisations (significantly, for a document concerned with user-centred support, this did not include any service user organisations). Transformation was again the word used in this document, which talked of a "shared vision and commitment to the transformation of adult social care" (HM Government, 2007, p.2).

'Transformation' is a very big and perhaps risky word to use in public policy. And yet

social care had already been the subject of a number of other such initiatives with transformative intent. The first of these was probably the establishment of local authority 'social services departments' in 1971. This was followed by a movement to switch to localised 'patch' or community social work in the mid 1980s (Beresford & Croft, 1986). This was then followed by the move to 'community care' in the early 1990s following the passing of the 1990 *NHS and Community Care Act* (Means *et al.*, 2008).

What is interesting, however, is that while each of these developments had major effects on social care thinking, structures, roles and organisations, it is questionable how much each actually improved the general experience of service users. A constant theme that comes out of consultations and research with service users is how similar their experience of social care has been over the years, regardless of reforms and reorganisations. This experience is usually presented in terms of their reliance on insufficient, unreliable, sometimes inappropriate and often poor quality services. They are more likely to talk of increasing cuts over the years, rather than improving performance (Harding & Beresford, 1996; Beresford *et al.*, 2005; Branfield *et al.*, 2005; Beresford, 2007a&b). Thus, the question that hangs over any new development in social care, however ambitious its transformative intent, must be whether it actually improves the lives and support of service users, their families and friends.

In July 2009, after numerous delays, the Government published its much heralded Green Paper on the future of social care funding, *Shaping The Future Of Care Together* (DH, 2009) - to which we shall be returning. This highlighted a quotation from a UK academic, which, implicitly arguing for reform, said:

We have a 1940 system [of social care] with 1940s aspirations and assumptions that we are trying to work with in the early twenty first century. (DH, 2009, p.34)

This is an interesting observation. Even if we put to one side for the moment the fact that the 1990 community care reforms marked a radical shift in ideology to the new political right, the market and consumerism, this comment still confuses more than it enlightens. It suggests that social care has remained stuck in the founding ideas and conditions associated with the creation of the welfare state. Yet, as the Green Paper itself observes elsewhere (p.32) and has been powerfully argued by Andrew Cozens President of the Association of Directors of Social Services (Cozens, 2003), social care in England is much more a child of the Victorian Poor Law, than of the UK welfare state reforms. It is the one area of social policy in the UK that remained largely unaffected and unchanged by the new welfare state culture and legislation associated with the first post-war Labour government. Social care was one service that was not fundamentally reformed by the creation of the welfare state. It remained with local authorities as a residual rather than universalist service (Means *et al.*, 2008). While the NHS was established as a universalist service, free at the point of delivery, social care continued to be a particularist provision which was means and needs tested, without universalist entitlement. This raises a second question; to what extent is the Green Paper likely to help social care throw off its Poor Law inheritance and, in that sense, truly transform it as a policy and service?

An ambitious vision

This brings us back to the Government concordat, *Putting People First*. Its proposals were far-reaching and offered a strong scent of universalism. They included:

- Personal budgets for everyone eligible for publicly funded adult social care support other than in circumstances where people require emergency access to provision;
- Direct payments utilised by increasing numbers of people;
- A universal information, advice and advocacy service for people needing services and their carers irrespective of their eligibility for public funding;
- Person-centred planning and self-directed support to become mainstream and define individually tailored support packages (HM Government, 2007, pp.3-4).

This clearly could be seen as a radical agenda. It was also an agenda which, unusually for social care, was commanding visibility and high-level political interest. Social care, more used to seeing itself as a Cinderella who never went to the ball, began 2008 with media headlines and a sense evident among its leaders that this was going to be their year. There was an upbeat, 'empowered' mood among senior civil servants. A minister, Ivan Lewis, was in place, who was commanding cabinet and indeed prime ministerial interest in, and enthusiasm for, social care.

Yet already as 2008 unfolded, the picture could be seen to be changing. Government plans for reform were themselves now taking a different turn. Where these had originally been framed in terms of a massive move to self-directed support through individual or personal budgets, now they began to be presented more vaguely as a move to reshape social care through personalisation. While this word had already been used by Government, it had tended to be equated with individual or personal budgets. Now the talk was in more general terms of customising support and tailoring it to meet individual needs. A more detailed circular followed *Putting People First* focusing on implementation and support, but now the emphasis was on

personalisation rather than personal budgets and the two were now clearly not synonymous (HM Government, 2007). As Jon Glasby and Rosemary Littlechild have written:

Increasingly, recent reforms have been described in terms of a 'personalisation agenda'... used to describe an overall approach in which 'every person across the spectrum of need [has] choice and control over the shape of his or her support, in the most appropriate setting' (DH 2008, p.2) While on one hand this seems a reasonable shorthand for a more complex and important series of changes, it arguably lacks much of the clarity and practical focus of In Control's notion of self-directed support (Glasby & Littlechild, 2009, p.83).

By then the social care minister had also been replaced for extraneous reasons, reinforcing the tendency in this field, adding to its difficulties and insecurities, for ministers to be of relatively low status and short duration.

This circular also confirmed the Government's enormously increased commitment to, and investment in, personalisation. It allocated more than half a billion pounds – an unprecedented sum in the usually cash-strapped world of social care – to fund a three-year programme for the transformation of social care. The Government had earlier commissioned an independent university-based evaluation of the social care individual budget pilots, known as the IBSEN evaluation (IBSEN, 2008). It had not waited even until the findings were available from this evaluation before committing itself to this policy and making this large-scale investment.

The scale of the Government plan and the potential risks involved can be seen to be enormous. Essentially this policy change entailed mainstreaming a small scale initiative, initially running into a few

hundred people accessing individual budgets, into one for many hundreds of thousands – yet with no models of how to roll out in such an enormous way here or in any other country. We know internationally that this is still relatively uncharted territory (Boxall *et al.*, 2009).

When, after much delay on the part of the Department of Health, the IBSEN evaluation findings were published, they also put a serious dampener on Government supported promises that self-directed support would provide better for cheaper. The evaluation indicated that there were no guarantees of significant economies, yet undoubtedly it was their promise that had first caught the eye of politicians. Older people, the largest group of social care service users, we heard, were not necessarily seeing individual budgets as a route to improving their wellbeing. Then early in 2009, the Commission for Social Care Inspection's final report on the status of social care revealed that progress on personalisation was patchy and hesitant (CSCI, 2009a) and a study it commissioned highlighted that progress was particularly limited in relation to service users with complex needs (CSCI, 2009b).

Thus a policy had been embarked upon which not only had a minimal evidence base, but which was not strongly supported by evidence when it did become available. One of the most interesting aspects of this policy shift was the speed and extent of policymakers' initial commitment to move to self-directed support and individual budgets when there was such little evidence that individual budgets could do what their advocates and enthusiasts were saying they could do.

The scale of the task

As Glasby and Littlejohn (2009) have noted, this then also became a vaguer policy, with the focus moving from self-directed support to personalisation. We may wonder whether

this has happened as the complexity and scale of the task they were embarking upon began to dawn and become clearer to policymakers. This shift certainly makes the proposed change different, but certainly no easier. Wasn't making social care fit better the needs of each service user what social care had been trying for years to achieve, with repeated new approaches and initiatives and failed to achieve? Wasn't this what was promised with care management and the community care reforms? How did repackaging it again now as 'personalisation' make it any easier? It also began to become clearer that, for this to happen, would require a very large number of ducks to be got in line. The list of what would be required is long. Some of the issues include:

- Developing a massively improved workforce, reworked with new skills in new roles working to a different user led set of person-centred values;
- Creating and developing a new market of customised support services;
- Finding positive ways of social care addressing issues of risk and being prepared to challenge negative media reporting where service users were truly allowed to experiment with new approaches to support;
- Developing equitable ways of resolving problems of means testing and ever-narrowing eligibility criteria in an essentially residualist service;
- Developing appropriate new approaches to regulation for new kinds of support and new roles, not least that of personal assistant, already contentious, but beyond that a whole range of new roles might need to be developed consistent with a transformed personalised approach to support;
- Establishing an effective infrastructure of information and support to enable people to benefit from offers of choice and control and to enable all service users who wish to, regardless of

impairment or circumstances, to access individual budgets.

These, however, were not the only issues to address. In 2008, as it was embarking upon its planned transformation of social care, Government was already warning that there was what it called a ‘black hole’ of six billion pounds funding shortfall for social care. To this must be added a range of other major issues that have been highlighted by social care and other commentators. These include:

- The demographics of a greatly enlarged population of older and very old people predicted for the near future;
- The expectation that it would be increasingly difficult to rely on a large and expanding body of unpaid carers;
- An ageing workforce which appeared to experts increasingly difficult to sustain on the scale required for the future (Beresford, 2008).

The origins of the initiative

It is important to remember that while the earlier movement for direct payments as part of a philosophy of independent living had been initiated by the disabled people’s movement (Morris, 1993; Zarb *et al.*, 1997), pressure for personalisation and individual budgets had not primarily come from service users. Instead it had come mainly from voluntary organisations like *In Control* and increasingly allies in statutory organisations, like the *Care Services Improvement Partnership* (Waters & Duffy, 2007; Hatton *et al.*, 2008). Of course, some service users were strongly supportive of individual budgets. This is hardly surprising. They were usually people who, until accessed to this opportunity under Government pilots and other special schemes, had inadequate or over-controlled services and support. Some had previously been on direct payments but experiencing these as unnecessarily bureaucratised and

over-controlled by local authorities (Winter, 2008). However, it is one thing to enable a few service users to access improved support as part of high profile time-limited schemes with additional resources, focus and commitment. This has little to do with developing equitable improved user-controlled social care. The history of modern social care is littered with such pilots, initiatives and programmes, which sadly have frequently made little impact on the long-term services and support available for most service users.

The history of the move to personalisation and individual budgets has yet to be written up critically and independently. In offering my own initial thoughts, I am drawing on my experience of being actively involved in an independent user-controlled service user organisation and network, of being involved in high level national policy bodies, of contact with many service users and practitioners at meetings, conferences and other events, and paying close attention to the emerging literature, including specialist social care news stories, for example, in *Community Care* and *Society Guardian* (e.g. Manthorp, 2009).

My experience over the first 18 months of this development highlighted three key features. First, the generally uncritical enthusiasm with which advocacy of individual budgets and self-directed support was received. Second, difficulties were evident in ensuring that a balanced range of viewpoints were offered on public platforms. Discussion tended to be framed at a highly generalised level accompanied by highly positive stories relating to the experience of a small and increasing well-known group of service users, some of whom had direct links with organisations campaigning for individual budgets. Third, there was the difficulty service users and their organisations had in getting involved at any significant level in the planning and development of this massive reform, both at

local and national levels, which again, ironically, was supposed to be user-led.

Realities on the ground

As journalists and conference platforms were offering upbeat accounts of what individual budgets and personalisation would offer, as I went to different places, met many more service users and practitioners, listened to different groups of service users, heard evidence as a member of the National Commission on Personalisation set up by Hampshire County Council, a different, far more complex, picture emerged (Hampshire County Council, 2008).

Service users, including mental health service users, disabled people, people with learning difficulties and older people, reported:

- Their lack of effective involvement in this change;
- Their fears about losing existing services through them being closed and uncertainty about what the alternatives actually put in place would be;
- Worries that the move to personalisation was a new way in which Government was trying to make cuts;
- Big questions about how two parallel systems - existing services and the new arrangements for support linked with individual budgets - could possibly be sustained to ensure real choice, at a time of limited budgets.

The major concern that face-to-face practitioners raise, whether professionally qualified or otherwise, is of being subjected to another top-down agenda, being presented as an obstacle in the way of it and left to feel scapegoats in the way of any progress. Practitioners who had been forced into increasingly controlled roles as care managers where their main responsibility

was to assess people out of support rather than to provide it, now feel that they are being presented as a reactionary group preventing person-centred support, when what they have been highlighting for years is the way the community care reforms and care management have subordinated their professional judgement to a cost-saving preoccupation with funding issues. There are also a growing number of reports of qualified social workers being replaced by unskilled and unqualified staff to take on the new procedures for supposedly 'self-assessment' under arrangements for individual budgets and the setting of the 'resource allocation system' or RAS.

It should be said, however, that the concerns that service user and practitioners have expressed about moves to personalisation do not mean that they are opposed to it in principle. We have just completed a three-year project, funded by the Joseph Rowntree Foundation, on person-centred support, based in eight sites and seeking the views, particularly, of service users, carers and managers. Initial findings published in 2008 showed that there was a remarkable level of support among both service users and practitioners for such person-centred support (Glynn & Beresford, 2008). But people want to see it done properly. Service workers are worried about being 'set up to fail'. Service users do not want to be left in the lurch without adequate, reliable or manageable support. These stakeholders take the move very seriously and can see great gains to be got from it. Their fears are about how and for what reasons it will actually be implemented.

The ambiguity of policy

Service users and practitioners both seem to see personalisation and individual budgets as having both progressive and regressive implications. The issue which seems to underpin their concerns is whether they are being pursued by Government with the primary aim of democratising social care

and empowering service users, or as an extension of the privatising and managerialist/consumerist agenda for public policy that was first embarked upon by Mrs Thatcher's governments. The major move to increased public, patient and user involvement in public services during the last part of the twentieth century and now in the early twenty first century, can be seen to have embodied both strands of ideology and intent (Beresford, 2002). The former has been developed in the emerging service user organisations and movements. Government policy, however, while helping to advance these movements and often incorporating their rhetoric, has tended to reflect more closely the managerialist/consumerist agenda, with its emphasis on market 'choice' and ongoing commitment to outsourcing and to private sector state/market partnerships like the Private Finance Initiative (PFI). Lord Darzi's 2008 report on NHS reform reflects this. While calling for the extension of personal budgets to the health service, key to its recommendations is the extension of the role of the market in the NHS framed in terms of repeated arguments for greater consumer 'choice' (Darzi, 2008).

It is interesting to compare the different central and local government responses that there have been to the original idea of direct payments developed by disabled people and the more recent calls for 'self-directed support' from organisations like *In Control*. While the implementation of direct payments was patchy and hesitant, as we have seen, Government quickly committed to the large scale roll-out of individual budgets (CSCI, 2004; Fernandez *et al.*, 2007). Why the difference? When the disabled people's movement pioneered direct payments, they argued that the level of funding set for them, for each individual, needed to be consistent with the support that people required to live their lives independently on as equal terms as possible as non-disabled people (Morris, 1993). By this they meant that people were enabled as

far as possible to have relationships, undertake activities, have a social life, perhaps have children, a job, education and training, be a volunteer, whatever they wished, like anyone else, through the support that they received. Thus the aim was for the nature and quality of support not to impede, but to be consistent with, the philosophy and values of 'independent living' and disabled people's access to mainstream services would also be equalised with that of non-disabled people.

More recently, with policy interest in individual budgets massively expanding, financial allocations have not necessarily retained this link. Instead, they have been based on calculations about the allocation of existing funding - which we know is inadequate - divided according to the needs externally calculated for any individual, then often top-sliced for administrative costs. This, as we have seen, has been called the RAS by *In Control*, the 'resource allocation system' (Duffy, 2005). This does not provide an adequate basis for meaningful independent living and effectively undermines the original underpinning goals and values of person-centred support. We need to look carefully at this issue in seeking to take forward personalisation. Unless this is resolved, any system of assessment and brokerage will inevitably play an arbitrary rationing role.

In stressing its aim to transform social care, the Government has highlighted its concern to offer a universalist service for the future. Now both self-funders and those supported by the state are to have access to help, through a 'universal offer' of information, advice and guidance. This is a further sign of the scale of the task policymakers have set themselves. To achieve the personalisation or person-centred support envisaged for social care, as we have seen, will mean major changes and improvements in the workforce, the market for care and support, occupational roles, eligibility criteria, risk assessment, regulation and

infrastructural support for service users. This will undoubtedly demand shifts in the culture of social care. But it also has clear implications for increased funding. Social care funding has long been inadequate, the demands upon it are generally expected to rise significantly. There is already a shortfall and current major economic difficulties mean that the expectation is of significant cuts in public spending. How is this circle of increased demand and funding realities to be squared? What ideas does Government have for a funding system to match the ambitiousness of its proposals for social care transformation?

Funding proposals

With the publication of the Government's Green Paper, *Shaping the Future of Care Together* (DH, 2009), we now have early information about its thinking. It can offer us some idea of which direction future policy is likely to be travelling in. Will it make possible the fundamental and liberatory reform of social care that service users want, or merely be another step in the marketisation of social care and increasing reliance on individual responsibility that they fear?

The Green Paper reiterates Government commitment to personalisation and transformation. It sets out three funding options for the future of social care. It styles these the 'partnership', 'insurance' and 'comprehensive' options. In the partnership option, anyone who is deemed to qualify for care and support gets some of it paid for by the state. In the insurance model, as with the partnership model, those eligible would get some paid for by the state and cover the rest through an insurance scheme, paid before or after retirement or after death, in instalments or a lump sum. In the comprehensive option, everyone over retirement age 'with the resources to do so' would 'be required' to pay into a state insurance scheme. Thus the costs of social care would be met through one or other scheme of co-payment

by state and service user and an increasing role can be expected for the private insurance market. The Green Paper also talks of looking at having a free care and support system for people of working age alongside this (DH, 2009, pp.17-8; Gentleman, 2009).

The Green Paper does not propose any increase in funding available for social care, apart from contributions people themselves may make and from transferring the funding from mainstream national benefits, like attendance allowance, to local authority social care. This latter proposal has been met with great concern by service users and carers and their organisations, who fear the loss of highly valued national benefits instead to be incorporated in discretionary local authority social care services where they may be spent on other things (Andalo, 2009; Salman, 2009). The Green Paper refers to two other funding options, first everyone paying for themselves, which it rules out because it would leave many people unable to afford support they needed and, second, funding from 'general taxation'. This is 'ruled out' as too burdensome for younger people. As the Green Paper puts it:

*In this system, people would pay tax throughout their lives, which would be used to pay for all the people who currently need care. When, in turn, people needed care themselves, they would get all their basic care free. This system would work for people of all ages. This is **ruled out** [original emphasis] because it places a heavy burden on people of working age. (DH, 2009, p.16)*

Yet the Green Paper also says that "many people told us that they thought an NHS-style system, where the full costs of care and support were met through taxation (i.e. it was provided to people free when they needed it] would be the fairest option" (p.116). It also acknowledged that:

*The advantage of this system is that it would be **universal**, and would probably be the **simplest** [original emphases] and most easily understandable way of funding care and support. (DH, 2009, p.16)*

The Green Paper's assumptions about funding social care through general taxation setting the generations against each other, however, would benefit from some more critical consideration. These assumptions seem to rest on some outmoded and narrowly based understandings. Social care meets the needs of a large and growing number of people of working age as well as the expected needs of a growing number and proportion of older people. Good social care can also make it possible for many people of working age to return to employment and increase the taxation contribution in this way. Older people are taxpayers too and also contribute in many other ways, for example, through the provision of childcare and informal support and increasingly we are told will need to stay longer in paid employment. Much more thoroughgoing and independent analysis of social care funding will be needed which looks on the provision of care and support as an investment, identifies the cost benefits of such support and does not only conceive of service users (both those of working age and above) crudely as a 'burden' (Andalo, 2009).

The funding options offered for future social care in the Government's Green Paper are not based on universalist principles. There is no suggestion that support should be 'free at the point of delivery' in line with the founding values of the NHS and, people who need support are, in one way or another, expected to contribute to its cost. There is no certainty that the funding options set out and their initial costings will ensure adequate and secure cover for all, or that sufficient funding will be generated by them to cover the rising bills from the growing demands predicted.

New Labour's social policies since 1997 have embodied many positive goals and aspirations; to reduce social exclusion, to strengthen communities, to support the family, to bring an end to child poverty, to improve health and wellbeing. But these policies have also been associated with a growing gulf in public policy generally and in social care specifically between the experience of service users and practitioners on the ground and the aims of policymakers and politicians who are shaping the practice, provision and context in which they must live and work. While official aspirations have often been rooted in positive values and ambitions, the day-to-day experience of people on the ground has remained less positive. The principled policy for people with learning difficulties, *Valuing People* (DH, 2001), is a good example of this – based on positive values but offered without adequate support or funding. We have seen this tension writ large in social care policy, where plans for personalisation and self-directed support have been presented as transformative in potential and empowering in practice, yet are often experienced and discussed by both service users and practitioners working with them as threatening and regressive.

Major policy reform almost invariably requires change in official and organisational attitudes, values and culture. But almost without exception it also needs to be properly funded. It is difficult to see how the Green Paper provides a helpful starting point for addressing the two key challenges with which social care faces policymakers. These are first, improving the fit between positive Government aspirations like personalisation and the routine experience of service users and carers and second, throwing off social care's Poor Law inheritance. It is difficult to see how the first can be achieved without significantly greater funding for social care. The first findings from the *Standards We Expect* (2008) project highlighted many ways in which inadequate funding created barriers in

the way of person-centred support. When people are offered money to spend as they wish - the basic principle of direct payments and personal budgets - demand increases.

Without increased funding and with threats of funding actually being significantly reduced, service users' and carers' fears that personalisation really means cuts by stealth, are unlikely to be put to rest. So long as people do not have meaningful entitlements to social care, talk of it offering universal services rings hollow. After all, information and advice have always theoretically been available to *all* potential service users, regardless of whether they are self or state funded. Access to support is still discretionary and determined by professional judgement, regardless of the talk of 'self-assessment'. Social care does not break from its Poor Law past so long as it is needs and means tested. Calling it a 'national social care service' will not change this, especially when local authorities and their organisations are still determinedly pressing for major levels of local discretion and differentiation. If social care is to be fully accessible to all service users and better integrated with health, then the two require consistent funding arrangements, which reinforce their overlaps and inter-relations rather than encourage their separateness and isolation.

For personalisation to be successful and for transformation to be meaningful, it will require consideration of the general taxation funding option as well as those others which put an inequitable and unsustainable burden on social care service users and carers.

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Peter Beresford is a Trustee of the National Skills Academy for Social Care, member of the Ministerial Reference Group for Social Care, the Transformation of Adult Social Care Programme Board and its User and Carer Reference Group. Shaping Our Lives is a Strategic Partner for user involvement of the Department of Health.

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