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Whose Personalisation?

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by Peter Beresford

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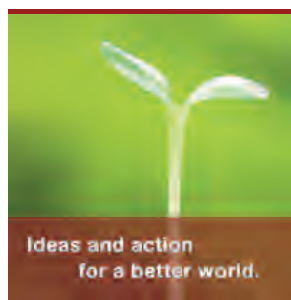
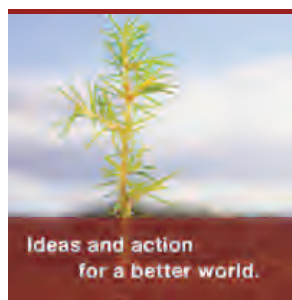
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Whose Personalisation?

by Peter Beresford

Peter Beresford looks at some of the issues raised by the government's rush to social care personalisation.

Social care insiders have often presented their field as a Cinderella, living in the shadow of a big-bucks, high-profile NHS. But this seemed to change in 2008. Suddenly there was a new interest in social care. It was getting attention in Whitehall, from the prime minister - and even from the press. There was talk of a new confidence and energy from its leaders; and 2008 was described by the social care minister as 'the most profoundly important year in a generation'.¹

All this flowed from the new 'p' word - 'personalisation'. There were heart-warming stories of service users whose lives had been radically renewed by personalisation pilot schemes. Even cautious commentators quickly sensed the need to be on the team: respected policymakers, writers and researchers were all endorsing personalisation. A term that had been little more than a vague idea in a 2005 Green Paper now seemed to have gained unstoppable force.

A radical change to the system

Government spokespersons have repeatedly said that the question is not whether personalisation goes ahead, but how it goes ahead. They even call it a 'transformation agenda'. A total of just over £1/2 billion has been allocated, over three years, to bring about the change. What doesn't seem to have hit home yet, though, is just how enormous a step the government's proposed move to personalisation in social care may turn out to be.

The main initial focus of this new agenda was a switch to individual budgets - the allocation of a sum of money to eligible

individuals for them to decide to spend as they wish on a 'package of support'. These individual budgets have been presented as 'radically changing the social care system so that people who use them get much more control over what they get ... people really being in charge of designing their support'.²

Currently there are only a few thousand people in the scheme, and of those many receive funds in the form of direct payments, a system which has been around for a much longer period of time

The planned fast-track rolling out of individual budgets will mean a massive change for millions of people, and for the whole social care system. It is acknowledged that the shift to personalisation is one that will require fundamental change in the 'care market' - in funding, the workforce, local authorities and indeed in the rest of us as potential service users. But we have minimal evidence as yet of what will work best in making such change, and little more than first thoughts on how to achieve the kind and scale of change required. Nonetheless, government has committed itself to personalise services by 2011, and it expects local authorities to deliver.

Some of the comments from key personnel in the field are reminiscent of the blithe assurances of generals in the first world war. Thus Martin Routledge, who has a lead responsibility for personalisation at the Department of Health's Care Services Improvement Partnership, commented in April 2008: 'This is going to be a long and challenging journey. Lots of worries and barriers in the way of it, but it's worth struggle and pain over the next few years'.³ Julia Ross, then the social care lead at Care Services Improvement Partnership - in advance of the completion of the government funded evaluation of the pilot programme of individual budgets - stated: 'I don't think we need more evaluation ... We can't afford to wait'.⁴ Some caution has begun to creep in recently, however; now that the count-down to 'transformation' has begun.

At the Community Care conference Routledge did acknowledge that it was not right or reasonable 'to expect personal budgets to solve the problems that social care faces ... [they] can't solve the demographic problems ... Personal budgets aren't a silver bullet'.

Yet this is exactly the kind of claim that has been made for individual budgets, and it is this, it can only be assumed, that has encouraged the political sign-up to them. In particular, it seems to be assumed that reduced bureaucracy will lead to efficiency savings. *In Control*, initially a government-supported project and now a voluntary organisation, as well as other advocates of individual budgets such as social commentator Charles Leadbeater, have repeatedly argued that they could offer better services for less money. In 2008, Leadbeater suggested that savings 'could be as high as 45%'.⁵ This, however, takes no account of the new infrastructure of advice, support and advocacy needed to make the new system accessible to all service users. Two characteristics have particularly been associated with IBs by their proponents. These are that they may include funding from a range of funding streams (not only social care) and also that, through a 'resource allocation system', service users very quickly know what their entitlement is.

The move to personalisation in social care has been presented as part of a broader shift in public policy, both to a personalised approach more generally, but also to seeing wider public policy as having a role to play in meeting the needs of social care service users. Thus specific social care policy is no longer taken to be the only vehicle to ensure people receive support in society. Instead it is to be recognised in other policies, for example, in housing, planning, employment and leisure. The rules of engagement are always changing, however. There have recently been major changes in how personalised social care is being presented. Policymakers have stepped back from offering individual budgets as the sole and main expression of



personalisation. Instead personalisation is now being offered in vaguer, more general terms of ensuring 'choice and control'. It is currently being sold as a different approach to social care service provision overall, and is extending across all forms of provision, from residential to day services. The aim has become one of ensuring that, whatever service or support people receive, regardless of who provides it, it is clearly based on improving 'outcomes' in their lives - as the official rhetoric now goes. This represents a fundamental shift in emphasis. Under In Control's 'total transformation' policy, some local authorities had already committed themselves to replacing all their social care services by 2010 with individual budgets.

One of the ironies of personalisation is that, while its mantra has been 'involving service users' and increasing service user 'choice and control', service users and their organisations generally feel they have had little say in its shaping or development.

Individual budgets were first developed with people with learning difficulties. Yet at a conference organised by the London Direct Payments Forum in 2008, a key selfadvocacy project worker reported that most people with learning difficulties knew little about personalisation, even those in the areas where it was being piloted.⁶ A broader picture is emerging, at this and other events, of service users having had little involvement at local level and none at central policy level in this supposedly 'user-led' development. The same worrying picture emerges with face-to-face practitioners - the group which will be significantly affected by this development, and will have a pivotal role in making it work. These workers are at best anxious about 'personalisation', and at worst see it as another top-down policy to restrict their practice and independence - just as the 'care management' initiated by Mrs Thatcher did, which is now being heavily criticised by supporters of personalisation. These developments are all the more worrying because social care is a neglected and misunderstood area of

policy that has long suffered from chronic underfunding and low public and political priority. Most people don't know what social care is or what it means.

Furthermore, this major reform is happening at an increasingly difficult time - of increasing political uncertainty, and probable economic recession.

Uncertain futures

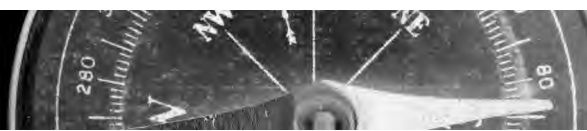
Already a wide range of scenarios are being suggested for the ways in which personalisation in social care will be played out. These reflect the big hopes already invested in it, as well as the significant fears it has generated. The range of scenarios being discussed, by people who are frequently very anxious about the future, is a reflection of the lack of serious planning for the programme, and of an increasing recognition of its enormous implications. The scenarios envisaged oscillate between the extremes of radical reform and minimal change; they are also contradictory, and often mutually exclusive. People feel uncertain about how the changes will affect them.

On the optimistic side, there are those who believe that, given the freedom to spend their individual budgets as they wish, service users will gain a new freedom, selecting their support from an ever-widening menu of possibilities. Skilled independent brokers will be available to help service users to plan and organise the package of support that they want in order to live their lives to the full. We may even enter a new era of social care where the consumer becomes king, able to pull down a much broader and more imaginative menu of support, either directly for themselves or for those close to them - all with state aid. Personalisation optimists also argue that social care will shift from being a residualised service to one that makes a universal offer of information, support, guidance and advocacy, regardless of whether people are 'self-funders' or supported by government funding.

Those with less faith in the rhetoric of personalisation fear that there may merely be a process of rebranding, where the language of consumerism and control does little more than overlay arrangements that remain essentially the same. While service users will notionally shape the support they get, there is a possibility that in reality their needs will continue to be assessed by the agency; they will use the services which it prescribes, and it will continue to hold the budget that is ostensibly theirs. They may now have a 'support' rather than care plan, but it will still be based on a bureaucratic process controlled by professionals employed by state agencies. It is also possible that increasing restrictions will be placed on how people may use their budgets, and who they will be able to pay to undertake support tasks for them, through the intervention of government departments such as the Department for Work and Pensions or the Inland Revenue - either to generate income, or limit the 'black economy' and restrict tax avoidance.

Another possibility is that professionally qualified social workers will be replaced by brokers trained and employed by the service agency to meet its requirements. In the current difficult economic and political times, it may be difficult to maintain political priority and momentum for the personalisation agenda, and this may result in an extended period of transition, without any clear hope of original goals being realised.

There is an anxiety that the traditional menu of collective social care services - such as day centres and respite care - will wither away, leaving people adrift in a complex and inadequately regulated market: existing collective services may be closed without adequate alternative support provision being offered in replacement. Indeed it may be that service users - no longer protected by access to the traditional range of regulated services - will be exposed to financial and personal risk, because of an enforced reliance on unregulated workers and services. Lack of funding may also mean that the trend



towards narrowing the eligibility criteria for support will continue, as demand for social care grows and budgets are increasingly restricted. There are also worries that obligations will increasingly be placed on people's families as 'informal carers', both to run support schemes and to provide support. Changing demographic conditions are likely to make these responsibilities increasingly difficult to fulfil.

There is also concern that the exciting and innovative ways in which some people have spent their IBs in the initial pilots might become subject to restrictions through fear of the risks involved, or of hostile media reaction. Furthermore, sensitive, good-quality small local providers of services may be driven out of business because of the insecurities generated by individualised commissioning. Meanwhile, the new arrangements will offer a free-for-all for large and multinational social care providers and financial organisations, which see social care as a new profit opportunity. These large providers rely for their profit on standardised services and economies of scale - both of which are antithetical to the customising rhetoric of personalisation.

The uncertainty that these contrasting scenarios reflect - increasingly underpinned by the realisation that the clock has started ticking on the government's tight timetable - is already raising some very big questions. Stakeholders are worried about the possibility that large for-profit companies will become dominant in the sector, as has so far generally occurred in other policy areas, from public utilities to public transport. As already noted, such companies are unlikely to offer people individually tailored solutions. It is even possible that personalisation will create perverse incentives to institutionalisation, because residential services offer the readiest area of reliable profit for private-sector social care providers. There are also concerns that there will not be enough public money to take account of the new needs generated

by the big demographic changes that lie ahead, in particular the rising numbers of older and very old people. There are also unanswered questions about how the reform of social care funding will in practice be able to respond to the customisation of support that is implied by personalisation, and the new needs that this is likely to identify. It is unclear, too, how a system based on rationing and eligibility criteria can be reconciled with a personalisation model based on allocating people the financial resources they require to meet their needs. Then there are questions about how the government will contrive to ensure that any new systems of support, particularly more mainstream and flexible ones, will be of a high enough standard of quality, reliability and risk awareness.

There is also a big question hanging over government assumptions that change across broader policy areas is likely to contribute to supporting people's needs and reducing the need for specialist social care. Pressures are currently largely heading in the opposite direction: for example there is increasing reliance on cars, more centralisation of shopping and amenities, continuing losses of public space and provision, and the running down of rural facilities. What is perhaps most interesting - and concerning - about personalisation in social care is that the government has made such strong commitments to it, not only without having clear answers to such questions, but without such key questions having been properly considered at all. As yet there doesn't seem to have been recognition that it might be worthwhile to try game-playing with personalisation to test how it might actually work out in practice. Nor has any comprehensive independent evaluation yet been set in train. What the future holds for the brave new world of social care thus remains extremely unclear.

Democracy and the market

Current proposals for social care reflect two competing agendas of our age: the emergence of a democratising collective impulse in public policy; and pressures to restore market dominance following its fettering by the post-war welfare state settlement.

These parallel developments have each heavily influenced public and social policy over the last thirty years. They have been embodied on the one hand in the emergence of service user movements, and on the other in the development of new agendas within the political new right, subsequently largely taken up by New Labour. The disabled people's movement provides the most helpful starting point for making sense of these developments. This movement, developing in the UK from the late 1960s, rejected the paternalism of state welfare policies. But it also abhorred the market and charitable sector, which it saw as similarly rooted in the medicalised individual understandings of disability that cast disabled people as the cause of their own problems and dependence. Members of the movement saw the 'tragedy' model of disability - which they felt their services perpetuated - as discriminating against people with impairments, marginalising, impoverishing and excluding them.

The disabled people's movement developed a new social model of disability, which distinguished between people's perceived physical, sensory and intellectual impairments and the negative social reaction to them - which they described as disability. From this flowed the philosophy of independent living, and an associated movement, which spread rapidly from its roots in California across North America and Europe. The key principle of independent living is that disabled people and other service users should have support and access to mainstream opportunities, so that they can live their lives on as equal terms as possible with non-disabled people.



This indeed is where the idea of individual budgets originated: to secure the kind of support that disabled people wanted in order to live independently, they themselves developed the policy and practice of direct payments. These were conceived of as representing a sum of money under the control of service users, which made it possible for them to identify, secure and control the kind of support that they wanted. This 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.

The level of the budget was determined by what was needed for each individual to live independently. A network of local user-controlled organisations, or 'centres for independent living', would 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. We know from the evidence that direct payments provided unprecedented opportunities for disabled people and other service users, who gained greater control over their lives, increased their life chances and even were able to improve their health and well-being. Yet though new legislation was introduced to facilitate such developments in Britain, progress has been very slow. Only a tiny proportion of service users were enabled to access direct payments; and the schemes were run by local authorities, which were criticised for being bureaucratised and over-controlling, with funding levels set in line with budgetary restrictions rather than with meeting the needs and rights of service users.

Running in parallel with this collective pressure for liberatory social policy was the move towards the private market and managerialism, initiated by the Thatcher administrations and perpetuated by New Labour. And within this dominating strand in UK politics and public policy, a key theme has been an increasing emphasis on participation, or 'user involvement' and

'choice'. Indeed user involvement has become a key ideological battleground. The same terminology has been used by government and service users to mean very different things. For service user movements, getting involved has meant the redistribution of power; democratisation and achieving change in line with their rights and needs. For the state and service system there has more often been a managerialist/consumerist model, framed in market terms. It has largely focused on intelligence gathering/market research activity; it consults with and seeks to incorporate public and service users, but without altering the locus of decision-making.

This same pattern can be seen with individual budgets. While there has been a strong rhetoric of empowerment and control, individual budgets have been very strongly sold in managerialist/consumerist terms. The focus has been on the individual and their receiving of a cash sum; and this has mainly been framed in terms of conventional service purchase, and exchange relationships. High profile examples include the ability to buy a season ticket so that a friend can go with a service user to football matches, or to pay for a holiday abroad, and to buy a domestic air conditioning unit to reduce breathing problems caused by asthma.

Some disabled people have suggested that direct payments and individual budgets are essentially the same. But their ideological origins have been significantly different, and the worry is that this difference will increasingly be seen in the way individual budgets develop. Direct payments grew out of the disabled people's movement, while individual budgets have come from state and traditional charity organisations. Direct payments were based on a social model of disability and the philosophy of independent living; whereas individual budgets grew out of work with people with learning difficulties, and were associated with the philosophy of 'normalisation' - which is typically concerned

with integrating disabled people into society rather than with challenging its barriers and discrimination. The aim with direct payments was to set them at a level that would ensure independent living; levels for IBs on the other hand have been set on the basis of available funding levels (the 'resource allocation system'), often top-sliced to pay the administrative costs of the system, and frequently reliant on family members or state-employed care managers for their running. With direct payments there has been a stress on the role of disabled people's organisations in supporting people in their access to payments; the In Control model of individual budgets suggests that anyone - family, friend or care manager - can take on the tasks of 'brokerage'.

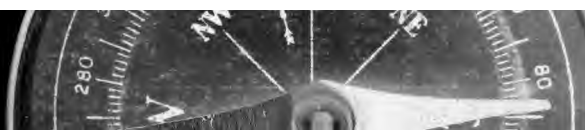
The crucial question now facing social care is the direction in which personalisation is likely to go. Will it be one inspired by the liberatory ethos of collective organisations and reflected in the original philosophy of direct payments? Or will it be the consumerist/managerialist agenda that is increasingly associated with modern western social policy? One significant indicator is that, while UK policymakers were slow to pick up on direct payments, they have given far stronger support to individual budgets.

However, as the questions raised in this discussion highlight, whatever the intentions of politicians and policymakers, there are some very large issues still to be addressed in any serious move to take personalisation forward.

Conclusion

There is perhaps an even more fundamental point to consider in relation to the future of health and social care. There is now increasing talk of social care making a 'universal Whose personalisation? offer' of advice and information to all service users as its funding comes under review.

Nonetheless it remains an essentially residual, underfunded service, for which



most service users are expected to pay. The NHS, on the other hand, despite all the inroads made into its founding philosophy, still continues to be a universalist service, free at the point of delivery. Lord Darzi's recent review of the NHS took a look at social care and recommends a pilot scheme giving 5000 people with long-term conditions access to 'personal budgets' within the NHS.⁷ This raises some far-reaching questions.

How can such cash payments be squared with the philosophy of an NHS whose services are meant to be universally free?

What consequences is the introduction of such payments likely to have on the philosophy and practice of the NHS? Why is an inadequately evidenced model from a policy area that is widely recognised to be problematic - social care - being considered as a way forward for a health service that is still seen by most people as one of the greatest achievements of twentieth-century Britain?

It is big issues like these which need to be kept under close scrutiny, as cosy stories of a few people's gains from individual budgets are used to sell one of the biggest, least evidenced, reforms to be introduced since the founding of the welfare state.

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Notes

1. M. Samuel, 'Social Care Experiencing "Its Most Important Year"', *Community Care*, 31.7.08.
2. Statement at a two-day event in late 2006 organised by the government's Care Services Improvement Partnership's 'Self-Directed Support Academy for People Who Use Services and Family Carers'.
3. Martin Routledge, plenary speaker at Community Care National Personalisation Conference, 30.4.08.
4. Julia Ross, speech at The Future Of Individual Service Designs, national conference, 26.3.07.
5. C. Leadbeater, 'This Time It's Personal', *Society Guardian*, 16.1.08.
6. P. Beresford, 'Self-Directed Support: If we are going to do it, let's do it right!', Report of a day conference organised by the London Direct Payments Forum, London Direct Payments Forum 20.06.08.
7. High Quality Care For All: NHS Next Stage Review Final Report, TSO 2008.



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