

Our Health, Our Care, Our Say - what could the NHS learn from individual budgets and direct payments?

Jon Glasby and Simon Duffy, August 2007

In 2007, the NHS in England is facing a series of challenges as it tries to deliver the vision set out in the White Paper, *Our Health, Our Care, Our Say* (Department of Health, 2006):

- Faced with a double whammy of demographic pressures and rising public expectations, health services are increasingly being tasked with delivering an individualised and person-centred approach which fits services around the needs of the individual rather than the other way round.
- Following high profile financial difficulties (and faced with a much tighter Comprehensive Spending Review), health services are having to concentrate on managing rising demand within cash-limited budgets.
- Tasked with promoting public health and well-being, health services are increasingly being asked to work in a way that encourages people to take control of their own health and to develop a preventative approach.
- While services will continue to be publicly funded, there is growing emphasis on opening up health care provision so that future services will be provided by a range of services across the public, private, voluntary and community sectors.

While many of these are new challenges to the NHS, they are longstanding issues in social care (which has often learned the hard way about what works and what does not work when tackling such issues). Although a number of different approaches have been developed over time, two of the

most exciting initiatives to date are **direct payments** and **individual budgets** – both of which have the power to revolutionise the lives of disabled people and the nature of social care services more generally. Despite the current emphasis on inter-agency partnerships between health and social care, both direct payments and individual budgets are being actively promoted in social care at the same time as they are being actively ruled out in health care (Department of Health, 2006, p. 85). At best this seems idiosyncratic; at worst it seems actively counter-productive.

In response, a momentum for change has started to develop in recent months, with calls for the introduction of direct payments and/or individual budgets in areas of health care coming from a previous Health Secretary (Milburn, 2007), from a previous health policy advisor to Tony Blair (Harding, 2005; Le Grand, 2007), from the Opposition (Conservative Party, 2007) and from a prominent think tank (Alakeson, 2007). At the same time, additional impetus has come from concepts such as the 'year of care' model being explored by the NHS Diabetes Support Team (Diabetes UK/Department of Health, n.d.), by a landmark NHS Ombudsman case (2003) and by thinking undertaken by the national in Control initiative to explore the different funding streams that could be integrated into current (social care) individual budgets (Waters and Duffy, 2007). Work by the government's Integrated Care Network (2007) is also exploring potential connections between direct payments/individual budgets and integrated care, while similar issues have previously been raised both in research (Glendinning *et al.*, 2000a, 2000b) and in policy debate (Glasby and Hasler, 2004).

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Against this background, this short discussion paper seeks to summarise the nature and impact of direct payments/individual budgets before moving on to consider ways in which the lessons learned in social care could inform current debates in the NHS.

What are direct payments and individuals budgets?

Described as holding out “the potential for the most fundamental reorganisation of welfare for half a century” (Oliver and Sapey, 1999, p.175), the Community Care (Direct Payments) Act 1996 enabled local authorities to make cash payments to disabled people aged 18-65 in lieu of directly provided services. While the subsequent direct payment can be used to purchase services from a voluntary or private sector agency, many people choose to use the money to employ their own personal assistants (PAs), essentially becoming their own care managers. Initially discretionary, direct payments were soon extended to other user groups (including older people,

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carers, younger disabled people and people with parental responsibility for a disabled child), became a key performance indicator and were made mandatory (for people who meet the criteria and want to receive a direct payment). Originally pioneered by disabled people in the US, this way of working was introduced to the UK in the 1980s by disabled people’s organisations, promoted by disabled people during the early 1990s, and introduced only after sustained lobbying by disabled people. Subsequently, it has been disabled people who have been most active in providing support to direct payment recipients and in campaigning for further extensions and greater take-up of the policy. Almost more than any other current policy, this is a concept developed, implemented and rolled out by disabled people themselves, and this alone makes it worthy of further consideration.

To date, all the available evidence suggests that direct payments lead to greater user satisfaction, to greater continuity of care, to fewer unmet needs and to a more cost-effective use of scarce public resources (see Bornat and Leece, 2006; Glasby and Littlechild, 2002; Hasler *et al.*, 1999; SCIE, 2005 for further discussion). Essentially, it seems as though direct payment recipients have more of a vested interest than the local authority in ensuring that each pound available is spent as effectively as possible and in designing support that enables them to have greater choice and control over their own lives. While take-up is inconsistent and low compared to the number of people who receive directly provided services, any remaining barriers seem to be the result of the way in which direct payments have been operationalised rather than of the concept itself. Where direct payments have been taken up enthusiastically, however, the biggest successes have often come where there is a user-led Centre for Independent Living to provide advice and peer support for people thinking about such an option and starting to test out whether it is for them.

In spite of many positives, a key limitation of direct payments is that such a liberating way of working has often been bolted on to the traditional and often very unresponsive system. While direct payments can transform the way in which people design and receive support, therefore, it has not yet changed the way in which people access services, the way they are assessed, the prevailing culture or the way in which the bulk of the social care budget is spent. In contrast, individual budgets seem to offer all of the advantages of direct payments, whilst also starting to transform the system as a whole. Set up in 2003 by the Department of Health, several local authorities and Mencap, in Control is a national organisation which has developed and is rolling out a new system of social care (often called self-directed support). In order to re-engineer adult social care, in Control stresses the importance of seven key steps (see Box 1). At its most simple, however, an individual budget is essentially about being clear with people from day one how much is available to spend on meeting their needs, and ensuring that the person and those close to them have as much control as they want over how this money is spent on their behalf. As in Control often says, this amounts to little more than “sensible delegation”, and can free up the time of trained social workers to focus in

more detail on those who need most help to plan their support.

Since 2003, individual budgets have been tested with over 2000 people. While further evaluation is underway, the initial evidence is very promising: not only are individual budgets delivering their primary purpose of giving people more power and control over their own support, they also seem to be leading to overall improvements in well-being and to greater efficiency. In particular, early pilot work with 60 people in six local authorities demonstrated (see Poll *et al.*, 2005 for all findings quoted below):

- Improved satisfaction levels for the people who use services (satisfaction with support went from 48% to 100%).
- Improved efficiency (cost savings ranged from 12% to over 30%).
- Increasing use of community and personalised support (for example, use of residential care reduced by 100%)

Above all, however, individual budgets appear to provide a particularly effective way of empowering people who use social care. As Table 1 demonstrates, a massive proportion of people in the early pilots were able to achieve the changes that they wanted to achieve in their lives over the course of one year.

Box 1: Seven key steps to self-directed support

Step 1 – Using in Control’s resource allocation system (RAS), everyone is told their financial allocation - their Individual Budget - and they decide what level of control they wish to take over their budget.

Step 2 - People plan how they will use their Individual Budget to get the help that is best for them; if they need help to plan, then advocates, brokers or others can support them.

Step 3 - The local authority helps people to create good Support Plans, checks they are safe and makes sure that people have any necessary representation.

Step 4 - People control their Individual Budget to the extent they want; there are currently six distinct degrees of control: ranging from direct payments at one extreme to local authority control at the other.

Step 5 - People can use their Individual Budget flexibly (including for statutory services). Indeed, the only real restriction imposed is that the budget cannot be used on something illegal (as long as people are meeting their eligible needs).

Step 6 - People can use their Individual Budget to achieve the outcomes that are important to them in the context of their whole life and their role and contribution within the wider community.

Step 7 - The authority continues to check people are okay, shares what is being learned and can change things if people are not achieving the outcomes they need to achieve.

Table 1: Impact of individual budgets

Desired change	% Achieved
Where I live	76%
Who I live with	81%
What I do with my time	69%
Who supports me	89%

Faced with such early achievements, the government has taken up the concept of individual budgets with enthusiasm, pledging to pilot this way of working and, if successful, implement it nationally. In a slight complication, official Department of Health pilots incorporate not only the social care budget (which is the prime focus of in Control), but also a series of additional funding streams, including various social security, housing and employment support funds. With some areas acting as a pilot for in Control and for the Department of Health, a degree of confusion remains and some clarification may well be required. However, what is most remarkable about both direct payments and individual budgets (for present purposes) is the extent to which they mirror key policy goals in the NHS, yet remain actively resisted in a health care setting.

What implications does this have for the NHS?

Open any recent health policy document, and commitments around choice, control and patient-centred services fit exactly with the ethos and values of direct payments and individual budgets. With policies focused on 'expert patients' and people with 'long-term conditions', the NHS seems to be seeking exactly the same change, responsiveness and citizen control in health care as social care has sought via individualised funding. With recent initiatives such as Payment by Results and Practice-based Commissioning, moreover, health care money is getting much closer to the individual patient, although we still do not trust individual patients enough to decide precisely how this money is spent on their behalf. However, perhaps the best example of this comes from the title of the 2006 health and social care White Paper – if the government really is committed to the principles of *Our Health, Our Care, Our Say* then some form of individualised funding seems almost inevitable if such concepts are to become a reality.

Already, we know that disabled people do not distinguish between 'health' and 'social care' needs, but see both as part of overall 'support' or 'personal care'

needs. This is partly because social care needs are often a consequence of underlying health needs, but also because good quality social care is felt to reduce the risk of subsequent health problems. There is also a persistent and underlying ambiguity about the distinction between health and social care more broadly. As a result, a pioneering study of people using direct payments with both health and social care needs (Glendinning *et al.*, 2000a, 2000b) found that participants were using their direct payments to purchase a range of services that would traditionally be defined as 'health care' (including physiotherapy, injections, dressings, footcare, tissue care, bowel and bladder management, nursing care while ill or in hospital, maintaining and using oxygen equipment, and alternative therapies for pain management and relaxation). For some, this was because mainstream health services were perceived to be unavailable (for example, long-term physiotherapy); in other cases health care was withdrawn or delegated to personal assistants (PAs) once health professionals realised that PAs were involved. Above all, it enabled health care tasks to be integrated into the disabled people's daily routines and therefore extended the choice, control and continuity created by their direct payments.

More recently, evidence from the US (Alakeson, 2007) has suggested that the introduction of individualised funding into the NHS could lead to:

- Greater personalisation of care.
- The ability to overcome capacity constraints in the NHS.
- Better coordination of care for individuals with complex health and social problems who are in receipt of a number of services.
- Greater transparency in the allocation of NHS funds.
- Greater equity by allowing personalisation within the NHS rather than through the market place.

- Better value for money through the development of personalised care that leads to health improvements without increasing costs.
- Greater innovation and service development, with people enabled to explore different ways of meeting their health needs.

A similar argument has been put forward by Waters and Duffy (2007), who observe that:

- There is considerable overlap between people who use social care and those who use the NHS, with such connections leading to ongoing scope for tensions and/or innovation.
- A substantial proportion of the NHS budget is spent on people who have conditions that are long-term in nature, and these may well include people who already receive direct payments for their social care.
- There are already several legal mechanisms to promote greater joint working, including measures to pool budgets and to transfer funding/lead commissioning responsibilities across the health and social care divide.
- Anecdotally, some health and social care communities have already experimented with joint approaches to individual budgets in individual cases.

Added to these lists is a crucial, but often overlooked, issue: at present, many of the funding sources being integrated via individual budget pilots are very small in nature, and there is a real risk that the complexity of integrating money from bodies governed by very different legal and accountability mechanisms is simply not worth the effort. In contrast, an approach which sought to explore the scope for a joint approach across the health and social care divide would be tackling a major policy problem and would have sufficient resources to be genuinely able to transform the whole system. Of course, the amount of money involved in such a scenario is both a major strength and a significant barrier to further progress – while the sums at stake mean that any positive change could have a major impact, the risk of destabilising the current system is equally significant.

Overcoming current misconceptions

Despite many potential positives from exploring the implications of direct payments/individual budgets in a health care setting, an early priority would be to overcome some of the many stereotypes and misunderstandings which surround these policies. In particular, a 2004 policy seminar to explore these issues (Glasby and Hasler, 2004) found that direct payments in particular could have a significant impact in health care, but that a 'battle for hearts and minds' would be needed (similar to that which took place in social care in the mid-1990s). Essentially, social care has developed very robust answers to such questions, but these would need restating in a health care context (see, for example, Box 2).

Conclusions and next steps

Direct payments and individual budgets have been major forces for change in adult social care, and there is considerable policy support for building on current progress and extending these concepts further in future. To date, there has not been such enthusiasm to examine the implications of these ways of working in health care (despite a similar policy commitment to person-centred services, to citizenship and to giving people greater choice and control over their services and hence over their lives).

To explore these issues in more detail, we recommend that individual budgets and direct payments are piloted in six main areas with a view to learning from the subsequent lessons (both positive and negative). In our view, areas that would benefit considerably from such a pilot include:

- Services for people with long-term conditions (including the funding of a current Centre for Independent Living to pilot a hospital admission prevention scheme based not on the current 'community matron' model, but on peer support).
- Mental health services (with a recovery budget for people recovering from severe mental illness).
- Maternity services (with scope to use a direct payment to hire an independent midwife to give the woman a birth of her choosing).

Box 2: Common myths about direct payments and individual budgets

Question: Won't people just misuse the money?

Answer: No – the individual has more of a vested interest than public services in spending the money as effectively as possible. Evidence to date has revealed no significant misuse, and a large amount of creativity and innovation.

Question: Isn't this best left to the experts?

Answer: It depends who you think the expert is – the person with the technical knowledge (who has a key role to play) or the person who knows what it is like to live with their condition and what they want their life to be like. In an ideal world, the relationship between 'professional' and 'service user' would be one of equals, with each bringing complimentary expertise.

Question: Isn't this just about privatisation?

Answer: No – it's about citizenship and the right to be in control of your life. At present, people with more money can afford to supplement or bypass public services. In contrast, direct payments/individual budgets nationalise these opportunities – creating a fair and universal service for everyone.

Question: Surely this won't work in practice as health care (unlike social care) is free at the point of delivery?

Answer: No – and this question is slightly disingenuous. While the divide between means-tested social care and free health care remains problematic, there is no essential difference between trying to integrate directly provided health and social care (which is current government policy) and trying to join up direct payments/individual budgets for health and social care (which isn't).

- Expensive out-of-area placements (where a significant and transparent annual sum is already being spent on specific individuals, with services and outcomes that are often felt to be less than optimal).
- Continuing health care (see Parliamentary and Health Service Ombudsman, 2003, for a specific example).
- Services for people with learning difficulties, which in our view, should in any case be the future responsibility of local government and not part of the NHS.

In a radical version of this proposal, there would even be scope to develop national tariffs for some forms of health care into an NHS version of the in Control resource allocation system to allow patients and general practitioners together to choose from an expanded range of providers for any given procedure (or, where appropriate, to explore alternative non-medical ways of meeting the same underlying health needs). Whatever happens, it is our belief that the current system of direct payments/individual budgets for social care but not for health care is both unsustainable and a major missed opportunity.

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This paper builds on previous discussions of direct payments/individual budgets and health care by Glasby and Hasler (2004) and of the integration of current funding streams by Waters and Duffy (2007).