

Active Patient

The case for self-direction in healthcare

Vidhya Alakeson

Editors: Simon Duffy, Jon Glasby and Catherine Needham

POLICY PAPER 05.01.2011





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About this series

Joint policy document series

In the summer of 2010 The University of Birmingham's Health Service Management Centre hosted a two day think-tank to explore whether recent innovations in health and social care might be the key to a more radical redesign of the whole welfare state.

As part of the think tank papers were produced which proposed significant policy developments. These papers were then subject to debate and criticism. The papers were then further developed for publication.

Each paper in the series has been produced by a leading practitioner and social innovator. The papers combine evidence and ideas for policy reform which are rooted in the real experience of bringing about change from the 'bottom-up'.

www.centreforwelfarereform.org

www.hsmc.bham.ac.uk

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A big thank you also to colleagues in the US with whom I worked during my time in Washington D.C. and who continue to collaborate in the development of self-direction.

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Preface

In the early twenty-first century, elements of the welfare state are in the middle of a ‘transformation’ process based on the concepts of personalisation and self-directed support. Beginning in adult social care, these approaches seek to recast users of state welfare away from being passive recipients of pre-purchased services towards a situation where they are active citizens with a right to control and shape their own support. Various described as a form of ‘co-production’ or in terms of individuals becoming the ‘micro-commissioners’ of their own support, this has been seen as a shift away from a ‘professional gift model’ towards a citizenship-based approach, arguably more in keeping with other aspects of our lives (Figure 1).

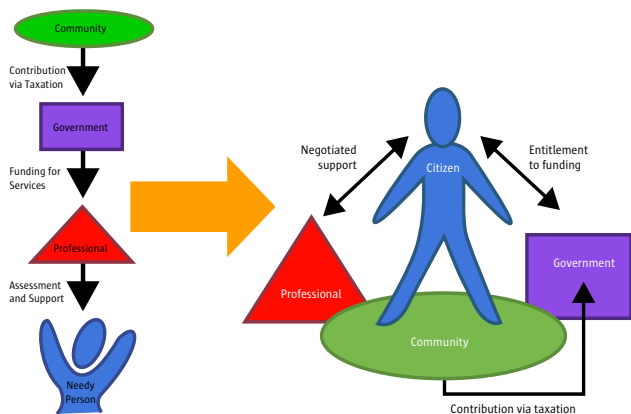


Figure 1. From Professional Gift to Citizenship Model

Central to this agenda to date has been the concept of direct payments (pioneered by disabled people's organisations and developing in the UK from the mid-1980s onwards) and individual budgets (developed from 2003 onwards by In Control). Beginning with 60 people in six local authority pilots in late 2003, there are now possibly 100,000 people receiving an individual budget and the government has stated that all adult social care will be delivered by this mechanism in future.

Although starting in adult social care, this approach is now being piloted in children's services and in healthcare, with several leading think tanks and commentators interested in its possible extension to other areas of state welfare (such as the tax and benefits system, housing, education, rehabilitation for ex-offenders, substance misuse services and support for young people not in education, employment or training). If privatisation was the key focus of the 1980s, it has been claimed, then personalisation could be the key focus of the early twenty-first century. Unsurprisingly, such issues have acquired even greater relevance in the current financial and political context, with debates about reduced state expenditure and potential government shrinkage.

Despite recent progress, much more remains to be done, including:

- Fully embedding personalisation in the training of social workers and other public service practitioners and managers.
- Exploring the implications of self-directed support for broader areas of state welfare.
- Understanding key levers for embedding change in policy and practice.
- Understanding more fully the implications for cost-effective use of scarce resources in a challenging economic climate.
- Developing more explicit theoretical and conceptual frameworks around citizenship, ethics and social justice.

Against this background, this series of papers was first presented and discussed at a national 'think tank' funded by the University of Birmingham's Advanced Social Sciences Collaborative (ASSC).

We invited real experts to explore the changes they think could bring about positive change in:

- Local government and civil society
- Services for children and families
- Our health and social care systems
- The criminal justice system
- The tax-benefit system

In turn these ideas were challenged and reviewed by an audience of leading policy makers, managers, practitioners, policy analysts and researchers. We are publishing these papers in their revised form.

Underpinning many current policy debates is a sense that the ethos, law and structures that underpin the current welfare state is dominated by 1940s thinking and assumptions – and that some of the concepts inherent in debates about personalisation and self-directed support could help to shape future welfare reform. The Beveridge Report is widely credited with establishing the thinking behind the post-war welfare state. It is time to engage in the same depth of thinking about the relationship between the state and the individual in the twenty-first century. We hope that these papers contribute some fresh thinking.

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Summary

This policy paper proposes that individual budgets can create a more patient-centred and integrated health and social care system; one that recognises individuals as experts by experience and engages them as partners alongside professionals in decisions about their own care. This will improve health outcomes, prevent individuals becoming dependent on specialist services and make the NHS more efficient.

A National Sickness Service

The current health service categorises individuals according to their diagnoses and disabilities not their assets and strengths. It focuses on services rather than outcomes and the divide between the NHS and social care separates health from other important aspects of life such as work, family and community. It prioritises professional expertise over the experience of individuals, despite the fact that effective management of chronic diseases depends more on individuals than professionals.

What individuals and families need

In life threatening situations, people will always want to hand over control to a professional. But in many areas of healthcare where there is more than one possible treatment, individuals and families want to be supported to be active partners with professionals in decisions about their care.

Individual budgets

Emerging evidence from pilots in England and the USA demonstrate that individual budgets can improve satisfaction with care and help individuals develop a more holistic approach to care. However, individual budgets present a significant challenge to the current organisation of the NHS and there is a risk that they will get bogged down by bureaucracy and be overtaken by structural changes in the NHS.

Making individual budgets work

Making individual budgets work will depend on a shift in thinking in three areas:

1. A shift in the balance of power between professionals and patients in favour of patients.
2. A shift from a system defined by the services it delivers to the health outcomes it secures.
3. A shift towards a whole person approach with one integrated budget per person covering all health and social care needs.

Note on terminology

The concept of an individual budget draws upon a long-standing international movement towards individualised funding in public services. It was first defined by Dr Simon Duffy as individual funding which could be controlled by a range of different methods and which was to be used to meet individual needs (Duffy, 2005).

However the concept was later taken up by central government's Individual Budget Pilot Programme that unsuccessfully tried to integrate different funding streams. Rather confusingly government has tried to redefine individual budgets as always requiring funding integration while now using the term 'personal budget' for an individual budget in social care. Further confusion is created by then referring to the concept of an individual budget in healthcare as a Personal Health Budget.

For the sake of clarity we will be using the term individual budget for the fundamental concept and will refer particularly to data from the UK and the USA where this concept has been tested; and we will only refer to a Personal Health Budget when we mean the specific programme in England to test the application of individual budgets in healthcare.

As I will suggest at the end of this paper the current terminological confusion also masks some important policy issues – in particular I would argue that we should make every effort to avoid multiple and competing systems of personal budgets; instead develop one coherent individual budget model which could be used by different public services – including health.

Introduction

The costs of healthcare are increasing across the developed world, fuelled by the rise in long-term conditions such as diabetes, chronic obstructive pulmonary disease (COPD) and heart disease (Sassi, 2008). In the UK, long term conditions like these account for around 70% of spending in the National Health Service (DH, 2010b). By their very nature, long-term conditions require day to day management to prevent conditions worsening and a subsequent emergency hospitalisation. This task falls far more to individuals and their families than to health professionals. If there are 8,760 hours in a year, the average person with a long-term condition in the UK spends no more than 3 or 4 hours a year with a health professional – that is less than 0.05% of the year (Hannan, 2010).

Growing appreciation for the central role that individuals play in managing their own health has led to a new focus on interventions that support self-management (Lorig, 2001; Coleman, 2006) and the development of peer to peer models of disease management, such as the NHS Expert Patients Programme (Expert Patients Programme, 2010). It has also strengthened the call for a transformation of the NHS away from a model of healthcare that is uniform and professionally driven to one that is more individually tailored and based on a partnership between individuals, families and professionals (Health Foundation, 2008).

There are few areas of healthcare where there is only one treatment option. In the vast majority of cases, there are several

possibilities, each with different risks, side effects and likelihood of success. Doug Eby, senior physician executive at the South Central Foundation in Alaska argues that it is only in relatively extreme high acuity cases that the professional is fully in charge of the situation, such as when the patient is in a coma, anaesthetised or collapsed. Eby argues that the less severe the symptoms, the greater the chance the patient will do what he or she wants to do and will take the professional's advice selectively (Crisp, 2010). The area between the two lines in Figure 2 below indicates significant scope in healthcare for co-produced solutions between individuals and professionals.

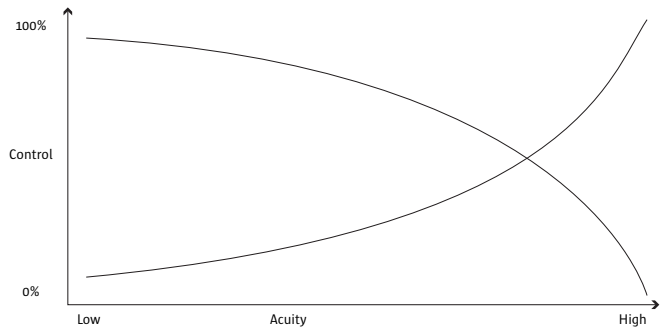


Figure 2. Acuity and Control

Failure to recognise that each individual has his or her own priorities and preferences for treatment can only undermine that treatment's success. Studies indicate that between 30 and 50% of patients do not take their prescription medication in full and that the annual cost of wasted drugs in the UK is around £100 million (DH, 2008). In a mental health context, Deegan and Drake argue that the common failure to take medications as prescribed often stems from the negative effects of prescribed medicines on facets of life that individuals consider important, such as their role as a parent or employee. Deegan and Drake describe these activities as 'personal medicine', recognising that everyday activities can have significant therapeutic value. A conflict between professionally recommended treatment and 'personal medicine' arises when medical professionals fail to consider the preferences

and life circumstances of individuals when making treatment decisions (Deegan and Drake, 2006).

For individuals whose lives are highly dependent on health-care, for example because they are oxygen dependent or use other medical equipment, the failure of the healthcare system to recognise their specific needs and preferences can not only affect the success of their treatment, it can significantly limit their quality of life by restricting their ability to play an active part in their families and communities. For example, individuals who are oxygen-dependent but do not have access to a portable supply, find themselves unable to travel to visit family and friends and also stay away from home, leading to isolation and poor mental well-being. (An example of the way in which a personal health budget can provide access to portable oxygen and consequently facilitate socialisation can be found in Brewis and Fitzgerald, 2010). Parents caring for technology-dependent children at home often find themselves unable to take their children on trips and on holidays because their agency provided carers are not permitted to work outside their home Primary Care Trust (PCT).

Writing recently in Health Affairs, Professor Robert Epstein put forward the following five reasons for creating more ‘patient-centred care’:

1. It is the right thing to do.
2. It leads to better care. Research has demonstrated that enabling patients to actively participate in all aspects of their care, such as choices about treatment and self-management, results in better adherence to medications and improved management of long-term conditions without increasing costs (Hibbard et al, 2004).
3. Patient-centred care improves well-being by reducing anxiety and depression and improving the ability of individuals to cope with adversity.
4. It is a vital tool for addressing disparities and inequity in access to care. Some kind of injustices and disparities demand increased sensitivity and personalisation.
5. It leads to better value for money, for example by contributing to patient safety by ensuring that

patients' behaviour, choices and needs are accurately communicated to clinical professionals.

(Epstein et al, 2010)

Over the last decade, self-direction has become an important feature of social care systems in the UK and in many other developed countries. Self-direction or self-directed care is an alternative way of delivering services that seeks to empower participants and their families by expanding the degree of choice and control that they have over the services they receive. It is based on the premise that giving individuals control, perhaps by the use of an individual budget for purchasing services, allows them to tailor care to meet their specific needs; draw on their assets as well as recognising that they need support; and is more effective at reconnecting them back into community life than traditional services - which often keep people trapped in segregated services.

One of the most consistent findings from international research on the impacts of self-direction in social care is that individuals who direct their own care are more satisfied with their care than those who receive services through a home care agency; in large part because they have access to services at the times they choose, provided by the people they choose and tailored to meet the needs and goals that they themselves identify. There is also good evidence that these improvements can be made without any cost increases and, in some cases, with cost savings (Alakeson, 2010; Tyson et al, 2010; Glasby and Littlechild, 2009; Glendinning et al, 2008). The success of self-direction in social care has generated interest in the possibility of extending self-direction into healthcare systems as one way of creating a more personalised and more effective service, particularly in the management of long-term conditions (Glasby, 2008).

This paper describes recent developments in self-direction in the NHS and in the Medicaid programme in the US. It presents early findings related to the impact of self-direction in health. It identifies implementation challenges for the NHS based on the early experiences of Personal Health Budget (PHB) pilot sites and finally highlights important areas where a shift in thinking is needed for self-direction to firmly take root within the NHS.

Self-direction in health in the NHS

In 2009, the UK Department of Health launched the first national pilot of self-direction in health in the NHS in England, testing what they named Personal Health Budgets (PHB). In total 64 Primary Care Trusts (PCTs) are involved in this three year pilot, of which 20 are taking part in an in-depth, controlled evaluation.

The recent health white paper, *Equity and Excellence: Liberating the NHS*, reaffirms government interest in PHBs, citing them as a means of promoting and extending public and patient involvement and choice in the NHS (DH, 2010a).

This was reaffirmed in the 2010 Comprehensive Spending Review in which the Chancellor announced an expansion of PHBs for children with disabilities, children with special educational needs and adults with long-term health conditions (HM Treasury, 2010). Paul Burstow, Minister of State for Care Services, described this approach as follows:

..personal budgets encapsulate what we [the coalition government] represent. Our single, radical aim: to change the relationship between the citizen and the state, to do less to people, and more with them. And to ensure Government steps back, making the space for people to lead the lives they want, how they want to. In health and social care, that means giving people real choice over their treatment; real control over how money is spent; and real power to hold local services to account.

(Burstow, 2010)

PCTs are developing PHBs for a range of diagnoses, including individuals:

- with mental health conditions
- with substance-abuse problems
- receiving continuing care
- using maternity services
- receiving end of life care
- receiving stroke services
- with diabetes

As part of the pilot, individuals are able to control NHS resources for certain parts of their care pathway and are able to use those resources in creative ways to meet their health needs. For example, an individual receiving intensive rehabilitation after a stroke may prefer, with the support of family members, to design an alternative rehabilitation package from the one available through his PCT. He may choose to employ personal assistants to help with personal care and mobility and a massage therapist to work with him to improve functioning and mental well-being, while maintaining the physiotherapy service he currently receives from the NHS.

Few restrictions have been imposed by the Department of Health on how money can be used. Pharmaceuticals and GP services are not included in a PHB. Alcohol, cigarettes, gambling, debt repayment and anything illegal are not permitted (DH, 2009). As of June 2010, there were at least 60 PHB holders and 9 pilot sites were able to offer a direct payment to individuals choosing a PHB, something that was illegal within the NHS before the 2009 Health Act. This means that they can offer individuals the choice of directly controlling their budget as cash. Sites that currently do not have the authority to offer a direct payment can use third parties, such as user trusts and social enterprises, to hold budgets on behalf of individuals or to allocate virtual budgets to individuals that continue to be held by PCTs. In principle there are in fact at least six ways of managing any individual budget as set out in Figure 3 (Duffy, 2010).

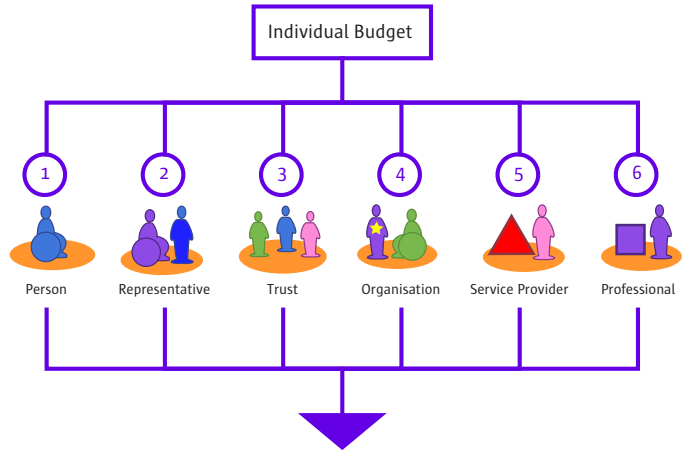


Figure 3. Tapered Control

The national pilot was pre-dated by a handful of interesting examples, including: an Individual Recovery Budgets programme run by Mersey Care NHS Trust, and a Community Integration pilot in adult substance misuse run by the Croydon Drug and Alcohol Action Team. Both programmes were based on a spot commissioning model in which small amounts of money are used by individuals to make one time purchases to improve their health, in addition to the care package that they already receive. It is common in public services that certain needs go unmet, even when individuals are in receipt of multiple services. This is largely because these needs do not fall within the purview of any one service and fall between the cracks. While these needs can be small, the inability to address them can be significant for the individual or family concerned. Spot commissioning can be an effective means of addressing these needs.

The Individual Recovery Budgets pilot conducted by Mersey Care NHS Early Intervention Teams involved 104 individuals over a twelve month period in spot commissioning for mental health. Purchases included computer equipment, gym memberships, clothing and transportation and average spending per client amounted to £545.50 (Coyle, 2009). The Community Integration pilot in Croydon involved 20 people, 8 with drug

and 12 with alcohol problems, each with a maximum budget of £1000 that could be used to reconnect individuals with their hopes, aspirations and ambitions through community integration. Purchases included educational courses, sewing equipment and tools (Colhoun, 2010).

Voluntary sector providers that work with the NHS are also starting to explore the possibilities offered by self-direction in health. For example, Macmillan Cancer Support has recently launched Macmillan Solutions, a pilot programme in which volunteers who provide support to individuals living with cancer and their carers are able to offer a small, flexible budget that individuals can use to improve their well-being in any way they choose (Macmillan, 2008). From 2005 a programme called Personalised Transition, based in Sheffield, has used individual budgets to integrate healthcare, social care and education resources for young people with complex disabilities leaving school (Cowen, 2010).

While we tend to think about individual budgets in the context of meeting individual needs, they can also be pooled to allow groups to jointly commission services in response to shared goals. For example, 10 young people receiving services from Solihull's mental health early intervention team have pooled their direct payments and set up a user-led social enterprise that commissions services on their behalf and on behalf of other young people in the early intervention service. Decisions are made by the 10 young people who form the organisation's board in consultation with other service users. Some of the organisation's money has been used to set up a weekly drop-in that is tailored to the needs and preferences of the young people involved and also provides a comfortable environment in which other services can be provided such as psychiatric consultations.

The development of a user-led social enterprise through pooled direct payments has positive spill over effects beyond the services that are commissioned, including the development of marketable skills among the young people on the board and the formation of strong friendship networks that extend beyond the early intervention service (Personal communication with Solihull user-led organisation, 2010).

Self-direction in health in the US Medicaid Program

Medicaid is the US public insurance system for those on very low incomes. It is jointly funded by state and federal governments and varies from state to state. Self-direction has become an established option in the delivery of home and community-based services in several states since a major evaluation of the approach in three states reported positive findings (Brown et al, 2007).

Home and community-based services are provided to children, working age adults and older people with mental health problems, learning disabilities and physical disabilities to prevent nursing home placement.

In some states, the range of services provided covers social care and some elements of healthcare, such as skilled nursing and long-term rehabilitative therapies including speech and language therapy and physiotherapy. In addition, a small number of states have initiated pilots that are designed to support individuals with serious mental health problems and children with behavioural problems in their recovery.

The first such programme, Florida Self-Directed Care (SDC) began in Florida in 2001. It currently serves 330 adults with serious mental health conditions (<http://flsdc.org>). Uninsured individuals who are not enrolled in Medicaid receive an annual budget of £2,213.76, while Medicaid beneficiaries who choose

SDC receive £1,159.72 because clinical services continue to be reimbursed by the Medicaid insurance system.

Participants can use their individual budgets to purchase clinical recovery services, recovery support services and recovery enhancements. Recovery support services are alternative services that are expected to produce the same results as clinical services, for example massage or weight loss programmes. Recovery enhancements are goods and services that are expected to enhance a person's integration into the community through employment, volunteering or socialisation. More recent programmes in Texas and Pennsylvania have built on the experiences of Florida SDC.

Box 1: Texas Self-Directed Care

Texas Self-Directed Care began in 2009 in the seven county region surrounding Dallas. As of September 2010, the programme had enrolled 110 participants with serious mental health conditions, each with a maximum budget of £2,560 per year to spend on goods, services, and supports for their recovery. People must be willing to leave their current services in order to join Texas SDC and they receive help navigating the program from an advisor who also has lived experience of mental health problems. Advisors are provided free of charge and budgets are approved by the programme director.

Participants are expected to spend 60% of their budget on traditional treatments such as psychiatrist visits, case management, group therapy and counselling. The rest of the budget can be spent on non-traditional goods and services such as gym memberships, transportation, education and employment. Legal expenses, clothing accessories, prescription charges and cosmetic services are prohibited. Purchases are made with a pre-paid credit card that makes purchases easy to track and reduces stigma for participants.

www.texasdc.org

Emerging evidence

It is important to note at the outset that existing evidence is limited, largely qualitative and does not come from controlled studies. Nevertheless, it is promising. Important new evidence will be generated by the evaluation of the Department of Health's Personal Health Budgets pilot programme and by randomised controlled trial evaluation of Texas SDC and of a similar programme for adults in Delaware County, Pennsylvania.

One of the clear early findings from self-direction in health is that individuals directing their own care purchase a far broader range of goods and services than would traditionally be provided by a healthcare system. Table 1 below shows the purchases made by participants in the Florida SDC programme in the Circuit 20 area of the state (OPPAGA, 2010). In large part, this diversity reflects the fact that individuals do not compartmentalise their lives into the silos created by public service systems. A long-term health condition can have a pervasive impact on a person's life.

According to a survey of over 2,000 individuals with chronic conditions in the UK conducted by the Picker Institute, 20% of respondents said that their condition largely or entirely restricted physical activities and 17% said that social activities were largely or entirely restricted. This was in contrast to 2% and 3% respectively for those without a chronic condition (Ellins and Coulter, 2005).

Conversely, health improvement can be pursued through activities that have little to do with traditional healthcare systems, such as education, physical exercise and socialisation. One of the strengths of self-direction is that, by virtue of disregarding bureaucratic boundaries, individual purchases can meet multiple goals that would traditionally be met by different public services.

Evaluations of self-directed social care programmes in the UK and US, for example, have shown improvements in self-reported health and reductions in adverse health outcomes, even when no healthcare services are being purchased. For example, mentally ill adults with physical disabilities in New Jersey were less likely to fall, have respiratory infections, develop bed sores or spend a night in hospital or a nursing home if they were directing their own personal care services than if they were receiving agency services (Tyson et al, 2010; Shen et al, 2008).

Type of Purchase	Amount (£)	% of Total
Transportation	7526.72	13%
Computers and accessories	6899.95	12%
Dental services	6662.59	11%
Medication management services	4897.87	8%
Psychotropic medications	4890.33	8%
Mental health counseling	4864.18	8%
Housing	4133.59	7%
Massage, weight control, smoking cessation	3017.13	5%
Utilities	1968.77	3%
Travel	1721.13	3%
Equipment	1615.88	3%
Clothing	1423.27	2%
Food	1390.25	2%
Crafts	1361.35	2%
Licenses/ certification	1253.35	2%
Entertainment (movies, eating out)	1216.12	2%
Vision services	1127.47	2%
Furniture	640.44	1%
Non-mental health medical	515.24	1%
Camera and supplies	477.47	1%
Education, training, materials	394.22	1%
Haircut, manicure, make up lessons	336.43	1%
Pet ownership	330.93	1%
Supplies and storage	282.12	<1%
Other	8.26	<1%
Total	58,965.40	100%

(Amount based on dollar/pound conversion rate on 31 May 2010. Therefore, individual items may not add up precisely to final total)

Table 1. Spending by 97 participants in Florida SDC in Circuit 20 in the first six months of fiscal year 2009-10.

The other important finding to be noted from the spending pattern shown in Table 1 is that 24% of total spending continues to be directed towards traditional mental health services: medication management, psychotropic medications and counselling. This indicates that individuals continue to value traditional healthcare services but choose a different balance between traditional and alternative services than the current system permits. A similar finding is emerging from purchasing patterns in the Texas SDC programme (Personal correspondence with Texas SDC Director, May 2010). Counselling is one of the top three purchases among participants in the programme. This is because the Medicaid-funded mental health system in the Dallas area is highly restrictive and does not provide access to routine counselling. Therefore, SDC participants are using their individual budgets to plug this hole in the traditional service system.

These spending patterns indicate that individuals can be sophisticated consumers of healthcare, choosing an appropriate balance of traditional and alternative goods and services and are not always prone to reject traditional treatment in favour of unproven alternatives. Concern that self-direction would lead to extensive use of unproven treatments is much greater in health than in social care because healthcare is more strongly rooted in a culture that supports the use of formal evidence to guide decision-making.

There is further evidence of individuals acting as active consumers in order to secure better access to services from the Cash and Counseling evaluation of self-direction in home and community-based services in Florida. Parents of medically fragile and technology dependent children proved themselves to be informed and active purchasers. They negotiated with providers of long-term therapies in the community to create more flexible packages of support than the Medicaid system was able to provide; swapped one therapy for another when they could see greater perceived benefit from the latter; and replaced skilled nurses with family members who were trained according to the specific needs of their child.

One mother described her experience of searching around for the best deal for her daughter as follows:

...for speech therapy I can get the therapist we want, we can get more therapy because we can negotiate the money, so she can get more hours of therapy with the same amount of money that we had before. With MedWaiver [Florida's Medicaid programme], we had to use the therapists they indicated.

(San Antonio and Niles, 2005)

Another strong emerging finding is that self-direction improves satisfaction with services compared to traditional service delivery (Alakeson, 2007a). A programme of family-controlled vouchers in Denver saw increased satisfaction and a reduction of 34% in the cost of hourly support (Block et al, 2002).

In a small, qualitative study of self-direction in mental health (Alakeson, 2007b), US participants attributed these improvements in satisfaction to the following:

- greater flexibility in meeting needs
- a more prevention-oriented, less crisis-driven approach
- greater access to support

Interviews conducted with participants in Mersey Care NHS's Recovery Budget pilot highlight the positive nature of the experiences of receiving and using a recovery budget for individuals in the early intervention service. This contrasts sharply with the negative language used to describe past experience of psychosis and the diagnosis of a mental illness.

One participant described his experience of having a recovery budget as follows:

I didn't even know about this organisation [the Individual Recovery Budgets programme] until I was informed about it and it was like for me it was sort of, I don't know, it was almost like a miracle to me at that time that I really needed something...that somebody and something was there and that I will never forget and since that holiday I've come back and I'm

a totally different person now because I'm more focused and more tuned into what I wanna achieve and what I wanna do.

(Coyle, 2009)

Findings related to the impact of self-direction on health and other life outcomes are very limited outside of the health 'spill-over effects' reported from self-direction in social care. One study of 106 participants in the Florida SDC programme reported that, on average, participants at the end of the programme spent a significantly higher number of days in the community than before entering the programme; scored significantly higher on the Global Assessment of Functioning scale; and were more likely to be in education and training (Cook et al, 2008). It is important to note that this is a pre-post study with no control group and, therefore, the findings are promising without being reliable.

A similar pre-post study of the Empowerment Initiatives brokerage in Oregon for adults with serious mental health conditions showed an 80% increase in the number of participants in employment after the first year and an 83% increase in the number of participants in education and training (Sullivan, 2006).

There is currently little reliable evidence on the costs of self-direction in health compared to traditional service delivery. Anecdotal accounts of the ways in which rigidities in the current system create fragmentation, duplication and waste, particularly at the boundary between health and social care, indicate significant room for improvements in cost effectiveness.

For example, the lack of integration between social care and NHS-funded Continuing Care (that is, free long-term care provided by the NHS) has proven to be particularly problematic. Individuals with well-developed, effective packages of support developed with an individual budget from social care suddenly lose any entitlement to direct their own support when they become eligible for NHS-funded Continuing Care. This creates major upheaval in people's lives, forcing them to sack existing staff and accept support from unknown agency staff.

One mother of a child with Batten’s disease who found herself in this situation commented on the disruption as follows:

...becoming 18 and going from children’s services into adult or from direct payments to Continuing Health Care should surely not mean changing a week that worked perfectly well for him with people he knew, trusted, and gained so much from. We do not feel replacement of these people by several strangers in our home is at all beneficial to L or us.

Family’s experience with Continuing Care described in communication with In Control

One robust cost-related finding comes from the Cash and Counseling evaluation in Florida which reported a 30% saving on private duty nursing costs for technology-dependent children in the experimental group, compared to the control group. Parents who were in control of their children’s care placed greater value on employing staff whom they could train to meet the specific needs of their child than on general professional training, hence the decrease in nursing costs (Brown, 2007).

While evidence is currently limited, the potential for improvements in health and in efficiency within the NHS is clear. In the case of residential and out-of-area placements, an individual budget could provide the means with which to develop an alternative, less costly package of care. This is well illustrated by Ali’s story, one of In Control’s early success stories with self-direction in health.

Box 2: Ali’s Story

Ali is a sixteen year old, physically disabled girl. Her family was struggling to cope with the stress of caring for her and the existing menu of local authority services was not able to provide an adequate solution. This could have resulted in Ali being transferred to a residential setting costing £170,000 a year. Instead, her PCT agreed to contribute £30,000 and her local authority £27,000 to an individual budget that Ali’s family uses to hire four personal assistants to help with her care. The budget allows the family to hire assistants with whom they feel comfortable and who have the specific skills to work with Ali (Alakeson, 2007a).

Efficiencies could also be created by using the flexibility and person-centred nature of an individual budget in a preventative way so as to reduce costs elsewhere in the NHS, particularly the costs of unplanned admissions and use of emergency services. For example, as part of Stockport Council's pilot for mental health, one service user was assessed for an annual individual budget of £35,000. Although this is much above average for the Council's pilot, it was seen as a cost effective investment when viewed from a preventative angle. The individual budget holder in question had spent 300 days in hospital in the previous 5 years and the alternative course of action would have been a low secure unit with an annual cost to the NHS of £120,000 (Putting People First Case Study, 2010).

The qualitative evaluation of the Individual Recovery Budgets pilot conducted by Mersey Care NHS highlights examples of purchases that prevented hospitalisation and school drop out and improved self esteem, community involvement and perceived mental well-being. One early intervention worker describes how a laptop and internet connection bought with an individual budget prevented an individual from being admitted into hospital by allowing him to remotely keep in contact with staff at a point when he could not bear face to face contact:

...on this occasion he didn't [go into hospital] and it was a totally different outcome. That person was able to maintain contact with ourselves, with other people and in that instance that person didn't come into hospital. Whereas given the risks and the concerns that we would have had in the set of circumstances, he would have done.

(Coyle, 2009)

Without the laptop, the individual would have been admitted to hospital given the perceived risk of him remaining at home alone and isolated.

Capitalising on cost savings may depend on effective targeting of individual budgets to individuals at risk of high cost service use. Effective targeting has been identified as a significant factor in the cost effectiveness of other interventions for long-term

conditions such as care co-ordination and disease management (Brown, 2009). Greater take up of predictive risk modelling in the NHS could provide a means of supporting effective targeting.

Implementing individual budgets in the NHS

The implementation of individual budgets in the NHS is still in its infancy but there are already several practical and policy questions that remain unresolved:

- The appropriate scope of an individual budget
- Developing a resource allocation system
- Engaging professionals
- Providing support for individuals

The appropriate scope of an individual budget

While it has always been possible to mix self-direction and agency-delivered services in social care, the tendency has been for individuals to take control of the entire value of the social care resources available to them in any one year. This will not be the case in the NHS. As a universal service, an individual's interaction with the NHS is broad, spanning GP services, pharmacy, acute care and emergency services. Much of this interaction will continue as before and has been explicitly ruled out of the PHB pilot programme. To include all parts of NHS care in an individual budget would mean shifting the entire risk for healthcare onto the individual.

Individual budgets will only cover an identified part of a care pathway where individual experience, expertise and control can make a real difference to the delivery and outcomes of care. Pilot sites are currently experimenting to identify the appropriate scope but most are erring on the side of caution, focusing on support services and excluding clinical care.

In order to understand where individual budgets were likely to add the most value, Dr. Paul Hodgkin, Chief Executive of Patient Opinion, first suggested the model shown in Figure 4 (Duffy et al, 2009).

This model has been further developed by Dr Simon Duffy and Vidhya Alakeson into a model which analyses interventions against two criteria:

1. The ideal point of control – some interventions depend heavily on individual preferences and expertise. Others require the citizen to give over control to another person (the professional) – e.g. you cannot do surgery on yourself.
2. The degree of clinical evidence available to support the effectiveness of the treatment – e.g. a particular operation may be the most effective way of dealing with cancer at a specific stage

The application of these two axes gives rise to four quadrants:

- A – Professionally Managed Treatment – these are treatments that require professional control and in which we can be confident because of strong evidence. They give us good reason to put ourselves in the hands of others.
- B – Citizen Managed Treatment – these are treatments that benefit from some professional definition, for there is reliable evidence that they are effective, but are most effective when we are in direct control and can decide when they are delivered and by whom.
- C – Professionally Managed Experiment – sometimes we choose to put ourselves in the hands of others, even if there is little evidence to support a treatment – perhaps because there are few other options.

- D – Citizen Directed Solutions – in many situations we need to be in control of both defining and managing solutions to meet our own needs – clinical evidence may be weak, but only because such solutions are outside the zone of clinical data.

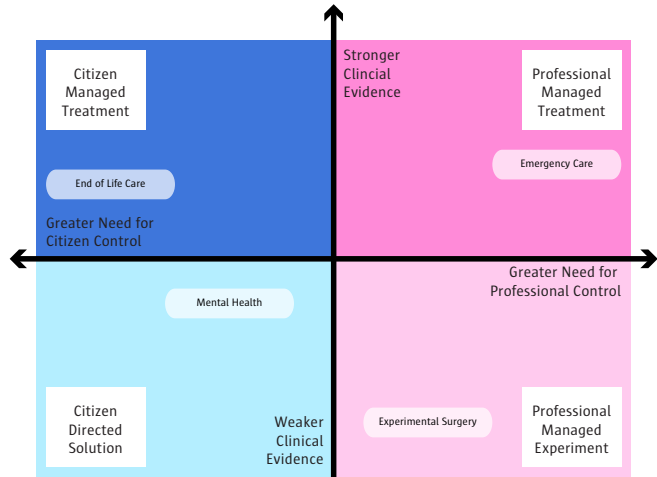


Figure 4. Health Decision-Making

What this model suggests is that when we consider funding models for healthcare we will need to take seriously questions of evidence and control. There are many possible funding models and these may apply in all four zones (e.g. vouchers, grants, tariffs, menus – as well as individual budgets). However individual budgets are actually most likely to be useful in zone D – where clinical knowledge and professional control is weakest. This observation may cause confusion – it may lead us to conclude that if clinical knowledge is weak, and the role of professional control is limited, then there is no significant need and hence no entitlement to support. Nothing could be further from the truth.

If someone is managing a complex impairment, a chronic health condition, severe mental health problems or even managing as his life comes to an end, what it takes to have a decent life will depend upon real factors that are outside the scope of current clinical knowledge: but this does not make the needs any less real nor the value of any help less significant.

In fact we could go further and observe that using this model might encourage professionals and policymakers to recognise that individual budgets (and other models which take seriously the active contribution of citizens to their own health and wellbeing) should begin to more seriously challenge our understanding of health and evidence. For instance, if a woman with a complex health condition is able to put air conditioning in her house and hence reduce her admissions to hospital then this woman has created evidence for an effective treatment.

Our understanding of what helps to improve health is not static and the use of individual budgets is actually a mechanism for enrolling citizens in wider learning about what is effective. It is a tool for innovation, research and increased clinical expertise. Individual budgets should not be seen as somehow taking resources 'out of' the health system, instead we should see individual budgets as enabling us to develop a richer and more accurate picture of the real factors that underpin our health and independence.

This model also suggests that policymakers need to avoid simplistic notions of choice and control or the desire for simplistic funding reforms. We need to learn much more about how best to give control back to citizens in a system whose default setting has been professional control. Sometimes this will require degrees of regulatory control, including the use of vouchers or tariffs; however there seems to be much more room for the use of individual budgets or grants – with full flexibility in many areas.

Much of the early evidence, even if still limited in scale, does seem to demonstrate the power and effectiveness of enabling the flexible use of often very modest levels of funding. Moreover, the likelihood of making significant improvements in cost-effectiveness or of individual budgets having a significant impact on the NHS as a whole will depend on those budgets having a broad scope and on individuals having choices over clinical treatments, as well as support services. For example, in the mental health context, there seems no reason to stop an individual using an individual budget to access privately-provided psychological therapies as well as a range of recovery support services.

Developing a resource allocation system

At a basic level, a resource allocation system is any system that assigns a budget to a certain level of need. This allows individuals to know at the outset how much money they will be entitled to and this enables them to develop their own personal plan. This improves transparency in the whole system, increases fairness and makes planning more effective because people begin planning knowing how much they have to spend. The concept of a resource allocation system (RAS) was developed in social care (Duffy, 2005) and sought to overcome much of the inequality in funding for different populations that had come to characterise adult social care.

With the introduction of personal health budgets, pilot sites have adopted different approaches to identifying the value of individual budgets: sites such as Doncaster have developed a resource allocation system for those mental health supports that are part of its personal health budget pilot; others are cashing out existing packages of care; others still are focusing on one-off purchases for which a resource allocation system is not necessary.

Work in Yorkshire and Humber has focused on developing a resource allocation system for personal health budgets for mental health based on the NHS payment by results tariff. The region is taking the lead for the NHS in England in developing a set of national tariffs for mental health through the care pathways and packages programme which tries to define an appropriate level of resource (and best practice pathways) for individuals with particular patterns of need. This can be seen as a RAS by a different name and provides a strong foundation on which to build personal health budgets (Duffy, 2010).

Payment by results is a central plank of the NHS and will be strengthened under the proposals in the new White Paper as a means of ensuring fair competition for providers entering the NHS. Where possible, building on the tariff could create greater

acceptance for the use of individual budgets in the NHS, rather than attempting to introduce an entirely new system that will take time to develop and gain acceptance.

Engaging professionals

While some of the early experiments with individual budgets were led by acute trusts, the national pilot has been led by Primary Care Trusts. This is problematic in light of the recent White Paper, *Equity and Excellence: Liberating the NHS*, which proposes to transfer most commissioning responsibilities to consortia of GPs. While PCTs will be in place until the end of the current PHB pilot phase, they will be scrapped by 2013 and are likely to face staffing shortages and other constraints on innovation in the interim. However policy leaders are proposing that the use of individual budgets is increased.

The success of individual budgets depends on all the relevant actors being engaged – users, professionals, carers, local authority and NHS commissioners and the voluntary sector. Current changes to the commissioning landscape in the NHS create a pressing need for professional engagement in the ongoing development and implementation of individual budgets.

Engagement will need to focus not only on GPs as commissioners and providers but also on the full range of professionals involved in secondary care and community services. In some cases, NHS foundation trusts may decide to offer individual budgets as a tool for shared decision-making and patient engagement within an existing service, such as end of life care.

It is not necessary for the development of individual budgets to be led by commissioners – they can be useful to any professional who wants to drive up the quality of care and the outcomes associated with their specialty.

Providing support for individuals

It is a common concern that individual budgets, as with other kinds of choice in the NHS, will exacerbate inequality as individuals who are better educated and have stronger support networks will be better able to make choices. To ensure that individual budgets allow everyone to meet their needs as effectively as possible, it is important that individuals have access to support when deciding how to spend their budget.

Evaluation of the London Patient Choice pilot found that there was no difference in the uptake of choice according to social class, level of education or ethnicity in large part because the pilot employed 20 patient care advisors to be a single point of telephone contact for people who were choosing where to undergo their surgical treatment (Dawson et al, 2004).

Furthermore, lessons from personalisation in social care highlight the value of the conversation around developing a support plan alongside the budget. The budget allows individuals to make choices. But the planning process helps them identify and articulate how they want their life to be different and the different choices they want to make (Brewis and Fitzgerald, 2010).

In contrast to other countries such as the US, the UK government has never had a consistent stance to the provision of support in the development of personalisation in health and social care in England. Ensuring that everyone who wants support in using an individual budget has that support is critical. This is not to say that everyone will need support. There should, however, be no assumption that a professional is required to provide support, as this is likely to add to the costs of self-direction and threaten cost neutrality within traditional NHS services (Duffy and Fulton, 2009).

Peer support can be particularly powerful because peers have community knowledge that professionals do not, such as where to get a cheap meal, and they provide hope and inspiration to

budget holders by virtue of their lived experience. For example, each participant in the Texas SDC programme for individuals with serious mental health conditions has access to a recovery coach to support them in deciding how best to use their budget. All recovery coaches are individuals with a lived experience of mental health problems. The programme also brings participants together every month to create a peer network among participants that can provide additional support.

If there is one overarching message in relation to the implementation of individual budgets, it is that existing NHS processes must not be allowed to distort the purpose of individual budgets. The sustainability of self-direction will depend on a proportionate response from the NHS in terms of management and governance processes. This is not currently the case. For example, Primary Care Trusts often use risk panels to make decisions about exceptional expenditure requests. In some PCTs, these same panels are being used to approve small one-off purchases being made with an individual budget. In many cases, the cost of the panel is significantly more than the whole budget in question.

Similarly, many people who receive secondary mental health services find that the current bureaucracy that is built in to the Care Programme Approach seems to be hard to reconcile with the more empowering approach demanded by individual budgets. As a result, individuals can end up with two plans both of which notionally deal with their care and support needs – one developed by professionals, the other by the person. If the processes put in place to manage individual budgets are not streamlined then the entire approach will become ensnared in bureaucracy and progress will stall.

Transforming the culture of the NHS

The practical and organisational challenges of self-direction in health are dwarfed by the cultural challenge of moving towards a more empowering approach. An important shift in current thinking is required in three areas:

- respecting the expertise of patients
- focusing on health outcomes
- erasing the health-social care boundary

Respecting the expertise of patients

Healthcare is a technically complex field in which technological and pharmaceutical innovation is rapid. The skills and knowledge of professionals will remain important, even if individuals choose to take greater control. Furthermore, professionals will continue to play a role in clinical governance.

However, healthcare professionals have tended to neglect the views of patients, despite general agreement that patient-centredness is a feature of a high quality healthcare system (Institute of Medicine, 2001) and clear evidence that patients want to make decisions about their own care. According to the Picker Institute, across Western Europe 75% of patients believe either they alone, or they with their doctor, should be deciding on the appropriate course of care and treatment

(<http://www.pickereurope.org/sharingdecisions>).

The emergence of individual budgets should be seen as ‘tipping the balance’ of power from professionals towards patients, while maintaining the central importance of the partnership between patients and professionals (Brewis and Fitzgerald, 2010). Working as equal partners with individuals and families rather than on their behalf will be a challenge for many healthcare professionals who have not been trained in this way. For example, where there is a conflict between individual preferences and clinical judgement, an individual’s behaviour is often described as ‘non-compliant’ rather than being perceived as the exercise of individual choice and preference.

A central part of achieving partnership will be to shift professionals away from seeing individuals receiving services purely in terms of illness and deficits, and to focus on their assets and expertise. Don Berwick, an internationally recognised leader in healthcare quality improvement and the current Administrator of the Centers for Medicare and Medicaid Services in the US, recently argued for patient and family-centred care to be a dimension of quality in its own right and not just through its effect on health status and clinical outcomes. He went on to state that the implication of this is that patient choices may sometimes trump evidence-based care (Berwick, 2009).

Focusing on health outcomes

The second big change that will be necessary to support individual budgets is to shift the focus of the NHS from services to outcomes. This is in line with proposals in the current White Paper to create an NHS outcomes framework. It is well established that health is driven by a range of things that have little to do with healthcare, including poverty, housing, nutrition, even education.

However the principle focus of the NHS has not been on promoting and maintaining health but on the provision of health-care to treat illness. This in turn has led to the even more perverse consequence that it may not be considered appropriate for the

NHS to spend public resources on things which promote health – but which are not viewed as health care.

In *Turning the World Upside Down*, Nigel Crisp, former Chief Executive of the NHS, argues that one of the many things that developed health systems could learn from poorer countries is the way in which they deal with health as part of people's lives and not as something completely separate. He identifies six features (see box 3 below) that characterise the approach to health adopted in many low and middle income countries (Crisp, 2010). Interestingly, these features have much in common with self-direction as an approach and far less in common with traditional approaches to care in the NHS.

Box 3: Approaches to health

Six defining features of the approach to health in low and middle income countries:

1. Social enterprises use business methods to achieve social ends
2. Empowering people means helping them become economically independent as well as having rights and a voice
3. Health is dealt with as part of people's lives and not as something completely separate
4. Health workers are trained to meet local needs and not just for the professions
5. Public health and clinical medicine are brought together
6. Best use is made of the resources to hand

Individual budgets start from an individual's identified health goals and impose few restrictions on how these health goals are met. The upshot of this orientation towards outcomes is that NHS resources can be spent on goods and services that have previously had no place in the NHS, for example computers, companion animals and gym memberships. Commissioners will

need to adjust to this shift and develop ways of judging performance based on whether an individual budget is meeting an individual's identified needs, irrespective of which services he or she chooses to use.

Erasing the health-social care boundary

The third area where new thinking will be required is in the relationship between health and social care. One of the unintended consequences of a greater focus with individual budgets on outcomes rather than services has been to expose once again the lack of a clear rationale for the divide between health and social care.

Department of Health guidance on direct payments in the NHS clearly states that the divide between the two services does not need to be maintained if disregarding it would improve an individual's health and wellbeing.

In some cases, it may be sensible for a PCT to agree a service which would normally be funded by social care, or another funding stream. If that service is likely to meet someone's agreed health and wellbeing outcomes PCTs should not refuse to purchase this because it has been traditionally commissioned elsewhere.

(DH, 2010c)

The development of personalisation to date has mirrored the bureaucratic silos it was designed to overcome, with 'personal budgets' developing alongside 'personal health budgets' in many parts of the country with little integration between the two. This echoes findings from the Individual Budgets Pilot Programme where sites struggled to integrate different funding streams, such as Access to Work, Disabled Facilities Grants and the Independent Living Fund with adult social care, because national legisla-

tion governing each funding stream limits the extent to which funding can be used flexibly at a local level (Glendinning et al, 2008).

For individuals this kind of rigidity makes no sense. They do not recognise the distinction between different funding streams such as health and social care and do not categorise their needs accordingly. For example, an individual may choose to use her personal health budget to go swimming at the local leisure centre in order to reduce her isolation. The same activity will also improve her health. But, which funding stream should pay for it? Furthermore, with public spending severely constrained, perpetuating waste and duplication between services is unjustifiable.

Next steps for national policy

There was tremendous resistance to the idea that individual budgets had any role to play in healthcare in the UK. However the combination of positive progress in adult social care and the enthusiasm of some policy leaders led to the limited testing of this approach within the Personal Health Budget pilots. There have been promising signs of progress from within these pilots; but their limited scale and highly constrained nature places limits on any success they might have.

The new coalition government has expressed its support for further testing of self-direction in strong terms. However it is easy to identify many obstacles to progress:

1. The termination of PCTs as commissioners leaves a strange void at the heart of the Personal Health Budget pilots and there is no clear professional leadership that will continue the real testing and implementation of these ideas. GPs are understandably preoccupied with the basics of setting up consortia and managing an £80 billion budget. It seems that central government is wishing the end, but has abandoned any consideration of the means to that end.
2. There seems to be little willingness to acknowledge the risks for professionals that arise from self-direction and individual budgets for existing services. There is

no doubt, if the conditions are right, that citizens can make good decisions about how to meet their own needs. There is also no doubt that these decisions will be different than those the current system makes for them – not always radically different, but different. If this is the case, then many organisations and professionals will naturally fear a loss of funding. This will impact many professions differently, some will even recognise that they might gain – for instance, independent midwives may see this new system as a route to providing support to more mothers at home. However, if individual budgets are working, then change and loss for some is inevitable. This is not only true for professionals working directly for people, it is even more so for commissioners and those who currently manage funding streams on behalf of the whole community. It will take real leadership and a willingness to directly engage the professions if further headway is to be achieved.

3. National policymakers seem unwilling to consider the logical consequences of their enthusiasm for individual budgets. The boundary-line between social care and healthcare, which has always been highly questionable, will inevitably breakdown if people are empowered to make the best and most rational decisions for themselves. However efforts to use individual budgets to integrate diverse funding streams may unravel in the face of the vested interests of the organisations who manage those funding streams. There seems to be no effort on the part of policymakers to clearly define the place of individual budgets as part of a continuum of individual control: how they are linked (or not) to personal income, benefits, taxes or means-testing or the scope for integrating different kinds of government support through individual budgets. This policy incoherence will undermine the willingness of professionals and organisations to make the radical and difficult changes required of them.

There is one particular policy issue which stands out as demanding clear leadership from the centre. It is vital that personalisation takes a whole-person approach and that individuals do not find themselves having to manage several individual budgets, each designed to meet different, but overlapping, sets of needs. Some people are already in this peculiar situation, managing three different bank accounts for three separate allocations: one from the NHS, one from adult social care and one from Supporting People.

To ensure that personalisation in health and social care is integrated around the needs of individuals not bureaucracies, the following principles should be adopted by central government:

1. Individuals must be guaranteed an integrated process, this means:
 - a single health and social care assessment
 - an integrated care and support plan to meet the full range of their health and social care needs
 - a joint review process to assess whether their plan is meeting their needs
2. Resource allocations from the NHS and social care must be integrated within a single individual budget. Ideally, there should only be one resource allocation process. But if this cannot be achieved in the short-term, there must be a commitment to ensuring that allocations are integrated at the level of the individual.
3. Other processes that underpin personalisation such as risk management, clinical governance and contracting have to be aligned between the NHS and local authority social care services in order to support an integrated budget.
4. Funding should be integrated into one bank account and individuals should be permitted to integrate these funds with their personal income in order to reduce unnecessary barriers to meeting individual need.

Largely this kind of personalised integration is absent from local reforms. But there are glimmers of hope in a few parts of the country where individuals receiving a Personal Health Budget and a 'personal budget' from adult social care - both as direct payments - are now able to receive a single, integrated payment.

Integrating health and social care has been a policy goal for decades. Some progress has been made through mechanisms such as joint commissioning and pooled budgets; but formal joint expenditure accounted for just 3.4% of total NHS and social care spending in 2007/8 (Audit Commission, 2009). Given the clear limitations of a top-down approach, it may be that integration is better pursued from the bottom-up by creating a seamless process for each individual that follows one simple rule: **one person, one budget.**

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