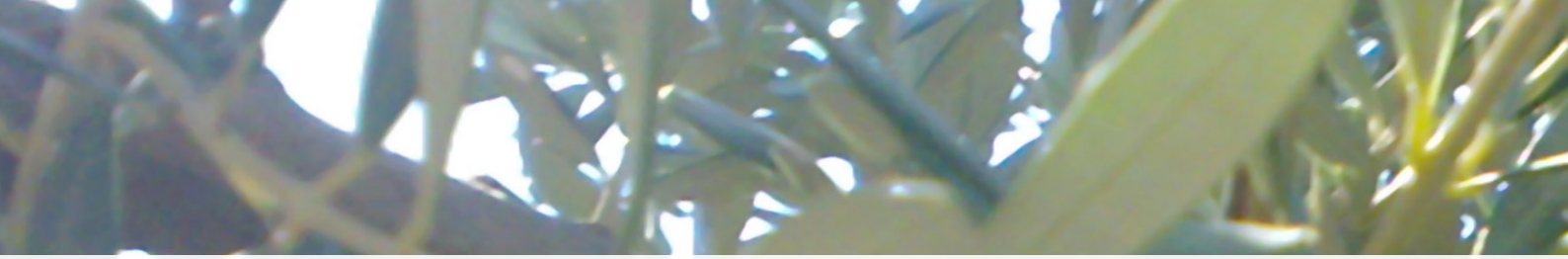

Health Efficiencies

THE POSSIBLE IMPACT OF PERSONALISATION IN HEALTHCARE

by **Vidhya Alakeson** and **Simon Duffy**

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Published by **The Centre for Welfare Reform**

With support from
Yorkshire & Humber Joint Improvement Partnership

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Publishing Information

First published October 2011

Health Efficiencies is published by The Centre for Welfare Reform
www.centreforwelfarereform.org
Designed by Henry Iles: www.henryiles.com
56 pp.
ISBN download: 978-1-907790-23-2

Thanks to:

For sharing their personal stories,
Katrina Ellershaw, Ruth McFall

Sheffield City Council, in particular Jeanette Thompson,
Anita Winter, Josie Bennett and Hannah Boneham

Barnsley Metropolitan Borough Council, in particular
Martin Farran, Wendy Lowder

Barnsley PCT, in particular Margaret Kitching

NHS Sheffield, in particular Kate Gleave

North East Lincolnshire Care Trust,
in particular Leigh Holton

Yorkshire & Humber SHA, in particular Andy Pilling

This project was funded with support from the
Yorkshire & Humber Joint Improvement Partnership.

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Summary

Introduction

The NHS has been a central force for promoting improved health within the UK since 1945. Today every citizen can expect to receive a high level of emergency care and access to most modern treatments for curable illnesses and conditions. Moreover services are provided in a way that is broadly equitable and, by international standards, relatively efficient.

However the very success of this approach can blind us to the changing needs of our society. Our success at saving and extending lives means that in the future our focus will have to shift to improving lives. But this can only be achieved by working in partnership with people living with impairments and long-term conditions that the NHS can continue to improve. This means making a shift towards personalisation.

The imperative for personalisation should be reinforced by considering its potential efficiencies in healthcare. The significant efficiencies in adult social care (about 9%) could be exceeded in healthcare for people with long-term conditions. Personalisation draws upon the skills and natural motivation of people themselves, an asset that the current system is not organised to respect or support.

Personalisation

Personalisation is not just about Individual Budgets. It involves an interlocking set of reforms to culture and systems and it is important to implement those reforms in a way that is sensitive to the different organisational cultures that exist within healthcare. Changing terminology or just changing organisational systems on their own will not lead to improvement or efficiency.

Individual Budgets

However Individual Budgets (currently called Personal Health Budgets (PHBs) within the NHS) will be particularly useful in some areas of the healthcare system where they can improve efficiency by making healthcare more self-directed, responsive, creative and effective. The particular merits of Individual Budgets suggest that they will improve healthcare efficiency in the following six areas.

1. End of Life Care

Most people die in hospital, although most people say they would rather die at home. Moreover recent research shows that 40% of those who did die in hospital could have died at home. If systems were redesigned, and Individual Budgets were integrated into a new system, it is possible that £420 million would be saved in England.

2. Mental Health

In 2007 £22.5 billion was spent on mental health services - much of this was in the form of hospital admissions. However the use of individual budgets for people with mental health problems in the UK and the USA has led to significant reductions in the use of more expensive hospital services. Personalised support seems to be consistent with increased prevention, control and community inclusion - all of which are good proxies for improved mental health.

3. Out of Area Placements

People often end up in expensive out of area placements because local systems have not the flexibility to develop suitable personalised responses. This leads to people being over-supported and cut off from their own communities. There are currently 10,000 people with mental health problems supported in out of area placements and research suggests that at least 5,000 of these are without any significant clinical justification. The use of Individual Budgets as part of an intentional programme to bring people back to their own communities with personalised support could save £100 million per year.

4. Continuing Healthcare

Over 50,000 people are using continuing healthcare packages at a cost of over £2 billion nationally. However many of those packages fund expensive residential care packages at costs that can be as high as £175,000 per year. Moreover the existing national pilot programme has already demonstrated savings which are running at 20% of previous costs.

5. Frequent Users

22% of emergency admissions among frequent users are for conditions that can be managed outside hospital. In theory, these could be avoided, saving £500 million a year. Personalised support which enables people to adapt their environment, lifestyle or to create more responsive emergency arrangements, will be the key to helping people manage their own long-term health more effectively.

6. Integrated Care

There are clear organisational benefits to integration - Torbay Care Trust saved £250,000 in its first year - but these could be dwarfed by an even more radical and integrated approach to meeting needs - focusing on the most effective way of meeting a need, rather than whether the 'style' of meeting that need is through 'healthcare' or 'social care'.

Conclusion: Implementation is Everything

There is good reason to believe that personalisation in healthcare could deliver potentially significant efficiencies. If implemented effectively it could deliver a saving of £1.85 billion from the current cost of long-term conditions (£20 billion). However these efficiencies will not be realised unless:

- **Clinicians begin to lead the development of the necessary reforms**
- **Efficiency is designed into the reforms from the beginning of implementation**
- **Personalisation is made user-friendly, easy to deliver and manage**

Too much of the debate about personalisation has been dominated by an assumption that personalisation is simply a set of defined processes that can simply be imposed upon the NHS. In reality personalisation must be a process of reform and improvement that must come from within the NHS itself.

Health Efficiencies

THE POSSIBLE IMPACT OF PERSONALISATION IN HEALTHCARE

Introduction

Globally we are at the beginning of a new phase in the development of healthcare and healthcare systems. There is much that is still unclear and the timeframe for change is uncertain. But important trends suggest that the current certainties and structures will have to be re-examined.

The primary focus of this report is the possible efficiencies that can be found if we applied some of the approaches and technologies that sometimes go by the name of 'personalisation' to healthcare. But it is important to see this possible development in its broader context.

Modern healthcare systems have developed into hierarchically organised systems of expertise and specialist knowledge. In Western welfare economies these systems have been underpinned by significant state support (often around 10% of the whole economy, around 20% of public spending). This combination of scientific expertise, professional organisation and universal entitlement has been one of the great success stories of the modern welfare state.

But it would be complacent to assume that these systems can remain static in the face of the following factors:

Health - Thanks to a mixture of improved healthcare and wider environmental factors, health and life expectancy have improved. In fact, in developed countries improvements in life expectancy have largely slowed down. The emphasis is shifting from living longer to living better. Increasingly this means an important part of the population will live much longer, but will have to manage their own health condition to get the most out of life.

Technology - Technological improvements have not slowed down. Information, equipment and communications are all becoming smarter, speedier and more effective. Increasingly these changes enable people to do things for themselves, more effectively, because more difficult and technical problems are resolved 'behind the scenes'.

Culture - Modern societies are less deferential and more democratic. Doctors and other healthcare professionals are still respected; but many of those who use their services do not see themselves as 'inferior' to their doctor. They may also seek advice from friends, the internet or do their own research. In an increasingly service-focused economy people expect increased levels of accountability and redress.

Economy - Current economic structures are coming under strain. The earlier phase of post-war industrial development that largely funded welfare solutions seems to be coming to an end. The modern economy is global with high levels of productivity plus high levels of insecurity. At an individual level this is reflected in increasing numbers of people finding themselves dependent on state funding, unemployed or in very insecure forms of employment. It is increasingly difficult to increase spending on the welfare state without putting global competitiveness at risk.

This is the context for thinking about personalisation in healthcare: not as some new government initiative, but as a thoughtful response to wider changes that will touch all of society and will inevitably change how healthcare develops.

Personalisation in healthcare is the attempt to better connect healthcare systems to the real capabilities and preferences of individual citizens. Its efficiencies are the result of making better use of the natural energies and skills of people and communities.

Quality Innovation Productivity and Prevention (QIPP)

These wider issues are reinforced by current policy and economic priorities. The NHS faces a spending gap between financial year 2011 and financial year 2013 of between £15 billion and £30 billion, depending on estimates. This will have to be made up through efficiency savings. To support the NHS locally to deliver efficiency savings, the Department of Health launched the Quality, Innovation, Productivity and Prevention (QIPP) programme in 2009. The purpose of the programme is to support commissioners and providers to develop service improvement and redesign initiatives that improve productivity, eliminate waste and drive up clinical quality (DoH, 2010).

QIPP has 13 priority work streams that fit into three categories: commissioning and pathways, provider efficiency and system enablers. The recent health White Paper (Equity and Excellence: Liberating the NHS) provides continuing support for the QIPP programme, arguing for renewed urgency and a greater focus on general practice leadership, reflecting the shift in commissioning responsibilities from PCTs to GP consortia by the 2012 financial year.

Individual budgets in health and social care can make an important contribution to to the QIPP programme by creating a more patient-centred, responsive NHS in which care reflects the specific needs and preferences of individuals. Individual budgets have the potential to shift the focus of spending towards prevention; engage individuals in their care; exploit their creativity and the expertise of lived experience; and break down the narrow silos of public services that lead to fragmented responses to need at the same time as duplication between services.

Personal Health Budgets

The Personal Health Budgets (PHB) pilot was also launched by the Department of Health in 2009 (http://www.dhcarenetworks.org.uk/PHBLN/). A PHB is the term currently given to an individual budget offered within the NHS, and the main characteristics of a PHB do not significantly differ from individual budgets.

Around 70 Primary Care Trusts (PCTs) are involved in piloting PHBs over three years, of which 20 are taking part in an in-depth, controlled evaluation. A number of evaluation sites have been given the authority to offer a direct payment. Pilot sites are developing PHBs for people with various conditions, including individuals with mental health and substance abuse problems, individuals receiving continuing care, maternity services, end of life care, stroke services and those with diabetes.

This paper builds on earlier work on the contribution of PHBs to the QIPP agenda and identifies six areas where there is significant potential for personal health budgets to contribute to efficiency in the NHS (Alakeson, 2010). It attempts to quantify the nature of the

efficiencies that could be made. The findings presented here are by no means conclusive and should be taken as indicative only.

The paper examines the following areas:

1. End of Life Care
2. Mental Health
3. Out-of Area Placement
4. Continuing Healthcare
5. Frequent Users
6. Health & Social Care Integration

In each case we will provide some detail on why this area has been selected as a potential site for greater efficiency, but overall it is perhaps obvious that all these areas of healthcare are not those areas where treatment involves surgery, prescriptions or other professionally controlled therapies.

The purpose of this paper

This paper has been written in order to help healthcare professionals and leaders in healthcare systems to think about the value of personalisation in healthcare. It was commissioned by the Yorkshire and Humber Joint Improvement Partnership and, therefore, the data and case studies focus on that region. But the information is intended to be nationally applicable.

The paper begins with an introduction to personalisation and the range of tools that can support personalisation in healthcare, including PHBs. This is intended to give healthcare professionals and leaders some background to the concepts before addressing the specific issue of efficiency.

However, the paper is not intended to be all encompassing. Its special focus is:

- What role, if any, should Personal Health Budgets or Individual Budgets play in healthcare
- Where these ideas are useful what kinds of efficiencies might be produced
- What has been achieved already in this field, particularly in Yorkshire & Humber

The authors are very clear that this is an emerging field and that there is much that we simply still do not know. However we do believe that there is enough evidence to suggest that leaders in healthcare systems should be keen to pilot and develop these ideas and, in particular, to make sure that they are effective by being clear (a) where they will work best and (b) how these new approaches are best implemented.

Personalisation

Personalisation is not all about Personal Health Budgets or Individual Budgets. In fact, to simply focus on financial systems is to fail to understand the purpose of these reforms and their likely impact on financial systems. Personalisation is an effort to rethink the relationship between welfare systems and citizens. Individual Budgets and other similar innovations can be useful - but they are simply a means to an end, and they only have value in the right context. It is first important to understand the purpose of personalisation.

A better way of understanding personalisation is through the recognition that we each shape the quality of our own individual life. We each have a personal inheritance (our gifts and our weaknesses) and we each live life in a wider environment that presents us with opportunities and obstacles. This does not mean we are ever in complete control of our lives or our destinies. Illness and death are two of the most potent reminders of our own limitations. However, neither can afford to take the individual out of the picture. We have our own life to live - each in our own way. We shape our lives using both what is within us, and what is available to us in the world.

One helpful way of thinking about this relationship between our own personal authority and the constraints upon us is to use the Real Wealth Model (Murray, 2010). In the Real Wealth Model we can distinguish five different factors that influence the outcomes we achieve - including our health outcomes:

1. **Strengths** - Each of us is endowed with a particular set of strengths and weaknesses. As modern genetics develops we can even see the traces of some of these within our own DNA. However these strengths go far beyond the physical and include our skills, our interests and even our needs. Traditional healthcare has been particularly focused on our deficits rather than on our strengths But we have many strengths from our physical strengths to other talents and gifts. Even our preferences and our needs are a form of strength because they give us our own unique personality.
2. **Relationships** - One of the most important guarantees of good physical and mental health is to have friends, family and people who love us. And when things go wrong or when we are sick or suffering then families are usually the most important source of support. Recent UK estimates are that the care and support given by family and friends is six times greater than care from paid staff and professionals.
3. **Community** - Most of what we want to achieve is only achieved to the extent that we are able to access appropriate opportunities from within our community. Work, education, contribution and personal expression are all forms of community action that rely on the existence of community opportunities. Sometimes healthcare systems can isolate people from valued community opportunities. Individuals take on the identity of service users rather than that of community members and citizens.

4. **Control** - Our ability to access the community, build on our relationships and use our individual strengths is all dependent upon the resources that give us control over our own destiny. If we lack the means to get where we need to be and to do what we need to do then this restricts our ability to achieve our goals. Moreover individual control and autonomy is often correlated with better mental health.
5. **Resilience** - Perhaps the most important factor that determines the ability of an individual to achieve good outcomes is their own sense of personal resilience, their attitude, their ability to see and value positive opportunities and to not be overcome by difficulties and problems. We might also think of this as hope.

These five dimensions are the dimensions of our Real Wealth and they are expressed in the diagram at Figure 1. We can improve our Real Wealth. We can also help improve the Real Wealth of other people, but there will always be limits and constraints. This model helps us to remember that a good life is not a function of one simple thing (we need more than money and more than good health). But is also reminds us that a good life is how we each, individually, make sense of and combine these different elements. We cannot be 'given' a good life - **we must make it for ourselves.**

Figure 1. The Five Dimensions of Real Wealth

Personalisation starts from this perspective - the perspective of the person living their own life, but as part of a wider community of friends, family and fellow citizens. However this analysis also offers a useful perspective on many public services.

If good outcomes are achieved by active citizens making best use of their Real Wealth then this raises a set of important questions for all public services, especially healthcare services:

- Do services recognise and support the strengths of the individual, their own particular interests, preferences and abilities? Or do we see these individual factors as threats or distractions?
- Do services value family and friends as partners in their work? Or do we use the professional-client relationship as a means to isolate individuals from their natural allies and loved ones?

- Do services make themselves open and accessible, enabling citizen contribution and engagement? Or do we protect ourselves from the community and treat the community as problematic?
- Do services enable people to feel in control of their own lives when they are offered support? Or do people have to simply accept what is offered on terms defined by the professional?
- Do services strengthen and respect personal autonomy, putting themselves alongside the person on their journey, seeing things from their perspective? Or do we accidentally fall into the trap of patronising and demeaning the people we are there to serve?

Public services do not intend to undermine the individual. Overwhelmingly, professionals working in public services are good, hard-working and respectful. But public services systems were largely designed in the mid-twentieth century when society was very different. Today, many parts of these systems are out-of-date and need reform.

We need better systems for the sake of our shared citizenship; but we also need better systems in order to be more effective in our professional roles. Personalisation is then an effort to systematically redesign public service systems so that they better support the development and utilisation of these different aspects of our Real Wealth. It reverses the tendency of public services to define people as 'service users' or 'patients'. Instead personalisation recognises that the individual has a whole life, and their own Real Wealth, and it tries to enable services to work with the fabric of that whole life.

Although personalisation is a powerful methodology for reforming public service systems it is still rather misunderstood. There is a tendency for commentators to focus on some of the most radical aspects of personalisation - such as Individual Budgets and Direct Payments - without understanding wider, and often more important, system changes.

It is perhaps more useful to understand personalisation in a broader way, as involving four systemic developments:

1. Self-directed support
2. Community-based support
3. Professional leadership
4. Individual funding

1. Self-directed support

Personalisation assumes that people can and should largely shape their own pathway - getting the best possible advice as they do so - constrained by rules and resources that are fair and reasonable. Self-direction does not mean doing everything for yourself or taking on unhelpful burdens. It means setting the direction and making sure support and treatment fits within the wider context of your life.

Self-directed support is not completely foreign to healthcare: the prescription system already offers an important - if highly limited - opportunity for greater control. However there seem to be many other opportunities for letting people themselves shape their use of healthcare services. The value of better enabling citizens to have access to our own medical records would be one prime example of how self-direction might work.

The seven-step model of self-directed support was originally developed to help analyse the process by which individuals could take more control and the different kinds of enablement and partnership which should underpin this approach (Duffy, 2010). This model is set out in Figure 2 and it involves:

1. Awareness of the need for help - access to diagnostic services or assessments
2. Identification of resources - including any entitlements
3. Development of a personal plan - on your own or with help
4. Determination to act - with suitable agreements if necessary
5. Practical implementation of support and care - with access to technical support
6. Living life while using these supports - active management
7. Reflecting on, amending, improving or ending any support - reviewing progress

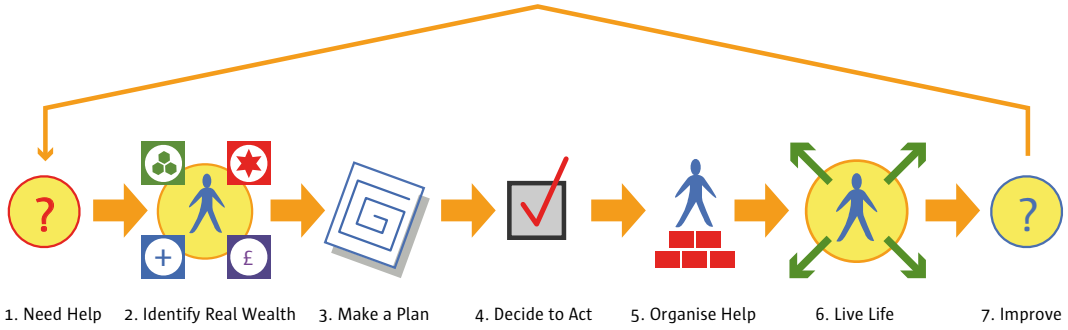

Figure 2. Self-Directed Support

If individual funding is used without a system of self-direction it may lead to increased transactional costs without improving the targeting of resources, and hence with no increase in efficiency. It is self-direction (rather than individualised funding on its own) that helps ensure that resources are better connected to the Real Wealth of the individual and used more effectively.

2. Community-based support

Personalisation means investing in an infrastructure that can support and enable effective decisions - this will be a mix of professional and other supports (Duffy and Fulton, 2010). Professionals will ensure that their expertise is communicated in a number of ways to strengthen this architecture. However it is important to note that professional expertise may be at its most effective if it is used to guide, inform and teach others.

This wider community support system will range from professional groups (e.g. general practitioners) to community and faith groups (e.g. local churches) and should include peer support. It is noticeable that many significant health improvements in developing countries have been driven by healthcare systems which focus on community development and use expertise in a more thoughtful way (Crisp, 2010).

Overall it is likely that community-based support will work best if there is both a full range of support available - including high-level professional expertise - but that people are encouraged to make use of low-cost resources that are part of their natural support or the wider community (see Figure 3). To make professional support the default setting for support will tend to build in an unnecessarily high level of inefficiency.

Figure 3. Community-based Support

Attention to the community-based support system helps to avoid the risk that the process of using individual funding will become more expensive, with more bureaucracy and undue levels of professionalisation.

3. Professional leadership

Paradoxically one of the most important conditions for the success of personalisation in practice is that there exists an appropriate system of professional leadership and coordination. For instance, personalisation has had a dramatic and positive impact in adult social care services in England; but this has been built around the leadership role of social workers who act as the lead professional in adult social care. Without clarity about that role and the changes required in that role then personalisation could not have developed.

Being clear about professional leadership is vital because personalisation is not something patients do on their own. Personalisation creates a new dialogue between the patient and the professional. Although the concept of personalisation seems to place the central focus on the person who is receiving support, it is just as valid - and in the context perhaps much more useful - to think of personalisation as a form of coproduction. That is, it is a way in which the professional and the citizen work together to achieve the best possible outcomes.

Coproduction stresses the need for the professional and the person to bring together their different forms of expertise to develop a planned response. Resources need to be organised to support the fulfilment of this plan as shown in Figure 4. However, as Murray argues, the relationship itself is often the most important asset for the person needing help (Murray, 2010).

The value of that relationship certainly depends to some extent on professional expertise; however what people also seem to value is:

Respectfulness - being treated as an equal who has something to contribute

Honesty - dealing with problems realistically and openly

Integrity - doing what you say you are going to do

Accountability - being responsible for actions and transparent about redress

However, coordination in healthcare is often more complex than coordination in adult social care. There is no exact equivalent to the social work instead points of coordination are likely to shift between different professionals:

- General practitioners
- Care managers e.g. community psychiatric nurses working within mental health teams
- Care coordinators e.g. community matrons
- Clinicians e.g. oncologist

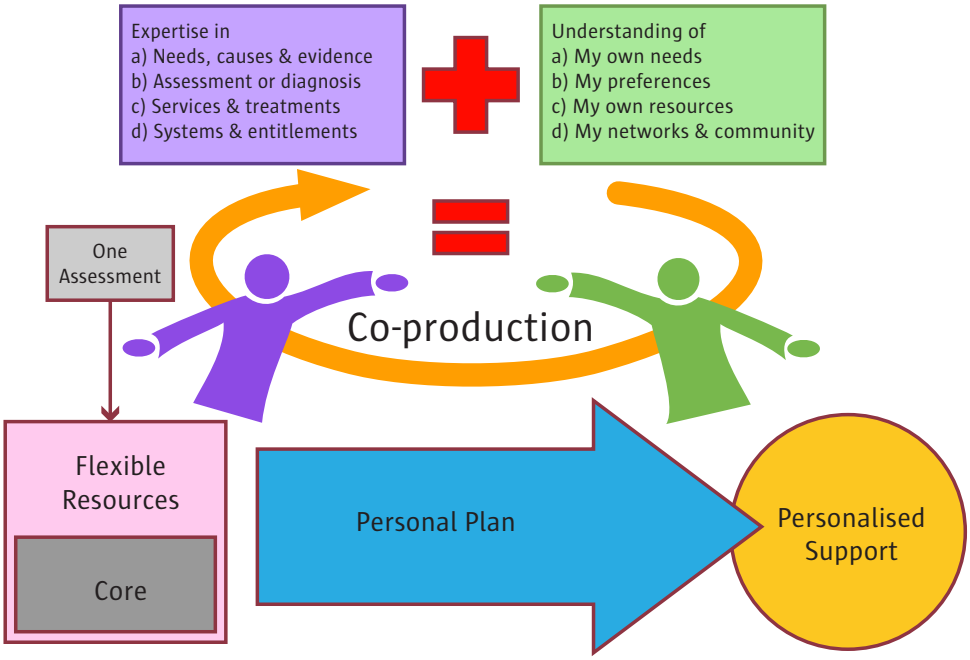

Figure 4. A Model for Coproduction

The flexibility of leadership within healthcare system is entirely appropriate. When health needs become more complex or acute we want the appropriate specialist to take a bigger role in co-ordinating our care. Care coordination does not always need to be the role of a new professional group - more often it should be a fundamental duty of the appropriate lead professional whether that be in primary or secondary care.

However personalisation does demand that professional systems focus on simplifying and clarifying the conversation that they have with the individual. Much more effort is required to ensure that there is absolute clarity about who supports the individual with decisions and in getting access to appropriate resources. There is no need to rule out any group from playing this coordination role - but it is essential that anyone playing this role is clear about their responsibilities and powers.

One of the current risks to the successful implementation of PHBs in England is that there will not be enough attention paid to the different professional context within the NHS. Our view would be that much more attention needs to be paid to the role of professional leadership within a healthcare setting. It seems much more likely that this will need to be more mobile and will be different at different points within the healthcare pathway.

For example, recent work by the Personalisation Forum Group - a group of people who use mental health services - suggest that they would prefer a model of professional leadership which combined:

- More community and peer support at the outset
- More coordination and flexibility within primary care
- Clear coordination and flexibility within secondary care
- Targeted support to avoid or leave institutional care

The model is described in Figure 5 and it implies changes in management, structure and funding at every level. In particular it means enabling general practitioners to have a greater range of flexible resources to respond to mental health needs earlier, before admission to secondary healthcare services. In addition it also means that within secondary mental health services the lead professional has much more to help people design and manage flexible packages of support aimed at recovery.

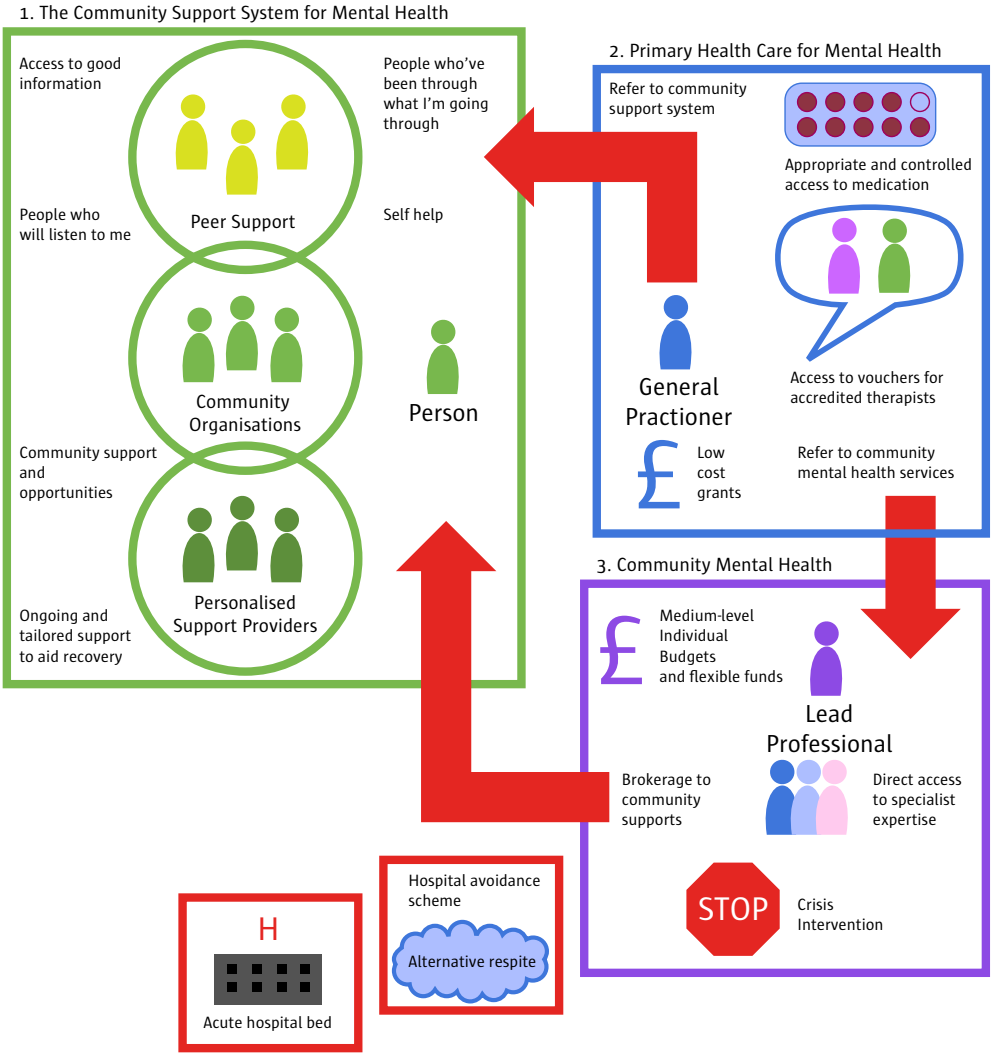

Figure 5. Personalisation Forum Group's Mental Health Model

The character of coordination in healthcare is one of the most important reasons why the implementation of personalisation in healthcare will not precisely mirror its

implementation in adult social care. Much more attention will need to be given to supporting clinical leadership and working with the grain of current systems - with all their inevitable complexity. Imposing new care coordinator roles on to the current healthcare system may not be the right solution, it may simply add costs and complexity.

It is particularly important to consider this aspect of personalisation because there is a natural tendency for personalisation to be perceived as a threat to existing professional identities. It is necessary for leaders within the healthcare system to recognise that these changes are the development of a more mature, grown-up and sophisticated system. Professional roles should not be undermined, but they are changed into more effective and rewarding partnerships with patients.

4. Individual funding

Personalisation means getting resources to work effectively - this will often mean more individualisation and flexibility. There are at least four different ways of using individual funding and each has its own merits:

Vouchers and prescriptions - Vouchers are useful when the precise treatment should be fixed but the provider or timing should be under the control of the individual. The most commonly used voucher system in the UK is a prescription for medicine: the doctor defines the medicine, the individual chooses where and when to purchase it and then self-medicates. However vouchers have also been successfully used for therapies and other services like education. In the right contexts Vouchers can improve outcomes and increase efficiency.

Grants - Grants are highly flexible, and usually one-off payments. They are ideal for low risk situations where someone might need a bit of help to overcome a problem but where existing services are simply not organised to respond appropriately. They are ideal where equipment, a small adaption or access to some opportunity is needed.

Direct Payments - Direct Payments are useful for people with disabilities and long term conditions because they give people direct control over the funding necessary for the delivery of any support services and enable people to employ their own staff. In the UK Direct Payments were made legal in 1996 for disabled people using social care services. Direct Payments were then used to enable disabled people to employ personal assistants to help them live independently. In 2009 Direct Payments were made legal within the National Health Service (NHS), but their use is currently limited to pilot sites approved by central government. Research on Direct Payments has consistently demonstrated that they are valued by those who use them and that they are an effective and efficient way of meeting needs. They are also used in many other European countries and in the USA, Canada, Australia and New Zealand.

Individual Budgets or PHBs - Individual Budgets are budgets that are specified, but which can then be used flexibly to achieve positive outcomes. They can be managed in a number of different ways - including being managed by healthcare professionals themselves. They are particularly useful for systems of personalised support for people with complex needs or mental health problems (Fitzpatrick, 2010).

In the UK this model was first developed in Scotland in 2000 where it was used by North Lanarkshire Council; however it came to the attention of policy-makers in England in 2004. The idea spread rapidly in social care and the government plans that all adult social care, for about one million people, in England will be delivered using Individual Budgets

by 2013. These ideas have also spread, somewhat more slowly, into healthcare, education and other areas (Cowen, 2010). The current PHB pilot programme is just one of several pilots currently underway across the welfare state in the UK.

It is particularly important to remember two things. First not all funding should be individualised. There is still a strong case for some funding to be used to provide the necessary infrastructure for services and support as shown in Figure 3. Second, not all individual funding should be delivered through Individual (or Personal Health) Budgets.

We will go on to describe Individual Budgets in greater detail. They can be very useful, but they have their own costs and they are not a panacea for all problems.

Individual Budgets

The idea of Personal Health Budgets is still very new. The term was first used by the Department of Health when the Personal Health Budget Pilot Programme was launched in 2009. The use of the term emphasised that whatever approach to individualising funding that was taken outside the NHS would need to be adapted within the NHS. This is surely correct.

However it may be helpful to start with the original notion of an Individual Budget, for although this was defined outside the NHS, it is essentially this innovation that is being tested out within the NHS - subject to appropriate safeguards. So we will describe the idea of an Individual Budget and point to some of the particular ways this idea is being interpreted within the NHS.

Individual Budgets are quite broad in their application and have at least three distinct features:

1. Outcome-focused conditionality
2. A tapered control system
3. Up-front entitlements

1. Outcome-focused conditionality

Individual funding systems are not benefits; they are not supplements to personal income that people can freely use. Instead all individual funding systems give individuals conditional control over resources, but how those resources are controlled differs. Vouchers give individuals a token that only has value if it is given to one of the limited number of agencies who can then cash it in. Direct Payments give people cash to meet defined needs, but how those needs are met will often be specified by the funding body.

Individual Budgets use a different control mechanism - outcome conditionality. This means that they specify the need that must be met, but they leave open how this will be achieved and who will achieve it. There are few initial constraints on how an Individual Budget can be used. The assumption is that it would be inappropriate to fetter the discretion of the individual and exclude solutions that may be more effective and efficient.

Having said this, an Individual Budget can still be subject to some side-constraints that limit how it is used. For instance, within the PHB pilot programme, Department of Health guidance currently limits the use of PHBs as follows:

> *There are a few things a personal health budget cannot be spent on. These are things that it would not be right for the Government to fund like alcohol, tobacco, gambling or debt repayment, or anything that is illegal. A personal health budget cannot be used to buy emergency care - for example if you break your leg, you would go to A&E as you do now - you would not use or receive a personal health budget to arrange for it to be x-rayed, set or*

> *plastered. You can't use your personal health budget to buy the services that your GP already provides to you either, for instance seeing your doctor to discuss your health or get a prescription. Other services recommended by your doctor, like physiotherapy, could be included*
>
> (www.personalhealthbudgets.dh.gov.uk accessed on 2nd September 2011)

However the primary control is not provided by these rules, instead it is provided by the outcome-conditionality of Individual Budgets. The budget will not be agreed if the individual (or their agent) cannot develop a reasonable plan; and the arrangement will be terminated if they cannot meet the eligible need. An Individual Budget is not a grant, but a contract that focuses on achieving the desired outcome.

2. Tapered control

Unlike Direct Payments, Individual Budgets can also be managed in different ways (see Figure 6). If the individual has the desire and capacity to manage the cash themselves then they can. However, as long as there are suitable checks and balances in place, an Individual Budget can also be managed by:

- A suitable representative, including family members
- A third party trust
- An intermediary organisation
- A service provider
- A lead professional

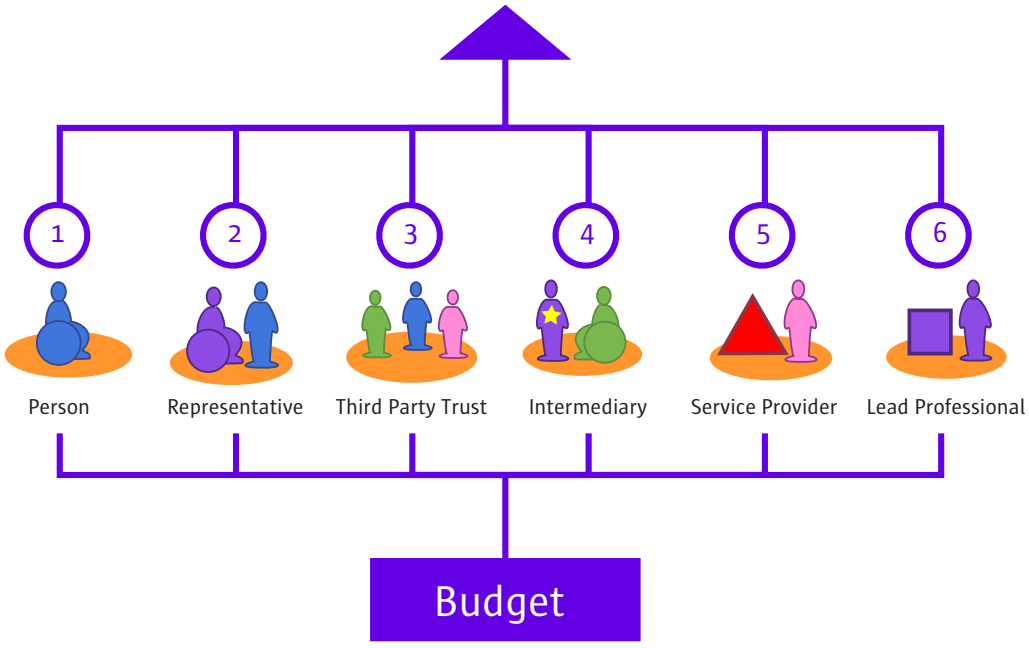

Figure 6. Tapered Control

In other words Individual Budgets use a system of tapered control that allows control to be assigned to the most appropriate person in the circumstances. This makes Individual Budgets attractive because they extend some of the advantages of Direct Payments to individuals who lack capacity or who do not want all of the responsibilities of Direct

Payments. This means that Individual Budgets can benefit people with dementia, cognitive disabilities, mental illness or people at the end of life. Some healthcare professionals themselves might manage an Individual Budget and find that it offers them a greater level of flexibility than the older system.

3. Up-front entitlement

Another distinctive feature of Individual Budgets is that the budget should be defined before the plan is agreed. Before the invention of Individual Budgets the typical procedure for setting a budget was for the professional to define a care plan, to cost the plan and then give the individual the chance to manage that budget. Individual Budgets work differently (see Figure 7):

1. An initial assessment, using a suitable Resource Allocation System (or RAS), defines an indicative budget and the outcomes that need to be achieved
2. The individual, with or without support, develops a plan setting out how they will achieve the agreed outcome within the budget
3. The plan and final budget would then be agreed by the lead professional, subject to any necessary change or negotiation

As we will go on to explore, it is this feature of Individual Budgets that enables more integrated and personalised solutions; resource transparency makes it easier to engage with the wider resources of the person and their community. When resource levels are hidden behind professionally led processes, the individuals cannot explore how those resources could be more intelligently used.

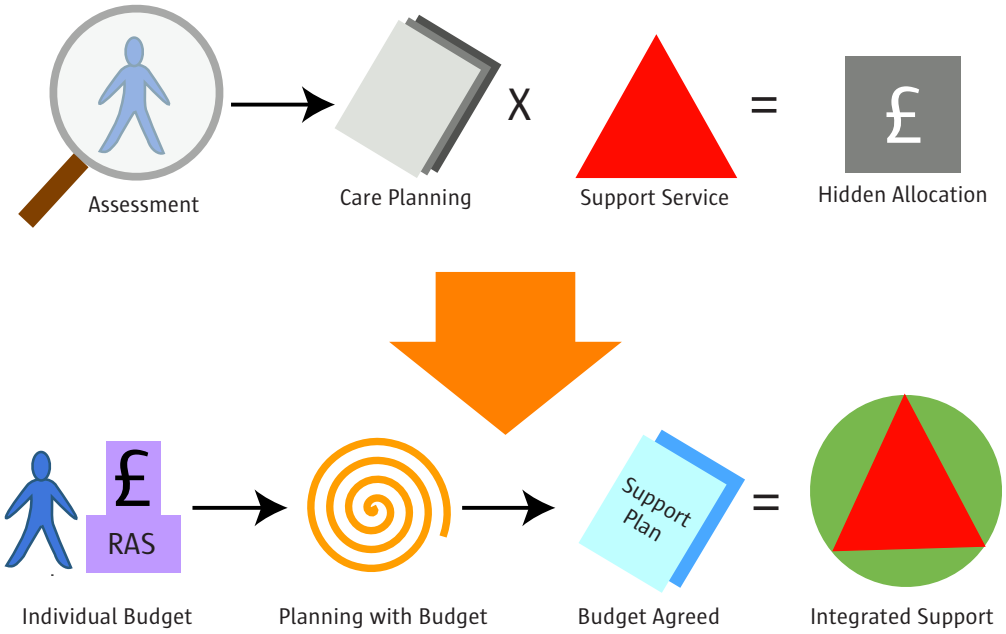

Figure 7. Individual Budgets as Up-front Entitlements

The benefits of Individual Budgets

For the individual there are four main benefits to Individual Budgets:

1. Self-determination
2. Responsiveness
3. Creativity
4. Personal fit

1. Self-determination

All forms of individual funding promote self-determination. The person gains greater control over their circumstances and this improves their sense of self-worth and dignity. This also improves relationships with others, encouraging more respect and accountability between the person and professionals. The person is seen as an active agent who is shaping their own care.

There is also particularly close correlation between increased self-determination and better mental health; and as good mental health also promotes physical health it should be important to maximise self-determination in healthcare where possible.

2. Responsiveness

Individual Budgets can be managed in different ways and they do not need to become a burden to the individual. However the flexibility of the system crucially allows the point of control to be moved closer to the person. This enables decisions to be made more quickly and more sensitively.

There is a clear trade-off here. If the quality of the relevant decision is highly dependent upon the expertise of an expert, someone who is inherently scarce (from the perspective of the individual) then it does make sense for the person to cede power and control to that expert. For example, if someone has a meningioma, then they need an expert to diagnose and treat the tumour. The critical issue for the patient is to maximise their chance of getting the right support from the right expert; once the expert has been identified it makes sense to largely give up control of both diagnosis and treatment and to invest a reasonable degree of trust in that expert.

On the other hand, if someone has been told that they are going to die from an incurable form of cancer, or if they are living with a chronic lung condition or if they have severe depression then these health problems should not be managed in the same way. In these cases the ability to personalise treatment, change lifestyle or improve the physical or social environment will make a significant difference to quality of life and to health outcomes.

In these cases the balance of control must be much closer to the citizen. As Alakeson argues, given that the average person with a long-term condition sees a professional for less than four hours per year, it is hard to believe that this time allows for effective direct management of dynamic treatments for changeable conditions (Alakeson, 2011). A model that shifts control as close to the patient as possible makes more sense. The professional's role is to use their expertise to provide guidance and over-sight.

3. Creativity

Shifting control towards the patient is not the only way in which Individual Budgets improve the quality of decision-making. As we saw above, Individual Budgets also introduce an indicative budget into the decision-making process: 'given your needs it seems like £x would be a reasonable budget to help you meet your needs'. Having some budget in mind often seems to be a spur to greater thoughtfulness and creativity.

For example, Julia was one of the first people in England to receive an Individual Budget. She decided to spend part of her budget on an air conditioning system for her home because she believed that her chronic lung condition would be better managed if she could improve the quality of air within her home. Her hypothesis proved correct and Julia has since been fitter and has radically reduced the time she spends in hospital.

Individual Budgets increase the chance of identifying better, non-standard, solutions. Arguably it is this aspect of Individual Budgets that should be of most interest to thoughtful health professionals because it opens up the prospect of exploring, in partnership with individuals, new and more effective forms of treatment. Patients become active agents of effective research and development.

4. Personal fit

Individual Budgets mean that we can fit services and support into the context of our own life. This is not just a matter of convenience - it enables a fundamental transformation of those resources when they can be used to improve the whole of life and where the resource is amplified by the way in which it is combined with those other aspects of the individual's Real Wealth.

Mainstream physical healthcare is primarily focused on alleviating physical symptoms - avoiding death, overcoming physical illness or trauma, reducing the risk of disability. However even those healthcare professionals who are focused on the body recognise that other factors can be very important to the success or failure of their interventions. For example it is well understood that one of the best treatments for mental illness is to get a job.

Healthcare professional needs to be mindful of these other factors. Patients are best placed to shape how these different factors are integrated in the context of their own life. Professionals need to to facilitate access to the kind of personalised support which builds on and enhances these other factors.

Individual Budgets are one useful tool for promoting this kind of personalised response because, by shifting power towards the individual, they give people the chance to integrate better healthcare within the context of their whole life.

The role of Individual Budgets

Individual Budgets will only have a limited role to play in some parts of the healthcare system. In particular it is extremely unlikely that Individual Budgets will improve:

- Emergency treatment
- Elective surgery
- Prescribed drug treatments
- Prescribed therapies

Doctors have developed reliable knowledge for a range of conditions that gives us good reason to entrust them with our bodies and our lives. Although ultimately we remain in control of our own lives, it is quite reasonable to entrust ourselves to the skill of the doctor if the doctor can offers a reliable treatment for an illness or an injury.

However much depends upon the degree to which medical knowledge is reliable and useful. In areas where reliable surgical interventions, drug regimes or other therapies are known to make a positive difference then Individual Budgets will add little value. However, there are many areas where medical knowledge is much more limited and the evidence less clear-cut.

For example, there are real limits to our understanding of mental health. Rosen has demonstrated that there were better long-term outcomes for schizophrenia in developing countries where mental health services are weak or non-existent. Rosen writes:

> *These findings still generate some professional contention and disbelief, as they challenge outdated assumptions that generally people do not recover from schizophrenia and that outcomes for western treatments and rehabilitation must be superior. However, these results have proven to be remarkably robust, on the basis of international replications and 15-25 year follow-up studies. Explanations for this phenomenon are still at the hypothesis level, but include (1) greater inclusion or retained social integration in the community in developing countries, so that the person retains a role or status in the society; (2) involvement in traditional healing rituals, reaffirming community inclusion and solidarity; (3) availability of a valued work role that can be adapted to a lower level of functioning; (4) availability of an extended kinship or communal network, so that family tension and burden are diffused, and there is often lower negatively 'expressed emotion' in the family.*
>
> (Rosen, cited in Crisp, 2010)

It is of vital importance that policy-makers, professionals and citizens begin to develop a more nuanced account of the possible value of Individual Budgets. We should neither dismiss it out of hand as irrelevant to healthcare nor should we pretend it is an appropriate model for every aspect of healthcare. Individual Budgets are a useful tool or technology and they will have value in particular areas of the healthcare system.

In particular they will be useful where well-being will be improved by:

- The actual exercise of self-determination, choice and control
- Responding quickly and effectively to resolve emerging problems
- New and innovative solutions
- Respecting personal preferences and and social circumstances

Target areas

We have decided to focus on a number of areas of the healthcare system where we think there is compelling evidence that personalisation could increase well-being and improve efficiency:

1. **End of Life Care** - where pain relief and the extension of life must be combined with support for the individual to die well, with dignity and in a manner that makes sense to them and their family.
2. **Mental Health** - which relies on supporting personal resilience, addressing an individual's whole life and is highly influenced by social and environmental factors.
3. **Out of Area Placements** - where people have been sent away from their community, often to institutional and expensive services, but where personalisation can enable people to return, reconnect and make better use of community assets.
4. **Continuing Health Care** – where complex needs need careful management in the context of an individual's whole life and where adapting homes or working with family support will be essential to sustainability.
5. **Frequent Users** - where repeated demands for acute or emergency care can be radically reduced by preventing illness, improving care at home and increasing resilience.
6. **Integrating Health and Social Care** - where the distinction between health and social care is weak or where similar kinds of support are being provided by two different public services in parallel.

In each section that follows you will find early efforts to identify the size of possible efficiencies and health improvements.

1. End of Life Care

National research indicates that 50 percent of the population would choose to die at home. Supporting people to fulfil this wish could save the NHS millions and ensure a better quality experience at the end of life for more people and their loved ones.

A review of patients who died in Sheffield in 2006 and 2007 found that 60% died in hospital, 16% in a care home and only 17% died at home. In some neighbourhoods of Sheffield, the percentage who died in hospital was as high as 75 or 80%, despite the stated wish of half the population to die at home. Those with cancer were most likely to die at home and the frail elderly were least likely to die at home.

Sheffield's figures are similar to the national picture. In 2008, 55% of people died in hospital, 18% died in a care home, 20% died at home and 5% died in hospice. As Figure 8 shows, there has been little change in these percentages since 2003 (DoH, 2010a).

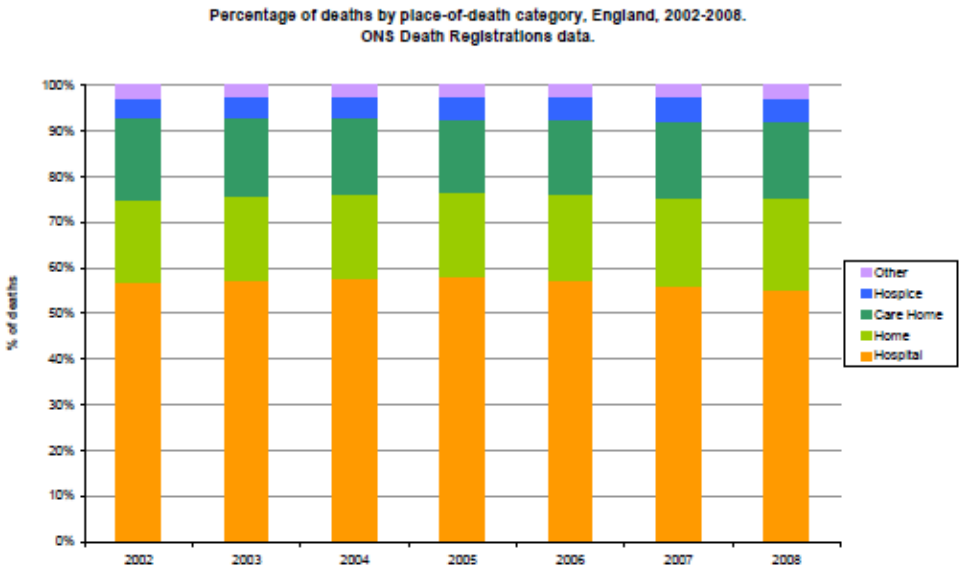

Figure 8. Place of death in England: 2002-2008

Not everyone who dies in hospital could be safely supported to die at home or in a less clinical environment but this would be possible for a significant proportion, if care packages could be developed quickly enough. A review by the National Audit Office of the case notes of 200 of the patients who died in Sheffield in 2007 found that 40% of those who died in hospital could have safely died at home or in another setting (see Figure 9) (Sheffield PCT et al. 2008).

The 80 patients for whom alternative places of death were identified used 1,501 bed days. This is 19 days in hospital per patient that could have been avoided for those particular patients. The average cost per patient of these unnecessary hospital deaths was £4,609 (based on a conservative cost per inpatient day of £250 which is roughly in line with current tariffs - although actual costs may be higher). However data from Sheffield suggests that the average cost of supporting people to die at home (using Continuing

Health Care -EOLC fast-track funding) is £57. This means the cost for the same period would be £1,083. This suggests that over £3,500 per patient is spent supporting each patient to die in hospital instead of their own home (Duffy, 2011).

There are 5,000 deaths a year in Sheffield and 3,000 of these are in hospital. If 40% of these did not need to be in hospital then this means that 1,200 people in Sheffield could have died elsewhere. This could lead to an efficiency saving of £4.2 million.

Looking at this from a national perspective, we can estimate national savings in two ways. Sheffield accounts for 1% of England's population. This means that similar reductions in the proportions dying in hospital across the country could potentially release revenue of up to £420 million.

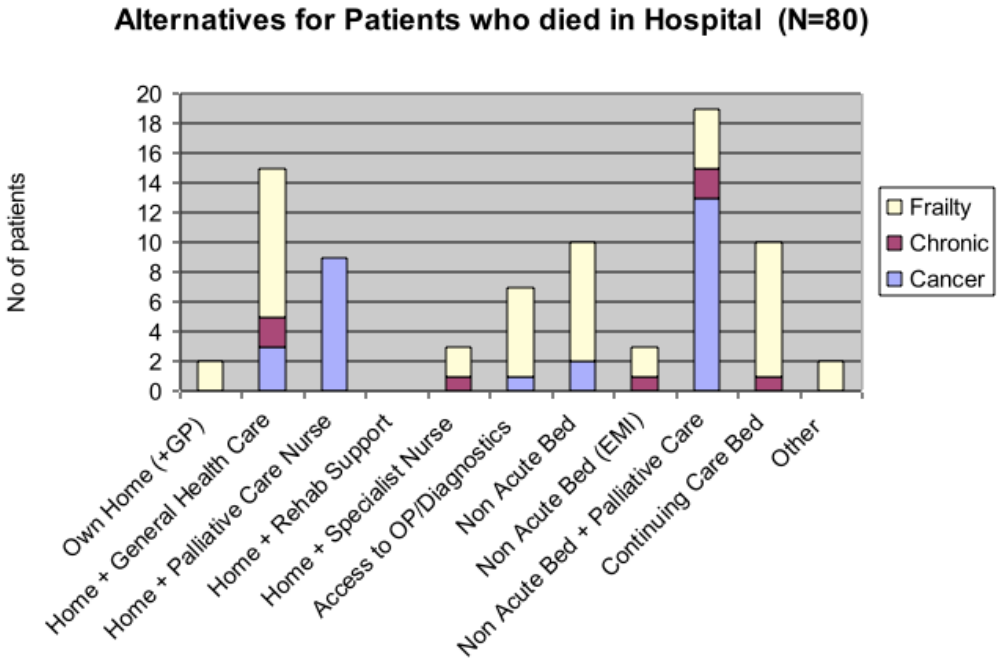

Figure 9. Options for care outside hospital

The potential of Individual Budgets

It costs less to support people to die at home if that's what they choose. But we are currently unable to make this happen for large numbers of people. In would appear that one of the main reasons why individuals who would choose to die at home end up dying in hospital is that existing services do not appear to support people to make the choice to die at home and then enable them to move home before they become too ill. In the case of Sheffield, the following service constraints to fulfilling people's wish to die at home were identified:

- A review of Sheffield's Intensive Home Nursing Service identified a significant lack of capacity in the service to support people to die at home.
- A review of palliative care services in Sheffield found that outside cancer care, few patients who died were known by palliative care services. A large number were, however, known by social care.
- Most decisions about death in end of life services were taken in the week before a patient died, making it hard to make arrangements or meet an individual's preferences for where they died.

Self-directed support has a strong track record of supporting people with complex needs to live in their own homes at significantly less cost than residential care. For example, Keith used his budget to leave residential care, to get a home of his own, get a job and get support from a coach who helped him lose weight. He achieved all of this with less money than had been spent on his place in a residential care home (see www.centreforwelfarereform.org accessed on 2nd September).

Case Study: Debbie & Brian

Debbie and Brian's story from the PHB pilot in Continuing Healthcare in Doncaster shows how a personal health budget was used to provide 24 hour support at the end of Brian's life, enabling him to remain at home as he and Debbie, his daughter, both wanted, while also providing support and respite for Debbie in her role as Brian's carer (www.personalhealthbudgets.dh.gov.uk/Topics/latest/Resource/?cid=7727).

According to Debbie:

"Dad died on 23 December 2009. In the end he only received his Personal Health Budget for two and a half months. However, the pilot scheme helped transform our lives beyond recognition. Had the Personal Health Budget not been in place I would never have forgiven myself if I had been forced to move Dad out of my house and into a nursing home.

The Personal Health Budget worked well for me because I felt in control. Previously it felt as if care was 'done to us'. A Personal Health Budget made Dad and I feel as though we were valued participants."

Individual Budgets are useful in End of Life Care if they can be set up quickly, with minimum bureaucracy and if they are available as managed budgets (not Direct Payments). Although PHBs are part of the Government's end of life strategy to support more people to die at home, the process currently in place to develop and award a budget and develop a support plan needs to be faster for individuals to benefit from a PHB in the last stages of life.

However, if PHBs were implemented effectively, then they could be used to help people not only avoid dying in hospital but also to help people avoid dying in nursing homes. This would bring further advantages and efficiencies.

2. Mental Health

Mental health conditions, including dementia, are a significant cost within the NHS. In 2008/9, the NHS spent 10.8 percent of its annual secondary healthcare budget on mental health services or £10.4 billion. Wider service costs, including the costs of social and informal care, were estimated to be £22.5 billion in 2007 in England and the wider economic costs from lost productivity and reduced quality of life have been estimated at £105.2 billion each year (Source: Health Episode Statistics Diagnoses (2009).

Condition	Annual costs
Depression	£7.5 billion
Anxiety	£8.9 billion
Schizophrenia	£6.7 billion
Dementia	£17 billion

Table 1. The costs of mental health by condition

One of the biggest contributors to high service costs are long inpatient stays for serious mental health conditions such as schizophrenia. The service costs of schizophrenia are estimated to be £10,687 per person of which 27% are from inpatient admissions. In 2004/5, individuals with schizophrenia accounted for 3 million NHS bed days or £750 million (assuming £250 per bed day). In 2009/10, there were 27,023 admissions for schizophrenia. The mean length of stay in hospital was 108 days (£27,000) and the median was 33 days. Over the same period, there were 33,907 admissions for mood disorders. For this group, the mean length of stay in hospital was 41.4 days (£10,350) and the median 19 (£4,750).

While some of these inpatient admissions may be clinically necessary, there is good evidence that a proportion of admissions and long hospital stays for mental health conditions could be avoided. Internationally, the length of stay for mental health conditions varies, indicating that there is more at stake in these decisions than individual clinical need. A study comparing a public hospital in the USA and one in Germany found the average length of stay for patients with schizophrenia was 21 days in the USA and 37 days in Germany and for major depression it was 11 days in the USA and 51 days in Germany.

Furthermore, interventions such as the development of joint crisis plans, have been shown to reduce admissions. A randomised, controlled trial involving 160 individuals with a serious mental health condition found that individuals who participated in developing a joint crisis plan together with a care coordinator, psychiatrist and project worker were less likely to be involuntarily treated or admitted to hospital. Individuals who had developed a joint crisis plan also spent fewer days detained in hospital, 14 compared with 31 for the control group.

The potential of Individual Budgets

Personal accounts of mental health recovery indicate that there are three central components to recovery:

- Hope - It is not possible to rebuild your life unless you believe that a decent life is possible and you need people around who believe in your possibilities.
- Control - Taking back control over your destiny, the challenges you face and the help you receive to overcome them.
- Opportunity - The chance to do the things that you value, access those opportunities that all citizens should expect and participate in society as an equal citizen (Perkins, 2011).

One of the central reasons why personal health budgets are effective tools in mental health is that the very approach embeds these three core components of recovery.

Hope - By virtue of engaging individuals actively in planning for their recovery and presenting the possibility of a better future, Individual Budgets support self-determination and rebuild hope. Supporting people to identify how they would like their life to change creates a sense of possibility in contrast to a focus on deficits and individual limitations that can be common in the mental health system.

Control - An experience of mental illness can lead to a significant loss of control of all aspect of life. Retaking control is an important step in moving on beyond illness to recovery. Giving individuals greater control is integral to Individual Budgets. Transferring resources to individuals gives them ultimate control over the ways in which their health needs are addressed.

Opportunity - By virtue of allowing individuals to break out of established service silos and focusing on individuals as whole people in their whole context', personal health budgets provide individuals with a means to access opportunities that they value and will help rebuild their life. Individual Budgets create opportunities for individuals to once again pursue their dreams and ambitions as part of regaining a life.

By building the capacity for individual recovery, Individual Budgets could contribute significantly to greater efficiency in mental health. First, there is anecdotal evidence from the Recovery Budget pilot run by Merseycare NHS Trust and from Stockport's pilot of self-directed support in mental health of individuals using a budget to avoid admission. For example, in the Merseycare pilot a young man in the early intervention service avoided admission by keeping in contact with his early intervention worker through a laptop and internet connection that had been bought with his recovery budget.

In dementia, older adults are using their PHBs to improve their independence and reduce their need for services by rediscovering activities that they used to enjoy before they became unwell. For example, one woman in the Nottingham City pilot used part of her budget to buy a kneeler to allow her to take up gardening again. This improved her independence and well being and made her less dependent on services.

Emerging evidence from the USA also suggests that Individual Budgets can be effective at supporting people to remain in the community and avoid hospitalisation (Cook et al 2008). One study of 106 participants in the Florida programme found that, on average, participants at the end of a year of the programme were more likely to be living in the community than in hospital or in prison, were more likely to be in education and training and had higher scores on the Global Assessment of Functioning scale (Florida Department of Children and Families, Mental Health Program Office 2007). Analysis of service use by

those in the programme and a sample of individuals receiving traditional services showed that those in the programme were more likely to use routine care and less likely to use crisis-related services than those receiving traditional services. However, neither of these two studies is based on a controlled design and, therefore, the findings are promising without being wholly reliable.

In addition, many of the alternative services that individuals may choose to access through their PHB are significantly less expensive than traditional NHS services. For example, the *Leeds Survivor-Led Crisis Service* provides a crisis house that is open to all and is significantly less expensive than a psychiatric inpatient bed but can demonstrate impressive outcomes. Similarly, individuals with Individual Budgets have demonstrated that bed and breakfasts can be as effective and much less expensive than traditional respite services.

Individual Budgets have the potential to reduce admissions and length of stay for each admission. In doing so, they could save millions and significantly improve individual quality of life by supporting a more preventative approach to care that keeps people well and stops them lurching from crisis to crisis.

Case Study: JoJo

One person benefiting from choosing her own personalised services is JoJo. She has been using mental health services for the last five years:

"*I used to work in the fashion design industry as a product developer until I became ill. This was a hard time in my life. I was diagnosed with paranoid schizophrenia and spent a year in hospital. When I came out of hospital, I moved into supported living and had some help from the Mental Health Recovery Team who were fantastic at supporting me to have the skills I need to be well. I now live in my own place.*

I was offered a personal budget and had support to write a plan that said what I was going to spend my budget on to help me meet my assessed needs. At first I used my budget to purchase some support from an agency, which helped me to regain some of my confidence.I've now had a personal budget for a few years. It helps me to feel happy again and gives me some confidence to keep moving forwards. It feels different because previously I had services organised for me.

As I am now on the road to recovery my budget has reduced. I have updated my plan myself and this has given me the opportunity to talk about what I want for the future. The opportunity to be creative is very important to me and is something that keeps me well. I now receive a little support and a one off payment which I use to help me to buy equipment to make jewellery. I hope that I will eventually be able to teach other people how to make jewellery to give something back. My goal is to start up my own jewellery business and be financially self-supporting, and the recovery team is helping me with this.

Without the support that I have I would still be wondering where my life is going, but now I have hopes for the future. I would definitely recommend considering a personal budget. You can really make it work for you in a way that I didn't know was possible. I feel lucky that I have been able to get back some of the life I have lost."

3. Out of Area Placements

Out of area placements are used in mental health and learning disabilities for individuals who are thought to need highly specialised services. Table 2 shows the spending by category on out of area placements in Yorkshire and Humber in 2009/10 (NHS Yorkshire and the Humber, 2010).

Specialist definitions	Spend (09/10)
Eating disorders	£6,871,851
Locked rehab	£3,395,592
Personality disorder	£1,863,660
Autism	£1,257,142
Neuro psychology	£735,000
Learning disabilities	£535,209
Perinatal	£260,129
Specialist psychological therapies	£230,000
Aspergers	£188,956
Deaf (MH) services	£178,243
ADHD	£53,571
Liaison psychology and psychosexual	£41,940
Gender	£24,000
Total	**£15,635,000**

Table 2. Yorkshire and Humber Regional Spending on Out of Area Placements (2009-10)

Annually, there are 10,000 people placed out of area for mental health reasons and approximately 11,000 people with learning disabilities are also placed out of area per year. Nationally, the National Mental Health Development Unit (NMHDU) estimated that out of area placements for mental health cost £690 million per annum, therefore the combined cost of out of are placements is likely to be more than twice that amount, that is over £1.5 billion (NMHDU, 2011). Of the total number of residential and nursing care placements for mental health each year, 22% are out of area.

By virtue of their specialised nature, out of area placements can be very expensive. In Calderdale, the average cost for out of area placements is: £101,000 a year for autism; £87,000 a year for challenging behaviour; and £105,000 a year for mental health and challenging behaviour. The costs of out of area placements have been estimated to be between 40 and 65 percent higher than local treatment. This range reflects the fact that there

is huge variation in the number and cost of placements across PCTs. In Yorkshire and Humber, the cost of bed days for eating disorders varied from £332 to £850 in 2009/10.

This is not just a cost to the NHS. Local authorities also fund out-of-area placements. For example, in Sheffield in 2008, the local authority and NHS together spent over £11 million on sending about 160 people with learning difficulties to placements outside the city (that is 5% of a population of 3,000 people with learning difficulties). 74% of the cost of these placements was borne by the local authority and their funding of these placements made up more than 33% of the total Learning Disabilities Purchasing Budget. The average cost of each placement was over £70,000 per year. In a sample from early case studies of people returning back home, 4 people together saved £0.25 million from their budgets which was an efficiency saving of 35% (Sheffield City Council, 2008).

One of the justifications for out of area placements is that individuals placed out of area required more specialised clinical care and support than can be delivered locally. However, research has shown that a significant proportion of out of area placements do not provide a higher standard of clinical care to individuals. Of the 10,000 out of mental health area placements each year, 50% have little clinical justification. A study of 40 people placed in non-forensic out-of-area treatment by Islington PCT and the local authority found that 25 were assessed as being potentially able to relocate back to their local area. Of these, 13 moved successfully, mainly to independent accommodation. The assessment indicated that these people had been over-supported in their out of area placements.

A small number of organisations have developed in other localities to design personalised support models at reduced costs. Encouraging the development of such services should be a local priority (Fitzpatrick, 2010). Naylor and Bell estimated savings of £65 million if half of those currently in out of area placements were brought back into area (Naylore & Bell, 2010).

The potential of Individual Budgets

Self-directed support has a proven track record of providing individual packages of support to people with highly complex needs and could be used to bring individuals back into the area. For example, one woman who was part of Stockport's self-directed support pilot for mental health was supported to remain in the community, despite having spent 300 days in hospital in the previous five years. She was awarded a budget of £35,000 which was more than others in the programme but the alternative was to send her to a low secure NHS facility costing £125,000 a year (www.puttingpeoplefirst.org.uk/_library/PPF/Self_Directed_Support_Case_Study.pdf).

Assuming that 50% of out of area placements have no clinical justification, 5,000 of the 10,000 people in out of area placements for mental health could be brought back into area using an Individual Budget and an individual support plan. If the average cost of an out of area placement is £35,600, a conservative estimate would be that people can be supported locally for 60% of that cost. This would save £71 million a year. If we assume instead that individuals could be supported at home for 40% of the average costs of an out of area placement, we could save a further £34 million a year.

Case Study: Dan

Daniel's story was told in the Sheffield Star - this is an excerpt:

Daniel, one of an estimated 3,000 people who live with a learning disability in Sheffield, said: "I wanted to come back to Sheffield for a long time. There was a lot to think about and when it started to happen I was very nervous about the move. I was worried about where I was going to live and what it would be like."

But he is now happy to have left his old life behind and is also receiving support from Dimensions in Sheffield, an organisation which provides services for people with learning disabilities and autism, to help the path run smoothly.

Daniel said: "*I've been back a year and I am very happy. My life has changed and it's better now. When I was is Plymouth I lived in a shared house. Now I have my own space. I chose my own support team before I moved in, and they now help me with things like finances and help me to work out my bills.*"

As well as making a successful transition to a new home, Daniel has also built up a varied social life. He enjoys art, swimming, visiting the gym and playing ten pin bowling and also attends college where he is learning new skills on a personal development course.

"*I'm very happy here,*" he added. "I've made new friends and all my support team are very supportive."

4. Continuing Healthcare

In 2009/10, 50,426 people were in receipt of NHS Continuing Healthcare packages in England. In London alone, there were 10,800 patients in NHS Continuing Healthcare costing £310 million per annum which is one twelfth of non-pay spend for the NHS in London.

The high costs of Continuing Healthcare (CHC) seems to be driven by the particularly high cost of some registered care home services - some costing as much as £3,500 per week. Table 3 shows the number of adult placements and overall cost of placements for Wirral PCT (Source: Which Freedom of Information Request made to Wirral PCT, 2011).

Date	Number	Total Cost	Per Person
2006-07	294	£6,391,671	£21,740.38
2007-08	170	£5,764,025	£33,906.03
2008-09	255	£9,482,937	£37,187.99
2009-10	439	£11,649,420	£26,536.26

Table 3. Number of adults receiving NHS Continuing Healthcare in Wirral PCT

The potential of Individual Budgets

Continuing Healthcare is one area where the national PHB pilot is already demonstrating efficiencies. Five pilot sites implementing CHC report average savings of 20 percent on existing care packages. For particularly high cost packages, greater savings have been recorded.

Savings come largely from the use of personal assistants to provide nursing care such as changing wound dressings rather than district nursing services and the direct employment of personal assistants instead of agency workers. For example, one site reported a 10% saving from the introduction of a PHB due to family members being directly employed rather than being employed through an agency.

Evidence from Individual Budget programmes in the USA support emerging evidence from the UK. The Cash and Counselling demonstration in Arkansas for adults and older people with disabilities in need of personal assistance services resulted in 18% lower nursing home use compared to the control group over the three year follow-up period. At the same time, individuals in the programme were less likely to have developed contractures or bed sores than those in the control group, indicating that efficiencies were not realised at the expense of individual health.

Similarly, medically fragile children in the Florida Cash and Counselling demonstration had 30% lower nursing costs than children in the control group because parents substituted nursing care for personal assistants who were trained to meet the needs of their child.

Case Study: AJ

Alexander James (AJ) is 18 and lives at home with his Mum and Dad. He has autism and severe learning disabilities and attends a special school in Sheffield. He will be leaving school in the summer of 2012. Through his childhood AJ attended residential respite services. This gave his family a useful break and, to begin with, AJ often enjoyed his time away.

However, as AJ grew older, he found it increasingly difficult to go away to residential respite and became increasingly upset. Moreover, the family - although grateful for the break - found they had no control of when and how respite was delivered. Fortunately AJ has benefited from being part of Sheffield's programme that has ensured that health and social care funding can be personalised.

AJ was assessed using the Decision Support Tool for NHS Continuing Health Care, and because of the following factors he was deemed to be entitled to full NHS funding for his support:

- challenging behaviour
- cognition difficulties
- limited communication - AJ doesn't speak
- problems with continence
- problems with medication

When AJ leaves school he may be entitled to £31,500 per year. However while he remains at school he is entitled to £14,700 for respite and additional support. The family has been able to make increasingly flexible use of this support for AJ's advantage to:

- Stay at home while Mum and Dad go away
- Go, with support, to a place he loves in Wales
- Go out and about in the week or at weekends - AJ loves travel
- Get support after school but before his parents get home from work

These arrangements are flexible and can fit around AJ, his wants and interests, and his family's needs. Of particular importance is the fact that AJ's family have been able to use old friends of AJ's, kids he's grown up with like Sophie, family members and young people from the local community to provide his support.

It seems that AJ doesn't want to go out with people who are not in his age range or who he does not know and trust.

AJ loves life and has many things he wants to do. He loves travel, being active, music, video and being with the right people - calm people - people he trusts. Ruth, his Mum said:

"I'm not sure I'd use an agency now - they don't seem able to get the right people who will stick with AJ - instead I can get support from some young people who I've known and seen grow up with AJ - people I can really trust."

The advantages of this approach are wide-ranging:

- AJ is happier and his behaviour is better - he is less likely to end up in residential care or some other form of expensive service
- The family are stronger and better able to cope and support AJ
- The family can stay at work - earning money and contributing (Ruth works for the NHS)
- More support can be purchased at more competitive rates than through agencies

If possible the family would like to see budgets becoming more flexible allowing even more creativity: transport, adaptions, rentals for breaks away etc. Given that the outer limit of the budget is fixed it is not clear why many of the current restrictions are placed on how the budget is used. The family are already better motivated than anyone to get the best value from their current budget. But they are very glad this new system is in place and that they do not have to try and rely on services that were increasingly wrong for AJ.

5. Frequent Users

Analysis by Dr Foster Intelligence found that high impact users of the NHS, those making three or more emergency visits a year, accounted for 1.1 million visits to Accident and Emergency (A&E) in 2003/4, costing £2.3 billion. Between 2004/5 and 2008/9, the number of attendances at major A&E units grew by 1.2% and the proportion of those admitted as emergencies grew by 14.3%, equivalent to 449,078 additional admissions in 2008/09. The average cost of an admission through A&E is £1,502.

The revolving door in healthcare is costing us a lot of money but a large number of visits could be avoided. Of the 1.1 million visits by frequent users identified by Dr. Foster, 240,000 were for one of 19 Ambulatory Care Sensitive conditions. The term Ambulatory Care Sensitive (ACS) condition refers to a set of conditions that can largely be managed outside hospital and, therefore, emergency admissions can potentially be avoided (Source: Keeping People Out of Hospital: The challenge of reducing emergency admissions (2006)). If all 240,000 emergency visits for ACS conditions had been avoided, this would have saved the NHS £500 million in 2003/4 (see Table 4). While it is likely that some of these could not have been avoided, avoiding 50% would have saved £250 million a year.

Condition	Number of admissions	Cost in £ million
Non-ACS condition	890211	1800
COPD	59504	142
Angina (without Major procedure)	32584	57
Congestive heart failure	28530	96
Convulsions and epilepsy	26822	36
Asthma	20557	23
Flu and pneumonia (> 2 months)	15485	45
Dehydration and gastroenteritis	15152	31
Ear, nose and throat infection	14144	11
Cellulitis (without major procedure)	10724	24
Diabetes with complications	9474	23
Iron-deficiency amaemia	2325	6
Gangrene	1735	10
Perforated or bleeding ulcer	1278	4
Pyelonephritis	1253	2
Pelvic inflammatory disease	1081	2
Hypertension	1008	2
Vaccine preventible conditions	826	2
Dental conditions	762	1
Nutritional deficiencies	11	0

Table 4. The causes and costs of emergency admissions in the NHS 2003/4

A similar study of frequent users in Barking and Dagenham PCT between 2002 and 2005 identified 1,638 frequent users per year who accounted for 40% of all emergency admissions. The three most common diagnoses among frequent users in Barking and Dagenham were COPD, unstable angina and chest pain, all ACS conditions. The study identified that frequent users were more likely to be older, with pensioners living in council housing in inner cities being particularly vulnerable. They were also more likely to live on a low income in more deprived areas.

The potential of Individual Budgets

PHBs are being piloted for a range of ACS conditions such as COPD and heart failure. PHBs have a preventative focus which could make a significant contribution to avoiding emergency admissions. Even users of social care personal budgets report improvements in their health status simply from having greater control of their support.

In addition, PHBs take a more holistic approach to an individual's needs than traditional NHS services and may be better placed to provide the kinds of social supports that can prevent people using A&E services by addressing isolation and a lack of access to other forms of advice and support. For example, individuals are currently using PHBs to pay for singing lessons for pulmonary rehabilitation instead of traditional NHS rehabilitation services. By doing so, individuals manage their COPD as well as developing a social network that can provide support. Other PHB pilots provide examples of the ways individuals have started to use their budgets to improve their health as well as reducing their social isolation by accessing community-based activities such as gyms and education opportunities.

One of the participants in the Stockport self-directed support pilot for mental health used to make frequent visits to A&E when she heard voices and became distressed, often several times a week. In one year, she cost the ambulance service close to £200,000 in clinically unnecessary call outs and trips to A&E. On most occasions, she was given a cup of tea at the hospital, comforted and then sent home in a taxi.

A talented artist, she used her Individual Budget of £2,000 to buy art materials so that she could distract herself when she heard voices and would not become as distressed. She is well known to the people in the local art shop where she gets a discount and can also go for support when she is anxious or distressed instead of using emergency services. Although she still occasionally uses A&E and calls an ambulance, this has dramatically reduced since she got an Individual Budget.

If personal health budgets were able to reduce avoidable hospitalisations by 10 percent, this would result in an annual saving of at least £50 million.

Case Study: Jonathan

Jonathan's health needs are complex, but since getting his individual budget his life has been full, positive and his health has been getting better and better.

Jonathan has a tracheostomy and needs to take a breathing unit with him at all times. He suffers from severe epilepsy which requires rectal medication for treatment. He has severe curvature of the spine, is double-jointed and has hypotonia. His health assessment described him as having severe learning

disabilities, severe behavioural problems, global development delays and no speech. He also has bilateral deafness and eczema.

In the last 3 years before leaving school Jonathan spent 150 days in hospital - responding to problems with breathing. In the 3 years since leaving hospital he has spent only 2 nights in hospital - for elective dental treatments. What has brought about this radical change in well-being? For Katrina, Jonathan's Mum the reasons for the change are obvious:

- Jonathan is happier, he does things he enjoys and is now learning more quickly than he ever did before
- Jonathan is contributing, working, doing deliveries and meeting different people
- He is much more active, getting out in the fresh air which he enjoys and which keeps him fitter
- His support is personalised, he has personal assistants who are trained in how to support Jonathan's complex healthcare needs

The reason that all this is possible is that Jonathan has been able to take advantage of one of the first cases of Individual Budgets being used by the NHS. His budget was set up before the PHB pilot programme in Sheffield. He was one of the students leaving Talbot School in Sheffield as part of the new Personalised Transition programme which brought together individual funding from:

- Adult social care
- NHS continuing healthcare
- Learning and Skills Council funding for tertiary education

In the first 3 years, his budget has been about £70,000 per year, and this was split between the NHS and the Learning and Skills Council (LSC). However the local authority has continued to play a critical role in integrating funding from different sources and enabling families to manage that funding directly. This has allowed Jonathan's family to oversee the development of a personalised package of support for Jonathan with flexibility, employment and learning - but not learning in college - learning on the job. Over the last 3 years, Jonathan has acquired two City & Guilds Qualifications and is now learning new independent living skills.

Over the last 3 years, the individual budget system has enabled Jonathan and his family to make significant efficiencies in the costs of his care and support and save the NHS:

- Over £100,000 in hospital stays
- Over £300,000 in residential care costs
- Over £100,000 of funding contributed by the LSC

Katrina and Jonathan's case also came to the attention of the Deputy Prime Minister Nick Clegg who spoke eloquently at the 2008 Liberal Democrat party conference of their case:

A couple of weeks ago in Sheffield, I met a wonderful woman called Katrina. She's got three disabled sons. The oldest is Jonathan, a charming, warm hearted

young man of 19. He can't walk or talk clearly, or feed himself alone. He's had a breathing tube in his neck since he was a toddler. Under a scheme the new Liberal Democrat council in Sheffield is extending, Jonathan's just got his own individual budget and care plan.

Now he's doing work with a local charity, attending a music group, has his own personal assistant - a child whose potential seemed so limited. Finally as a young man, engaged in life in a way he and his mother never thought possible. Katrina told me with the biggest smile I've ever seen, she said: We've gone from having nothing to having everything. I wish every child's needs would be taken this seriously.

(Nick Clegg, 17 September 2008).

6. Integrating Health and Social Care

There is a significant grey area between health and social care. In both the US and UK, Individual Budget programmes in social care have led to improvements in health. The distinction between what is health and what is social care is not clear and this creates duplication, fragmentation and waste at the boundary between the NHS and social care.

There is good evidence from a number of demonstrations and pilot programmes internationally that integrating health and social care can improve outcomes and reduce costs:

- Early intervention programmes that integrate healthcare and wellbeing services can generate resource savings of between £1.20 and £2.65 for every £1 spent.
- Programmes that integrated health and social care with housing support have been shown to deliver significant savings. The Supporting People programme provided net financial benefits of £3.41 billion a year.
- Integrated care teams to support people with complex needs can release savings. For example, the Denver Housing First Collaborative for the chronically homeless integrated health, mental health, substance use and housing services and produced savings of nearly £3,000 per person.
- The creation of Torbay Care Trust with an integrated management structure across NHS and social care generated £250,000 in the management cost savings alone in its first year.

Despite strong evidence, formal joint financing expenditure for health and social care was just £3.4 billion in 2007/8 or 3.4 percent of total health and social care expenditure. It should be noted that many PCTs have informal ways of working with Local Authority colleagues to deliver joint services and, therefore, this figure is likely to be an under-estimate.

The potential of Individual Budgets

Individual Budgets allow individuals to disregard the bureaucratic boundaries of the service system and to meet their health needs as they choose, including by buying goods and services that would otherwise be considered 'social care'. In the current PHB pilot, very little of what is being purchased by individuals is traditional healthcare. In fact, most expenditure is going towards community-based activities such as gym memberships and art classes and goods that are commonly available.

Given that several needs can be met in the same way, for example a job programme can improve employability and health, PHBs are likely to lead to greater efficiency in how people choose to meet multiple, often overlapping, needs.

There is emerging evidence of the ways in which PHBs, when offered as a Direct Payment, are reducing administrative costs. Once the individual becomes the commissioner through a Direct Payment, there is no need for invoices to be attributed to either the NHS or social care as they are when joint commissioners purchase services. Individual Budgets holders simply make purchases without having to define them as either healthcare or social care. Other administrative savings will flow from the development of an integrated support plan across health and social care which is underway in several sites.

In some areas such as mental health an integrated approach to budget setting could be developed, increasing efficiency. Instead of having two separate allocations that need to be coordinated at the individual level, a single allocation of resources for health and social care could be made, with decisions about how to combine resources being made by commissioners.

Case Study: Barnsley Telehealthcare Centre

The Barnsley Telehealthcare Centre provides a powerful example of how local authorities and NHS partners can combine to develop integrated responses to improve health and increase efficiency. Local partners are working to develop a successful international model which has shown:

- 25% reduction in bed days
- 19% reduction in hospital admissions, and
- 85% satisfaction rating among participants

Barnsley has been one of the leading pioneers of personalisation nationally and it treats individual budgets - funded by health and social care as an essential element of its support system to improve health and personal independence.

Conclusion: Implementation is Everything

In the first part of this report we described how personalisation can be seen as a powerful process for engaging the energy of communities and citizens and for improving the value and efficiency of public services. In particular we described one narrower innovation - the Individual Budget - and argued that (in the right context) it could be a useful tool for improving healthcare.

In the second part of this report we used a mixture of case study and national data to outline the possible efficiency savings that could arise if greater use were made of personalisation in healthcare.

The methodology we have used has been flexible and has relied on exploring different dimensions of personalisation and its possible impact in healthcare. Some of these investigations overlap. For example, mental health services seem particularly ready for reform, not only because personalisation has proved to be more effective in improving outcomes for people with mental health needs than in any other area (Glendinning et al., 2008).

If we are to try and get some sense of what the overall impact of impact of extending personalisation to healthcare then it may be useful to start with long-term conditions. The Department of Health currently estimates that we spend £20.5 billion a year on long-term conditions (which is a category that includes many of the areas we have considered above). Empirical evidence of efficiency improvements in adult social care indicated a saving of about 9% (Leadbeater et al. 2008). If we assume that similar levels of efficiency improvement are possible in the management of long-term conditions that this would suggest a possible efficiency of £1.85 billion - which is also close to 10 percent of the efficiency savings that the NHS currently needs to achieve.

However none of these efficiencies will be realised unless personalisation is implemented effectively; and there is already a grave danger that the potential of personalisation is being undermined by wasteful practices and policy confusion. It is our view that personalisation in healthcare will only be effective if all of these three conditions are met:

1. Effective clinical leadership
2. Efficiency is designed into new systems
3. Personalisation is made user-friendly

Effective clinical leadership

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 transfer of commissioning responsibilities to GP consortia. 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.

The success of PHBs beyond the pilot phase will depend on greater engagement with clinical professionals. Signs are that a lack of adequate engagement with clinicians has led to significant resistance among clinicians towards PHBs. For example, a survey of mental health clinicians found that only 28 percent felt enthusiastic about PHBs. This partly reflects the fact that very few of the survey respondents had a good understanding of what a PHB is and how it can be used.

Greater engagement with clinicians of all kinds will be critical but GPs should be a priority. GPs need to be convinced of the value of personal health budgets as tools for dealing with their toughest and most expensive challenges: patients who are frequent users of services. They also need to see PHBs as an extension of patient education and self management rather than as something new and faddish.

Engagement with providers will also be important. In some cases, NHS foundation trusts may decide to offer a personal health budget 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 PHBs to be exclusively 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.

Efficiency is designed into new systems

There is clear potential for personal health budgets to improve the efficiency of certain parts of the healthcare system. But for this potential to be realised, there needs to be a focus on efficiency as PHBs are rolled out. In the pilot phase, it has been possible to implement processes that have not been designed to maximise efficiency. The costs of implementation have been identified as a stumbling block by the evaluation team for the PHB national pilot programme. But if PHBs are intended to meet the needs of large numbers of people with long-term conditions, this will no longer be possible. For example, efficiency concerns need to be built into resource allocation systems. For conditions where we would expect to see improvement, resource allocations need to be designed with a taper that recognises improvement and adjusts budgets accordingly.

Similarly, many pilots are using professional brokers to support individuals with planning. If everyone who wants a PHB is given a professional broker, this will build significant administrative costs into the system, making it more costly than traditional services. The financial sustainability of PHBs demands a more creative approach to the provision of support for those who want it. Family members, friends and other personal health budget holders can all support individuals with planning and many will do so without payment. If everyone who develops a support plan volunteers to support just one other person, this will significantly hold down the costs of implementation (Duffy and Fulton, 2010).

Personalisation is made user-friendly

The process around PHBs does not need to be complex and time-consuming. If this is the case, it is because decisions have been taken to make it so. The use of panels to approve support plans is a case in point.

Risk panels are commonly used in the NHS to approve large or exceptional spending. They are intended to ensure that the NHS is not placed at undue financial or clinical risk. By virtue of their very nature, PHBs entail exceptional spending because each budget is a personalised package of care. Instead of setting clear rules for how personal health budgets can be used and adopting a light touch approval process, many pilot sites are using risk panels to approve every single personal heath budget spending plan. This is even the case for small one time purchases, making the cost of the risk panel about ten times the value of the PHB. The use of risk panels as a general approval process will make PHBs too expensive to be rolled out beyond the pilot phase and will put professionals in the position of adjudicating over the appropriateness of individual choices. This will drive down creativity and increase the time taken for approvals, making PHBs unpopular with individuals and clinicians.

Keeping PHBs simple will be critical to making them financially sustainable and popular among individuals, clinicians and administrators. If they become overburdened with lengthy processes and rules, their potential to enhance Real Wealth will be seriously eroded.

As a tool for personalisation in health, PHBs present a real opportunity to improve efficiency by creating opportunities for greater partnership between clinical expertise and the expertise of people with lived experience in areas of healthcare where medical evidence is not definitive and the preferences and needs of individuals affect outcomes. This report identifies six of these areas where there is significant potential for efficiency gains. However, realising theses efficiencies will depend on the approach taken to implementation. We must keep the processes around PHBs simple, building efficiency into implementation from the outset and ensure that clinicians are engaged in the future development of PHBs and wider personalisation in health.

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PUBLISHED BY THE CENTRE FOR WELFARE REFORM
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