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2 Putting Patients In Control: The case for extending self-direction into the NHS

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Executive summary

In its recent policy review of public services, the government identified personalisation as the next goal for public service reform. This report argues that greater personalisation in healthcare could be achieved through the extension of self-directed care policies such as direct payments and individual budgets into the National Health Service (NHS). These allow individuals to receive public money rather than directly provided services and to decide how best to use that money to meet their needs. The institutional divide between health and social care that currently restricts the scope of self-directed care should be removed to extend the benefits seen in social care into the NHS.

The report identifies two areas where there is a strong case for introducing self-directed care: NHS funded long term care and chronic disease management. In the management of mental health conditions, for example, the report estimates that at least a quarter of the existing NHS budget could be directed by individual patients. Currently, only 0.1 percent of direct NHS spending on mental health is paid to service users. Based on evidence from social care and from self-direction in the US, the report identifies the following benefits from introducing self-directed care in these two areas:

- greater personalisation of care
- the ability to overcome capacity constraints in the NHS
- better coordination of care for individuals with complex health and social problems who are in receipt of a number of services
- greater transparency in the allocation of NHS funds
- greater equity by allowing personalisation within the NHS rather

than through the market place;

- better value for money through the development of personalised care that leads to health improvements without increasing costs.

The report identifies five important features that need to be developed as part of the implementation of self-direction:

1. individual resource allocations based on need
2. clear prices for individual services
3. overall spending policy
4. individual spending plans
5. services to support participants in making informed decisions and in managing the transactions associated with directing their own care.

Implemented together, these features protect equity by ensuring that those who need support in making choices have access to it and can choose advice that is independent of service providers. They also provide a mechanism for monitoring spending and ensuring accountability over the use of public resources, while maintaining a light touch system that encourages participation.

Introduction

‘The governing idea of the next phase of reform is that services need to be personalised according to the needs and preferences of users’¹

Seven years after the government committed to transform the National Health Service into a patient-led service, it has conceded in its recent policy review that current public services, including the NHS, are still some way away from offering a personalised experience.

As Chapter 1 argues, creating more personalised healthcare is an important dimension of improving the quality of care provided by the NHS. It is tempting to think that personalisation can be achieved within the existing, top down structures of the NHS. But large, centrally managed bureaucracies are poorly equipped to provide an individualised approach to services. They rely on standard menus put together by professionals and bureaucrats. Service users have little say. As a result, services continue to be funded that users do not want and services that they do support are not available or remain underfunded. There is no transparency over how much is spent on particular services which makes it difficult for users to assess the value for money of the care they receive.

Personalisation can only be achieved by shifting the balance of control over the different dimensions of service delivery – the who, when, where and what – from professionals and bureaucrats to individual service users. This report argues that one way of achieving this would be to extend self-directed care policies such as direct payments and individual budgets into the NHS. As outlined in Chapter 2, these policies have successfully shifted the balance of power in social care.

By extending self-direction into healthcare, patients would

¹ Cabinet Office (2007)
Building on Progress

enjoy greater choice of treatment and could develop their own package of care, mixing clinical and alternative therapies to meet their individual needs. A lot of emphasis has been placed on choice of provider but who provides a service is only one dimension of choice and a fairly limited one. Greater choice of treatment is central to the idea of personalised or patient-centred healthcare.

Chapter 3 of the report draws on evidence from self-directed care in the US to identify the range of possible benefits from extending current policies into the NHS. There is strong evidence from the US that self-direction leads to greater choice of provider and also supports greater individual choice over the types of services used. It has been found to significantly improve satisfaction with services and to promote a more preventative approach to care by providing greater access to support services. This is associated with a shift away from costly, acute interventions.

One of the main barriers to extending self-direction into the NHS has been concern that it will exacerbate inequality. Chapter 3 considers the impact of self-directed care on equity in the US. Self-direction has been successful in Medicaid which serves a less well educated and lower income population than other parts of the US healthcare system. Within the Medicaid population, there is evidence that self-direction can work for some of the most vulnerable groups.

Chapter 4 identifies two areas within the NHS where the introduction of self-directed care would be expected to lead to the type of benefits seen in the US context: NHS-funded long term care and the treatment of chronic diseases. The assumption has long been that individuals receiving NHS funded long term care, largely through Continuing Care, are too vulnerable to direct their own services. However, recipients and their carers have themselves argued for the introduction of self-direction as this would allow them to better organise and coordinate the care they receive. In the treatment of chronic diseases, harnessing the expertise of individual patients is vital to success. Effective disease management depends on behaviour change that can only be achieved by patients themselves. Self-direction creates the flexibility to personalise self-care, making it more likely to succeed.

Chapter 5 focuses on the implementation of self-directed care in the UK. It identifies five design features that need to be in put in place: individual resource allocations based on need; a price list for individual services; an overall spending policy; individual spending plans; and support services. The successful implementation of these features will ensure that self-direction in the NHS promotes fairness and protects equity, improves health outcomes and creates value for money.

Chapter 1: Creating a patient-led NHS

2 Institute of Medicine (2001)
Crossing the Quality Chasm

3 Department of Health
(2006) *Resource Accounts
2005-6*, HMSO

4 Department of Health
(2004) *Chronic Disease
Management: A compendium
of information*

In its 2001 landmark report on quality improvement, The Institute of Medicine in the US identified patient-centred care as one of six principles for improving the quality of health-care. It defined it as ‘care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions’. In other words, patients should be in the driving seat. Similarly, it is easily forgotten in the professionally dominated environment of health-care that the actual definition of ‘evidence-based’ medicine places equal emphasis on patient values as it does on research evidence and clinical experience².

The importance of involving patients in today’s NHS is strengthened by the fact that chronic diseases such as diabetes, coronary heart disease and mental health problems take up an increasingly large share of the NHS budget and will continue to do so. In 2005/6, these three conditions together cost the NHS £15 billion, or close to a quarter of its entire budget³. A large part of the effective treatment of these conditions depends not on professionals but on patients understanding and learning how to manage their condition day to day.

There is good evidence that patients who are more involved in their own care make better progress. A review conducted by the Department of Health’s Operational Research Division found that improving self care could reduce the length of hospital stays for mental health problems, reduce accident and emergency visits for patients with asthma and halve the number of sick days off work for people with arthritis⁴.

Care that is more tailored to individual needs and prefer-

ences – personalised care – is more likely to be effective because individuals will tend to stick with it. For example, despite the effectiveness of current medications in stabilising the symptoms of severe mental illness, non-adherence to prescriptions among mental health service users is usually 50 percent or higher. In many cases, this is because the effects of prescribed medications interfere with other aspects of life such as parenting or work that patients consider equally or more important to their mental health but do not always share with their doctor⁵.

A central part of the government's strategy for transforming the NHS into a patient-led service has been to extend patients' ability to choose their healthcare provider, supported by an increase in capacity and diversity on the supply-side to make choice a reality. By 2008, any patient needing planned hospital care will be able to choose to be treated by any provider in the country that meets NHS standards and prices. In primary care, new providers will be permitted to set up in areas where supply is restricted.

A lot of political heat has been generated by the introduction of provider choice. But it is only one building block of a more responsive system. Choice of provider still leaves control over the when, where and what of service delivery in the hands of professionals and managers. But these other dimensions of choice matter to patients, as demonstrated by responses to the national consultation on patient choice held in 2003. The three areas of choice that were most important to people were:

- The opportunity to share in decisions about their health and healthcare and to make choices about that care where appropriate;
- The right information, at the right time, as well suited to their personal needs as possible, to enable this choice;
- Services shaped around individual needs, instead of individuals being expected to fit the system.⁶

The NHS booking system is an attempt to shape the system around individuals by giving patients greater say over when services are provided. But if the goal is to create a patient-centred and personalised health service, the most important dimension of choice is not who or when but what – allowing indi-

5 Patricia E. Deegan and Robert E. Drake (2006) 'Shared decision making and medication management in the recovery process', *Psychiatric Services*, Vol. 57, No.11

6 Department of Health (2003) *Building on the Best: Choice, responsiveness and equity in the NHS*

viduals to choose the types of services that meet their particular needs and to develop individually tailored packages of care.

This is an area where patients report significant failings in the current NHS. Table 1 below shows results from the Commonwealth Fund's 2005 International Health Policy Survey of Sicker Adults. When it comes to patient-centred practice in primary care, there is room for improvement in all six countries, with the greatest need for improvement being in the UK. Only 29 percent of patients surveyed in the UK reported that their GP always asked for their ideas and opinions about treatment choices.

Table 1: Results from Commonwealth Fund 2005 international health policy survey of sicker adults

<i>How often does your doctor...</i>	<i>Always</i>	<i>Often</i>	<i>Sometimes</i>	<i>Rarely/Never</i>
Make clear the specific goals for your care or treatment				
Australia	56	20	13	9
Canada	54	22	12	10
Germany	51	24	12	9
New Zealand	59	21	9	7
United Kingdom	50	17	15	12
United States	50	21	17	10
Tell you about care or treatment choices and ask for your ideas and opinions				
Australia	32	18	19	27
Canada	35	21	18	22
Germany	34	19	15	27
New Zealand	41	18	18	19
United Kingdom	29	14	20	30
United States	30	18	21	28
Give you clear instructions about symptoms to watch for and when to seek further care				
Australia	56	20	11	8
Canada	52	21	12	12
Germany	54	21	10	12
New Zealand	68	14	10	6
United Kingdom	51	18	14	13
United States	51	19	16	12

Source: Commonwealth Fund (2005)

As with other forms of choice, those with least access to treatment choices tend to be the least well off. This is because access under the current system depends on having the spending power to buy additional or alternative services outside the NHS. This explains why surveys of choice in public services consistently find that the least privileged groups are most in favour of choice, while high socio-economic groups are more ambivalent. For example, a survey conducted by MORI for the Audit Commission in 2004 found that social classes D and E were most likely to rate choice as ‘absolutely essential’ in all the service areas tested⁷.

Several experts and commentators⁸ have suggested that one way of giving people greater access to care that meets their individual needs and engages them fully in the care process would be to allow them to control and direct certain aspects on their own care. In his forthcoming book, Professor Julian Le Grand at the London School of Economics proposes ‘patient budgets’. Rather than directly receiving a package of services put together by a doctor or care manager, a patient would be allocated a share of the public resources used for his care to develop his own package of goods and services⁹. The introduction of self-direction into the NHS would build on the strong track record of direct payments in social care and, more recently, individual budgets.

7 Audit Commission (2004) *Choice in Public Services*

8 Experts and commentators include: Charles Leadbeater, Julian Le Grand, Alan Milburn, Jon Glasby, Caroline Glendinning and Jennifer Rankin.

9 Julian Le Grand, *The Other Invisible Hand: Delivering public services through choice and competition*, Princeton University Press (forthcoming)

Chapter 2: From direct payments to individual budgets

10 Commission for Social Care Inspection, *Take Up of Direct Payments as of 31st March 2007*, unpublished

Direct payments were introduced under the Community Care Act of 1996 and have been quietly transforming a small corner of the public services landscape ever since. They were the result of a long and arduous campaign by disabled people to wrest control of their lives from service providers and the state and live independently.

Direct payments are cash payments made to recipients of social care services or their carers in lieu of or in combination with the direct provision of services. For example, if on the basis of a local authority social care assessment, an individual is deemed eligible for a certain type and amount of support, the individual can choose to receive that support as services organised by the local authority or to receive the financial value of the support and organize his own care.

Direct payments give service users flexibility over how best to meet their needs and the financial control to develop the service package they choose. Direct payments go further than giving users choice in public services. They put users in direct control of all aspect of public service delivery: who, when, where and what.

Direct payments is a relatively new policy and the percentage of the eligible population using a direct payment remains small. In March 2006, 41,623 people were in receipt of a direct payment in England, up from 33,760 in September 2005¹⁰. Take up varies significantly by user group and by local authority, despite the fact that take up is part of the local authority

performance framework and authorities have a legislative duty to offer direct payments to anyone who is eligible. Some local authorities, particularly those with high levels of in-house homecare provision, have resisted the introduction of direct payments, fearing a loss of power and the need to reorganize services¹¹.

Despite these teething problems, there are many powerful stories about the ways in which the control service users have through direct payments has transformed their lives and given them a level of independence that was not possible with traditional services. (see Box 2.1). Evaluation results reflect these positive stories, emphasising the increase in choice and flexibility that service users experience and the positive impact this has on quality of life. A further advantage noted by the National Centre for Independent Living is that direct payments generate greater value for money. Services purchased directly by individuals cost between 20 percent and 40 percent less than the equivalent services provided in-house¹².

11 Fernandez et al. (2007) 'Direct payments in England: factors linked to variations in local provision' in *Journal of Social Policy*, 36, 1, pp.97-122, Cambridge University Press.

12 National Centre for Independent Living (2003) *Clarifying the Evidence on Direct Payments into Practice*

Box 2.1: Jane Campbell, Chair, Social Care Institute for Excellence and member of the House of Lords

As Chair of the Social Care Institute for Excellence (SCIE) and a disability rights commissioner, I have a demanding daily schedule of meetings, conference presentations and national negotiations. My personal assistants [hired using a direct payment] get me up for those breakfast meetings and they put me to bed after midnight when I am required to attend networking dinners. They patiently type as I compile briefings and drive me to meetings and conferences up and down the country as I promote the work of my organisation...

There is not a statutory service in this country that would offer me the flexibility and type of personal assistance I need in order to do this work effectively... A direct route to a career and independence: this is what direct payments means to me. For others it will be a different life plan. However, what is probably common to all direct payments users is that they start us on a road to participating in society as equal citizens.

13 Robert Wood Johnson Foundation (2006) *Choosing Independence: An overview of the Cash and Counseling model of self-directed personal assistance services.*

14 The six funding streams are: Local Authority provided Social Care services for adults; Supporting People funding; Independent Living Fund; Disabled Facilities Grant; Integrated Community Equipment Services; and Access to Work. For further information, visit www.individualbudgets.csip.org.uk

15 www.in-control.org.uk

16 Poll et al. (2006) *A Report on In Control's First Phase 2003-5*, In Control Publications

17 Department of Health (2006) *Annual Report*

International evidence supports positive findings from the UK. The Cash and Counseling programme is a major self-directed care programme in the US currently operating in 15 states that gives older people and the disabled control over personal assistance services, much as direct payments do. The programme's current design is based on the findings of a controlled experimental evaluation conducted in New Jersey, Arkansas and Florida between 1998 and 2002. The Cash and Counseling approach was found to significantly reduce unmet personal care needs and significantly improve quality of life for participants and their carers. Participants did not report poorer health as a result of self-direction and in some cases, they were less at risk than those in the control group. States were able to design their programmes so that they did not cost more than the traditional system, despite providing better access to services¹³.

As choice emerged as a defining theme of public service reform, the government became eager to publicly recognise and build on the transformative potential of direct payments. In the adult social care green paper published in 2005, it committed to pilot a self-directed care model that combines six funding streams into one individual budget¹⁴. The government's individual budget pilots are based on a model of self-directed supports developed by the charity, In Control¹⁵.

Since 2003, In Control has been working with local authorities, initially to give people with learning disabilities greater control over the resources spent on their care. An evaluation of the first two years of In Control's work reported dramatic life improvements. Overall satisfaction with support services rose from 48 percent to 98 percent. 100 percent of people who were in registered care in 2003 had moved into their own home by 2005 and average costs for local authorities were at least 12 percent lower than under the traditional system¹⁶.

Health services were explicitly left out of the individual budget pilots. But the bulk of people's care needs are not met by social care but by the NHS and health spending dwarves the social care budget: £67 billion compared to £19 billion in England for 2004/5¹⁷. Based on experiences in social care, we could expect an extension of self-directed care into the NHS to lead to the following benefits for individuals and the healthcare system:

- **Greater personalisation of care**, including greater choice of provider and the flexibility to select from a broader range of treatments and services than is currently available through the NHS;
- The ability to **overcome capacity constraints** in the NHS either by seeking alternative providers in the private or third sectors or by developing alternative packages of care that rely on different services;
- **Better coordination of care** for individuals with complex health and social problems who are in receipt of a number of services by allowing individuals to integrate care to suit themselves;
- **Greater transparency** in the allocation of NHS funds that permits individuals to shop around to maximise the value for money of the care they receive;
- **Greater equity** by allowing personalisation within the NHS rather than personalisation being dependent on an individual's ability to purchase additional or alternative services in the market place;
- **Better value for money** through the development of personalised packages of care that improve health outcomes without increasing costs.

18 House of Commons
Health Committee (2005)
*NHS Continuing Care. Sixth
Report of Session 2004-05.*
Volume 1

But the scope of self-directed care is currently limited by the institutional divide between health and social care. It remains illegal for the NHS to pay money directly to citizens. Even where health and social care budgets are pooled and a common assessment conducted, if a procedure or type of care can be defined as health rather than social care, it cannot be offered as a direct payment. In reality this means that integrated budgets and services are often separated out in order to comply with legislation on direct payments. This is despite the fact that the divide itself is contested. In its 2005 Report on NHS Continuing Care, the Health Select Committee concluded: 'the question of what is health and what is social care is one to which we can find no satisfactory answer, and which our witnesses were similarly unable to explain in meaningful terms'¹⁸.

Recipients of direct payments feel that their care is compromised by this institutional divide. Professor Caroline Glendinning at the University of York has conducted research with 44 recipients of direct payments with complex, high-level support needs. Over three quarters were using their direct pay-

19 Caroline Glendinning (2000) 'Bridging the Gap: Using direct payments to purchase integrated care', *Health & Social Care in the Community*, Volume 8 Issue 3

ment to pay their personal assistant to perform health-related tasks. They were doing this because they could not get access to health services and because it improved the flexibility and coordination of their care to integrate their health and personal care needs. Users in the study wanted direct payments to be formally extended to acknowledge and legitimate the help they were already receiving and to enable them to receive more¹⁹.

There have been a few successful attempts to work around these institutional silos. In a high profile case brought before the Health Service Ombudsman in 2004, Barbara Pointon challenged the legitimacy of the health and social care divide and won. Having battled to get access to NHS Continuing Care for her husband, Mrs Pointon stood to lose her ability to direct her husband's care when funding switched from social care to the NHS. The Ombudsman's ruling allowed her to receive NHS Continuing Care resources as a direct payment. Under the Health Act 1999, it is legally possible for Primary Care Trusts to transfer funds to local authorities or to independent living trusts so that NHS resources can be included in a direct payment but this rarely happens.

The current situation puts institutional concerns ahead of patients. It is far from the patient-led vision of the NHS Plan. But if the institutional divide makes little sense, why is current policy being driven by it rather than by the needs of patients? There are three main objections to giving individuals control over NHS resources that are currently holding back policy development.

First, there are concerns about individuals misusing public money. These range from individuals overspending their allocation and finding themselves without sufficient resources to meet their health needs, to individuals deliberately defrauding the public purse. There are also concerns about the types of purchases that individuals make and whether or not these fit with 'scientific' notions of high quality healthcare and can justify the use of public funds.

Second, as with other types of choice in public services, there is concern that self-direction will exacerbate existing inequality in the NHS. The assumption is that those who are able to choose effectively because of high levels of education and good social networks will be well served by the flexibility

of self-direction, leaving the less well educated to cope with the consequences of poor choices. There is greater concern in health than in social care because of the complexity of healthcare and the information asymmetries between professionals and patients when it comes to treatment.

The third objection also relates to equity. There is strong concern that directly paying NHS money to individuals will allow them to top up public resources with private income and buy access to more and better services. As was noted in Chapter 1, the better off are already able to do this and this is a source of inequality in healthcare but they have to go outside the NHS to do so. Within the boundary of the NHS, access to care is based on need alone. Many are fearful that the introduction of self-directed care will erode this founding principle of the NHS. The validity of these objections will be addressed in the following chapters.

Chapter 3: Evidence from the US

20 Jennifer Schore and Barbara Phillips (2004) *Consumer and Counselor Experiences in the Arkansas IndependentChoices Program*, Mathematica Policy Research

Although the US healthcare system is frequently characterised as a private insurance market, half of all healthcare spending occurs in the public sector. One of the major public programmes is Medicaid which supports low income individuals and families. Medicaid is funded by a combination of state and federal dollars and varies significantly from state to state in terms of who it covers and what services it includes.

Much innovation in the US system comes from the public sector and self-directed care has developed in Medicaid. Self-direction is also relatively new across the Atlantic but US experience offers strong evidence of the possible benefits that we could expect to see from extending self-direction into the NHS. The US evidence comes from two areas of Medicaid: home and community based long term care services and mental health services.

There are two ways in which self-direction in long term care in the US is relevant to the extension of self-direction into the NHS. First, evaluations show that individuals use the flexibility of a budget to plug gaps in Medicaid healthcare services for which they would otherwise not be eligible. For example, 78.3 percent of consumers in the Cash and Counseling demonstration in Arkansas reported that their personal attendant helped with routine healthcare tasks such as dispensing medication, checking blood pressure and doing exercise.²⁰ This is similar to the trend in the UK noted by Caroline Glendinning in her research with recipients of direct payments. Consumers are also able to use their budgets to purchase health-related goods that are not provided by Medicaid, or where the type of good pro-

vided by Medicaid does not meet their needs. For example, 5 to 10 percent of the treatment group in the Cash and Counseling demonstration in New Jersey used their budgets to purchase durable medical equipment and pharmaceuticals.²¹

Second, some long term care programmes allow consumers to direct a wide range of services, including some health services such as physio-, occupational and speech therapies. This is particularly the case for those with developmental disabilities and their families as services for this group tend to be generously funded compared to services for the elderly and physically disabled. For example, in the Massachusetts state-funded programme for individuals with developmental disabilities each individual has, on average, a budget of \$38,000 (£19,700) to be spent within nine service categories, including clinical, employment, recreation, education and transportation services.²²

Self-direction in mental health is an area of current innovation in the US. Florida, Iowa, Maryland, Michigan, Oregon and Texas are all currently operating or developing pilots in self-directed care for adults with serious mental illness. A family directed care programme for children with serious emotional disturbance is under way in Florida and another will be up and running later this year in Pennsylvania. Crisis stabilisation and other in-patient services continue to be provided through the traditional system, with individuals having access to budgets of between \$2000 and \$3000 (approximately £1,000 to £1,500) to purchase clinical care, alternative therapies and other support services to improve their mental health and ability to function in the community.

21 Meiners et al. (2004) *Clarifying the Definition of Personal Care: Findings on the purchase of equipments, goods and services under the Cash and Counseling Demonstration and Evaluation Cash Option in Arkansas and New Jersey*

22 Presentation given by Public Partnerships at National Home and Community Based Waiver Conference, 5 October 2006

Box 3.1: Empowerment Initiatives Brokerage

Empowerment Initiatives Brokerage operates in Multnomah and Clackamas counties in Oregon and is run exclusively by people in recovery from mental health conditions. In addition to traditionally provided clinical services, the county mental health departments provide budgets of \$3000 (£1555) to around fifty individuals a year with serious and persistent mental illness to support their recovery. Individuals can be said to be in recovery when they are able to live independent lives, fully participate in their communities

and are no longer dependent on specialist services. The purpose of the brokerage is to kick start the recovery process and to move people in the course of a year to a level of independence that can be sustained without the brokerage.

The \$3000 budget has to be spent on goods and services that improve an individual's mental health. But, in contrast to the traditional Medicaid system which operates under strict medical necessity criteria, Empowerment Initiatives has greater flexibility over how money is spent. The brokerage recognises that mental illness affects many facets of a person's life and, therefore, an individual's mental health can be improved by art therapy or meditation as much as by medication.

At the beginning of the year, participants are assigned a resource broker who works with them to identify goals in each of six areas: personal health, productivity, hobbies, environment, personal relationships and spirituality. The individual and resource broker then plan steps to achieve each goal, including how best to use the \$3000. Resource brokers also help individuals navigate the public system to access other sources of financial support and free community resources, thereby multiplying the impact of the money the brokerage is able to provide.

Participants and brokers stress the importance of the brokerage alongside the budget in creating sustained improvements in the mental health and lives of participants. The goal setting process and support provided by brokers is critical in helping participants manage their condition, avoid regular hospitalisation and, in some cases, move off benefits into work. The fact that brokers are peers with a personal understanding of mental illness and the mental health system is an important dimension of the support they are able to offer.

The rest of this chapter outlines the existing evidence from self-direction in long term care and mental health in the US. It presents evidence relating to the personalisation of care through self-direction as well as its impact on health outcomes and costs.

Access to personalised care

There is strong evidence from the US that self-direction leads to greater choice of provider and also supports greater individual choice over the types of services used. In long term care, the

flexibility of a budget allows individuals to purchase a greater diversity of goods and services than is available through traditional service delivery. As Table 2 below illustrates, analysis of consumer spending patterns in New Jersey as part of the Cash and Counseling demonstration found that the 556 consumers in the treatment group purchased items in 25 different categories. This diversity and personalisation of support is in contrast to the traditional personal care service through which consumers can only purchase home and vehicle modifications and some equipment to help with personal care, in addition to receiving hands-on support²³.

In long term care programmes that include some self-discretion over health services, personalisation leads to a shift away from clinical goods and services. For example, consultants working with states to implement self-direction for individuals with developmental disabilities report a complete shift away from certain traditional services, such as behavioural therapy and nutrition services²⁴. In the Massachusetts programme, spending on clinical and social services decreased by about \$13,000 (£6,615) per consumer between 2002 and 2006, a reduction of 78 per cent²⁵.

23 Meiners et al. (2004)

24 Interview with Tom Nerney, Center for Self Determination, 18th December 2006

25 Public Partnerships (2006)

Table 2: Use of self-directed funds in New Jersey from November 1999 to November 2002

<i>Category of spending</i>	<i>Number of consumers represented in category</i>	<i>Percentage of consumers represented in category</i>
Directly hired worker	547	98%
Transportation	258	46%
Laundry service	206	37%
Insurance	202	36%
Small kitchen appliances	57	10%
Small appliances – general	53	10%
Pharmaceutical supplies	48	9%
Durable medical equipment	47	9%
Prepared food/ delivery	44	8%
Large appliances	41	7%
Shopping and errands	40	7%
Home modification	33	6%
Agency worker or aid service	28	5%

26 Gregory B. Teague and
Timothy L. Boaz (2003)
*Evaluation of Adult Mental
Health Self-Directed Care
Project*, Florida Department of
Children and Families, Mental
Health Program Office

Grooming services and supplies	22	4%
Housecleaning	21	4%
Computer equipment and supplies	13	2%
Telephone equipment and supplies	8	1%
Outside chore service	8	1%
Vehicle purchase or modification	8	1%
Massage or therapy	8	1%
Postal and office supplies	7	1%
Moving expense	7	1%
New ads	5	<1%
Exercise equipment	4	<1%
Personal alarm system	3	<1%
Small equipment for self-help	3	<1%

Source: Meiners et al. (2004)

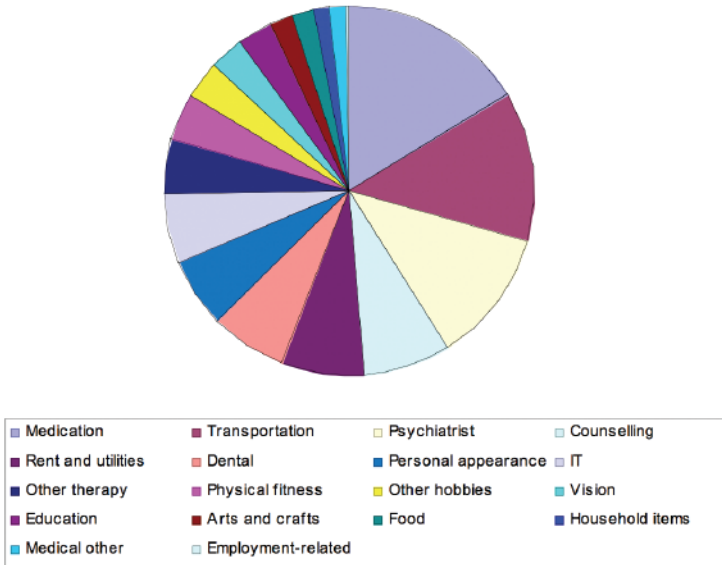
During the first three months of 2007, participants in the Florida Self-Directed Care programme for mental health bought traditional clinical care such as counselling, psychiatric consultations and medication alongside computer courses, membership of weight watchers and furniture (See Figure 1). The programme allows participants to craft a package of services that achieves the right balance for them between clinical and non-clinical care and addresses all the facets of their life that affect their mental health. It also allows them to overcome the traditional service boundaries that restrict the types of support that people can normally access. For example, Medicaid would not traditionally pay for non-healthcare services such as a writing course²⁶.

For Nancy Fudge, one of the original advocates for the Florida programme and one of its earliest participants, using money from her budget to join weight watchers became central to her recovery. ‘This provided me with a totally community integrated support system, nutritional education, kept me from isolating which is one of the symptoms of my illness, increased my self esteem, [allowed me to] practice commitment skills, reduced the need for certain medications... and I lost 78 lbs’. Since joining the Florida Self-Directed Care programme six years ago, Nancy has not been hospitalised once. In the years preceding the creation of the programme, she was hospitalised

on average twice a year²⁷.

Figure 1: Number of purchases made by category in Self-Directed Care in District 8 in Florida January – March 2007 (No. of requests for reimbursement)

27 Nancy Fudge, *The Role of the Provider in a Person-Centered, Person-Directed Care Practice*, received through personal correspondence



Source: District 8 Programme Office, Florida (2007)

An important dimension of personalising care is the ability to overcome capacity constraints in the traditional system, either by accessing providers outside the system or by developing alternative packages of care. The mother of an adult child with development disabilities in the Florida Cash and Counseling demonstration commented on her ability to get better therapeutic care for her daughter at a lower price outside the Medicaid system:

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

28 Patricia M. San Antonio and Kelly J. Niles (2005) *The Cash and Counseling Qualitative Study: Stories from the consumer-directed care program in Florida*

29 Ibid

30 www.kff.org/mfs

31 Interview with participant in Clackamas County housing brokerage

cated, and now I can get therapists from the community and the pay is less, so it comes out as more hours of therapy. The same happens with the massage therapy, we got a therapist who does it for less money and we can get more hours for the same money²⁸.

Similarly, another mother in Florida was able to switch prescribed options to overcome a skill shortage in her area, while still getting her daughter the care she needed. ‘Marilena had money for counselling services, but we changed it for companion money, because she seems to get more benefit out of that. Also, we couldn’t get a psychologist who had experience with autistic children [to do the counselling]’²⁹.

There is little evidence from the US to suggest that greater personalisation of services comes at the expense of equity, as some in the UK fear. First and foremost, self-direction has been successful in Medicaid which serves a less well educated and lower income population than other parts of the US healthcare system. For example, in Oregon, working parents are only eligible for Medicaid if they earn less than £8,592 a year which is 100 percent of the federal poverty level. In Florida, eligibility is restricted to working parents earning less than £5,006 a year, or 58 percent of the federal poverty level³⁰.

Within the Medicaid population, there is evidence that self-direction can work for some of the most vulnerable groups. For example, through Empowerment Initiatives, people with mental health conditions in Clackamas County in Oregon have successfully moved out of group residential facilities to live independently. These individuals represent some of the most disadvantaged in society, living with ongoing symptoms of serious mental illness and a monthly income of around £350. But interviews revealed that, with the support of a resource broker, they are able to make decisions about how their budget can best support their ongoing mental health recovery.

‘Empowerment Initiatives is like having a sponsor in AA. If you don’t have one, your chances of staying sober are bad. If you have one, you have someone to talk to. We [the participant and resource broker] are a team trying to complete a mission. Other services are strictly business’³¹.

The design of self-directed programmes has a strong bearing on how well they serve more vulnerable populations. An

evaluation of the Florida Self-Directed Care programme in mental health found that participants were better educated than non-participants in the mental health system. 86.3 percent of participants had completed high school compared to 34.4 percent of non-participants³². Independent evaluators of the programme point out that it is structured to expect both considerable initiative and a high tolerance for independent paperwork. They conclude that ‘this aspect of programme design may limit its applicability: a wider group of individuals could potentially benefit if they were provided more explicit support for developing skills in identifying goals, making decisions and planning recovery’³³. Chapter 5 looks in greater detail at the nature of the support required to make self-direction accessible and inclusive.

Impact on outcomes and costs

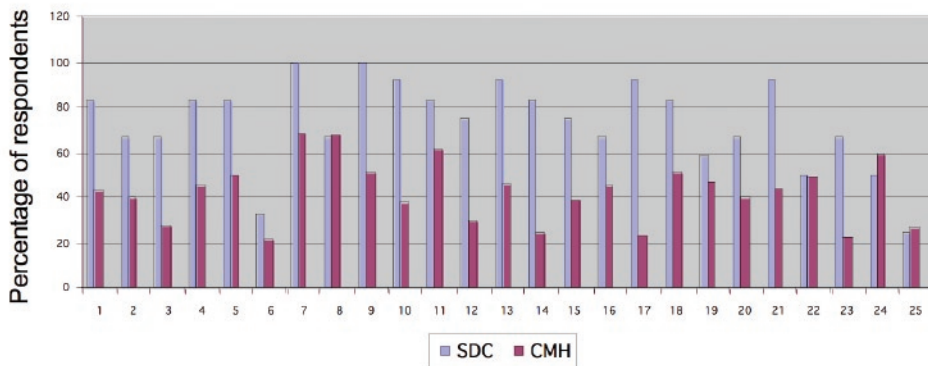
By putting individuals in control, self-direction significantly improves satisfaction with services. Figure 2 below compares the self-reported experiences of participants in Florida Self-Directed Care with those of participants receiving traditional community mental health services. Figure 2 uses personal outcome measures developed by The Council for Quality and Leadership that address quality of life rather than simple satisfaction. Similarly, participants in the first year of Empowerment Initiatives gave self-directed care a higher rating in every category than the traditional system. They felt that self-directed services involved them more, were more culturally sensitive and gave them more of the information and education they needed to reach their recovery goals³⁴.

32 Florida Department of Children and Families, Mental Health Program Office (2007) *Report on the Effectiveness of the Self-Directed Care Community Mental Health Treatment Program as Required by s.394.9084, F.S.*

33 Gregory B. Teague and Timothy L. Boaz (2003)

34 Ami Sullivan (2006) *Empowerment Initiatives Brokerage: Service quality and outcome evaluation*, Oregon Technical Assistance Corporation

Figure 2: Comparing personal outcomes measures for self-directed care and traditional community mental health services in Florida



1. People Choose Personal Goals	7. Choose Their Daily Routine	13. Interact With Others in Community	19. Are Connected to Natural Supports
2. Choose Living Arrangements	8. Have Privacy As Needed	14. Perform Different Social Roles	20. Are Safe
3. Choose Where They Work	9. Decide To Share Information	15. Have Friends	21. Exercise Rights
4. Have Intimate Relationships	10. Decide When To Share Info.	16. Are Respected	22. Are Treated Fairly
5. Are Satisfied With Services	11. Live In Integrated Environments	17. Choose Services	23. Have Best Possible Health
6. Are Satisfied With Life Situation	12. Participate In Life of Community	18. Realize Personal Goals	24. Are Free From Abuse & Neglect
			25. Experience Continuity & Security

Source: Florida Peer Network (2007)

35 Florida Department of Children and Families, Mental Health Program Office (2007)

36 Foster et al. (2004) *Do Consumer-Directed Medicaid Supportive Services Work for Children with Developmental Disabilities*

Contrary to expectations that individuals will make bad choices about their care, there is no evidence that outcomes are worse under self-directed care than under professionally-controlled services. On the contrary, early evidence is that outcomes improve. As Figure 3 shows, participants in self-directed care in Florida have been found to make significantly less use of crisis stabilisation units and crisis support compared to non-participants and greater use of routine care and supported employment³⁵. This reflects a general finding that that self-direction promotes prevention and early intervention by providing greater access to support services rather intervening following an acute episode. In the Cash and Counseling evaluation in Florida for children with developmental disabilities, self-direction had the effect of reducing spending on private duty nursing in the treatment group compared to the control group³⁶. In Arkansas, Cash and Counseling reduced nursing facility use by

18 percent over three years³⁷.

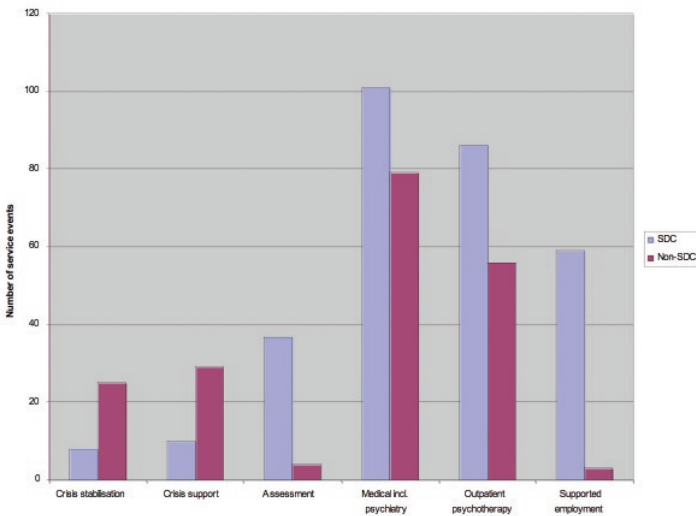
The results from the first year of Empowerment Initiatives are equally promising. Before the start of the programme, only 23 percent of participants were in employment and 8 percent were in education. By the end of the first year, this had risen to 47 percent and 44 percent respectively, suggesting an improvement in mental health stability as well as social integration³⁸.

37 Stacy Dale and Randall Brown (2006) 'Reducing Nursing Home Use Through Consumer-Directed Personal Care Services', *Medical Care*, 44(8)

38 Ami Sullivan (2006)

39 Public Partnerships (2006)

Figure 3: Comparing the utilisation rates for services of SDC sample and matched non-SDC sample in 2005/6



Source: Florida DCF, Mental Health Program Office (2007)

There is no evidence that these improved outcomes are associated with higher costs. For the most part, individuals are good stewards of public money, spending less than their budgeted amount. Analysis of the spending patterns of 51 individuals in the Massachusetts programme for developmental disabilities showed that consumers spent on average 87 percent of their annual budget and were actively involved in managing choices and spending³⁹. Programmes report few cases of fraud and abuse, if any, and these can be minimised through effective spending policies as discussed in Chapter 5. In fact, it is more common for programmes to report that the greater transpar-

40 Interview with former participant in Multnomah County Brokerage

41 Larry Fricks, *Recovery and Systems Transformation for Schizophrenia*, unpublished

ency of an individual budget prompts participants to actively seek to improve value for money. Individuals who choose to self-direct in the Michigan mental health system are presented with a cost breakdown of their service package. Many choose to use the money in different ways from the traditional system, feeling that they are not getting value from their current package of services. Similarly, a former participant in Empowerment Initiatives who is now a member of staff described her ability to get more for her money by bargaining with providers.

'I did rolfing and massage. I had thyroid cancer so I was always hunching forward and now I can sit straight without hurting and the massage helped me to not be keyed up all the time. I did that twice a month. I was able to get a really good deal. I went and said, this is what I'm trying to do with my life, this is how much money I have, can you help? They did and they helped others in EI too'⁴⁰.

Many of the self-directed programmes in the US have been approved by the federal government on the basis of cost neutrality in comparison with traditional service delivery. However, even in the absence of such an administrative constraint, it is possible to identify savings. Many of the alternative services that participants choose are far less expensive and can be as effective as their clinical equivalents. In the state of Georgia, for example, day treatment which is typically provided for people with serious and persistent mental illness, much as it is in the UK, costs on average \$6,491 a year (£3,359) compared to peer support which costs \$1000 a year (£518). Over a 260 day period, adults with schizophrenia, bipolar and severe depression receiving peer support showed a statistically significant improvement in the following three outcomes compared to those in day treatment: symptoms/behaviour, skills and needs/resources⁴¹.

The most significant savings from self-directed care are brought about by the shift to greater prevention and early intervention and the reduced need for costly, acute services. It is early days and more longitudinal data is required to provide strong evidence of the rebalancing of services towards prevention and early intervention. However, tentative evidence exists. In the Cash and Counseling demonstration in Arkansas, the cost of other Medicaid services, primarily nursing home and other types of long-term care, were around 20 percent lower

for those directing their own services than for the control group over a three year period⁴². It costs Clackamas County in Oregon between \$40,000 and \$60,000 a year (£20,000 - £30,000) to house an individual with a serious and persistent mental health condition in a group home. For \$10,000 per person per year (£5,000), Empowerment Initiatives has successfully helped nine people since June 2006 to move into supported independent housing. This includes the value of the individual budget, the costs of a resource broker and the administrative costs of the programme. The housing itself is paid for by the individual and by rent subsidies but is not funded by mental health services. Freeing up places in group homes has allowed the county to move nine people out of the state mental hospital, saving at least \$100,000 per person per year (£50,000). Other savings are generated by participants moving into work and off benefits but these have not been calculated.

42 Stacy Dale, Randall Brown and Barbara Phillips (2004) *Does Arkansas Cash and Counseling Affect Service Use and Public Costs*

Chapter 4: The case for self-directed care in the NHS

43 Derek Wanless (2006) *Securing Good Care for Older People: Taking a long-term view*, Kings Fund

44 Department of Health (2006) *Resource Accounts 2005-6*, HMSO

45 Mental Health Strategies (2006) *The 2005/6 National Survey of Investment in Mental Health Services*

46 House of Commons Health Committee (2005)

The current policy on self-directed care in the UK is driven by an institutional barrier that few agree makes any sense. A patient-centred approach to determining the appropriate limits of self-direction would start with a patient's needs and consider which ones could be more effectively met through self-direction rather than traditional service delivery. Social care services are considered to be suitable for self-direction because social care needs are relatively stable and there is considerable individual discretion over how needs are met. Building on this, the following criteria could be used to identify areas within the NHS that would be appropriate for self-direction:

- needs are reasonably stable and predictable
- individuals have unique knowledge about their needs and how they can best be met
- there are genuine alternatives as to how needs can be met
- alternative sources of supply exist or can be developed outside of local authority or NHS services.

Based on these criteria, it is clear that self-direction would not be appropriate in emergency situations because needs are unpredictable and people do not want to make decisions about their care in an emergency. It is also not applicable to in-patient care because, once in hospital, a patient is dependent on the services provided within that institution. Two areas of NHS funding that relate to long term care needs and would, therefore, be more appropriate for self-direction are NHS funded long term care and chronic disease management.

NHS funded long term care

The NHS supports long term care through the costs of Continuing Care and nursing care. Individuals qualify for NHS funded care rather than social care on the basis of having more complex, less predictable needs that require clinical care and the supervision of medical staff. Although individuals receiving Continuing Care often live in a residential setting, they can qualify while continuing to live in their own home and this is in line with government policy to keep people in the community where possible.

It is difficult to find accurate estimates of the amount the NHS spends on Continuing Care but piecing together several different estimates, it would appear that the figure comes close to the amount spent by local authorities on social care. The King's Fund's 2006 review of social care led by Sir Derek Wanless estimated that the NHS contribution to long term care for older people in England was £3 billion in 2003⁴³. The Department of Health's programme budgeting indicates that the NHS spent £2.6 billion on learning disability related problems in 2005/6⁴⁴. Continuing Care for individuals with mental health conditions was estimated to cost £384 million in 2005/6⁴⁵. Together, this represents around 10 percent of the total NHS budget.

The complex nature of the needs of individuals who qualify for Continuing Care has led many to conclude that it is not a suitable area for self-direction. However, recipients of Continuing Care and their carers are in support of greater self-direction. When questioned by the House of Commons Health Select Committee, Barbara Pointon was clear that the single biggest improvement that could be made to Continuing Care would be the introduction of direct payments⁴⁶.

Furthermore, the Pointon case and others have highlighted the numbers of people with intensive support needs who do not qualify for NHS funded long term care and only receive support through social care. This means that, despite the complexity of their needs, they are able to receive that support in the form of a direct payment. In reality, assessments place people on one side or the other of the health and social care divide and that determines whether or not they are able to direct their own care rather than their absolute level of need.

There are currently a small number of individuals who already receive individual budgets to direct their own care that are jointly funded by PCTs and local authorities. PCTs choose to transfer NHS funds to a local authority that can then pay those funds directly to an individual or family. These tend to be individuals who would otherwise be transferred to a residential facility. Table 4 shows the number of residential placements and the cost per placement for different populations in eight North West London PCTs in 2004/5. The cost of placements varies dramatically across disabilities and across authorities, despite their close proximity, but is in general high.

Table 4: Continuing Care placements in North West London PCTs 2004/5

	Elderly		Learning disabilities		Mental illness		Physical disabilities	
	No. placements	Cost per placement	No. placements	Cost per placement	No. placements	Cost per placement	No. placements	Cost per placement
Brent	257	13,943	111	72,230	177	61,656	111	19,544
Ealing	143	23,424	72	124,141	54	37,852	46	46,348
H&F	134	33,063	85	72,370	27	67,553	17	40,334
Harrow	250	12,576	205	45,107	105	60,314	98	26,357
Hillingdon	267	14,661	12	77,676	18	55,793	47	44,139
Hounslow	103	36,204	161	58,893	12	65,432	35	47,769
K&C	138	33,239	11	70,800	66	11,502	24	29,081
Westminster	180	11,339	128	34,749	73	15,836	48	21,001

Source: Tribal Secta (2005) *Continuing Care: Financial and placement audit and analysis. North West London PCTs*

Ali and Suzanne are served by local authorities that have been working with In Control to develop self-directed supports and both benefit from joint health and social care budgets. Their cases illustrate that self-direction can support individuals with highly complex needs to receive more appropriate care at a far lower cost than would be provided in a residential facility.

Ali is a sixteen year old, physically disabled girl. Her family was struggling to cope with the stress of caring for her and the existing menu of local authority services was not able to provide an adequate solution. This could have resulted in Ali being transferred to a residential setting costing approximately

£170,000 a year. Instead, her PCT agreed to contribute £30,000 and her local authority £27,000 to an individual budget that Ali's family uses to hire four personal assistants to help with her care. The budget allows the family to hire assistants with whom they feel comfortable and who have the specific skills to work with Ali⁴⁷.

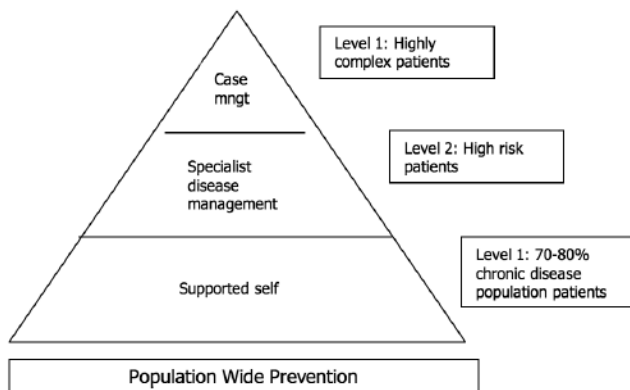
Suzanne is a fifty two year old with limb-girdle muscular dystrophy. As well as having the highest possible level of physical support needs, she also requires assisted ventilation. The settings on her ventilator need to be changed daily but personal care agency staff are not allowed to do this because it is classified as a nursing task. By employing her own personal assistants using a direct payment that is funded 70 percent by the PCT and 30 percent by social care, Suzanne is able to overcome this. The alternative would have been for Suzanne to move into an intensive care facility where nursing staff would have been on hand to change her ventilator settings. This would have been an extremely expensive and inappropriate use of an intensive care bed and would have destroyed Suzanne's independence.

These two cases alone represent savings of several hundred thousand pounds a year for the NHS and a better quality of life for the individuals concerned. As with all types of self-direction, the choice to have greater control over services must remain with the individual and his or her carers. While few older people who qualify for Continuing Care may take up the option to direct their own care, it may be more relevant to other disabled groups whose needs are equally complex but who are less frail. It is worth remembering that arguments about social care recipients being unsuitable for self-direction due to their vulnerability were made prior to the introduction of direct payments and continue to be made by some care managers.

Chronic disease management

If managed effectively, chronic diseases are reasonably stable, long term conditions. Their long term nature means that individuals develop a lot of expertise about their condition and their experience of living with it. Harnessing this is a vital part of chronic disease management because only individuals themselves can achieve the required change in behaviour. As Figure 4 below shows, around three quarters of the chronic disease pop-

ulation has a condition that can be relatively stable if actively managed on a day to day basis by the individual. This is the self care category. Failure to do so causes people to drift upwards and for the complexity and cost of conditions to dramatically increase.



Source: Kaiser Permanente

Viewed in narrow treatment terms, it may appear that there is little room for individual discretion in the care of many chronic diseases. For example, an asthma patient may have little choice over whether or not to use an inhaler if he wants to manage his condition. But if the source of his asthma is damp housing, by choosing to install double-glazing, he could produce a lasting improvement in his condition. Self-direction creates the flexibility needed to personalise aspects of chronic disease management in this way, making it more likely to succeed. There are real alternatives as to how to achieve many of the health objectives required and many different ways in which patients want to be supported in managing their condition. Furthermore, many people with a chronic disease also receive support from social care services due to the disabling effects of their condition. Extending self-direction to cover aspects of healthcare will streamline the care package for these patients and improve the effectiveness of their care.

The rest of this chapter looks at self-direction in the context of two chronic diseases: mental health conditions and diabetes.

Example 1: Mental health

About one in six people in the UK experience a mental health problem at any one time and one in a hundred is diagnosed with a serious mental illness that requires specialist services⁴⁸. If effectively managed, the symptoms of mental illness can be stabilised, crises avoided and individuals can enjoy productive work and family lives. In 2005/6, £4.679 billion was spent on mental health services for adults of working age in England. Of this, £3.748 billion was for direct service provision. Table 5 below shows how this spending is broken down by service category.

48 Sainsbury Centre for Mental Health (2005) *The Future of Mental Health: A vision for 2015*

Table 5: Direct costs of mental health services for adults of working age in England 2005/6

Cost group	Direct costs £ 000s	Percentage of direct costs (%)
Access and crisis services	368,773.08	9.8
Accommodation	361,770.27	9.7
Carer's services	18,697.79	0.5
Clinical services	837,741.10	22.4
Community mental health teams	549,206.91	14.7
Continuing care	384,283.64	10.3
Day services	150,547.15	4.0
Direct payment	2,484.49	0.1
Home support services	91,440.73	2.4
Mental health promotion services	3,146.40	0.1
Other community and hospital professional	86,010.75	2.3
Personality disorder services	10,401.07	0.3
Psychological therapy services	142,047.13	3.8
Secure and high dependency provision	660,634.99	17.6
Services for mentally disordered offenders	37,906.34	1.0
Support services	43,387.36	1.2
Total direct costs		3,748,479.20

Source: Mental Health Strategies (2006)

More than other conditions, experience of mental health is highly individualised and recovery is a very personal issue. In its most recent publication, *Our Choices in Mental Health*, the Department of Health committed to giving service users greater

49 CSIP and NIMHE (2006) *Our Choices in Mental Health: A framework for improving choice for people who use mental health services and their carers*

50 Healthcare Commission (2006) *Survey of Users of Community Mental Health Services 2006*

51 Warner et al. (2006) *Choice Literature Review: A review of the literature and consultation on choice and decision-making for users and carers of mental health and social services*, Kings Fund and Sainsbury Centre for Mental Health

52 Interview with Patricia Deegan, 18th December 2006

choice over their care to reflect the individualised nature of recovery⁴⁹. But the Healthcare Commission's latest survey of community mental health highlights the gulf between rhetoric and practice for many service users. Just over half of all respondents said that they had been given or offered a copy of their care plan, although policy states that all should receive a copy. 42 percent of respondents felt that they had definitely been involved in decisions about medication for their mental health problem, 40 percent felt involved to some extent and 17 percent not at all. 34 percent reported not being told about the side effects of medication⁵⁰.

For many service users, the choice they can most easily exercise is to refuse treatment. The choice they most commonly want is greater access to talking therapies but waiting lists can be up to two years long. They also support a less medicalised approach to care that recognises the value of a range of non-clinical services and supports in successfully managing mental health conditions. This includes consumer and peer-run services, complementary therapies and self-management approaches⁵¹. While some people prefer the security of an environment that is exclusively for people with a mental health diagnosis, others would prefer to be integrated into the community. Patricia Deegan, a consumer/researcher, describes the change she would like to see:

'People typically get to choose what are called services in a ghettoised mental health system. Given the option to unbundle services, you might choose more integrated settings, for example a pottery class in a community college not at a day treatment centre. Then the challenge is to convince the state that taking a pottery class in a community college that is accessible to everyone is a service. People will choose more services in integrated settings where they feel less stigmatized and disabled'⁵².

At present only 0.1 percent of the direct costs for adult mental health services in England is paid as a direct payment (see Table 5). Using the criteria presented at the beginning of this chapter, Table 6 identifies a set of services that would be suitable for self-direction. Based on a conservative assessment, the table illustrates that at least 26 percent of the total budget for mental health services could be directed by individuals. It is possible that the actual figure could be far higher because the

aggregation of spending data by category makes it difficult to identify the nature of the activities that are being funded.

Table 6: Mental health services that are suitable for self-direction

Cost group	Direct costs £000s	Percentage of direct costs
Accommodation excl. residential care	88,319.58	2.4
Carer's services	18,697.79	0.5
Continuing care	384,283.64	10.3
Day services	150,547.15	4.0
Direct payment	2,484.49	0.1
Home support services	91,440.73	2.4
NHS Daycare Facility (part of clinical services listed above)	59,485.15	1.6
Psychological therapy services	142,047.13	3.8
Support services	43,387.36	1.2
Total	980,693.02	26.3

Source: Mental Health Strategies (2006)

Giving individuals greater control over the current budget for mental health services would allow them to personalise care and improve their ability to manage their condition. For example, they could choose to receive support from a peer counsellor, attend art classes at an adult education centre or receive a massage to relieve the physical symptoms of anxiety. This would build on promising evidence from the US that self-direction supports a more preventative approach to mental health and can help people rebuild a life in the community. This would not be a departure from the current National Service Framework but a way of realising its vision.

An important concern is the ability of individuals with mental health conditions to make effective judgements. At times of crisis, people do struggle with decision-making but this is not a permanent state and there are ways around it. As well as providing support for decision-making, the use of advance directives in which individuals describe how they want to be treated when they are not in a position to decide for themselves should be encouraged. Participants can also nominate a repre-

53 York and Humber Public Health Observatory (2006) *Diabetes Key Facts*

54 Derek Wanless (2002) *Securing Our Future Health: Taking a long-term view*, HM Treasury

55 Department of Health (2001) *National Service Framework for Diabetes: Standards*

56 *ibid*

57 Sara Corben and Rebecca Rosen (2005) *Self-Management for Long-Term Conditions: Patients' perspectives on the way ahead*

sentative, such as a family member or friend, to make decisions on their behalf when they are unable to do so.

Diabetes

2.2 million people in the UK, about 4.6 percent of the population, are diagnosed with diabetes. In 2005/6, the NHS spent over £800 million on diabetes⁵³. This figure rises to at least £1.3 billion, if the cost of diabetes related complications is included⁵⁴. Given the importance of self management and life style issues, such as diet and smoking, in the treatment of diabetes, moves to promote patient engagement are already an important part of the National Service Framework. Standard 3 of the NSF states that 'the provision of information, education and psychological support that facilitates self-management is, therefore, the cornerstone of diabetes care'⁵⁵. A good example of Standard 3 in practice is the Expert Patient Programme: a self-management course for patients with a long-term condition that teaches them to manage their own condition as well as skills to make coping with everyday life easier.

There are huge health and financial opportunities from patient engagement in diabetes care. The Department of Health estimates savings of between £350 and £400 for every £100 invested in self care and patient engagement⁵⁶. But recent evidence suggests that existing services are not meeting the needs of all patients. A report on self-management of long term conditions published by the Kings Fund in 2005 found that some people would like to be more involved in managing their own conditions but find that services are not flexible enough to allow this. There are three main dimensions to the flexibility that patients say they want:

- More information and greater access to alternative sources of advice such as peer counsellors
- Better access to assistive technologies to support self management
- Services that fit with the rest of their lives, for example more courses run in the evenings for people who work⁵⁷.

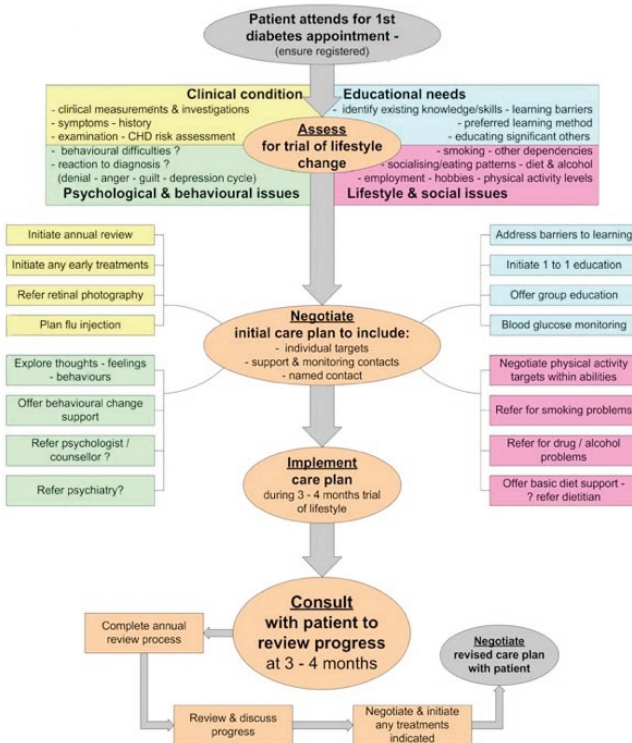
Diabetes UK's State of the Nations 2006 report maps access to services against standards of care set by the NSF for diabetes

58 Diabetes UK (2006)
 Diabetes: State of the Nations
 2006: Progress made in
 delivering the national
 diabetes frameworks

and finds similar gaps in support and self management services. It reports that individuals who have recently been diagnosed with diabetes often experience a lack of basic emotional support. This includes professional psychological help and peer support. Only 27 percent of Diabetes UK members who had been diagnosed in the past twelve months participated in a structured education course. Those who had been offered a course and had not participated reported that the time, date or location prevented them from doing so. The report also finds inequalities in access to glucose testing strips, podiatry and dietetic services, all important services for effective prevention and self management⁵⁸.

Figure 5: Pathway for initial care of type II patients

Pathway for initial care of type 2 patients
 (following application of triage pathway)



Source: Leeds NHS Public and Community Information

Figure 5 shows the initial care pathway for Type II diabetes. There are four dimensions to care: clinical condition, educational needs, psychological and behavioural issues and life style and social issues. It would be possible for an individual patient to take control of the three non-clinical dimensions of care where personal preferences and experience weigh heavily and where there are real choices about how to achieve the desired goals, such as weight loss or smoking cessation. Rather than being sent to a hospital based nutritionist, the patient may prefer to join weight watchers or buy gym membership. Regular GP check ups would continue and would be used as a way of monitoring progress. If the patient's condition deteriorated under self-direction, it would be necessary to review the patient's chosen approach and adopt a different one. If the patient was found to struggle with self-direction, it would be possible to hand control back to a professional.

Chapter 5: Implementing self-direction in the NHS

In seeking to extend self-direction into the NHS, it is tempting to design a system to address the concerns of the policy's opponents in order to win their support. Their three main objections are that self-direction will exacerbate inequality, lead to the misuse of public money and that it will allow top ups. Protecting fairness and equity in the NHS is an important objective and the system must be designed to ensure that self-direction supports choice and personalisation for all patients. Concerns about the misuse of public money are unfounded, both in the US and in social care in the UK. The number of cases of outright fraud rather than a failure to understand the rules are insignificant. However, it is important to design a system that allows oversight over the responsible use of public resources to ensure ongoing public support for self-direction.

The issue of top ups has been a major political stumbling block. The perception is that self-direction increases the ability of individuals to add private income to public money to purchase more or better services. In reality, self-direction would maintain the wall between public funding and private income. Individuals would account for how they spend public money from the NHS separately from how they use their private income. This may be comforting but it does nothing to change the reality that individuals with greater income can purchase additional services in the private market, whether or not they receive traditional services or direct their own care. To restrict the scope of self-direction on this basis is to deprive those who are dependent on the NHS alone of the opportunity to personalise the care they receive within the public system.

To implement self-directed care in the NHS so as to address all the objections raised by its critics would be unfounded and would tie patients up in unnecessary rules and bureaucracy. Instead, the system should be designed to be light touch from the user's perspective, while ensuring that those least able to exercise choice are well supported to do so and guaranteeing adequate financial oversight. To strike this balance, the following elements need to be put in place:

1. individual resource allocations
2. clear prices for individual services
3. an overall spending policy
4. individual spending plans
5. support services

1. Individual resource allocations

The first step in implementing self-direction in the NHS would be to create a resource allocation for each individual who is eligible for care based on an assessment of need.

This approach shifts the system from one that provides standard service packages at differing costs depending on location, to one that provides the same level of resources to people with similar levels of need but allows considerable creativity over how that money is used.

It is by no means straightforward to develop needs based allocations by condition and stage of condition. But work has already begun to move the NHS in this direction, for example the year of care in diabetes programme. One objective of the programme is to develop a specific tariff for a year of diabetes care. This is intended to be a national tariff but with some scope for local variation. In the interim, it may be necessary to rely on cashing out the value of current service packages as a way of developing an individual resource allocation. This is the approach currently taken for direct payments but has the disadvantage of perpetuating inequalities in funding for similar conditions between local areas.

In all cases, the cost of emergency treatment caused by poor management of chronic conditions would be retained by Primary Care Trusts. If an individual's condition changed significantly, a reappraisal would be triggered and a new allocation

made. Both of these provisions ensure that self-direction does not transfer undue risk to patients by expecting them to bear the costs of unexpected changes in their condition.

At the end of each year, any unspent money would be reclaimed by PCTs, unless it was being saved for a specific purchase. In this respect, individual budgets do not have the same status as cash benefits. Although allocated to individuals, the money does not become private income but remains public.

Overspending remains a greater concern than unspent budgets, despite a lack of evidence that this is a genuine problem. Self-direction does demand greater personal responsibility than traditional service delivery and all the evidence is that individuals rise to the occasion. Over-spending an individual budget is no different from overdrawing a bank account. The amount has to be recouped in the following months. It is possible to develop oversight procedures to deal with this, if it should arise, without undermining the care individuals receive. This is discussed below in the context of individual spending plans.

Where individuals are eligible for NHS and other support services, a single, combined allocation would be made. A single allocation would eliminate institutional silos that can lead to duplication and poor coordination, particularly between health and social care services. This would involve combining means-tested support with healthcare that is free at the point of use. This may expose differences in funding regimes that are less explicit under the traditional system but this does not prevent funding from being combined within the same individual allocation.

2. Service costs

As well as developing individual allocations by condition, self-direction also depends on being able to identify the cost of specific services. In some cases, this process has already begun as part of the development of a national tariff under payment by results. However, in other areas, such as mental health, there is little information currently available either because services are bundled together or commissioned en bloc. But experience in Michigan demonstrates that this can be overcome. Ten years ago, when self-direction was introduced into mental health, there was little information available about the cost of individu-

al services. Today providers in one county can supply a price list for every service available under the community mental health system.

3. Overall spending policy

Any self-directed care programme requires an overall spending policy to establish the parameters of what is an eligible purchase. This involves two things: specifying a goal or goals against which the appropriateness of individual purchases can be judged; and providing a list of prohibited items. US programmes commonly prohibit all illegal goods and substances, alcohol, cigarettes and debt repayment. Some also prohibit purchases, such as manicures and pedicures, that could cause undue negative publicity because of the perception that public money is being wasted, even if a case could be made that they contribute to well being.

A short list of prohibited items rather than a long list of allowable purchases shifts the focus from services to outcomes. Current public services tend to be defined by the type of services they deliver. For example, health is distinguished from social care by the service in question and who performs it. In contrast, self-direction is focused on outcomes. As long as a purchase helps a patient meet his health goals, it should be allowed. For example, if double glazing will bring about a sustained improvement in a patient's asthma, it should be a permissible expense. An outcomes approach will lead to a far greater proportion of NHS spending going to services that are not strictly health services, for example massage or art therapy. It also challenges current definitions of high quality healthcare.

The current system is driven by professional notions of high quality care, many of which disregard the expertise of patients and individual preferences. Concern that patients will choose goods and services that are not supported by evidence and this will cause their health to deteriorate are not borne out by evidence from self-direction in the US or in social care. Furthermore, the existing evidence-base is skewed in favour of clinical treatment and, therefore, evidence from other forms of practice is often disregarded. Quality in self-directed care should be judged by the results of the choices individuals make. If patients' choices improve satisfaction, deliver better health and

reduce costs, there should be no reason to challenge them simply because they differ from professional notions of high quality.

4. Individual spending plans

A spending plan accounts for how an individual intends to use his or her allocation to meet health goals, within the framework created by the overall spending policy. The most effective spending plans tend to be the outcome of a person-centred planning process. This is different from most care planning processes in two important respects. First, it is driven by the patient and, therefore, engages his or her experience, expertise and creativity in health improvement far more than professionally dominated processes. Second, it looks at a patient's wider health and life goals rather than focusing exclusively on a diagnosis. Many of the causes of poor health or barriers to effective treatment are not clinical or even health-related and are, therefore, more likely to be captured by starting with the person rather than their care.

Individual spending plans are the primary vehicle for ensuring oversight over how public money is spent. Plans would have to be approved by the relevant PCT. This should be a light touch process that involves verifying that no prohibited purchases are being made and that the budget calculations have been done correctly. Participants would only have to seek reapproval if significant changes were made to their plan. A certain amount of flexibility to make changes involving small sums of money would be allowed to ensure that the system did not become too onerous for users. If an individual's actual purchases were found to deviate significantly from his or her spending plan without a change being requested, the PCT would intervene and contact the participant for an explanation. This oversight mechanism would prevent significant over-spending because additional expenses not accounted for in an individual's plan would trigger intervention early on. The development of electronic systems and smart cards, as Kent has developed in partnership with the Royal Bank of Scotland, would provide a way of streamlining the approval and oversight process.

59 Commission for Social Care Inspection (2004) *Direct Payments: What are the barriers?*

5. Support services

Individuals should always be able to choose the level of control they wish to have over their care. Some will want no direct control and will continue to receive services as before. Those who do choose to self-direct some of their care must have access to support services. This is critical to maintaining equity in a self-directed system and making choice accessible to all. Otherwise, choice favours the better educated and better off because participants have to actively seek out information and fight to exercise choice.

At present, the availability of support services for users of direct payments is inconsistent across local authorities and often dependent on the pre-existence of voluntary sector organisations or an Independent Living Centre. Local authorities that are not in favour of direct payments have tended not to invest adequately in support services, and this has suppressed take up. This inconsistency must be addressed as part of any extension of self-direction into the NHS⁵⁹.

There are two distinct areas where individuals often require support. The first is in identifying their goals, making informed decisions about how best to meet them and developing a spending plan. In terms of this advice function, individuals should be able to choose from a range of options, including third sector organisations, Independent Living Centres and peer providers. For example, if self-direction were extended to chronic disease management, charities such as Diabetes UK or Mind would be well placed to fulfil this function. Advisers should always be independent of any service provider and be accountable to the individual service user.

Individuals also require support in managing the financial and administrative transactions that accompany self-direction. It should be possible for participants to hand over responsibility for these tasks to a third party. This would leave them with control over how their individual allocation is spent and allow them to maximise value without the burden of managing the money directly. Controlling how money is spent is the critical feature of shifting the balance of power in public services and matching services to individual needs. It should be made as easy as possible for individuals to exercise this kind of control. Where third party organisations are involved, it would be possible for PCTs

to hand over financial oversight to these organisations.

The majority of programmes in the US provide both types of support and, in some cases, these two functions are combined into one brokerage organisation, such as Oregon's programme for development disabilities (see Box 5.1).

Box 5.1: Oregon's Support Services Brokerage

In six years, the state of Oregon has created from scratch a brokerage system for adults with developmental disabilities. Adults who qualify for support but do not qualify for comprehensive, twenty four hour services or whose total support package is less than \$20,000 in value receive brokerage services. There is no alternative service delivery system for this group.

The brokerage system currently serves 4,200 people through 9 independent brokerage organisations and will serve 6,000 when fully implemented. Brokerages are profit and not-for profit organisations that operate under direct contracts with the state rather than working within the traditional county-based system. The decision was taken to by-pass the existing county case management system in creating the brokerage model as it was felt that this would impede rather than support self-direction.

The primary function of the brokerage organisations is to support individuals to direct their own care. Each service user is assigned a personal agent who helps that individual develop a support plan, obtain available resources necessary to implement the plan and select providers. Participants can fire a personal agent at any time and for any reason, or can take an issue to the brokerage administration through a complaint process. Support services brokerage is an entitlement based programme and, therefore, participants are not screened to determine their ability to self-direct. Instead, personal agents have to provide adequate support to make the brokerage model inclusive.

<http://www.oregon.gov/DHS/dd/adults/supports.shtml>

Local authorities and PCTs need to invest in the capacity of a range of organisations to provide support services in order to guarantee that individuals have access and can choose the most appropriate type of support for them. A percentage of funding

currently used for care management can be used to cover some of the costs of support services. Furthermore, early evidence from the US indicates that additional costs can be offset and even exceeded by savings made through the reduced use of more costly, acute services. If support services are funded directly by a PCT or local authority, individuals must retain the right to choose who they work with and change advisers if they are not satisfied with the service. This ensures that support services are primarily responsible to participants. Another approach is to add the cost of support services to each individual resource allocation and for individuals to employ advisers directly.

Conclusion

The government has increasingly recognised the role of public service users as co-producers of outcomes and the limits to achieving sustained improvements and personalised approaches without engaging users in the process. The state is increasingly referred to as an enabler of the individual or, as Gordon Brown described it in the speech launching his leadership campaign, a 'servant state'.

Despite this recognition, the government has shied away from transferring power over the different dimensions of public services – the who, when, where and what - to users in a meaningful way. It has experimented with self-direction in social care and other long term support services and seen considerable success. But it has kept self-direction at the margins and has so far resisted extending the approach into the core of public services, namely health and education. Instead, it has preferred to entrust professionals with the task of personalising and coordinating services in the interests of citizens, whether through lead professional budget-holding or the common assessment framework.

By extending self-direction into the National Health Service, the government has a real opportunity to engage citizens on a grand scale. By putting users in control of the purse strings and unleashing their creativity, self-direction allows those who stand to benefit most from personalised care – the users of that care – to design and develop solutions to meet their individual needs. Extending self-direction would allow the government to shed its nanny-state image for good by demonstrating a belief in the capacity of individuals with the right support to develop solutions to improve their health and their lives. This is all the more necessary given the growing burden of chronic disease in the UK and the need for more effective self

management to improve health and contain costs.

All the evidence is promising. Self-direction in the NHS would improve the individual experience of healthcare, while not increasing costs in the system as a whole. Concerns about the impact on equity in the NHS have been a significant in limiting the scope of the existing policy. But self-direction is compatible with a strong concern for equity. Extending choice and flexibility in the NHS does not inevitably favour the better educated and better off. If there is consistent support available through a system of independent organisations, self-direction can increase access to individually tailored services within the public system. In the current NHS, this often depends on access to the private healthcare market. Far from undermining the founding principle of fairness in the NHS, the introduction of self-directed care for those with long term chronic conditions would enhance it.

