

IMPROVEMENT IN PRACTICE:

THE PERSONAL TOUCH



July 2011

The Dutch
experience of
personal health
budgets



Identify Innovate Demonstrate Encourage

‘THE AIM OF THIS CASE STUDY IS TO SUPPLEMENT THE AVAILABLE FORMAL EVIDENCE WITH LEARNING FROM THE NETHERLANDS WHERE PERSONAL HEALTH BUDGETS HAVE BEEN POLICY SINCE 1996’

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The mantra of more personal, patient and client centred care is now a central part of health policy across the UK. In England, while there is still a degree of uncertainty about the detail of the current NHS reform plans, politicians are clear that the changes will put the patient at the heart of healthcare.

Commentary

Personal health budgets are just one intervention being mooted to give patients more choice and control when it comes to their healthcare.

Centrally-funded pilot sites are now spread across England and are being independently evaluated. Until the evaluation of the pilot is complete we don't know what the full consequences of personal health budgets will be, despite some pointers from international research in the field. In the meantime, more sites have been encouraged to join the pilot scheme and personal health budgets enjoy political backing.

The Health Foundation believes that personal health budgets have the potential to contribute to changing the relationship between patients and the health service. As such, the aim of this case study is to supplement the available formal evidence with learning from the Netherlands where personal health budgets (persoonsgebonden budget, known as PGB) have been policy since 1996. Through a range of perspectives, from the Health Ministry to a carer, we explore all sides of the Netherlands' personal health budget programme and develop a clearer picture of what has worked, and where, and what else needs to be done.

In general, the people interviewed seem positive about the personal health budget system and what it has meant for patients and their families. The system seems to be popular with service users and offers a sense of freedom and choice about the care provided. Everybody interviewed told us that they see a secure future for the personal health budget programme in the Netherlands because of this popularity and its political backing.

However, this case study flags some warning signs for fledgling personal health budget programmes in England. There is still little evidence that personal health budgets improve clinical outcomes. The introduction of the programme in the Netherlands did not spark greater innovation from established providers in the way envisaged by policy makers. Crucially, the Dutch programme tells us little about designing a personal health budget system that reduces, or at least controls, health and social care costs in the long term, a policy objective which is of prime importance in the current economic climate.

No one doubts that personal health budgets are popular with patients but popularity ►

‘TOOLS LIKE PERSONAL HEALTH BUDGETS REQUIRE AN INTEGRATED APPROACH THAT SUPPORTS CLINICIANS AND PATIENTS TO MOVE TOWARDS A NEW RELATIONSHIP’

cannot be the only measure of success of the initiative. A number of important questions about their impact on different dimensions of quality still need to be answered. We know that they improve the user experience and functional outcomes, but we also need to know whether there are ways of implementing personal health budgets so that they are effective at improving clinical outcomes. We also need to know more about their impact on equity and their utility for different population groups, particularly the elderly and those who might be less able to manage their budgets.

The Health Foundation runs a number of programmes which aim to inspire improvement through changing relationships between people and health services. From running these programmes we have learnt that tools like personal health budgets require an integrated approach that supports clinicians and patients to move towards a new relationship. This is characterised by collaboration, information sharing, shared goals and an understanding that both parties have an active role to play in improving health outcomes. We are evaluating these programmes and building our evidence and experience into future programmes of work.

Policy makers need to do the same before rolling out a personal health budget programme across the NHS. They should consider the findings from the evaluation of the English pilot programme, the international evidence and emerging case examples from the Netherlands and England. An approach informed by the best evidence should improve implementation, optimise outcomes and reduce the risk of unintended consequences. ■

‘In general, the people interviewed in the Netherlands seem positive about the personal health budget system and what it has meant for patients and their families’

‘There was a belief that delegating the control of budgets to the end user would help to control costs’

CHALLENGE

The Netherlands stands out as a consistently high performer in Commonwealth Fund international health policy surveys.¹ Patients are confident about the care they receive and clinicians are confident in the resilience and effectiveness of the services they are providing. Like most countries in Western Europe, the Netherlands is facing growing pressures on health services as their population ages and cases of chronic disease grow rapidly. More broadly, they also face the challenge of meeting societal and political demands for more self-directed, less paternalistic healthcare.

STRATEGIES

The Netherlands has been among the pioneers of patient-held budgets and has been using PGB since 1996. The drive for PGB arose partly from limitations in the traditional healthcare system but also as an opportunity to offer patients and service users greater choice and control over their healthcare. In addition, there was a belief that delegating the control of budgets to the end user would help to control costs. Implementation has not been without its difficulties, but PGB have been highly popular with both the public and politicians, and appear to have a secure future. ►



SUMMARY

PROGRESS TO DATE

PGB have become increasingly popular, to the point that the government has struggled to meet demand. While this is an indication of PGB's success, it has created an overspend in the overall budget and prompted the temporary closure of the scheme to new applicants.

The Dutch government has responded by tightening eligibility criteria. Certain areas of PGB cover have shifted to local government provision and other elements have been incorporated into the basic private health insurance package. The government has also cut tariffs in a bid to contain costs and oblige budget holders to contribute more to the cost of their own care.

With evidence that the system has been complicated by the emergence of intermediary agencies to manage the budgets, the law has been changed to disallow direct payments to intermediary agencies and a voluntary code of practice for those agencies has been introduced.

The full impacts of legislative and organisational changes and the budgetary cuts are as yet unknown, as these will take at least a year to take effect. However, PGB have not prompted innovation and quality improvement among traditional care providers in the way that the government had hoped. There is also concern that PGB may be driving down the wages of those supplying services and that this is impacting on the nature and quality of the provision. Despite efforts to manage the risk, fraud continues to be an issue.

LESSONS

- Personal health budgets are popular. Users like the freedom and choice they provide and the ability to tailor care to their needs.
- They have the potential to spark innovations in practice and care provision, though this is not occurring on the scale expected.
- A well-developed supportive infrastructure needs to be in place to enable people to use them. This has cost implications.
- Not everyone wants to take on the complexities of budgeting and employment legislation that becoming a budget holder entails. This may exclude some groups, particularly the elderly.
- It is difficult to provide objective measures of success and to address regional variations in eligibility criteria.
- Unless carefully designed, personal health budgets will not necessarily reduce health and social care costs in the long term, nor will they automatically improve quality of traditional services through competition.
- There is a risk that, as the schemes expand, people for whom a personal health budget may not be suitable will be forced to use them as traditional care services decline.
- Too many restrictions on eligibility criteria may destroy the flexibility of personal health budgets. ■



INTRODUCTION

The guiding principle of personal health budgets is that budget holders make a positive choice to buy in services tailored to their needs within a set budget. They use funds that would otherwise have been spent by the state or insurer (or both) for less personalised and often more traditional care.

This case study seeks to provide an overview of how the system of personal health budgets works in the Netherlands, looking at the successes and the challenges that the country has experienced.

The study is based on interviews with: senior government officials; those working in agencies designed to support PGB users; professional and informal carers; a budget holder; and a health economist.

See www.health.org.uk/phbcasestudy

What are personal budgets?

Personal budgets for health and social care have been introduced in several developed nations in North America, Australasia, Scandinavia and much of Western Europe. A personal health budget is an amount of money that is spent on meeting the healthcare and wellbeing needs of people, generally those with a long-term illness or disability. As they are held by the service user or their carer themselves, they are thought to provide greater flexibility, choice and control for service users. Governments also see them as an effective means of curbing or even driving down the escalating costs of health and social care (presumably on the basis that individuals take greater responsibility for delegated budgets) while at the same time boosting quality and innovation. These issues have been brought into sharp focus in England as the government attempts to rein in public spending. ►

INTRODUCTION

Who we spoke to:



- Frans van der Pas, information and policy advisor at Per Saldo
- Bernard van den Berg, reader in health economics, University of York
- Johan Knollema, PGB national coordinator for Health Care Insurance Board (CVZ)
- Lex Tabak, nurse and independent contractor
- Auke Blom, deputy director of MEE Nederland
- Patrick Jeurrisen, coordinator of the Economic Affairs and Labour Market Policy Strategy Group at the Ministry of Health, Welfare and Sports
- Cule and Luka Cucic, PGB users, and Luka's carer, Lubna

Personal budgets have been a feature of adult social care in England since 1996. A recent Audit Commission report² shows that take-up has been poor, as low as 6% of those eligible in some parts of the country. Nevertheless, the government is keen to press ahead with plans for personal health budgets, not least because the concept fits well with its intention to build the 'big society', by devolving more and more care from state to citizen.

It has recently announced plans to extend the scheme, with £400m of funding made available through the NHS for carers' breaks, and the expectation is that local government will provide personal budgets for social care to one million eligible people by 2013.

Some 70 pilots for personal budgets in healthcare are now under way across England. They are being evaluated and the findings are due to be published in 2012.³

The system in England allows for direct payments to the budget holder, or to a service that will manage the funds on their behalf but where the users have choice and control as to how the money is spent. Care can be purchased from the public, private or voluntary sectors.

But given that personal budget holding is still at a relatively early stage in England, what might we learn from countries that are already some way down the track?

The Dutch experience is instructive. Not only is the Netherlands dealing with similar fiscal and demographic pressures to those of the UK, but its scheme focuses on people of all ages with long-term conditions and disabilities. These are the very groups the UK government hopes will increasingly opt for personal health budgets. ■

A useful glossary



AWBZ: (Algemene Wet Bijzondere Ziektekosten) universal health insurance deducted through income tax which pays for exceptional medical expenses (including long-term care services) in the Netherlands

Care in kind: care provided by an existing healthcare provider

CIZ: The National Care Assessment Centre

CVZ: Health Care Insurance Board

IGZ: The healthcare inspectorate

MEE Nederland: a national support and advice organisation for people with disabilities

Per Saldo: An organisation representing the interests of budget holders

PGB: (Persoonsgebonden budget) the Dutch personal health budgets scheme

SVB: Social Insurance Bank

WMO: local government budgets for social care

Zvw: obligatory private health insurance in the Netherlands

PERSONAL BUDGETS IN THE NETHERLANDS

Personal health budgets (persoonsgebonden budget or PGB) are an increasingly popular option for people with long-term care needs in the Netherlands. So much so that the Dutch government has been struggling to keep up with demand.

The Dutch experience

In 2010, the monies allocated for PGB – 10% of the overall 2010 budget of €23bn for long-term conditions – ran out in July. And, unlike in previous years where extra cash was pumped in, the government coffers were empty. This forced around 13,000 applicants to join a waiting list.

Personal budgets were first introduced in 1996 under the terms of the Exceptional Medical Expenses Act 1968 [Algemene Wet Bijzondere Ziektekosten or AWBZ], which mandated universal health insurance for a range of long-term care services that have gradually expanded over the years.

The concept was prompted by caps on spending for long-term care amid persistently rising demand, which drove up waiting lists and eroded quality. The cash payments provided by PGB aimed to free up the supply of services and offer a tailor-made and cheaper alternative to existing provision (care in kind) for those whose needs did not warrant long-stay care.

Around 600,000 people out of a population of 17 million have physical and/or mental healthcare needs in the Netherlands. Around half of this group are cared for at home, approximately one in three of whom has opted for a PGB.

In July 2010, there were 123,000 personal budget holders, compared with 5,401 in 1996. Each month 2,000 people apply and 1,000 leave the PGB system. The result is a monthly net growth of 1,000. ■

The Dutch healthcare insurance system

All residents of the Netherlands are required to take out a basic package of healthcare insurance (Zvw). This covers basic medical care such as visits to a GP and some hospital treatment. The government pays some of the costs if people are on low incomes. People can also choose to purchase additional private healthcare insurance to cover wider medical costs such as dental care and physiotherapy.

The Dutch also pay a national insurance known as AWBZ which is deducted through income tax. This covers the cost of long-term care services not covered by health insurance, known as 'exceptional medical expenses', for example care for disabled people. Some social care is also paid for through local government budgets (known as WMO).

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How PGB works



PGB currently covers four categories of care:

- Personal care for help with daily living.
- Nursing care, including help with taking medicines.
- Support services, such as day care or learning to cope with a disability.
- Short stays away from home, including respite care.

The process involves several steps:

1. An application is made to a local office of the independent National Care Assessment Centre (CIZ), or Youth Care Agency for those under 18 with mental health problems, and a needs assessment is carried out.
2. A set of weighted tariffs, fixed by the government, are applied to the type and amount of care needed. This creates a budget ‘indication’ valid for up to a year, even if care is needed for longer. Applicants can choose between a PGB, care in kind (care provided by an existing healthcare provider), or a mix of both.
3. For those over 18, deductions are made for monthly personal contributions (a maximum of 33% for personal care and 20% for nursing care), which are related to annual income.

The PGB value is 25% lower than the equivalent costs of care in kind, on the grounds that there will be fewer overheads.

4. The budget is paid directly into the applicant’s bank account, yearly, biannually, quarterly, or monthly, depending on the sum allocated.

5. The budget holder chooses and pays for the carer(s) s/he wants and must account for the monies spent – annually if under €5,000 a year, biannually if more. Up to €1,250 (1.5%) of the annual budget does not need to be accounted for.

6. Any surplus is repaid. Around 10–15% of budget holders repay some of their annual allocation.

Other health and social care provision falls under two separate pieces of legislation:

- Treatment of any kind comes out of obligatory private health insurance (Zvw) and is not available through PGB.
- Social care, including domestic help, adaptations to the home, mobility devices and transport, comes out of local government budgets (WMO). This used to be available through PGB until 2007, when WMO became law.

WHO USES PGB?

Information for 2008 from the Dutch Ministry of Health, Welfare, and Sport indicates that: one in five budget holders is disabled; just under a third have mental health problems; half have physical health problems. However, despite an ageing population, only one in five PGB users is over the age of 65. The fastest growing group, who now make up 45% of the total, are the under 18s. A significant proportion of this group have autism or hyperactivity disorders, although it is not clear exactly how many fall into this category.

Meeting need or creating it?

Johan Knollema, PGB national coordinator for the Health Care Insurance Board (CVZ), a government body that coordinates the implementation of the health insurance system, says that gaps in traditional services explain these figures.

‘Home care for the elderly already exists, and they often don’t want to pay for care themselves [via PGB], so the system works well for them. But for young people with autism and ADHD, it’s quite different. Twenty years ago these conditions weren’t recognised, but they are diagnosed early now, and the kind of care these children need is simply not available through traditional services.’ ▶



WHO USES PGB?

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But the growth in this sector has prompted reflection as to whether PGB is meeting existing need, or creating it. Particularly because budget holders are entitled to employ anyone they choose, including family. According to Mr Knollema, around a third of carers are thought to be relatives and neighbours.

‘Financially speaking, this is an area of concern. What we don’t know is if the money we are investing at the moment will pay itself back in fewer problems later on. It’s difficult to know whether we are saving or actually spending more, because we are paying relatives who wouldn’t otherwise be paid.’

Frans van der Pas is information and policy advisor for Per Saldo, an organisation which represents the interests of around 25,000 PGB users. He is clear that personal budgets are fulfilling a need, not creating one.

‘Autism is difficult to handle, so PGB is a very important means of support. Everyone is entitled to good standards of care and a good quality of life, and that’s what the budget enables you to do. That’s its power.’

Auke Blom is deputy director of MEE Nederland, a national support and advice organisation for people with disabilities. She says that the assessment criteria have tightened, meaning people with a mild disability are no longer eligible and there are fewer services for young people. But she doesn’t think that PGB should be plugging gaps in service provision, particularly for vulnerable groups. ‘Some people choose PGB, when they are not really able to handle it [due to mental health problems], because there are no other options. It should be a positive choice, not one made out of desperation’, she says. ■



EQUITY AND EXCLUSION

One of the criticisms levelled at PGB is that it can be complicated and demanding to manage, which may exclude the more socially disadvantaged. There are several support services in place, many partly or wholly government funded. The Social Insurance Bank (SVB) assists with the management of payroll functions for contracted carers free of charge. Per Saldo, which represents budget holders, runs courses for users explaining the intricacies of employment regulations and moving from carer to employer.

How to ensure equal access?

The figures I see don't suggest that it is predominantly used by the well educated. Its use is widely spread across society, so it's not worsening inequalities', contends Frans van der Pas from Per Saldo.

But Cule Cucic, whose seven year old son Luka has been the beneficiary of a PGB since the age of three, does not agree. Despite a high level of education and a senior position within the Dutch health system, he encountered the complications and demands of managing PGB after nearly falling foul of employment law when one of his appointed carers became ill.

'You need a reasonable level of education, life experience, time and energy to manage [PGB]', he says. 'Choice and quality are the key advantages, but the biggest pitfall is acting as an employer. I would not recommend it to everyone. And if you are really financially dependent on it, one small problem can create havoc.'

'Choice and quality are the key advantages, but the biggest pitfall is acting as an employer. I would not recommend it to everyone'

Bernard van den Berg, reader in health economics at the University of York (formerly of the University of Amsterdam), argues that PGB was never intended as an instrument of equality. 'AWBZ provides the equity, because everyone has access to that and it is income related. The more you earn, the less you are entitled to PGB might disfavour those less able to help themselves and it might be worth exploring how to help those groups use it to the maximum. But you can't restrict the more able from using it.' ►

PGB in action: Luka's story



Luka, now aged seven, has Down's syndrome. His carer, who is paid for from a PGB, is 19 year old Lubna, who has no formal childcare qualifications. Her sister Saba was doing the job until ill health forced her to take a break and she recommended Lubna to take her place.

For €730 per month, Lubna looks after Luka from 3.30pm to 6pm, four days a week. It's mostly play, but she also helps him with his schoolwork. 'It feels good to do this work,' she says. 'With other jobs, I felt I had to do them. But I really look forward to this one. It has given me vital experience in a field that I am very keen to work in.'

Luka's father, Cule, says that when his son was three, it became obvious that his day care centre was simply unable to provide for his needs. The alternatives were few and expensive, Cule recalls, and a PGB seemed an attractive option. 'I was used to managing budgets in my previous job, so I wasn't fazed by that requirement,' he says.

Disability support organisation MEE helped set up a needs assessment at home. As both Cule and his wife were from the former Yugoslavia, neither could draw on nearby family support, and both worked full time. They were given a budget of €15,000 for the year, to pay for personal care, educational assistance and respite care.

'We didn't need respite care, and used this allowance for the other two [elements] as you can use the money as you deem fit, but the next time we were evaluated, we lost that part.' Cule has also repaid part of his allowance every year.

The family employed a carer advertised on the Down's Association website for Luka's personal care. They paid a traditional agency for his educational assistance until he started a special school.

To date, Luka has had five different home carers, only one of whom proved problematic. Disentangling the contractual arrangement was difficult. Cule explains, 'You don't have the same boundaries that you have in an office. The relationship is complex: are you employer or friend?'

But he has no regrets. 'Luka has definitely benefited from PGB. It would be much more difficult to organise this sort of care without it, and there's plenty of help out there to enable you to access and manage it. You definitely feel that you have more control than if you were contracting a large agency or dependent on the black market. It gives you choice and quality, and it provides more personalised care.'

Concerns have also been raised that the definitions of care have been inconsistently interpreted across different regional areas. This is in spite of government guidelines and regular attempts to tighten up eligibility criteria.

'The lines are a little blurry on what is accepted care for people with disabilities,' says Mr van der Pas. 'Regional offices do differ. They shouldn't, but they do. It's a major issue for budget holders: you can't always buy the care you need.'

The new minority government, formed in 2010, plans to shift more PGB elements to local government in a bid to decentralise care. This worries Auke Blom, who thinks the boundaries are already imprecisely drawn. But there's a further cause for concern. 'There are limited resources in local government and we have more than 400 municipalities, who are not always qualified to help people with disabilities,' she contends. ■

'The lines are a little blurry on what is accepted care for people with disabilities'

The government's reluctance to impose minimum standards for PGB carers means that budget holders have to make up their own minds on quality. There is a healthcare inspectorate (IGZ), but it is not resourced to monitor individual care providers. Local governments are encouraged to train informal carers with no professional qualifications, but it's not clear how common this practice is.

Quality and value for money?

MEE (a national organisation that assists people with disabilities in accessing support, including the PGB) helps people with a disability find carers by putting them in touch with members of its 10,000 strong database, most of whom come through personal recommendation. But it only meets the carer if it has any grounds for suspicion or the client has voiced concerns. There are many different places and websites to look for potential carers and it is not always easy to know what to look for.

‘The fact that there is no official system of supervising the quality of care is something that surprises everybody,’ says Johan Knollema from the Health Care Insurance Board (CVZ). ‘But what we find is that people are very careful about who they contract when they need nursing care or help to look after a child with a mental disability.’ CVZ does, however, make a point of warning clients about the need to check care providers outside the home, including running criminal record checks. ▶



‘The fact that there is no official system of supervising the quality of care is something that surprises everybody’

Frans van der Pas from Per Saldo says that it is up to the budget holder to define quality and be accountable for that. Qualifications don't necessarily translate into good care, he suggests. 'How do you recognise quality when there is no evidence base?' he says. 'Quality is help that works. And if it doesn't work, it's your responsibility to sort it out.'

A 2010 Health Foundation review of the available evidence on personal health budgets⁴ shows that most of the research has come from the US, Germany, and the Netherlands. But there has been little empirical research and there are clear gaps around the impact of personalised schemes on health outcomes and cost effectiveness.

'There hasn't really been any evaluation of PGB's value for money because the assumption is that people optimise their budget, and that if they don't like the care given by a particular person, they can find someone else to do it,' says Bernard van den Berg.

But feedback from surveys carried out by Per Saldo suggests that most budget holders are very happy with the quality of care they receive. There is no evidence to suggest that anyone has come to any harm as a result of the care they have received through PGB. Johann Knollema says that 70% of the 13,000 people on the PGB waiting list would prefer to wait until the new funding allocation comes on stream rather than opt for traditional care. ■



THE FUTURE OF PGB

The Dutch government announced a 3% cut in PGB tariffs for 2011 from 1 January which, combined with inflation, is more likely to be 4.5%. It is also looking at other ways of cutting costs.

Strategies for sustainability

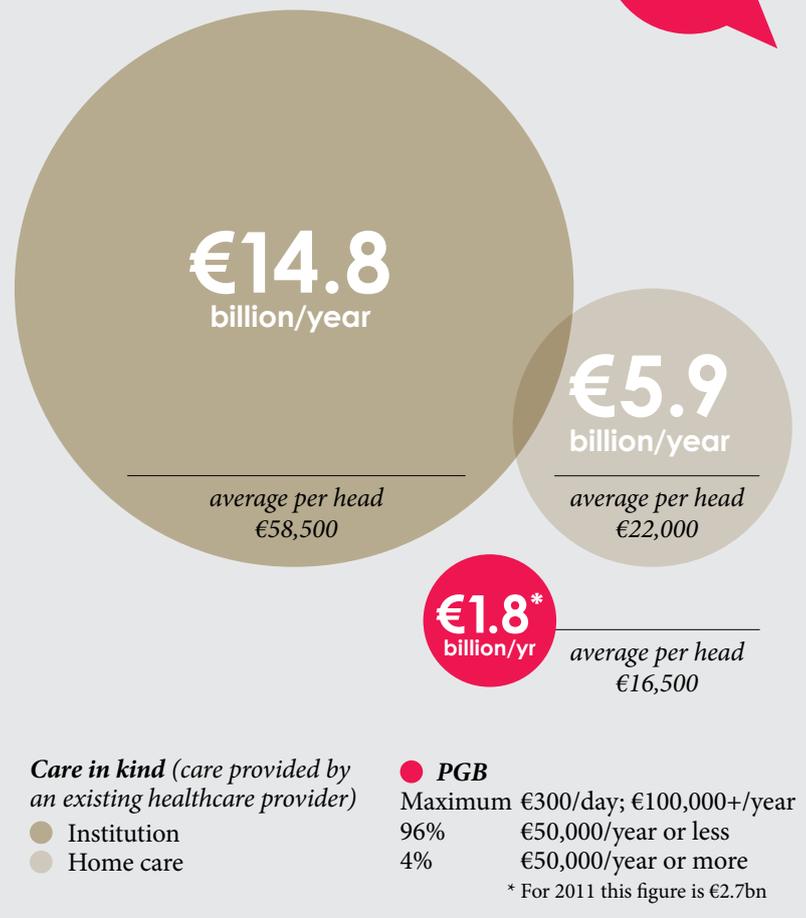
‘We analysed PGB use and found that it is mostly younger people who are responsible for most of the 30% overspend,’ says Patrick Jeurrisen, coordinator of the Economic Affairs and Labour Market Policy Strategy Group, at the Ministry of Health, Welfare and Sports. ‘So the debate at the moment is whether we should pay for disorders like autism in the way we do now.’

Support services have the lowest impact on health and are likely to be shifted to local government. This currently accounts for 40% of the PGB budget.

The remaining 60% of PGB, which is currently paid out of taxes and government subsidy set by central government, could become part of the basic health insurance package under Zvw. ‘That will mean the insurer will have to pay for anyone who is entitled to a PGB,’ he explains, adding that this will strengthen entitlement, but could increase insurance payments.

Legislation will be required to make these changes, so the earliest they could take effect would be 2012 and Mr Jeurrisen ▶

Costs of long-term care (2008)



Source: Ministry of Health, Welfare and Sport 2009⁵

THE FUTURE OF PGB

is not entirely convinced that the new government will take this route. He is clear, however, that the scheme's enduring popularity with politicians and users will ensure its survival in some form or another.

And he defends the design of PGB. 'If we designed a system in such a way that each additional entitlement to PGB means one less entitlement to traditional care, we would save money. But we designed it in such a way that PGB would not be a substitute for regular care,' he says. 'If it were, it would have to be less flexible.'

Bernard van den Berg suggests that the Netherlands might follow Austria's example, with eligibility for PGB arising only after 40 hours of care a month. He also thinks the government has missed a trick by not offering more incentives to budget holders.

'If budget holders have to pay back unspent monies, they will potentially start to pay higher prices because there's no incentive to negotiate lower ones. If the government wants PGB to act as a mechanism to make people more price conscious, it could allow them to keep what they haven't spent by way of an incentive,' he suggests.

But Frans van der Pas from Per Saldo is more worried about the immediate impact of the cuts on the small organisations that cater for PGB. '[They] are already very efficient, so the only result of the cut will be lower wages, more unpaid informal care, and the need to pay for services out of your own pocket...Care budgets are easy targets and people don't die of their disability; they just have fewer possibilities to improve their quality of life.'

The cuts have already started to bite for Luka Cucic. His total budget has already been cut by 30% following a re-evaluation of all existing PGB user

'Care budgets are easy targets and people don't die of their disability; they just have fewer possibilities to improve their quality of life'

needs in 2010. On top of this, another form of child benefit for all children with disabilities has also been stopped.

'What is left can just about cover Lubna's hours,' his father Cule says. 'Her contract is due to end soon. We may have to pay her 6-7% less than she's getting now. She knows that it will mean fewer contracted hours and more ad hoc casual hours that we often need, on which occasions we will pay her cash in hand.'

PGB in the Netherlands have had their implementation challenges and, as with any intervention in a complex healthcare system, problems and unintended consequences have called for varying degrees of adaptation and, in some cases, significant legislative changes. The ongoing popularity of PGB amongst users, however, suggests that they are meeting needs and reflect societal demands. In spite of the teething problems, there is also political commitment to PGB and, in general, the future would appear to be bright for PGB in the Netherlands.

The Dutch experience offers rich insight for burgeoning personal health budget initiatives across Europe and in the NHS, enabling those who follow to learn from mistakes and better uncover the benefits. ■

ENCOURAGING INNOVATION

The government had hoped that PGB would encourage greater competition and spur traditional providers into offering more responsive services to capture this growing market. Johan Knollema, PGB national coordinator, admits this hasn't happened.

Market driven innovation?

‘**W**e hoped that PGB would be innovative and prove to traditional providers that this is the kind of care people really want. So it's quite a disappointment that they are not learning from PGB and have been very slow to adapt... We hoped competition would change the market, but because the number of elderly and people who need care are growing, [traditional carers] have more than enough work. So this incentive doesn't seem to be working.’

But if the traditional providers have been slow to innovate, the PGB market has not.

Auke Blom explains: ‘I think PGB is very good for innovation. People are more creative because they are thinking about what they really want.’ She cites examples of the 500 farms that have opened up as short stay centres for children with disabilities, and the establishment of small group facilities, such as Thomas Houses⁶ where children and young people can live together.

‘PGB allows people to pool their budgets, and we see that happening a lot with the parents of disabled children. They club

together and start up their own project’, she says.

PGB has also spawned a thriving service industry in the form of intermediary agencies, willing to take on the entire management of the budget on a client's behalf. Sometimes this is for hefty fees, for which budget holders are not reimbursed. Before the law was changed in 2009, these agencies were able to have the PGB paid directly into their own account and in some cases money was stolen.

There is now a code of practice for these agencies, but it's voluntary and some deploy very aggressive marketing tactics, claims Mr Knollema. He says that good local governance, which was supposed to support the transfer of the domestic service element of PGB to local council control under WMO, has still not prevented money going missing.

‘Fraud is a real problem. But our belief is that this is no bigger than in any other financial system. Most people don't abuse PGB, and because budget holders have to account for everything, it's more transparent than care in kind.’ ■

Personal health budgets are a new concept for the NHS and are currently being tested in a pilot programme across England. However, direct payments have been used in social care since 1996. Vidhya Alakeson, Research and Strategy Director at the Resolution Foundation looks at what we have learnt so far and asks if personal budgets in health can improve care and encourage innovation and efficiency in the NHS.

Personal budgets and the NHS

Unlike countries such as the Netherlands, take-up of personal budgets in social care in the UK has been slow. In 2006/7 only 3% of people in England received some of their services in the form of a personal budget, compared to nearly 10% in the Netherlands and 79% in Germany.⁷ The UK government wanted to see 30% of community-based social care users in England adopting a personal budget by April 2011, prompting an acceleration in take up as local authorities rushed to meet the target.

The launch of the English personal health budgets pilot in 2009 signalled a new wave of innovation in self-direction.⁸ In most European countries self-direction began in long-term care, focusing on a limited range of clinical services such as nursing care and some therapies. The introduction of personal health budgets into the NHS gives people wider control, allowing choice over more traditional, clinical services. This is in line with the types of choice that patients say they want and with research showing that patient engagement in care improves satisfaction, safety, health outcomes and

‘Stories of how personal health budgets have improved people’s lives and are saving money are already emerging. But it will be some time before there is reliable evidence about their impact’

value for money.^{9,10,11} Among the 70 or so personal health budget pilots underway are pilots focusing on depression, maternity care, chronic obstructive pulmonary disease (COPD) and diabetes.

By introducing personal health budgets, the NHS in England has gone further than other countries in extending the reach of self-direction. ►

‘PATIENTS WITH COPD ARE USING SINGING LESSONS TO INCREASE LUNG CAPACITY INSTEAD OF PULMONARY REHABILITATION’

It is early days, with only 500 personal health budget holders across the country. However, innovation in the choices individuals are making is clear. Patients with COPD are using singing lessons to increase lung capacity and steady breathing instead of pulmonary rehabilitation. A woman in the maternity pilot has employed a doula to support her during pregnancy and after her child is born, having had difficulties with post-natal depression in the past.¹²

Stories of how personal health budgets have improved people’s lives and saved money are already emerging.¹³ But we do not yet have reliable evidence about their impact. A national evaluation of 20 in-depth pilot sites will report in the autumn of 2012. In the meantime, the challenges that personal health budgets pose to the NHS are becoming clear. They focus on outcomes not services, eroding established ideas of what is legitimate use of NHS funding and breaking down the institutional silos of public services. They create a shift in power in favour of patients and necessitate a change in practice from clinical professionals. They challenge the risk-averse culture of the NHS by supporting individuals to make choices for themselves, recognising that individuals are generally safer if they are involved in their care.¹⁴

‘The launch of the personal health budgets pilot in 2009 signalled a new wave of innovation in self-direction’

The coalition government has stated its strong commitment to personal health budgets as a tool for putting patients at the heart of the NHS. However, they are being implemented at a time of huge structural reform and significant financial pressure in the NHS.¹⁵ While personal health budgets have been included in the latest NHS operating framework, there will be no targets to drive take-up as there have been in social care.¹⁶ As a result, much of the future success of personal health budgets lies in the hands of GP consortia. ■

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The Health Foundation is an independent charity working to continuously improve the quality of healthcare in the UK.

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