

Research that makes a real difference

Doctor knows best? The use of evidence in implementing self-directed support in health care

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The concepts of personal budgets and self-directed support are well-established in adult social care and have been successfully piloted in the NHS. However, a key debate – particular for clinical staff – has been around the nature of the evidence base required to justify a more fundamental shift in traditional ways of working. Against this background, this policy paper explores what comprises valid evidence in the first place and potentially more fruitful ways of considering the ‘evidence’ of what works in future.

In 2009, the UK Department of Health (DH) launched the first national pilot of self-direction in health in the National Health Service (NHS) in England, testing what they named personal health budgets (PHBs). In total sixty-four local areas participated in this three year pilot, of which 20 took part in an in-depth, controlled evaluation (Forder *et al.*, 2012). Following the publication of the national evaluation in November 2012, the government confirmed its commitment that all recipients of continuing health care should have the right to ask for a PHB from April 2014. A less firm commitment to extend PHBs to all those with long term conditions who could benefit from April 2015 was also made.

According to former Minister of State for Care Services, Paul Burstow MP:

Personal budgets encapsulate what we [the coalition government] represent. Our single, radical aim: to change the relationship between the citizen and the state, to do less to people, and more with them. And to ensure Government steps back, making the space for people to lead the lives they want, how they want to. In health and social care, that means giving people real choice over their treatment; real control over how money is spent; and real power to hold local services to account. (Burstow, 2010)

PHBs allow individuals to control NHS resources for elements of their care and to use those resources in creative ways to meet their health needs. For example, an individual receiving intensive rehabilitation after a stroke may prefer, with the support of family members, to design an alternative rehabilitation package from the one available through his Clinical Commissioning Group (CCG). He may choose to employ personal assistants to help with personal care and mobility and a massage therapist to work with him to improve functioning and mental well-being, while maintaining the physiotherapy service he currently receives from the NHS. Few restrictions have been imposed by NHS England on how money can be used – although pharmaceuticals, emergency, inpatient, public health and GP services are not included in a PHB, and alcohol, cigarettes, gambling, debt repayment and anything illegal are not permitted (DH, 2009).

Although personal health budgets are new in the NHS, they have a much longer track record in adult social care and in other developed countries (see, for example, Glasby and Littlechild, 2009; Alakeson, 2007; SCIE, 2005, 2007, 2008). At its most simple, a personal budget is nothing more complicated than being clear with people upfront how much money is available to spend on meeting their needs and allowing them greater say over how this money is then spent

on their behalf. In principle, this ensures that decisions that matter to people are made as close as possible to the person they affect (ideally by the person themselves or someone who knows them and cares for them), freeing up the person, their family and/or the worker to be more innovative about how to meet need (see Glasby and Littlechild, 2009 for a more detailed overview of the nature and history of direct payments and personal budgets – two key approaches to what is often termed a ‘personalisation’ agenda or a system of ‘self-directed support’).

One of the most consistent findings from international research on the impacts of self-direction in social care is that individuals who direct their own care are more satisfied with their care than those who receive services through a home care agency; in large part because they have access to services at the times they choose, provided by the people they choose and tailored to meet the needs and goals that they themselves identify. There is also good evidence that these improvements can be made without any cost increases and, in some cases, with cost savings (Alakeson, 2010a; Tyson *et al.*, 2010; Glasby and Littlechild, 2009; Glendinning *et al.*, 2008).

Throughout the implementation of personal budgets, the issue of ‘evidence’ has been a constant theme (see, for example, Glasby, 2012) – and policy makers advocating the development of personal health budgets made the roll out of the approach contingent on the results of the national evaluation. Thus, the initial Darzi Review emphasised that the pilots would be subject to “rigorous evaluation” (Darzi, 2008, p.42), while the evaluation website was also keen to stress that the evaluation was a “rigorous” study (www.phbe.org.uk). Andrew Lansley’s 2011 announcement that PHBs would be rolled out for continuing healthcare carried the caveat that roll out would be “subject to the evaluation of the pilot programme” (Department of Health, 2011). Similarly, the NHS Confederation highlighted the importance of securing positive evidence from the PHB evaluation before roll-out proceeded (NHS Confederation, 2011). The British Medical Association (BMA) expressed concern that PHBs could lead to extra bureaucracy, greater inequality and to health care being perceived as a commodity, adding that:

The BMA welcomes the government’s commitment to undertake a comprehensive and robust pilot programme... As the Department of Health is already aware, while the BMA will certainly look at the findings of the pilot, we have a number of overarching concerns. (BMA, 2010)

Whether this means that the BMA was awaiting the results of the evaluation with interest as it suspected they would confirm its concerns or whether they would have been concerned irrespective of what the evaluation concluded isn’t quite clear. As a very anecdotal – but nonetheless interesting – example, a fascinating reaction was provoked on the website of *Pulse*, a GP magazine, which ran a feature with the headline ‘personal budgets to allow patients to buy homeopathy and acupuncture’ (Praities, 2009). Overall, the article seemed to be concerned that patients would be able to spend public money on complementary and alternative therapies and “other non-traditional services” such as “personal assistants, equipment... or transport.” According to one GP interviewed:

I think there seems to be some confusion in Government policy. On the one hand they have been quite clear that the NHS should use resources based on evidence-based guidance developed by NICE [National Institute for Health and Clinical Excellence], but there seems to be some confusion about the degree of flexibility patients will have. For example most complementary therapies are not supported by NICE guidelines.

Even more revealing was the subsequent web-discussion underneath the article which focused almost entirely on complementary therapies, with a series of concerns about evidence and science (see Box 1).

Box 1: Reactions to Pulse feature on PHBs

“Can someone please explain why tax payers should be subsidising people to indulge in pseudomedical flim flam?”

“Would it not be even simpler to abolish all science, reason, logic, evidence etc in one big bang, rather than returning to the dark ages in agonisingly painful steps?”

“So much for evidence-based medicine. It’s back to magic again. Bring on the leeches, bleeding and cupping. And all on the good old NHS!”

At a practitioner level, key questions posed to the current authors at various national events have included (personal communications, health care practitioners):

- How will workers handle support plans that seemed to defy clinical evidence of what works?
- How will the system respond to proposed supports of unproven value?
- How will this fit with current governance arrangements (for example, the notion of ‘clinical governance’ and the role of national bodies such as NICE)?

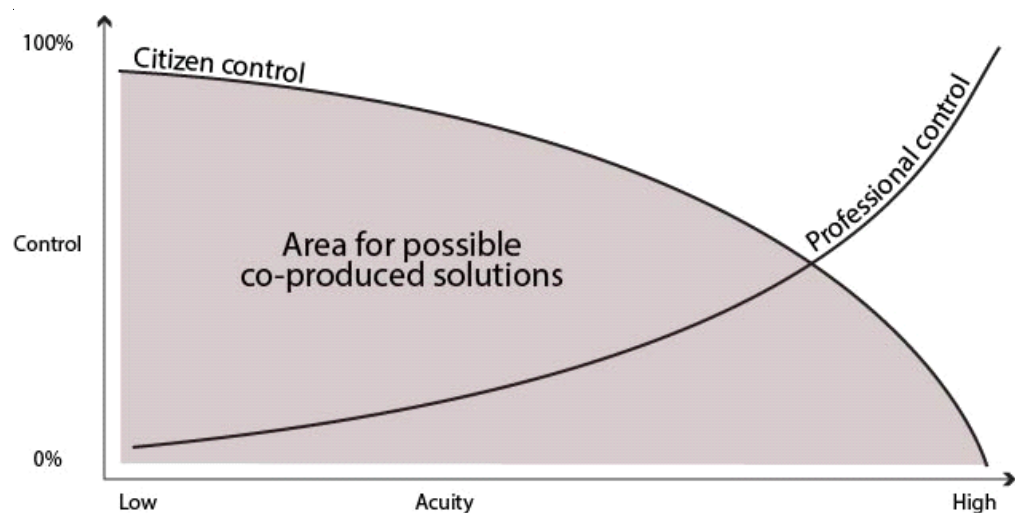
As PHBs have spread, we have detected something of a shift from outright opposition (from some audiences) to a desire to understand PHBs more fully and explore how best to implement them. However, concerns about evidence have remained. Against this background, this policy paper *does not* review the evidence for and against PHBs (see Forder *et al.*, 2012 for a detailed evaluation). Instead it considers the challenges that such approaches might pose to traditional notions of what constitutes valid evidence in health care, and proposes alternative ways of viewing the debate about ‘what works’.

Self-direction in health care

The costs of healthcare are increasing across the developed world, fuelled by the rise in long-term conditions such as diabetes and heart disease (Sassi and Hurst, 2008). In the UK, long-term conditions account for around 70% of spending in the National Health Service (DH, 2010b). By their very nature, long-term conditions require day to day management to prevent conditions worsening and a subsequent emergency hospitalisation. This task falls far more to individuals and their families than to health professionals. If there are 8,760 hours in a year, the average person with a long-term condition in the UK spends no more than three or four hours a year with a health professional – less than 0.05% of the year (Hannan, 2010). Growing appreciation of the central role that individuals play in managing their own health has led to a new focus on interventions that support self-management (Lorig, 2001; Coleman, 2006) and the development of peer to peer models of disease management (Expert Patients Programme, 2010). It has also strengthened the call for a transformation of the NHS away from a model of healthcare that is uniform and professionally driven to one that is more individually tailored and based on a partnership between individuals, families and professionals (Health Foundation, 2008).

There are few areas of healthcare where there is only one treatment option. In the vast majority of cases, there are several possibilities, each with different risks, side effects and likelihood of success. Doug Eby, senior physician executive at the South Central Foundation in Alaska, argues that it is only in relatively extreme, high acuity cases that the professional is fully in charge of the situation, such as when the patient is in a coma, anaesthetised or collapsed. Eby argues that the less severe the symptoms, the greater the chance the patient will do what he or she wants to do and will take the professional's advice selectively (Crisp, 2010). The area between the two lines in Figure 1 below indicates significant scope in healthcare for co-produced solutions between individuals and professionals.

Figure 1: Acuity and Individual Control



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

For individuals who are oxygen dependent or use other medical equipment, the failure of the healthcare system to recognise their specific needs and preferences can not only affect the success of their treatment, it can significantly restrict their ability to play an active part in their families and communities. For example, individuals who are oxygen-dependent but do not have access to a portable supply, find themselves unable to travel to visit family and friends and also stay away from home, leading to isolation and poor mental well-being. Parents caring for technology-dependent children at home often find themselves unable to take their children on trips and on holidays because their agency-provided carers are not permitted to work outside their local area.

Writing in Health Affairs, Epstein and colleagues (2010) suggest five reasons for creating more 'patient-centred care':

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

The success of self-direction in social care has generated interest in the possibility of extending self-direction into healthcare as one way of creating a more personalised and more effective service, particularly in the management of long-term conditions (Glasby, 2008). The PHB pilot demonstrated that self-direction in healthcare can improve individual quality of life and well-being and reduce service utilisation and costs (Forder *et al.*, 2012). However, if self-

direction is to become a reality within the NHS then there are a number of cultural barriers that will need to be overcome – three of which relate to the issue of evidence:

- The role of patients in identifying what works for them
- Focusing on outcomes
- Innovation as a component of evidence

Key issues I: respecting the expertise of patients

Healthcare is a complex field in which technological and pharmaceutical innovation is rapid. The skills and knowledge of professionals will remain important, even if individuals choose to take greater control. Furthermore, professionals will continue to play a role in clinical governance. However, healthcare professionals have tended to neglect the views of patients, despite general agreement that patient-centredness is a feature of a high quality healthcare system (Institute of Medicine, 2001) and clear evidence that many patients want to make decisions about their own care. According to the Picker Institute, across Western Europe 75% of patients believe either they alone, or they with their doctor, should be deciding on the appropriate course of care and treatment (www.pickereurope.org/sharingdecisions).

The emergence of personal health budgets should be seen as ‘tipping the balance’ of power from clinicians towards patients, while maintaining the central importance of the partnership between patients and clinical professionals (Brewis and Fitzgerald, 2010). Working as equal partners with individuals and families will be a challenge for many healthcare professionals who have not been trained in this way. For example, where there is a conflict between individual preferences and clinical judgement, an individual’s behaviour is often described as ‘non-compliant’ rather than being perceived as the exercise of individual choice and preference. A central part of achieving partnership will be to shift professionals away from seeing individuals receiving services purely in terms of illness and deficits, and to focus on their assets and expertise. Don Berwick, an internationally recognised leader in healthcare quality improvement, has argued for patient and family-centred care to be a dimension of quality in its own right and not just through its effect on health status and clinical outcomes. He went on to state that the implication of this is that patient choices may sometimes trump ‘evidence-based care’ (Berwick, 2009).

In addition to this, the current authors have often argued that PHBs might work best in areas where:

- Knowing how much money is available upfront would help to improve outcomes
- There is genuine scope for the person and those close to them to be creative and flexible in meeting needs
- Having something that is truly personal is a fundamental component of making something a quality service

Applying these tests might lead to PHB working well for people with mental health problems coming out of hospital, people with learning difficulties leaving NHS campuses, continuing health care, end of life care and for people currently in expensive out-of-area placements (Alakeson and Duffy, 2011). Interestingly, many of these areas are parts of the NHS where we know relatively little about 'what works' – hence high rates of 'revolving-door' readmissions to mental health in-patient care, for example. These are also areas where we suspect that only something that is truly personal will work – again, we know relatively little about how to support someone to recover from severe mental illness, but presumably the most effective approaches have to be tailored to the needs and circumstances of the individual and go beyond symptom management to consider wider aspects of a person's life. In this sense, PHBs could offer an opportunity to generate new evidence about what works – but in the form of 'practice-based evidence' rather than more traditional 'evidence-based practice'.

Similar arguments have also been put forward by Glasby and Beresford (2006) and Glasby *et al* (2007), who argue that the NHS has become too dominated by quantitative and medically orientated notions of what constitutes valid evidence (especially RCTs and systematic reviews) – and that this neglects the practice wisdom of front-line staff and the lived experience of service users and carers. In contrast, Glasby and Beresford argue for a broader and more inclusive notion of 'knowledge-based practice', which rejects traditional hierarchies of evidence and argues that for some topics proximity to the issue being studied can be more important than traditional notions of distance and objectivity. In the case of PHBs, perhaps the question isn't 'do personal health budgets work?' – but rather who decides what success should look like in the first place and what outcomes can service users and staff working together with greater scope for innovation and creativity achieve that might not have been possible within mass purchased or produced services?

Key issues II: focusing on health outcomes

The second big change needed to support personal budgets is to shift the focus from services to outcomes. This is in line with the focus of the NHS outcomes framework (in contrast to more process-based indicators). Typically, the NHS has focused on generating research evidence into particular types of treatment and service interventions – focusing on the process to be adopted. In contrast, personal budgets start from an individual's identified health goals and impose few restrictions on how these health goals are met. The upshot of this orientation towards outcomes is that NHS resources can be spent on goods and services that have previously had no place in the NHS, for example computers, companion animals and gym memberships. Commissioners will need to adjust to this shift and develop ways of judging performance based on whether a personal health budget is meeting an individual's identified needs, irrespective of which services he or she chooses to use.

A good example is the story of a person who was overweight and who used a personal budget to buy a dog. While there may not be a formal research study or NICE guidance to assess the cost-effectiveness of dogs for weight loss and there is unlikely to ever be such a study, this seems a simple way of getting someone walking more – and could work better than more traditional weight

loss programmes. Here the focus is on the outcome to be achieved – and ways that could help deliver that outcome for specific individuals – rather than on the process by which the outcome is achieved. In a mental health context, a woman with a serious mental health condition who used to make frequent ambulance call outs and visits to Accident and Emergency used her personal health budget to buy art materials. These provide sufficient distraction when she hears voices to prevent most emergency visits. In addition, the local art shop has become an important source of social support which has reduced her sense of isolation and helps her manage her anxiety. Not only has the personal health budget improved her well-being, it has saved the NHS hundreds of thousands of pounds a year. In one of the PHB pilots for individuals with Chronic Obstructive Pulmonary Disorder, several people used singing classes as an alternative to pulmonary rehabilitation. As well as stabilising their breathing, the singing provided more social interaction and a greater sense of well-being than the traditional service. For many people with continuing health care needs, the value of a personal health budget to them and their families has had less to do with making alternative purchases and more to do with being able to hire personal assistants at times that fit the family's needs. For example, a daughter caring for her father at home at the end of his life used a personal health budget to purchase respite care on a Saturday so that she could continue to watch her son's football games (more examples of how personal health budgets are being used can be found at <http://www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/>).

Key Issue III: The role of innovation in developing evidence

Research and development in modern medicine matches the existing disciplines and technologies by which doctors can act on the human body to bring about beneficial change; primarily these are through the administration of drugs or the application of surgical techniques, including the use of radiation and similar therapies. All such developments rely not just on evidence but also upon the primary innovation which is then tested by experiment. What is more there is an important industry in place to serve doctors by developing new drugs and surgical operations. In return for developing new drugs and treatments the industry generates profits that can be distributed back to those who invested in the development of the original innovation.

There is no doubt that this process has many positive effects, but it is also important to note that it also tends to create a rather self-serving notion of innovation and evidence. There is no similar investment to support innovations that do not create profit or that extend beyond clinical treatment. Furthermore, the scope of possible innovations does not seem limited to new drugs or surgical operations. Here are two examples of possible innovations that fall outside the scope of mainstream medicine, but which still seem like potentially useful and positive developments:

1. Julia has a chronic lung condition. She used an individual budget to purchase air conditioning for her home and this has radically reduced the frequency at which she has to stay in hospital (Alakeson, 2010b).

2. Vinny has ADHD and a history of depression, self-harm and attempted suicide. However he has found that cycling gives him a release which helps him improve his mental health and become less reliant upon mental health services (Duffy, 2012).

In the case of Julia it might be that many other people with the same objective condition would benefit from a similar adaptation; in the case of Vinny the benefits of cycling are just as dramatic but the 'treatment' is perhaps more personal to Vinny and to his own preferences. However, while both developed innovative approaches to improving their health, both faced, to different degrees, challenges in getting their approach accepted. For Julia (who had been a nurse) her treatment was eventually accepted as a valuable innovation. However Vinny, who lives on a very low income, could not find the money to replace his old broken bike and could not get financial assistance from mental health services. He underwent three months of intensive engagement with mental health services before he found the necessary money, himself, to purchase a suitable bike.

The challenge for healthcare professionals will be to see these kinds of approaches as genuine innovations in healthcare. Clearly these particular innovations cannot be industrially replicated; instead they are a response to a health condition, a person's lifestyle and the details of their physical and social environment. However it is a mistake to think that innovation, experiment and evidence can only be generated by industrial-style approaches.

In fact there is always a danger that the notion of scientific evidence will be distorted into something that is less than scientific; particularly when there are significant commercial interests or vested-interests at stake. As Kuhn, Popper and others have observed, a truly scientific approach is one that accepts that current evidence can never prove the validity of any current theory (Kuhn, 1970; Popper 1959). Rather, evidence can only disprove a current theory or hypothesis and our theories change and improve in the light, not just of evidence, but of the paradigms or models we apply to the world. A truly scientific approach to evidence in healthcare will be sensitive to the limitations of current theory and aware of the possibility of new ways of understanding health and delivering improved healthcare. True science demands humility and curiosity.

Indeed the healthcare professional must recognise two particular limits to their own knowledge. First, there are clearly many treatments, or forms of care, that are best designed and controlled by the individual because the individual is the only person with the relevant body of experience. In Julia's case the standard, professionally delivered solutions to her healthcare needs seem to be less effective than a treatment tailored by her to her own needs. Second, there are many needs that are significant, but for which there is no known and reliable treatment. In Vinny's case the non-standard solution certainly fell outside any norms of professional practice. But for Vinny this solution was far more effective than any standard healthcare solution; for our knowledge of how to improve mental health seems very limited.

To accept that there are real limits to professional knowledge does not degrade professional expertise; rather it invites professionals to engage in a more genuinely scientific approach to their work. Looked at in this way, personal health budgets open up the possibility of bringing innovation into the heart of

the therapeutic relationship between the professional and the person. Together they can create new theories about what may work for them, and develop new tests for these theories. Contrary to some of the current fear of doctors, this could be seen as an opportunity to further increase the scientific validity of medicine.

Conclusion

Whatever one's prior knowledge of or attitude to personal health budgets, the development of this new way of working poses important challenges for the NHS. This paper has focused on three such challenges in relation to the issue of 'evidence' and broader debates about what constitutes valid evidence in the first place. While ongoing research will always be important, the discussion above draws attention to the importance of recognising the expertise of patients, focusing on outcomes and expanding traditional notions of innovation. Just as important as the evidence produced by the government's pilot programme is the broader issue of what constitutes valid evidence in the first place and who decides.

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