

An investigation into mental health service user experiences of an individual budget pilot scheme reveals some unexpectedly positive results

## Individual budget projects come under the microscope

### KEY WORDS

The IBSEN evaluation  
Personalisation  
Direct payments  
Individual budgets

**M**ental health users happy with individual budgets' ran a headline on the Social Perspectives Network news site on 24 October 2008, reporting what, for some people, was a surprising finding from the independent evaluation of the individual budgets (IBs) pilots.

The story reported the evaluation's finding that people using mental health services, alongside physically disabled people, were the most satisfied with the new IB arrangements of a range of groups that included other groups of social care service users and a comparison group not offered IBs.

While many physically disabled people have been found to be keen on aspects of self-directed support, such as direct payments or cash for care services, the experiences of people using mental health services have not been looked at in similar detail.

In this article, we outline the major conclusions of the IB evaluation, drawing on the final report (Glendinning *et al.*, 2008) and use these to suggest some explanations for these findings and other developments.

### The individual budgets concept

The IBs initiative sought to extend the principles of self-directed and more flexible support to a broader range of social care user groups than had been using direct payments. Under a direct payments scheme, people are offered a sum of money to arrange and

manage the support or services they need themselves rather than have to use those organised by care managers. However, unlike direct payments, the IBs scheme sought to combine a number of different funding streams that often support an individual, such as access to work or the independent living fund.

The aim was to bring choice and control closer to the consumer, partly by aligning assessments and resources from different funding streams, encouraging self-assessment and introducing transparent resource allocation so that a person knows what resources make up his or her IB. One major distinction between IBs and direct payments is that people have more flexibility in how IBs can be used than they do with the direct payments. They can be used to meet outcomes or support needs beyond personal care.

IBs, which are now often referred to collectively as personal budgets, can be deployed flexibly, but they are more likely to make use of social care funding alone from local authorities without necessarily integrating any wider funding streams. This article refers to IBs, since they were the subject of the evaluation, but many of the points made also apply to personal budgets.

### Principal aims

IBs were piloted in 13 local authority areas in England starting in 2005–6. Building on this background, the Department of Health has already announced the extension of personal budgets across adult social care

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in England as part of the transformation of social care, and as an element in the policy process called personalisation (see Department of Health, 2008).

The Department of Health commissioned the evaluation of the IB pilots, known as the Individual Budgets Evaluation Network (IBSEN), to look in detail at what worked and for whom, and to check whether IBs were more costly than existing forms of support and how much they cost in a unique social care experiment. Specifically, the evaluation aimed to test if IBs gave people using publicly funded social care services the following:

- more control over their lives
- more understanding of the resources available
- more flexible ways of meeting their needs.

Across the 13 pilot sites, 1,594 people using services originally agreed to take part in a randomised comparison study of outcomes for people receiving IBs compared with those in similar circumstances who were not allocated IBs. Not all of these volunteers remained in the study, and the final sample comprised 959 people. The sample can be broken down as follows:

- 34% were of working age and physically disabled
- 28% were older people
- 25% had learning disabilities
- 14% used working-age mental health services – this group included people with early-onset dementia.

The sample included a good range of groups representing different ages, ethnic groups and household compositions. However, the group of people of working age using mental health services was smaller than other groups. This reflected the ways in which the pilot areas developed their IB schemes, focusing on certain groups or certain areas or ages.

Only four of the 13 pilot sites initially planned to offer IBs to mental health service users, although more sites extended IBs to this group during the course of the pilot. The sample of IB users typically did not have experience of holding an IB for very long: just less than half (45%) of the people in the IB sample were actually in receipt of an IB at the time they were interviewed – which was about six months after the IB had been agreed – or had had less than a month's experience of their new support arrangements.

Study researchers interviewed IB lead officers, care co-ordinators/care managers, team managers, providers of social care services (home care agencies, for example), commissioning staff, and local government training and safeguarding/adult protection staff.

### Resource allocations

The original policy proposals for IBs made no recommendations about how social care funds were to be allocated to users, although means testing, charging and eligibility criteria were to remain. Each site developed its own resource allocation system (RAS), often adapting the 'in control' model initially.

These were seen as being workable in some places. But they could be controversial, leading to some cynicism among frontline staff that 'points would mean pounds' and that the resource allocation system was not fine tuned enough.

Pilot sites started by developing separate RASs for each group of social care service users, although many hoped eventually to develop a single RAS covering all user groups. We found little agreement on the appropriateness of a formulaic RAS compared with assessment processes, where professional judgement and discretion play greater roles, or with the outcomes-focused approaches that tended to be adopted, to a greater or lesser extent, in a few sites.

A debate is needed on the equity implications of any RAS and the principles that might underlie any redistribution of resources between user groups that might result. Given the transparency that is fundamental to personalisation, the principles underpinning any RAS and their desired outcomes need to be democratically decided. We will see if this thorny issue is informed by the current consultation on the future of adult social care and the green paper due early in 2009.

### Fair access

There were debates within pilot sites about the operation of eligibility criteria for fair access to care services (FACS). This was in the context of a move towards more outcome-focused self-assessment, or joint assessments between people seeking services and professionals. FACS criteria were poorly aligned with some of the funding streams that were to be included in IBs and, of course, they do not always align with mental health assessment systems.

Similarly, many sites experienced difficulties with existing charging policies, particularly when IB users opted for mixed deployment options (such as taking up the option of buying a service and also using an existing service for which there was a contract for several people with a provider). Charging policies, therefore, also need review as personalisation is extended.

Across the pilot areas, senior managers, care co-ordinators and people using services raised questions about the boundaries and legitimate use of adult social care services provided from public funds. Resources were allocated on the basis of need and risk, but IBs allow these resources to be used in new and creative ways that focus on goals, outcomes and inclusion.

This was a particular issue with people using social care mental health services, who tended to use IBs to purchase 'unconventional' services, such as gym membership, help from a personal trainer, aromatherapy or training in new activities such as pottery or photography. The evaluation concluded that it will be important for these new approaches to be endorsed and legitimated in public and policy debates. They may also need to be discussed within families and in small group settings.

### Success factors

Experience of IB pilots has revealed the key factors for success. Like other processes of managing change, facilitators included active support from senior managers and decision makers in the local authority, and an implementation team that was enthusiastic and able to solve problems and bring in other people as required. →

In the pilot sites, such staff received considerable support, but they also worked under pressure. Such change processes within large statutory services are likely to impact on other mental health service providers who have to respond to the changes of personalisation. How will local authorities and providers work together to develop the kinds of services that will increasingly be needed? Some answers are already emerging from organisations such as Norfolk Mind (2008).

Concerns about financial and individual risks for IB users were widespread, and these may have inhibited creativity, although there was little evidence about risks.

Local priorities included developing monitoring and reviewing systems that safeguard individuals and address the quality of support, both when approving support plans initially and on an ongoing basis. Locally, adult safeguarding systems, in which mental health groups and professionals are key players, will need to work out new policies, and they will need to include personalisation in their awareness training.

### Deployment options

Although many people were offered IBs as a direct payment, a number of different ways of managing IBs (deployment options) were possible. These included care managed 'virtual budgets', where the care manager manages the IB on behalf of the individual, agent or trust arrangements, or individual service provider accounts.

Such arrangements provided different ways of giving responsibility to third parties to manage the individual budget with, or on behalf of, the person using services. A social care provider could, for example, manage the budget and work with an individual to identify the best services to achieve their objectives. Alternatively, the money could be held in trust, with a number of family members, for example, taking decisions on behalf of the person using services about how to spend it.

However, relatively little use was made of these new options, probably because the evaluation was undertaken at such an early stage. Most people opted for the direct payments option to employ a personal assistant, and some made use of care managed budgets. We concluded that alternatives to the direct payment approach need further thinking through and that greater flexibility in budget management within the local authority care management system is required. Few of the proxy financial arrangements available under the Mental Capacity Act (2005) have been used because the act had not been implemented at the time of the early IB pilots.

As with direct payments, frontline social care staff played a key role in introducing people to IBs and helping them through unfamiliar and potentially stressful or exciting changes. We concluded that intensive staff support and extensive training and communication activities, supported by levels of ring-fenced funding, are needed.

Will such training include voluntary and support groups? What role will people using services have in the provision of continuing professional

developments? Priority may need to be given to developing skills in support planning and brokerage, either in local government or in organisations such as third sector groups. What do the trustees of mental health groups in the third sector think about going down this path?

### Developing new services

Although there was little change in services during the lifetime of the pilots, in the longer term, local authorities may need to encourage the development of new services and support arrangements for IB holders. Some of these developments may have been inhibited by prior contracts with existing providers, such as a contract for several 'beds' in a short-break scheme or care home.

But alternatives are not always easy to develop and the effects on staff of flexibility may not be universally welcome. Accounts are common of the difficulty of finding people to work as personal assistants, perhaps because the work is likely to involve irregular hours or work patterns, and it is often temporary. Will mental health groups want to get involved in acting as brokers or employment agencies (with the resulting registration requirements)? Will people with experiences of mental health services want to work in this new form of adult social care? What plans are local mental health groups making to sustain their current services if they think that they are effective and well regarded?

Given the relatively small impact of the new funding arrangements on existing services in IB sites so far, we need longer-term research into the dynamics of local social care provision (profit making and non-profit making) following personalisation. This needs to cover the impact on provider stability and service unit costs if block contracts become replaced by individual purchasing. It will need to assess the quality and supply of personal assistants and other supporters. If IB users want greater flexibility from providers and individual workers, this may increase costs.

### Outcomes and alignments

The most important evaluation question for the study concerned the effects of the new payment arrangements on individual service users. When the research interviews took place, user experiences were quite limited, because many users had not managed their own budget for long, so users were asked what benefits and drawbacks they anticipated.

The comparatively short follow-up period and the longer amount of time it took to set up an IB probably affected people's views. Given this, it is not surprising that the overall finding was that there were few outcome differences between the IB and comparison groups. Nonetheless, it was found that:

- Mental health service users in the IB group reported a significantly higher quality of life.
- Younger physically disabled people were more likely to report higher quality of care. They were more satisfied with the help they received and the choice and control they experienced. Also they felt they had the opportunity to build better quality support networks.

- People with learning disabilities in the IB group were more likely to feel they had control over their daily lives. However, those involved in the IB process were less likely to feel as fully occupied in activities. Self-perceived health appeared to be significantly lower compared with the comparison group, although when responses from proxies were excluded this became less significant.
- Older people with all kinds of needs were less likely than other people in the sample to report higher aspirations as a result of the IB process. They reported lower psychological wellbeing than those in the comparison group. They did not appear to want the perceived additional burden of planning and managing their own support.
- Thus, people using mental health services were found to have the most positive outcomes in overall wellbeing, although they were a relatively small proportion of all IB users in the research. IBs offered these individuals a greater range of support arrangements and more flexibility, which were welcome.

Including NHS resources was considered essential for the continued success of IBs for many people with mental health problems, given the high levels of integration of funding and services in several local authority areas. Consequently, sites often had to unpack partnerships, and they pooled budgets to identify social care money for IBs, which was difficult for jointly provided services.

Sometimes this meant that pilot sites could be funding the whole of an IB for someone who would otherwise have been expected to use jointly funded services. One result of this was that outcomes (that is reduced day hospital use or acute hospital admission) benefited the NHS while the full costs of the IB were borne by local authorities.

These issues were more sharply felt because of the reported increase in demand for IBs over conventional mental health services. It was also difficult for pilot sites to implement IBs with frontline staff who were NHS employees in integrated care trusts, due to differences of culture and complex or non-existent line management relationships.

Difficulties in distinguishing between health and social care needs and outcomes emerged, not surprisingly, which lead to concerns over the potential use of IBs to purchase services such as complementary therapies. When an IB-funded personal assistant or relative carries out health related tasks, professionals may raise concerns about where responsibilities for training, quality assurance and risk management should lie.

Original plans for the pilots involved pooling resources from a number of funding streams, including adult social care, as we noted earlier. Lead officers for IBs were positive about aligning and integrating the non-social care funding streams. Some expressed disappointment at the slow progress made towards integration, but were positive that just raising the issues had increased understanding and awareness of various funding streams and options among frontline staff. This meant, for example, that social workers were often better informed about funds to support people into employment.

The evaluation raised particular questions about the impact of IBs on older people. Concerns were raised about how older people would deal with the responsibility of employing care workers, for example. These were backed up by the lower levels of wellbeing among older IB holders. The evaluation suggests that some older people might see IBs as a potential burden.

### Cost-effectiveness

There was some evidence that IBs produce higher overall social care outcomes given the costs incurred, save for older people. We analysed cost-effectiveness for user groups separately:

- **Mental health services.** IBs appeared to be more cost-effective than standard arrangements on both the social care and psychological wellbeing outcome measures.
- **Younger physically disabled people.** There was a small cost-effectiveness advantage in relation to outcomes.
- **People with learning disabilities.** Regarding the social care outcome measure, there was a cost-effectiveness advantage for IBs when concentrating only on people with support plans already in place. Regarding psychological wellbeing outcomes, standard care arrangements appeared to be slightly more cost-effective than IBs.
- **Older people.** There was no evidence of a difference in cost-effectiveness when looking at the social care outcomes measure. Standard support arrangements looked marginally more cost-effective than IBs when looking at the psychological wellbeing measure.

## Take home message

Our main conclusion was that IBs have the potential to be more cost-effective than standard care and support arrangements. The cost-effectiveness advantage looks clearer for some people with mental health problems and younger physically disabled people than for older people or people with learning disabilities. As a whole, the IB group were significantly more likely to report feeling in control of their daily lives and the support they accessed. Holding an IB was also associated with better overall social care outcomes and perceived levels of control, but not with overall psychological wellbeing.

## Points to ponder

Commenting on the IBSEN evaluation on the Social Perspectives Network website ([www.spn.org.uk](http://www.spn.org.uk)), the Network's director, Terry Bamford, asked where the evaluation left the state of knowledge for mental health services users. He raised three points.

First, he argued that mental health services users should be given high priority in developing IBs. This, of course, reflects 'where he is coming from'. It may well be that this, perhaps surprising, success story enables further creativity in social care services and encourages people with mental health problems to →

take up their rights to social care services. However, it does not follow from this that they should be given priority.

Second, Bamford argued that the rush to local authority and NHS partnership boards and NHS foundation trusts has created a new set of organisational boundaries to the delivery of IBs. This organisational complexity may affect people using mental health services, although the evaluation itself had more to say about the complexities of NHS and local government relationships overall. Members of foundation trusts, who may increasingly be recruited from community and voluntary sector groups, might be able to exercise some leverage here.

Bamford's third point is that there would be huge cultural changes around the introduction of IBs because staff are likely to feel threatened and be risk averse. Such views were reflected in a recent survey of practitioners reported by *Community Care* (23 October 2008). Of 600 social workers surveyed, only 11% viewed the plan to extend personalisation (probably meaning IBs or personal budgets) to all service users as 'appropriate', and 96% of local authority social workers thought that this would risk making service users more vulnerable. Such concerns were also raised by practitioners taking part in the evaluation. However, much depends on the interpretation of words like 'appropriate', and the concerns of practitioners are detailed in the evaluation

## Debating points

Individuals and carers, user organisations and pressure groups, and professional supporters may wish to debate a number of points. First, decisions are needed as to the best way to incorporate additional funding streams into social care funding (local authority adult services monies and Supporting People funds) and which funds should be covered.

Second, what legislative and accountability barriers identified in the early days of IBs should be tackled to improve outcomes and to enable professionals to feel confident and that they are acting lawfully?

Third, national policy decisions are needed about whether all or some of these barriers can be removed and about the inclusion of NHS resources in social care personal budgets, particularly mental health expenditure. These resources were widely viewed as important for increasing the gains from personalisation.

Fourth, IBs need to be offered to people in a range of ways which offer more flexibility than a direct payment, ranging from a flexible and user-responsive care managed budget at one end of the spectrum to a direct payment at the other.

Finally, it will be important that the forthcoming NHS personalisation pilots build on some of the learning from the social care IB pilots, particularly in terms of the problems identified around the NHS–local authority interface. ■

### Further reading

- *Personalisation: a rough guide*, published by SCIE online, Adults Services report number 20, 2008.
- The publication of a 'guide to action' for personal budgets in mental health, to be provided by the Department of Health shortly (no details yet).
- Mental health and personal budgets information materials, including a DVD, to be provided by the Department of Health shortly (no details yet)
- Evaluation of the Individual Budget Pilot Programme: final report, by Caroline Glendinning *et al*, 2008, is available on the Department of Health website.

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See also page 21, Bigger picture, by Terry Bamford.

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