

Individual Budgets

Michael Calnan on behalf of the 'Making the Most of Evaluation' research group

Background

Cash payments for social care users have formed part of government policy in England for some time. The Community Care Act Direct Payments Act (1) was passed in 1996 and since 1998, local authorities have been able to offer direct payments instead of services in kind to disabled adults: this was extended to older people, carers and disabled 16 and 17 year olds in 2000. Direct payments were introduced in response to demands by younger disabled people for greater control and choice over their support arrangements and tended to be used to employ a personal assistant who can provide help in flexible way.(2) Evidence about the impact of cash payments on outcomes is in short supply although there is a body of relatively small scale studies mainly employing qualitative methods which suggests that those who receive direct payments experience greater choice, control and wellbeing than those receiving conventional services (2-6). However, the evidence also suggests (7) that overall take-up of direct payments had been low and varied between different care service user groups and local authorities suggesting major barriers to uptake and implementation.(8)

The emphasis in the previous governments' policy on consumerism and personalisation (9) encouraging users of social care services to exercise more control and choice was manifest in the decision to pilot individual budgets (IBs)(10) which built on both the direct payments scheme and the In Control scheme developed for people with learning disabilities. IBs were first proposed in the 2005 Cabinet Office report 'Improving the Lifechances of Disabled People'. The commitment

to pilot IBs was repeated in the 2005 Green Paper on adult social care(11) and subsequently taken forward in the White Paper 'Our health, our care, our say'(12). IBs appeared to have the potential to address the White Paper's key themes of providing more support for people with long term needs, better prevention and early intervention for improved health, independence and well-being as well providing stronger voice and more choice (12). IBs (or personal budgets) remain at the forefront of the government policy on social care, despite the change in administration as reflected in both political statements (13) and policy documents (14-15). In 2008 the Department of Health announced that personal budgets would be made available to all users of adult social care. Drawing on different funding streams, personal budgets are also being piloted for disabled children and younger people and by Department of Work and Pensions in its right to control trailblazer projects.

IBs can be distinguished from the approach used in Direct Payments in a number of ways (16). First, needs identified following assessment are translated into an indicative budget expressed in monetary terms rather than hours per week. Secondly, people have the choice of using services directly from a local authority or making their own arrangements or a mixture of both. Thirdly, as well as adult social care funds, IBs include funding streams that cover housing support, adaptations and equipment for disabled people and financial support to enable disabled people to work. Finally, IBs can be used to purchase a wide variety of support options, including mainstream goods and services, that contribute to meeting users desired outcomes.

Aims

Individual Budgets were believed to be an effective method for giving people more control over the support they that receive and tailoring this

support to an individual's needs – not just to what is available. The intention was to build on the best features of the direct payments scheme and In Control, whilst finding a way to overcome some of the barriers to uptake and implementation (12). IBs also aimed to reduce unnecessary duplication and assessments by bringing together different sources of support in a single budget that could be used flexibly according to individual priorities and experiences

The initiative

IBs built on the In Control model developed with learning disabled people but the IBs in the trial had several new features such as multiple funding streams so IBs in this form were being evaluated for the first time. This was a cross government project involving the Department of Health, the Department for Work and Pensions, the Office for Disability Issues and the Department for Communities and Local Government. The 13 local authority pilot projects tested the inclusion of a range of income streams: local authority-funded adult social care, Supporting People, Access to Work, Independent Living Fund and Disabled Facilities Grants and included all the main adult groups that social care is provided for:

- Older people
- People with physical and/or sensory disabilities
- People with learning disabilities
- People with mental health problems

The evaluation

Aims and objectives

To identify whether individual budgets offer a better way of supporting older people and adults with social care needs compared to conventional methods of funding,

commissioning and service delivery; and the relative merits of different individual budget models for different groups of users.

The specific objectives were to:

1. Describe the processes of implementing individual budgets, including identifying those factors that facilitate and inhibit implementation and the potential implications for sustainability and roll out.
2. Assess the effectiveness and cost-effectiveness of different models of implementing individual budgets, for different groups of service users, compared to standard funding, commissioning and service delivery arrangements.
3. Assess the experiences of individual budgets for different groups of service users and carers.
4. Assess the wider impacts of individual budgets on social care and other services.

Design

This evaluation was carried out by IBSEN (9, 17) which was a consortium of three DH-funded research units across five universities drawing on a range of different disciplines and methodological expertise.

The evaluation adopted a mixed methods design, the core of which was a randomised controlled trial (RCT) examining the costs, outcomes and cost-effectiveness of IBs compared to conventional methods of service delivery. Unusually for research into social care, individuals were randomised and then approached to take part in the study. 2,521 individuals were randomised across the thirteen pilot sites of which 1,594 (63%) agreed to take part in the study. Not all of these people remained in the study and in all 959 service users were interviewed six months after they

were allocated to either the IB group (510) or to standard services (449).

The primary outcome measures used were the general health questionnaire (twelve item) and the Adult Social Care Outcomes Toolkit (ASCOT) supplemented by secondary outcome measures which included satisfaction measures and self reported impact of IBs on daily life. The distribution of the sample across 'primary' user groups was:

- 34 per cent were working-age physically disabled or sensorily impaired people.
- 28 per cent were older people.
- 25 per cent had learning disabilities.
- 14 per cent used working-age mental health services.

In-depth interviews were conducted with a subsample of 130 people (selected from across the 13 pilot sites and covering all user groups) about two months after they had been offered an IB to explore their first experiences of the new processes and what benefits and drawbacks they anticipated.

Interviews were also conducted with lead officers responsible for IB implementation, and with other staff responsible for commissioning, resource allocation, support planning and brokerage, service provision, and different funding streams.

Representatives of user and carer organisations in some sites were interviewed and each interview examined implementation processes and experiences. Front-line staff (care co-ordinators) and first-tier managers in the 13 pilot sites were also interviewed about the impact of IBs on their workloads, job satisfaction, training needs, and adult safeguarding, as well as collecting staff activity data.

In a separate study, not directly commissioned by the Department of Health, funded from the 'the

response mode 'resources held by two of the three DH-funded units that carried out the main evaluation, structured interviews were conducted with up to 200 carers from the samples of service users who took part in the IBSEN evaluation. Half were carers who looked after an Individual Budget holder and half were carers of people using conventional services. This enabled comparison of the health and well-being of carers between the two types of support arrangements. The impact of IBs on carers was further explored through semi-structured interviews with a small group of carers approximately six months after the service user had been awarded an Individual Budget. The interviews focused on the carers' expectations of any change, how these were realised, any difficulties that arose and how they were overcome.

Semi-structured telephone interviews were also conducted with Carers Lead Officers in the Individual Budgets Pilot sites about their involvement in the implementation of IBs; this data was compared with extracts from the interviews with IB lead officers in the main IBSEN evaluation about the implementation of IBs and the involvement of carers in IBs.

Evaluation team's findings and conclusions

Outcomes: When pooling data across the sample as a whole, the findings showed that the IB group were significantly more likely to report feeling in control of their daily lives, the support they accessed and how it was delivered. No significant differences between the IB and comparison groups were found in the other outcome domains, although the tendencies in the data generally suggested that the IB group was experiencing slightly better outcomes. There were variations in outcomes by user group. The most positive outcomes in overall well-being were found in the mental health group with the least benefit

from IBs being observed in older people.

Almost half of those who accepted the offer of an IB who were interviewed for the qualitative study described how their aspirations had changed as a result, in terms of living a fuller life, being 'less of a burden' on their families, and having greater control and independence. These informants were also more likely than other IB holders to report satisfaction with the support planning process and financial arrangements. IBs were typically used to purchase personal care, assistance with domestic chores, and social, leisure and educational activities.

Costs: There was very little difference between the cost of support received by the comparison group and the cost for IB holders. Over the full sample, IBs funded an average of about £280 of support per week compared with an estimated mean weekly cost of about £300 for support packages for people receiving standard mainstream services. This difference was not statistically significant, but it is likely from this evidence that IBs could be cost-neutral, if the significant costs of implementation were disregarded.

Integration of funding: IBs rarely included resources from different funding streams due to major legal and accountability barriers. This aim of the IB pilots was not successful. On the other hand, local authority staff were highly critical of the exclusion of NHS resources from the IB pilots as this undermined the considerable efforts they had made over the previous decade to develop integrated health and social care provision, particularly in relation to mental health services.

Cost effectiveness: For people who use mental health services, IBs appeared to be more cost effective than standard arrangements on both the social care and psychological well-being outcome measures. Similarly, for younger physically disabled people, there appeared to be a small cost-effectiveness

advantage for IB over standard support arrangements with respect to both the social care and psychological well-being outcomes. For people with learning disabilities, IBs were found to be cost-effective with respect to social care, but this advantage is only visible when the data covered only people who had support plans in place. Standard care arrangements appeared to be slightly more cost-effective than IBs with respect to psychological well-being. There was no evidence of a cost-effectiveness difference between IBs and standard support arrangements for older people in terms of social care outcomes. Standard support arrangements were marginally more cost-effective than IBs with respect to psychological well-being.

One conclusion from these analyses is that IBs have the potential to be more cost effective than standard care and support arrangements but only for certain groups of clients.

Workforce implications: Major shifts in working culture, roles and responsibilities were reported for in-house staff. Some saw these shifts – and IBs more generally – as a reinvigoration of social work values, while others saw them as eroding social work skills. On the positive side, the opportunity to work with people to identify a wider range of goals and aspirations, and to develop support plans to achieve them, were specifically linked to traditional social work roles. But particular concerns were that the care management process was being fragmented, that professional skills and qualifications would not be thought to be needed to undertake tasks related to IBs, and that crisis work, safeguarding and high-end complex casework would come to dominate social work practice.

A widespread view among staff was that more and better training was needed in order to implement IBs. Analysis of data from care co-ordinators diaries showed that those staff with some IB holders on their caseloads spent significantly more

time than others on a number of activities: completing assessments with service users, assessing carers needs, support.

Key concerns for staff included determining the legitimate boundaries of social care expenditure within a support plan; and managing the potential financial and other risks sometimes involved with achieving desired outcomes while at the same time being responsible for safeguarding vulnerable adults. Interviews with service providers in a subsample of pilot sites showed little activity on the part of local authorities to commission new types of services attractive to IB holders. Providers also anticipated increases in service costs (as local authorities lost the benefit of economies of scale associated with former large block contracts) and exposure to new financial risks.

Impact on carers: The separate study described above investigated the impact of IBs on carers in terms of assessment, support planning, costs and outcomes. When carers of people with IBs were compared with carers of people using conventional services, IBs were significantly associated with positive impacts on carers' reported quality of life and, when other factors were taken into account, with social care outcomes (7). Positive outcomes for carers partly reflected their being more able to engage in activities of their choice. It is also likely that positive outcomes reflected the greater opportunities available to some carers to participate in planning how the service user's IB was to be used and, for example, to build in some opportunities for a regular break from care-giving

There was no statistically significant difference between the costs of IBs and conventional services, nor in the time spent or opportunity costs of the help given by carers in either group, although the direction of effect suggested higher opportunity costs to carers in the IBs group.

The thirteen pilot sites varied in how help from carers was treated in service users' IB assessments. Especially early in implementation, carers' own needs risked being overlooked. Where carers' needs were included in IB assessments, this did not always comply with current legislation giving carers rights to assessments of their own needs. Sites also varied in how help from carers was treated in calculating the monetary value of service users' IBs. Typically IB amounts were lower if help from carers was taken into account in assessing the service user's needs. Only a minority of carers received any payment from service users' IBs. This was always far lower than the value of the help they actually gave. Local authority officers had very mixed views about paying carers from service users' IBs.

Interpreting the findings

The IBSEN study, using a mixed method approach, was the most extensive and rigorous evaluation of self-directed support to date in England and one of the rare robust RCTs conducted within adult social care. The general message which emerged from the RCT provided ammunition for both those who were enthusiastic or sceptical about IBs in that it showed IBs had some, if limited benefits, and only for some groups such as those using mental health services and to a lesser extent for those people with physical and/or sensory impairment. IBs were more cost effective than standard care for these two groups but there was little evidence of any benefits for older people, whose lower levels of allocated resources may not allow access to a wide range of choice and an extensive range of services, once immediate needs for personal care have been met. The significant levels of impairment (including cognitive impairment) and poor health experienced by many older people eligible for publicly-funded social care may also preclude enjoyment of choice and flexibility. The process

evaluation showed the implementation of IBs had significant implications for the staff and the organisations involved including non-statutory service providers. Moreover, there were major barriers to integrating funding streams which was one of the key aims of IBs. When carers of people with IBs were compared with carers of people using conventional services, IBs were significantly associated with positive impacts on carers' reported quality of life.

The strength of the evaluation appears to lie in the design of the study and the use of a randomised controlled trial, supplemented by the more detailed qualitative investigations of the implementation, processes and experiences from, perspectives of a wide range of users and stakeholders. The process evaluation made a major contribution to recognising the challenges all local authorities would likely face in implementing IBs. RCTs have not often been used in social care partly because of feasibility as they are difficult to implement and partly because of the appropriateness of using experimental or quasi-experimental designs on their own for evaluating complex, social interventions (18). However, IBSEN was a multi-method study; the additional process evaluation and qualitative strands of the study reflected a methodological approach that was informed by the principles of realistic evaluation, which is appropriate for a wide-ranging intervention of this kind.

In some ways this study illustrates some of the difficulties of using an RCT design in the evaluation of complex policy interventions. Although it represents a large investment of resources there were many complications which limit the usefulness of the findings. Many of these limitations are recognised and discussed by the authors (17).

First, it is unconventional to randomise individuals before approaching them to participate,

although this is sometimes necessary when whole organisations or areas are randomised ('cluster randomisation') which is not the case here. The disadvantage is that different sorts of people are likely to agree to take part in each comparison group, depending on what sort of care they would like. Indeed the consent rate in this study was different for those recruited to the IB and the comparison group, and although the evaluators maintain the two groups remained comparable, this introduced potential bias. This approach was a result of local pilot authorities' ethical concerns about gaining consent before randomisation, who felt that they could not inform users and promote the idea of IBs, and then to refuse them the IBs because of the randomisation outcome.

Second, there are problems of generalisability. This is often the case when evaluations are done on sites which are early pioneers for an intervention, and during the early stages of implementing that intervention. In this example, the thirteen sites which took part in the pilots had particular advantages. Senior officers and most care co-ordinators and team managers expressed enthusiasm for the principles of IBs, they were backed up by a dedicated national implementation team and they may have been motivated by the spotlight of a high profile national pilot and evaluation. These features may not be present in wider rollout, or at least not on the same scale. Additionally (but less positively) the pilot sites were subject to stringent implementation targets set by DH, including target numbers of people to be offered IBs. Each pilot site had a much higher uptake of direct payments than the national average prior to the study. This raises a further problem, in that 26% of the people in the study (in the comparison arm as well as the IB arm) had already received direct payments even though IBs are different to direct payments in terms

of resource allocation and support planning. However, this could have diluted the potential of the study to detect any differences between the IB and comparison groups.

Third, the evaluation timescale set by the Department of Health, compounded by implementation delays, permitted only a six-month interval for users to receive their IB and commission their own services before the follow-up interviews, whereas a longer follow-up period would have allowed more time to develop a more accurate picture of experiences and impacts. Around a quarter of the interviews carried out after six months were carried out with someone other than the service user (usually a family member) although subsequent analyses of the study outcome data has attempted to control for the effects of proxy interviewees. Some of those offered IBs in the 'IB' arm did not take them up and others did not receive them before outcomes were collected at six months. Only 45% of the people in the IB sample were actually in receipt of the IB at the time of the six month interview and of these around a half had held the IB for under a month. Thus, the restricted timescale severely limited the strength of the evidence which emerged from this large scale study. This suggests that interpretation of the analysis of the outcome data should be treated with caution and may reflect a missed opportunity to carry out a 'land mark' study in this area.

Fourth, and related to the above two problems, the pilot sites were evaluated while they were still at an early stage of implementing the IB initiative, so the evaluation may not represent 'steady state' implementation, in particular the costs associated with a widespread transition from commissioning and providing services in kind to individualised purchasing through personal budgets. There were, in addition, a number of policy changes and external pressures on the sites during the period of the evaluation,

so the evaluators were trying to take a 'snap-shot' of something which was in reality a moving picture. For example, during the course of the pilots, the Department for Work and Pensions decided to relax the objective of integrating Access to Work resources within IBs.

Finally, there are a number of other limitations to the RCT aspects of the study. Few details are provided to justify the size of the sample included, which is important in understanding the power of the study to detect meaningful differences. There is no statement a priori of which outcomes are considered primary or most important. Related to this is the problem of multiple outcomes. Data were collected about a wide range of outcomes. For most of these outcomes, no significant differences were detected between the groups, but the few differences which did reach statistical significance are highlighted in the results. But if many outcomes are examined (and in this case each outcome was also analysed for four groups of people) then a number of 'statistically significant' differences are likely to arise by chance. This may explain the inconsistent findings of the effect of IBs for different groups of people. However, the different effects on different groups of people is supported by various strands of the qualitative research which illustrates the value of using mixed methods where the qualitative research findings were also used to explore, validate and interpret the quantitative findings.

Other relevant evaluation work

An innovative action research evaluation was carried out in one of the pilot sites (19) commissioned by the local authority who wanted a more detailed picture of the local experiences of IBs. It was carried out by a team from Coventry University (20,21) and involved the use of a range of different qualitative methods (including group artwork, film projects, posters, dictaphones to

record individual thoughts) to elicit and construct stories from users (n=30) about their views and experiences of IBs and the extent to which IBs have been effective in empowering them to make decisions for themselves. The findings showed that IBs had been a very positive development for family roles, independence and promoting person-centred approaches. However, the evaluation identified a range of barriers to the use of IBs which included: the varied levels of knowledge and awareness of IBs; the difficulties in users obtaining IBs; lack of supply of good care staff; having the right skills to become an IB holder; the need for supply to be more responsive and flexible and the need for professionals to recognise that their role is changing. The findings from this local evaluation were disseminated widely in an imaginative and accessible form (19).

Conclusions about the evidence that the initiative achieved its objectives and delivered policy goals

The main aims of IBs are listed again below, with comments about the evidence so far available:

Improved outcomes/cost effectiveness: There is some evidence that IBs may have a positive impact on social care and psychological outcomes and can be cost effective but only for some groups of service user. Previous research suggest cash payments are attractive to younger, disabled adults and the evidence from this study suggests it could be extended to mental health users although the latter were the smallest of the user groups and diverse in terms of problems. The variable impact of IBs on different user groups needs to be explored in future research. However, the linked study showed that IBs could be cost-effective for carers, especially if carers are able to contribute to planning how the service user deploys the IB.

Improved patient choice/control: There is some, if limited evidence, that IBs increased feelings of control amongst some groups of user. IBs were typically used to purchase personal care, assistance with domestic chores, and social, leisure and educational activities although this did not indicate a significant increase in the exercise of choice. IB holders perceived they had more control over their lives and appreciated the extra choice over use of services, albeit with variations by user group. However, problems of power relations, equity and the constraints implied by the public nature of decision-making were complicating and limiting factors in producing the benefits envisaged (22). Positive outcomes for carers partly reflected being more able to engage in activities of their choice.

Costs: There was very little difference between the cost of support received by the comparison group and the cost for IB holders. However the evaluation identified a range of other factors likely to affect the overall and long term costs of implementing IBs on a national scale for all adult social care users.

Workload for social care workers/managers: Major shifts in working culture, roles and responsibilities were reported for in-house staff and there was a need for more and better training. Key concerns for staff included determining the legitimate boundaries of social care expenditure within a support plan; and managing the potential financial and other risks sometimes involved with achieving desired outcomes while at the same time being responsible for safeguarding vulnerable adults (23). The implementation of the personalisation pilots had implications for working relationships in they sometimes jeopardised inter-sectoral relationships and threatened some of the collaborative arrangements that had developed over the previous decade (24).

Integration of funding: Little evidence that IBs included resources from different funding streams due to major legal and accountability barriers. Other implementation problems were encountered because of the exclusion of NHS resources from the IB pilots.

White Paper goals: In terms of the White Paper goals (12), it is consistent with ensuring that some user groups have more control and have greater independence and a better quality of life. However further evidence is needed before it can be concluded that IBs are associated with major improvements in long term social care and psychological outcomes. It must also be remembered that this initiative, or different models of it, formed part of government policy on social care some time before the White Paper was published. Moreover, before the evaluation was completed, the Department of Health announced the roll-out of Personal Budgets (involving only social care resources) to all adult social care users; a 30 per cent target was set for 2011.

Despite this uncertainty about effectiveness, individual budgets continued to remain high on the government policy agenda and the concept was exported from social care to health care as the Department of Health launched a pilot programme in 2009 to explore the potential of personal health budgets (24) although different models were being examined. The stated aim of personal health budgets was to give individuals more choice and control about how to achieve their desired outcomes although because of the uncertainty inherent in the provision of health care the relevance of the concept of choice in this context has been contested (25-27). It was thought that personal health budgets were particularly suitable for certain groups of people, such as those eligible for NHS continuing healthcare, mental health care or end-of-life services. Those with chronic conditions who are frequent

users of healthcare may be a more generic group targeted (28). This pilot programme is currently being evaluated to identify whether personal health budgets ensure better health and social care outcomes when compared to conventional service delivery and, if so, how they should be implemented. The NHS White Paper (29) set out the Coalition Government's long-term plans for the future of the NHS with a continued but greater emphasis on choice and competition. Thus, it was proposed to use the evaluation results of the personal health budgets pilot programme in 2012 to inform a wider roll-out of personal health budgets. However, the research reported here raises the more general question about the influence of evidence generated from evaluations of health policy initiatives and it suggests that for high profile policies such as IBs the evidence about implementation maybe more influential than the evidence of effectiveness but for a less politicised policy the reverse may be true.

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