

# The Individual Budgets Pilot Projects: Impact and Outcomes for Carers

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## Abstract

Personalisation is central to the government's political agenda for reforming the delivery of adult social care in England. Currently, the implementation of individual or personal budgets (IBs) is central to this change, with the main aim of placing control in the hands of people using social care services by allowing more choice in the organisation of the allocated resource and purchasing of support. The implementation of individual budgets was piloted within 13 local authorities 2005-07 and the Department of Health commissioned an independent evaluation of this pilot. The focus of the IB pilot projects was primarily on service users rather than exploring the separate (but linked) needs and rights of informal and family carers. However, placing more control in the hands of the service user could actually lead to a change in the amount and type of care provided by informal carers. The impact of IBs on carers was therefore explored in a separate but linked study. Carers of service users who had consented to take part in the main IBSEN study were identified and invited to take part in a follow-up study aimed at exploring how IBs impacted on carers. The study found that only a minority of carers received any payment from the service user's IB; in all cases this was far lower than the value of the help they actually gave. However, service users' receipt of IBs was significantly associated with positive impacts on carers' reported quality of life and, when other factors were taken into account, with social care outcomes. These outcome gains were achieved despite no higher costs being incurred to the public purse, thus suggesting that IBs for service users are cost-effective for carers. The benefits of IBs appeared to be associated with the level of flexibility that was afforded to carers.

## Introduction

Individual budgets (IBs) were first announced in the Cabinet Office Strategy Unit report *Improving the Life Chances of Disabled People* (Cabinet Office, 2005) as a way to increase choice and control over how support needs are met among older and disabled people. While increasing control among people eligible for publicly funded social care is not new (earlier such initiatives include Direct Payments and *In Control*<sup>1</sup>), individual budgets aimed not only to overcome many obstacles associated with previous initiatives but also to go beyond local authority social services resources. In addition to adult social care, additional funding streams were to include resources from Access to Work; the Independent Living Fund; Supporting People; Disabled Facilities Grants; and local Integrated Community Equipment Services.

In the UK Direct Payments were introduced in 1996 with the aim of giving control to people by providing monetary transfers to enable them to directly employ personal assistants. However there were many obstacles to this initiative including people not wanting the

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<sup>1</sup> In Control, is an umbrella organisation campaigning for people with learning disabilities to control and direct their own support ([www.in-control.org.uk](http://www.in-control.org.uk)).

responsibility of managing the direct payment (Davey et al., 2007). The obstacles contributed to the low up-take, particularly among people with mental health problems and older people (Davey et al., 2007). IBs aimed to overcome this problem by allowing flexibility in the way people receive their allocated resource. As well as direct payments, other possibilities include resources managed by a care manager, service provider or by a third party; or establishing a trust fund. The possibility of individuals choosing to organise their budgets via a combination of these deployment options has also been emphasised. Furthermore, unlike direct payments, the greater flexibility of individual budgets opens up the possibility of paying close relatives, including spouses, parents and adult children for the assistance that they provide. However there were the same restrictions as direct payments, in terms of not normally paying close co-resident relatives.

The IB approach built on the 'In Control' model (Poll and Duffy, 2006) in delivering social care. As part of the initial assessment process, the level of resource required is established based on the 'Resource Allocation System'. This system assesses the level of needs across a series of domains which are scored to provide a total number of points which were assigned care values. Once the amount of money in the IB is agreed, individuals are actively encouraged to be involved in the support planning process in terms of working out their own priorities and goals and the services they wish to purchase. Help with planning support (if needed) might come from the person's family and friends or could also involve a care manager, an in-house or external specialist support planner or a service provider. A team leader or senior manager approves the support plan and also considers the level of risk and possible adult safeguarding concerns (Glendinning et al., 2008).

In July 2005 the Department of Health invited local councils with responsibilities for adult social care to bid to pilot individual budgets. Thirteen local authorities volunteered and the pilot projects ran from November 2005 to December 2007. Using a randomised trial design, the evaluation examined whether IBs offered a better way of supporting people with social care needs than conventional methods of commissioning and service delivery. A full description of the methodology used and the data collected in the evaluation can be found in Glendinning et al., (2008). However, the focus of individual budgets was on the service user rather than the carer, despite the potential impact on informal carers receiving payment for the assistance they provide. Although the same legal restrictions exist as paying carers with direct payments, IBs were supposed to be used more flexibly, therefore we might expect some increase in payments to carers. Indeed, the potential positive impact of IBs on carers was highlighted in the revised English National Strategy for carers by suggesting that these new arrangements will offer better outcomes, as carers and service users will have more choice and control over services (HM Government, 2008). The Strategy makes a longer-term commitment to extending flexibility in how personal budgets and direct payments can be used; this increased flexibility is intended to strengthen further the choice that families can exercise over the care they provide and the services they receive (Glendinning et al., 2009).

The issue of paying informal carers from publicly funded resources has gained considerable national and international policy interest and one where empirical research does exist. One such scheme that has recently been researched is the personal budget (PAB) scheme in the Flanders region of Belgium (Breda et al., 2006). Here, almost half of budget holders use their PAB to pay informal carers and a labour contract must be drawn up between the disabled

employer and the employed relative. A survey of paid family members found they were more likely than unrelated personal assistants to cite emotional and affective reasons for taking the job, whereas the latter were more likely to cite job-related motivations. The research carried out by Breda et al., (2006) suggests that, despite the potential protection that could be offered by formal employment contracts, carers paid from IBs may nevertheless also experience some disadvantages (Glendinning et al., 2009).

Building on the design of the main IBSEN study, an additional study was conducted into the impact of IBs on carers. Specific questions addressed by the research were:

- What changes occur in the levels and types of support provided by informal carers following the award of an IB?
- Are any patterns identifiable in these changes, for example, among particular groups of carers or among carers supporting particular groups of service users?
- Do IBs affect the well-being and quality of life of carers, compared with carers (and service users) who receive conventional services? If so, in what ways for which groups of carers?

This paper draws on the full report of the study (Glendinning et al., 2009) to describe the impact and outcomes of individual budgets on carers.

### **The Carer Study**

In the main IBSEN evaluation (Glendinning et al., 2008), a randomised trial was used to randomly allocate eligible service users to either the intervention (IB) group, or the comparison group who would receive conventional services. The offer of an IB was only delayed for six months for those randomly allocated into the comparison group. In the carer study, carers of service users who had consented to take part in the main IBSEN evaluation were invited to take part in this follow-up study. We approached carers of people from nine of the 13 pilot sites who had been randomised to the IB group and comparison group to participate in a structured or semi-structured interview. The structured interviews used the same or adapted outcome measures reflecting social care outcomes, well-being and quality of life as the main IBSEN evaluation, plus an additional measure devised specifically to assess the impact of the care-giving role. Carer demographic information was also collected during the interviews. The interviews with carers were conducted between December 2007 and May 2008, after data collection for the main IBSEN study had been completed<sup>2</sup>.

#### *Psychological well-being*

The psychological well-being of service users was measured by the 12-item version of the General Health Questionnaire (Goldberg, 1992) which explores whether respondents have experienced a particular symptom or behaviour over the past few weeks. Each item is rated on a four-point scale (for example less than usual, no more than usual, rather more than usual, or much more than usual). There are two scoring methods; the Likert scoring scale (0

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<sup>2</sup> The study also included interviews with carer leads and IB leads about implementation. The findings are not reported in this paper.

to 3) which generates a total score ranging from 0 to 36, with higher scores indicating worse conditions; and the bi-modal (0 to 1) scoring style that indicates the likely presence of psychological distress according to a cut-off score of 4 or more.

#### *Self Perceived Health*

The perceived health question was based on the five point scale suggested by Robine and colleagues (2003) as part of a European project on health indicators. This question asks respondents to rate their health in general according to five categories ranging from 'Very good' to 'Very bad'. A person's perception of his/her own health has been found to be a reliable predictor of objective health, in terms of functional decline (Ferraro, 1980), chronic disease (Shadbolt, 1997) and even mortality (Idler and Benyamini, 1997).

#### *Perceived quality of life*

The quality of life item was developed as part of a project funded under the ESRC Growing Older Research Programme (Bowling et al., 2002). This measure is based on a seven-point scale, with categories ranging from 'So good, it could not be better' to 'So bad, it could not be worse' (Bowling, 1995).

#### *Social care outcomes*

The Adult Social Care Outcomes Toolkit (ASCOT) is a developing tool aimed for measuring and monitoring outcomes that are addressed by social care interventions (Netten et al., 2006). The measure is applicable across all user groups and has seven domains ranging from basic areas of need such as personal care and food and nutrition to social participation and involvement and control over daily life. Some of the domains are not relevant for carers and therefore this study included only five of the seven: social participation; employment and occupation; control over daily life; personal safety; and carer support. The questions asked respondents to choose from a series of three deteriorating situations, which of the options best describes their situation. In this way the question aims to capture no needs, low level needs and high level needs. The responses are weighted to reflect the relative importance of each domain and level of need, drawing on previous work on population preferences (Burge et al., 2006).

#### *COPE index*

The Carers of Older People in Europe scale (COPE index) was used to explore carers' perceptions of their caregiving role. McKee et al., (2003) developed the COPE index to identify those carers who may be in need of supportive intervention and require a comprehensive assessment of their needs (Balducci et al., 2008). There are three components to the COPE index: negative impact of caregiving; the positive value of caregiving; and the quality of support (Balducci et al., 2008).

#### *Satisfaction and quality of services*

Satisfaction and quality of care measures were based on quality indicators derived from the extensions to national User Experience Surveys for older home care service users and younger adults (Jones et al., 2007; Malley et al., 2006).

Semi-structured interviews were also carried out with a separate sample of carers providing support to people who received an IB within the main IBSEN evaluation. The interview covered:

- The informal and formal support arrangements that both the carers and the people they supported received before and after the IB was offered.
- Carers' involvement in assessment, support planning and managing the budget and the support arrangements.
- Any payment/reimbursement for the care the informal carers provided.

## Data analysis

All qualitative interviews were tape recorded (with the interviewee's permission), fully transcribed and anonymised. A researcher carried out systematic coding using MaxQDA software and qualitative analysis using the framework approach (Ritchie and Spencer, 1994). The coded data was summarised onto a series of charts and recorded separately for each set of interviewees. Data was analysed thematically and recorded separately for each site so that differences in policy or operational issues could be identified. Conclusions were verified by returning to the transcripts and via on-going discussions within the research team (Glendinning et al., 2009).

All quantitative data was analysed using SPSS 15 and Stata 10.

## Results

### Sample

We had baseline information on demographic characteristics, household circumstances, service user group, abilities in activities of daily living (ADLs) and instrumental ADLs (IADLs) from the main IBSEN evaluation for 129 carers who participated in the structured outcome interviews<sup>3</sup> and for the 24 carers participating in the semi-structured interviews for this study<sup>4</sup>. Forty-seven per cent (n=60) of carers who participated in the structured outcome interviews provided assistance to service users who had been randomly allocated to the IB group, and 54 per cent (n=69) of carers assisted service users in the comparison group. Among the sample of carers who participated in the semi-structured interviews, 22 provided assistance to service users in the IB group, and two assisted service users originally randomised to the comparison group who had since been given an IB.

It was originally intended to focus the study on only carers of older people and people with learning disabilities, as it was anticipated that these carers were most likely to be affected by IBs, albeit in different ways. Therefore by design, half (54 per cent) of the carers were supporting service users with learning disabilities and about a quarter (26 per cent) were supporting older service users. Lower proportions of the carer sample were caring for people with a physical disability (15 per cent) or a mental health problem (5 per cent). The semi-structured interviews were carried out with 11 carers of older people and 13 carers supporting learning disabled adults who received an IB within the main IBSEN evaluation.

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<sup>3</sup> The majority of structured outcome interviews were conducted face-to-face although 25 of the 129 were conducted over the telephone.

<sup>4</sup> Twenty interviews were conducted face-to-face and four interviews were conducted over the telephone.

Table 1 shows the characteristics of the carer and the relationships between the carer and the person they were caring for in our structured and semi-structured interview samples. Of the carers participating in the structured outcome interviews, 74 per cent were female and 26 per cent were male. There was a similar pattern in the semi-structured interview sample, where 18 were female, five were male and one interview was conducted with both parents of a service user. The age distributions of the interviewees suggest that the carers participating in the semi-structured interviews tended to be slightly older; about a third of structured interviews were conducted with carers over the age of 60 compared with just under half (46 per cent) of the semi-structured interviews. Carers from black and ethnic minority groups accounted for nine per cent of the structured outcome interview sample, and only one of the carers who participated in the qualitative interviews did not describe him/herself as white. In both samples the largest single group of carers was those caring for an adult child, which is what we would expect, given the service user groups that people were caring for. From the perspective of the analysis the most important comparison is between carers in the structured interview IB and comparison groups.

**Table 1: Carer characteristics**

	<i>Structured interviews</i>		<i>Semi-structured interviews</i>	<i>Total</i>
	IB group % (n)	Comparison group % (n)	% (n)	%(n)
Female carer	77 (46)	73 (50)	75 (18) <sup>5</sup>	75 (114)
Male carer	23 (14)	28 (19)	21 (5)	25 (38)
Age				
25-34	2 (1)	3 (2)	0	2 (3)
35-44	10 (6)	3 (2)	13 (3)	7 (11)
45-59	57 (34)	58 (40)	42 (10)	55 (84)
60+	32 (19)	36 (25)	46 (11)	36 (55)
BME	13 (8)	6 (4)	4 (1)	9 (13)
Caring for:				
Adult child	50 (30)	51 (35)	45 (11)	50 (76)
Partner	15 (9)	19 (13)	21 (5)	18 (27)
Parent	23 (14)	17 (12)	16 (4)	20 (30)
Other	12 (7)	13 (9)	16 (4)	13 (20)

As we would hope, Table 1 shows the pattern was very similar and there was no statistically significant difference between the carers in the IB and the comparison group in this study. However we did find some evidence to suggest that our sample may be caring for slightly more dependent people than those in the main IBSEN evaluation. In the carer sample, significantly higher dependency levels among service users for three activities of daily living

<sup>5</sup> One interview was carried out with both parents and so gender was not reported.

were found for those in our sample compared with those with carers in the main IBSEN evaluation not included in the carer sample. These activities were getting out of doors ( $p < 0.001$ ); washing their face and hands ( $p < 0.01$ ) and washing their hair ( $p < 0.01$ ). Although as we would hope, within the structured interview carer sample, similar dependency levels were found between service users in the IB and comparison group, with no statistically significant differences. Any differences in outcomes between carers in the IB and comparison groups could therefore be attributed to the IBs received by the service users who the carers were supporting.

### **Progress through the IB process at the time of the interview**

From the structured interviews, 58 per cent of carers ( $n = 33$ ) in the IB group reported that the person they assisted received support and services paid for by the IB, although this low proportion needs to be interpreted with caution. We did not have information from local authorities about whether support plans were in place at the time of the carer interviews and carers may have failed to report that IB-funded support was in place for a number of reasons: they may not have been involved in the care and support management process; there may have been insufficient difference from the previous situation for this to be clear (for example, when 'virtual budgets' bought the same services that were in place before); or they may have not understood the question. Among the carers who reported that the person they provided assistance to had been receiving IB-funded services, 81 per cent reported that the services were being received for more than three months. A further 15 per cent reported that services paid for by the IB were in place between one month and three months prior to the outcome interview. In the semi-structured interviews with carers, 20 service users were reported to have had their new support arrangements funded through the IB in place from between two weeks to just over a year. Four people had started the IB assessment and support planning process but were still not in receipt of an IB or had not started to use the IB at the time of the interview with their carer.

A high level of satisfaction was reported among carers providing assistance to IB holders in the structured interviews. 83 per cent (33) of carers were satisfied with the value of the IB, 88 per cent (35) were satisfied with the way the IB was paid and 57 per cent (20) were satisfied with the amount of paperwork involved. However, from the semi-structured interviews, a number of carers of people with learning disabilities felt that the size of the IB, the restrictions on how to use the budget and their lack of knowledge about what those restrictions were, could not allow them to use the IB more flexibly.

### **Carers' involvement in assessment and support planning for IBs**

In the structured interviews, carers in both the IB and comparison groups were asked about their experiences of the service user's support or care planning process respectively. Table 2 shows that 36 per cent ( $n = 21$ ) of carers supporting service users in the IB group were either extremely or very satisfied with the support planning process, compared with 22 per cent ( $n = 15$ ) of those caring for service users in the comparison group. While clearly the experience was no worse for the IB group, we cannot be confident it was much better as the difference did not reach statistical significance. Moreover, in both groups, a substantial proportion of carers expressed some dissatisfaction and these views were noticeably stronger in the IB group. Among carers of IB holders there was lower satisfaction with the

support planning process than with the amount of the IB or the financial arrangements. The user group of service users who had assistance from the carers in this study did not have a significant impact on the level of satisfaction with the support planning process. Although, from the semi-structured interviews, most carers of people with learning disabilities reported that the support planning process had not really considered how their lives could be made easier. While they agreed that the IB had benefited them in some ways – for example by giving them some free time or giving a better quality of life to the person they supported – it had not opened up more opportunities for carers.

**Table 2: Overall satisfaction with the support planning process**

	<i>IB group</i> n=58 % (n)	<i>Comparison group</i> n=67 % (n)
Extremely satisfied	7 (4)	9 (6)
Very satisfied	29 (17)	13 (9)
Quite satisfied	38 (22)	40 (27)
Neither satisfied nor dissatisfied	5 (3)	9 (6)
Quite dissatisfied	5 (3)	9 (6)
Very dissatisfied	10 (6)	9 (6)
Extremely dissatisfied	5 (3)	10 (7)

Table 3 shows that from the structured interviews, carers in the IB group were significantly more likely to report that they had planned the support together with the service user (38 per cent;  $p < 0.01$ ) compared with those in the comparison group. However, carers in the comparison group were significantly more likely to report that they themselves played a major role (31 per cent;  $p < 0.05$ ) or they actually did it all (43 per cent;  $p < 0.05$ ) compared with those in the IB group (16 per cent and 36 per cent, respectively). Carers providing assistance to service users with learning disabilities were significantly more likely to play a major role in the support planning process (31 per cent;  $p < 0.05$ ) compared with those caring for service users with either a mental health illness or physical disability, or an older person (16 per cent). A consistent picture was found in the semi-structured interviews; carers of people with learning disabilities appeared more likely to make a greater contribution to the support planning processes than carers of older people.

**Table 3: Involvement in support planning**

	<i>IB group</i> n=58 % (n)	<i>Comparison group</i> n=68 % (n)
Service user alone	12 (7)	4 (3)
Service user took lead role support carer played a minor role	9 (5)	10 (7)
Carer and service user did it together**	38 (22)	12 (8)
Carer played lead role, service user played minor role*	16 (9)	31 (21)
Carer did it all*	26 (15)	43 (29)

Significance level: \*  $p < 0.05$  \*\* $p < 0.01$

### **Carers' receipt of support and services, care-giving activities and costs**

In total, information on service use and costs was available from the main IBSEN evaluation for 70 of the service users who were assisted by the carers who took part in the structured interviews for this study. Information about mainstream services was available for 30 service users in the comparison group from the six month interviews conducted for the main IBSEN evaluation, and for 40 in the IB group from their support plan records and the six month interviews. Overall, the costs of services received by the comparison group were higher than in the IB group, although the difference did not reach statistical significance. Within the carer subsample, the average value of IBs across all user groups was £270 per week (median £170; range £2.00 to £950) compared with £390 (median £350; range £3.00 to £1,190) in the comparison group. In the main IBSEN evaluation the difference in overall weekly costs between the IB and comparison group was not as marked for those where an informal carer had been identified; mean £280 (median £190; range £2.00 to £1,640) and £320 (median £160; range £1.00 to £3,170, respectively). This result suggests that IBs for people with a carer tended to be lower than IBs for people without carers, although the difference did not reach statistical significance<sup>6</sup>.

From the structured carer interviews, only six of the carer interviewees and five other family or friends providing assistance received payment from the care recipient's IB or other sources, either directly or in kind (for example in the form of a meal or gift). Over half (58 per cent) of carer interviewees felt that it was not appropriate to pay family members for the care they provided. Among the carers that responded to the question, this view was slightly more prevalent in the comparison group (60 per cent; n=40) compared with the IB group (54 per cent; n=14), but the difference was not statistically significant. A further six carers were

<sup>6</sup> Due to the small sample size, any firm conclusions need to be made with caution.

identified as receiving payment from the IB among the sample who participated in the semi-structured interviews.

The principal cost to the carer is the opportunity cost of the time spent on caring<sup>7</sup>. A key question was whether this is affected by the use of an IB. Not surprisingly given that only a small proportion of carers were receiving payment from the IB, there was very little difference between hours of assistance being reported. Carers of IB holders spent 81 hours per week caring, compared with 72 hours among carers in the comparison group, although this was not statistically significant. In addition, in both groups, other informal carers were reported to spend on average over 21 hours per week on caring. A whole array of caring activities was reported, ranging from personal care to looking after pets, DIY and gardening. Unsurprisingly, there was very little difference between the two groups in patterns of care-giving activities. In the semi-structured interviews, carers reported that the IB allowed them to gain some free time by employing someone else to do some tasks such as personal care or household chores. However all the carers in the semi-structured interviews who had taken on the responsibility of managing the accounts reported that the IB had created more paperwork.

### **The outcomes of IBs for carers**

Table 4 brings together our findings using the measures of quality of life, well-being, social care outcomes and the COPE index for all carers who provided care to service users who had originally been randomised to either the IB or comparison group. Despite no significantly higher costs to the public purse, carers who provided assistance to service users in the IB group were significantly more likely to report higher quality of life (mean 4.72;  $p < 0.05$ ) compared with those in the comparison group (mean 4.25). From the other measures, there was no evidence of poor outcomes for carers in the IB group compared with those in the comparison group. There was some indication of better outcomes but no statistical differences. The client group of service users who had assistance from the carers in this study was not associated with a significant impact on responses. In contrast, in the semi-structured interviews, carers of older people tended to be more satisfied with the IB than those caring for people with learning disabilities. The benefits of IBs appeared to be associated with the level of flexibility that was afforded to carers. Semi-structured interviews also suggested benefits for carers through their involvement in support planning, particular for those caring for older people.

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<sup>7</sup> Other costs include costs to their health and financial costs in the shorter and longer terms.

**Table 4: Quality of life, well-being and met needs**

	<i>IB group</i>	<i>Comparison group</i>
<b>Quality of life *</b>	<b>n=60</b>	<b>n=69</b>
So good, it could not be better	2 (1)	0
Very good	22 (13)	9 (6)
Good	38 (23)	29 (20)
Alright	28 (17)	51 (35)
Bad	5 (3)	6 (4)
Very bad	5 (3)	1 (1)
So bad, it could not be worse	0	4 (3)
<b>GHQ-12</b>	<b>n=59</b>	<b>n=69</b>
Mean score <sup>1</sup> (sd)	12.59 (5.42)	14.17 (6.45)
Percentage <sup>2</sup> scoring 4+	29%	42%
<b>ASCOT<sup>3</sup></b>	<b>n=58</b>	<b>n=66</b>
Current met needs mean score (sd)	1.90 (0.65)	1.66 (0.76)
<b>Self-perceived health</b>	<b>n=58</b>	<b>n=69</b>
Very good	19 (11)	13 (9)
Good	40 (23)	42 (29)
Fair	28 (16)	39 (27)
Bad	10 (6)	3 (2)
Very bad	3 (2)	3 (2)
<b>COPE index</b>	<b>n=55</b>	<b>n=62</b>
Negative impact <sup>4</sup> (sd)	21.20 (4.33)	20.26 (4.78)
Positive impact (sd)	13.38 (2.52)	12.84 (2.13)
Quality of service	9.96 (3.13)	10.02 (3.09)

Significance level: \*  $p < 0.05$

**Notes:**

<sup>1</sup> GHQ item scoring 0-3, higher GHQ scores indicate poorer outcomes

<sup>2</sup> Using GHQ item scoring 0-1

<sup>3</sup> Higher scores indicate lower levels of need

<sup>4</sup> Higher scores indicate fewer negative responses

**Social care outcome domains**

The ASCOT measure is designed to pick up on those aspects of life that are particularly the focus of social care interventions for service users. Five of the domains are relevant to carers and were therefore included in the structured interviews. Responses for each of the ASCOT domains are shown in Table 5.

Carers in the IB group were significantly more likely to report that they were fully occupied in activities of their choice (38 per cent;  $p < 0.05$ )<sup>8</sup> compared with those in the comparison group (20 per cent). Carers in the IB group were also more likely to report that they were in control over their daily lives and that they provided the kind of support that they wanted to provide compared with those in the comparison group, although the difference was not statistically significant. There was no evidence of improved social participation and involvement or feelings of safety among carers in the IB group. Carers of older people (50 per cent;  $n=16$ ;  $p < 0.05$ ) were significantly more likely, compared with carers of the other user groups (27 per cent;  $n=25$ ) to report that they had a social life (no needs for social participation and involvement). However, due to the small sample sizes, this result needs to be treated with caution.

**Table 5: ASCOT outcome domains for all service user groups combined**

	<i>IB group</i>	<i>Comparison group</i>	<i>Overall</i>
	% (n)	% (n)	% (n)
<b>Social participation and involvement</b>			
No needs	33 (19)	33 (22)	33 (41)
Low needs	47 (27)	39 (26)	43 (53)
High needs	21 (12)	27 (18)	24 (30)
<b>Control over daily life</b>			
No needs	42 (25)	32 (22)	36 (47)
Low needs	55 (33)	55 (38)	55 (71)
High needs	3 (2)	13 (9)	9 (11)
<b>Safety</b>			
No needs	73 (44)	75 (52)	74 (96)
Low needs	27 (14)	20 (14)	23 (28)
High needs	3 (2)	4 (3)	4 (5)
<b>Occupation and employment*</b>			
No needs	38 (23)	20 (14)	29 (37)
Low needs	58 (35)	67 (46)	63 (81)
High needs	3 (2)	13 (9)	9 (11)
<b>Caring role</b>			
No needs	55 (33)	45 (31)	50 (64)
Low needs	42 (25)	52 (36)	47 (61)
High needs	3 (2)	3 (2)	3 (4)

Significance level: \*  $p < 0.05$

<sup>8</sup> A four point scale was used for this domain which could have affected carers' responses. For the purpose of the overall measure this was reclassified into three levels. Responses to 'With help from services I can do the things I want to do' and 'I don't do many of the things I want to do' were classified as representing low needs in the occupation and employment domain.

## Caregiving role

The COPE index, which measures the impact of the caregiving role, has three components reflecting the positive and negative aspects of caregiving and the level of support provided. Table 6 shows that although the differences for each item within the three components did not reach statistical significance, there was a trend to support the view that carers in the IB group were more likely to appraise the caregiving role positively, compared with those in the comparison group.

**Table 6: COPE index**

	<i>IB group</i>	<i>Comparison group</i>
	Mean (SD)	Mean (SD)
<b>Negative impact of caregiving<sup>1</sup></b>		
Does caregiving have a negative effect on your emotional well-being?	3.05 (0.95)	2.81 (0.92)
Do you find caregiving too demanding?	2.78 (0.90)	2.79 (0.82)
Does caregiving have a negative effect on your physical health?	3.05 (0.79)	3.04 (0.91)
Does caregiving cause difficulties in your relationship with your family?	3.16 (0.97)	3.12 (0.94)
Do you feel trapped in your role as a caregiver?	2.81 (0.96)	2.59 (1.01)
Does caregiving cause difficulties in your relationship with your friends?	3.13 (0.96)	2.90 (0.90)
Does caregiving cause you financial difficulties?	3.28 (0.90)	3.03 (1.07)
<b>Positive aspects of caregiving<sup>2</sup></b>		
Do you find caregiving worthwhile?	3.46 (0.88)	3.25 (0.85)
Do you have a good relationship with care recipient?	3.62 (0.74)	3.66 (0.61)
Do you feel that anyone appreciates you as a caregiver?*	2.90 (1.11)	2.65 (1.05)
Do you feel you cope well as a caregiver?	3.40 (0.66)	3.24 (0.86)
<b>Quality of support?<sup>3</sup></b>		
Do you feel supported by your friends and/or neighbours?	2.53 (1.12)	2.69 (1.09)
Do you feel well supported by your family?	1.96 (1.07)	1.95 (1.13)
Do you feel well supported by health and social services?	2.73 (0.96)	2.67 (0.99)
Overall, do you feel well supported in your role of caregiver?	2.65 (1.06)	2.61 (0.97)

**Notes:**

<sup>1</sup>Lower scores represent a negative appraisal

<sup>2</sup>Higher scores represent a positive appraisal

<sup>3</sup>Lower scores represent higher perceptions of quality

## Satisfaction with services

We might expect that in the majority of cases when there is the flexibility for people to organise their own support or to plan jointly with carers or take into consideration carers circumstances, this might result in higher levels of carer satisfaction with that support. For

the carers of people in the IB group, questions in the structured interviews about satisfaction with services referred to the help paid for by the IB, while for the majority of carers supporting service users in the comparison group, this question referred to help commissioned by social services. We did not find a statistically significant difference in satisfaction: 22 per cent of carers (n=13) in the IB group and 18 per cent of carers (n=12) in the comparison group were either extremely or very satisfied with the help that the service user received (Table 7)<sup>9</sup>.

**Table 7: Satisfaction with help paid for from IB or from Social Services**

	<i>IB group</i> n=60	<i>Comparison group</i> n=68
	% (n)	% (n)
Extremely satisfied	2 (1)	2 (1)
Very satisfied	20 (12)	16 (11)
Quite satisfied	42 (25)	43 (29)
Neither satisfied nor dissatisfied	13 (8)	21 (14)
Quite dissatisfied	10 (6)	4 (3)
Very dissatisfied	8 (5)	6 (4)
Extremely dissatisfied	5 (3)	9 (6)

### Variations in outcome

It is important to explore variations in outcome further, to allow for the fact that the comparisons reported above were between carers of service users who had been randomised into the IB and comparison groups as part of the main IBSEN evaluation, rather than between carers who had been randomised themselves. We used statistical models to explore the implications of receipt of an IB and to explore other potential influences on outcomes. Potential influences included measures of baseline needs; carer and service user characteristics; circumstances (such as age, gender and whether the carer was living with the service user); and operational measures such as whether or not an IB holder had their support plan in place at the time of the structured interview with the carer. This type of analysis has two advantages when considering the impact of IBs. First, we can check whether, once we have allowed for other influences, any differences identified through straight comparisons still hold; secondly, differences that are not statistically significant because of the relatively small sample sizes can sometimes be identified.

The results are described below. The equations show the influence of each factor, after taking into account the effects of all other included variables<sup>10</sup>. There was very little variation

<sup>9</sup> People who were interviewed by telephone were significantly more likely to report being satisfied than people interviewed face-to-face.

<sup>10</sup> Tests of interaction were also conducted (for example IB effects by user group for each outcome domain) but none was found to be significant.

for the COPE index, as shown in Table 8. This meant that it was not possible to identify a satisfactory statistical model for this outcome measure.

### Quality of life

The positive relationship between carer-reported quality of life and receipt of IBs described above was maintained when other factors potentially associated with quality of life were allowed for ( $p < 0.05$ ). Other support-related effects were having had a break with the service user in the previous six months, which improved carers' quality of life ( $p < 0.05$ ) and being satisfied with the support planning process ( $p < 0.01$ ). Other factors significantly associated with better quality of life were, unsurprisingly, having a good relationship with the service user ( $p < 0.001$ ) and spending fewer hours caring for the service user ( $p < 0.05$ ).

**Table 8: Predicting quality of life**

	<i>Coefficient</i>	<i>P</i>
Individual budget group	0.36	0.04
Having a good relationship with the service user	0.57	0.00
Having a break with the care recipient	0.42	0.04
Being satisfied with the support planning process	0.13	0.02
Hours caring for care recipient	-0.01	0.05
Constant	1.80	0.00

**Notes:**

Model estimated using a linear multiple regression. Positive effects denote improvements in the outcome.  $R^2 = 0.28$ ;  $n=114$ .

Prob > chi<sup>2</sup> 0.80. RESET test 0.31.

### Social care outcomes (ASCOT)

Although the overall ASCOT score was not significantly different when we compared the IB and comparison groups, we identified positive relationships between IBs and some domains of social care outcome, in particular with the occupation domain. When other factors were allowed for, IBs were significantly associated with higher overall ASCOT scores ( $p < 0.05$ ). Other factors that had a positive impact on social care outcomes included being satisfied with the support planning process ( $p < 0.001$ ) and, in terms of the care provided, spending fewer hours caring for the service user ( $p < 0.04$ ) and care giving not causing problems with the family ( $p < 0.001$ ).

**Table 9: Predicting social care outcome (ASCOT)**

	<i>Coefficient</i>	<i>P</i>
IB Group	0.23	0.04
Satisfaction with support planning process	0.09	0.00
Hours caring for service user	-0.003	0.00
Care giving does not cause problems with the family	0.34	0.00
Constant	0.41	0.08

**Notes:**

Model estimated using a linear multiple regression.  $R^2=0.40$ ;  $n=111$ .

RESET test 0.71. Prob >  $\chi^2$  0.40.

**GHQ-12**

For ease of interpretation, we recoded GHQ-12 so that positive outcomes were associated with positive values. Table 10 shows that in terms of the support provided, even when other factors were allowed for, the service user receiving an IB did not have a statistically significant impact on carers' psychological well-being. However, psychological well-being was significantly associated with having a regular arrangement for someone to take care of the service user to enable the carer to have a break ( $p < 0.01$ ). The overall cost of the service package for the carer and service user was also significantly associated with higher levels of well being when included in the model ( $p < 0.05$ )<sup>11</sup>. Other factors significantly associated with better psychological well-being for carers were when carers were not living in rented accommodation and care-giving did not cause financial difficulties or difficulties in relationships between family members ( $p < 0.001$ ).

**Table 10: Predicting GHQ-12<sup>12</sup>**

	<i>Coefficient</i>	<i>P</i>
IB Group	1.25	0.18
Living in rented accommodation	-4.08	0.00
Care giving not causing financial difficulties	1.62	0.00
Care giving not causing difficulties in relationship with family	2.52	0.00
Regular arrangement for someone to take care of service user to give carer a break	2.58	0.01
Constant	13.53	0.00

**Notes:**

Model estimated using linear multiple regression.  $R^2=0.34$ ;  $n=120$ .

RESET test 0.19. Prob >  $\chi^2$  0.18.

<sup>11</sup> This is not shown in table 9 as the number of observations was reduced considerably because of missing data.

<sup>12</sup> GHQ-12 item scoring 0-3, lower GHQ scores indicate poorer outcomes.

## Discussion

While the study identified important effects of IBs on carers, there were distinctive features that are likely to have influenced the findings which need to be acknowledged when interpreting the results.

The sample size was smaller than had been planned due to problems in tracking down the carers of the original IBSEN study participants. We had originally intended to focus the study solely on carers of older people and people with learning disabilities, as it was anticipated that these carers were most likely to be affected by IBs, but potentially in different ways. However, in practice, we had to draw on a somewhat wider range of carers for the structured interviews and quantitative analyses.

The majority of carers in this follow-up study were supporting adults with learning disabilities or older people, resulting in more carers in this study than in the main IBSEN evaluation living in the same household as the person they were supporting; the people they were supporting were more likely to be younger, and to be owner-occupiers. There was also some indication that the people being supported by the carers in this study were more dependent, on average, than the service users in the main IBSEN evaluation. This probably reflects the operation of Fair Access to Care Services eligibility criteria, whereby disabled and older people with carers (particularly co-resident carers) are less likely to be assessed as being at high levels of risk than those without, all other factors being equal.

The fieldwork for this study was conducted after the main IBSEN evaluation study had been completed. Consequently a higher proportion of the IB group in this study had an IB in place, and those IBs had been in place for longer, than in the main IBSEN evaluation. This means that the IB users and their carers had had longer to experience the impact of this new way of delivering social care support. To some extent, therefore, the findings of this study reflect this longer time period and raise some issues and perspectives that might also have been revealed had the main IBSEN evaluation been able to examine outcomes over a longer time period.

### **Carers' involvement in assessment and support planning for IBs**

The qualitative interviews revealed that some carers had played very significant roles in the IB assessment, particularly where they were asked to act as proxy respondents for the person they were supporting. Indeed, a number remarked that this was the first time they had seen an assessment document and been able to contribute to it. Similarly, carers supporting IB users were slightly more likely to be very satisfied with the support planning process, compared to carers of standard social care service users – but a substantial proportion of both groups also expressed some dissatisfaction. It would seem from the results that the nature, level and scope of carers' involvement in the support planning processes may all have contributed to carers' satisfaction levels. In the structured interviews, carers of people offered an IB were significantly more likely than those in the comparison group to report that they and the service user had planned together how the IB would be used; comparison group carers were more likely to report that they played the major role or did all the planning of the service user's conventional social care services. On the face of it, this involvement would seem likely to lead to positive views of the process. However, a few

carers (particularly of learning disabled people) reported in the semi-structured interviews that their own concerns about the person they were supporting had been ignored in the support planning process. As carers also considered that their involvement in assessment and support planning was critical to its success, this exclusion could be expected to lead to a more negative view of the process. In contrast, carers of older people were more likely to report that their care-giving role had been recognised and the IB was at least partly being used to support them in that role.

The contrasting experiences of carers supporting an older person and those supporting a learning disabled service user can be seen as complementing the results of the main IBSEN evaluation, which found poorer outcomes for older IB users compared with older people using standard services. It may be that for some older people, the benefits of IBs are experienced as much by carers as by the service user. These contrasts may reflect different cultures and processes within adult social care teams working with older people and learning disabled people respectively.

Overall, IBs gave at least some carers new choices and opportunities, which included the option of paying someone else to do things that had previously been their sole responsibility, whether providing personal care or supervision for an older person or taking a young learning disabled adult out for social activities. A minority were able to increase or decrease their own care-giving inputs as they wished. A further, very important, source of satisfaction and benefit for carers arose when the IB clearly offered the disabled person a better quality of life or greater independence. This interdependence between outcomes for carers and outcomes for service users was clearly revealed in the semi-structured interviews; if the IB user was happier, then carers were more likely to be positive too.

### **Carers' receipt of support and services, care-giving activities and costs**

Among the service users whose carers were included in this study, the average cost of an IB was lower than the average costs of the standard social care services received by service users in the comparison group. Although this difference did not reach a level of statistical significance, it was more marked than in the main IB evaluation. In addition, although again the difference did not reach statistical significance, carers in this study who were looking after an IB user appeared to spend more time on care-related tasks than carers supporting someone in the comparison group who was continuing to receive standard social care services. As a result the opportunity costs for carers of IB users constituted a higher proportion of the overall costs of care for the IB group. While there was no difference in types of activity undertaken between the two groups, the semi-structured interviews revealed that carers of people with IBs were extensively involved in assessment and helping the person they were supporting to plan how to use the IB; in managing the financial aspects of the IB; and in co-ordinating the support purchased with the IB. Only a small minority of those carers who took part in either the structured or semi-structured interviews received any payment from the service user's IB for either their care-related responsibilities – whether providing direct, hands-on care or managing the IB. However, over half of all carers were receiving Carer's Allowance and/or other care-related benefits.

Together these findings suggest that the slightly lower costs of IBs compared with standard social care support, as revealed in both this study and the main IBSEN evaluation, may be

offset by greater inputs of time – and the associated opportunity costs – on the part of informal carers. However, this conclusion needs to be treated with extreme caution; the difference in levels of formal resource inputs to the service users supported by carers in the IB and comparison group was not significant and sample numbers were relatively small.

### **IBs and outcomes for carers**

Multivariate analyses of the structured interview data showed that IBs were associated with positive impacts on carers' quality of life, social care outcomes and psychological well-being. In relation to all these outcome measures, carers of IB users scored higher than carers of people using standard social care services; the difference between the two groups of carers was statistically significant in relation to carers' quality of life, indicating that IBs helped to keep them 'mentally and physically well'. Moreover, in relation to the COPE index, which measures the impact of the care-giving role, carers of IB users were no more likely to view their role negatively than carers who were supporting people using standard social care services. These results were achieved at no greater cost to the public purse, suggesting that for carers IBs are cost-effective. The evidence of positive outcomes for carers from this study is less equivocal than the evidence from the main IBSEN evaluation of the benefits for some groups of service users. This may simply reflect the different times at which the two studies were conducted. As noted above, a higher proportion of service users in the present carers study had an IB in place, and for longer, at the time of the interview. Thus the findings may to some extent simply reflect the longer period for IBs to have had an impact. In another respect, the findings from this study tend to support the suggestion from the main IBSEN evaluation study, that different groups of service users – and their respective carers – may have rather different experiences of IBs. The main IBSEN evaluation found less evidence of positive outcomes for older people compared to younger disabled or mentally ill IB users. This study suggests that IB processes may differ too, particularly with respect to carers' involvement in assessment and support planning, and that these processes can also impact on overall outcomes for carers. However, the study also draws attention to a vitally important issue for both policy and practice – that of the processes for assessing and meeting the needs of disabled and older people and those who support them and the interdependency of their respective outcomes.

### **Recommendations for policy and practice**

Despite the small number of carers involved, this study has shown that IBs did have a positive impact which is clearer and more consistent than the evidence of positive outcomes for IB users in the main IB evaluation. It suggests strongly that developing practice around IB assessment and support planning for IBs needs to include carers' perspectives; and that further research into the impacts and outcomes of IBs should take a wider perspective and include the impacts on carers and family members as well. One helpful finding from the study is the association between the measure of satisfaction with the support planning process and outcomes for carers, whether or not the service user was receiving an IB. This would be a simple measure for local authorities to collect as an indicator of the impact of services on carers.

However, the study has also revealed some issues which need addressing at both policy and practice levels as personalisation in social care is rolled out more widely. First, there is

evidence of inconsistent practice in relation to different groups of carers – this inconsistency may extend beyond the carers of older people and learning disabled people who were the main focus of this study. Also there is a need for greater clarity and consistency on how far carers can be paid from the IB of a service user; the conditions (such as employment contracts) that should be attached to such payments; and the interactions between such payments and carers' entitlements to social security and other benefits.

The findings suggest that personal budgets have the potential to deliver core outcomes of the revised National Carer Strategy (HM Government, 2008). The finding that occupation was the social care outcome domain where most impact was identified suggests IBs could support carers having a 'life of their own'. In addition the evaluation process itself has pointed to indicators that could be used to monitor progress in these objectives. The quality of life indicator and ASCOT outcome indicator are all relatively low burden measures that should reflect change where there are improvements in performance.

### **Further research**

The authors reported on the limitations on what was possible in the scope of this study and highlighted that the interpretation and conclusions drawn need to be made with caution. Carers are a large and diverse group, important sections of which, for example carers of people with mental health problems, have been under-represented here. It has not been possible to investigate whether there are implications for particular groups, such as BME carers. A larger scale or more targeted study on particular groups of carers might investigate the impact of personal budgets in more depth.

The report (Glendinning et al., 2009) concluded that a clear message that emerged was the importance of carers' satisfaction with care planning process and some indications that this varied depending on the service user group that the person they care for belongs to. It was suggested that this is likely to depend on other factors such as involvement in the assessment process and the degree to which their needs are taken into consideration both in this and in the resources allocated to the budget. More evidence is needed of variations in practice across carers of different service user groups, good practice, and approaches that can be used to ensure that the carer perspective is reflected in the resources allocated, subsequent plan and its implementation.

There was limited use of IBs to pay carers but this is a key flexibility that may have important implications of the value of personal budgets to carers, on the wider social care workforce and provider market. Potentially there are impacts across the whole of the social care economy, but if the resistance to paying carers expressed by respondents in this study is widespread the effect may be limited. Payments of carers and the receipt of budgets as direct payments have implications for whole family budgets as well as at the budgets allocated to the individual family members involved. Further research is needed that focuses not only on the implications of personal budgets on other family income sources such as employment and welfare benefits, but also on the implications for the care workforce (Glendinning et al., 2009).

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