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The Individual Budgets Pilot Projects: Impact and Outcomes for Carers

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A note on terminology. The study reported here included carers of older people, carers of people with learning or physical disabilities and carers of people with mental health problems. We have used the term ‘service user’ to describe those people receiving support from the carers in the study. We recognise that in many instances carers will themselves be using services to support them in their care-giving role; some carers may also have disabilities or other problems that make them eligible for services in their own right. However, for the purposes of this report, we use the terms ‘carer’ and ‘service user’ to distinguish between the two groups.

Chapter 1 Introduction: Policy and Research Contexts and Study Aims

1.1 Introduction

This chapter sets out the policy and research contexts for the study. It first summarises the individual budget pilot projects and locates these within the wider context of policy initiatives aimed at giving disabled and older people greater choice and control over their support arrangements. It then summarises the somewhat separate development of policies and practice aimed at identifying and meeting the needs of informal and family carers. The third section of the chapter briefly reviews research evidence, from the UK and elsewhere, on the impact on carers of policies intended to increase choice and control for disabled and older people. These three themes together provide the context and shape the aims of this study into the impact and outcomes of individual budgets on carers.

1.2 Individual budgets

Individual budgets (IBs) are central to the Government's ambitions for 'modernising' social care in England. They were first proposed in the Cabinet Office Strategy Unit report *Improving the Life Chances of Disabled People* (Cabinet Office, 2005) and the proposal was repeated in the UK strategy for an ageing population (HMG, 2005). In the same year the Green Paper on adult social care *Independence, Well-being and Choice* (DH, 2005) also called for the piloting of individual budgets so that older and disabled people could have more choice and control over how their support needs are met:

> People could have individual support to identify the services they wish to use, which might be outside the range of services traditionally offered by social care. … For those who choose not to take a direct payment as cash, [individual] budgets would give many of the benefits of choice to the person using services, without them having the worry of actually managing the money for themselves
> (DH, 2005: 34).

In July 2005 the Department of Health (DH) invited local authorities with responsibility for adult social care to bid to pilot IBs. Thirteen local authorities were selected. They covered a range of authority types (two London boroughs, five metropolitan boroughs, four counties and two unitary authorities), spread across England. The IB pilot programme ran from the end of 2005 until the end of 2007.

The 13 pilot sites varied widely in their demographic and socio-economic characteristics, adult social care activity and overall performance. However, as a group the sites were no different from the English averages except that, together, they had higher than average take-up of direct payments. Some also had significantly higher than average expenditure on direct payments, particularly for people with mental health problems and learning disabilities. Many were already working with *In Control* (see below), usually in developing new support arrangements for people with learning disabilities. Nevertheless, significant innovations in social care organisation and practice were required in order to implement IBs. The IB pilot programme was subject to a rigorous, multi-method evaluation (Glendinning *et al*., 2008).

1.2.1 The principles underlying individual budgets

The IB pilots had the following objectives:

- Individuals should play a greater role in assessing their needs for support.
- Individuals should know the level of resources available to them before planning how they would like those needs to be met. The IB pilots were encouraged to build on tools developed by *In Control* (see below), particularly the Resource Allocation System (RAS), to determine how much money an individual should receive.
- The IB pilots should test the feasibility of aligning or integrating resources from several different funding streams into a single IB. In addition to adult social care, additional funding streams were to include: Access to Work; the Independent Living Fund; Supporting People; Disabled Facilities Grants; and local Integrated Community Equipment Services. Multiple assessment processes and eligibility criteria should be simplified and integrated or aligned, with adult social care as the gateway to an IB.
- In planning how to use an IB, individuals should identify the outcomes they wish to achieve and the ways they wish to achieve them. IBs could be spent on a wide range of services, including existing statutory or commercial services (for example, day centre attendance or gym membership), or to pay relatives and friends for the help they provide. However, paying close relatives from an IB was subject to the same restrictions as affect direct payments (see below).
- Support, including information on the costs and availability of different service options, should be available to help individuals plan how to use their IBs.
- The IB pilots were to experiment with different ways of managing and using IBs. As well as direct cash payments, other possible arrangements included care manager-managed ‘virtual budgets’; provider-managed individual service funds; payments to third party individuals and Trusts; and combinations of these.

1.2.2 Antecedents to IBs: Direct payments and *In Control*

Individual budgets build on two previous initiatives aimed at giving social care service users greater choice and control over their support arrangements. First, direct payments – the option to receive the value of services in the form of a cash payment – were first introduced in 1997, initially for disabled people aged 18 to 65, and extended to 16 and 17 year olds and older people in 2000. At this point, direct payments were also extended to the parents of disabled children and to carers of adults and older people, who also became able to receive cash payments instead of services to meet their assessed needs. However, direct payments could not be used to purchase health care, local authority services or employ a close co-resident relative.

Despite the fact that local authorities are now mandated to offer direct payments as an alternative to services in kind, and a £9 million Development Fund has been established to increase take-up (Glasby and Littlechild, 2006), take-up has remained relatively low and highly variable – between the different countries of the UK; between local authorities within those countries; and between different groups of social care service users (Riddell *et al*., 2005; Davey *et al*., 2007; Fernández *et al*., 2007).

The *Valuing People* White Paper (DH, 2001) led to a different approach to enabling people with learning disabilities to have greater choice and control over their support arrangements, promoted by the social enterprise organisation *In Control*. The *In Control* approach encourages self-assessment; the allocation of resources to individuals according to relative levels of need rather than the value of equivalent services (as with direct payments); transparency about the resources allocated to each person; and support in planning how those resources are used to meet individual priorities. Whereas direct payments are generally used to employ personal assistants to provide help with personal care and daily living activities, *In Control* encourages greater flexibility and the use of a wide range of ordinary community-based services and supports. *In Control* connects closely with the principles underpinning direct payments but has a broader aim of redesigning social care systems towards ‘self-directed support’ (Duffy, 2005).

1.2.3 The evaluation of the IB pilot projects (IBSEN)

The potential impacts of IBs are potentially profound. The Department of Health therefore commissioned an independent evaluation of the IB pilots. The evaluation (hereafter referred to as the Individual Budgets Evaluation Network – IBSEN) began in August 2005, went ‘live’ in April 2006 and ended in March 2008. The report of the evaluation was published in autumn 2008 (Glendinning *et al*., 2008).

The evaluation of the IB pilot projects aimed to:

- Examine whether IBs offer a better way of supporting older people and adults with social care needs than conventional methods of funding, commissioning and service delivery.
- Examine the relative merits of different IB models for different groups of people using services.
- Explore the impacts of IBs on the workforce involved.
- Examine the factors facilitating or constraining implementation of the policy, including changes in assessment practices, resource allocation processes, support planning arrangements, service provision and integration of multiple funding streams.

However, the evaluation did not examine the impact of IBs on carers. Building on the design of the main IBSEN study, this present investigation was conducted into the impact of IBs on carers.

1.3 The development of policies for carers

The recognition of carers' needs and the development of services to meet those needs have evolved along rather separate lines from policies for disabled and older people. Thus the 1995 legislation that first gave carers the right to an assessment of their own needs was linked to the statutory duty of local authorities to assess the needs of disabled and older people. However in 2000 carers' rights to assessment were extended, even where the person being cared for refused an assessment. Subsequently the 2004 Carers (Equal Opportunities) Act aimed to ensure that carers are informed about their rights to an assessment. It also gave local authorities powers to enlist the help of housing, health and education services in supporting carers; and required that employment, lifelong learning and leisure are included in assessments of carers' needs.

However, carers' experiences fall far short of these ambitions. Half those carers providing substantial amounts of care are unaware of their rights to assessment and some are not even aware that they have been assessed (Carers UK, 2003). Even those carers who are aware of their rights may be wary of assessment, fearing that assessment might lead to institutional care of the person being supported (Arksey and Glendinning, 2007).

Around 353,000 carers received a carers assessment or review during 2006-07, either separately or jointly with the service user. Approximately 108,000 (31 per cent) of these carers were assessed or reviewed separately from the person they cared for. Of the 353,000 carers assessed or reviewed, an estimated 315,000 carers (89 per cent) received a service following a carers assessment or review. Of these, 56 per cent received 'carer specific' services, and 44 per cent received information only (The Information Centre, 2008).

As noted above, since 2000 carers have also been able to receive direct payments in their own right. However, take-up of direct payments by carers has been low and, again, highly variable between English local authorities (Fletcher, 2006).

The revised English National Strategy for carers draws attention to the advantages of direct payments, personal budgets and individual budgets for carers (HM Government, 2008: 61-3). The Strategy suggests that these new arrangements will offer better outcomes, as carers and service users will have more choice and control over what services – for example respite services and short breaks – best meet their needs. 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. It includes a promise that over the next few years every person using social services, including carers, will be given a personal budget. The revised Strategy also requires NHS services and health professionals to work together with local authorities to develop 'joined up' services for carers; this requirement may sit uneasily with policy ambitions of personalisation that are currently restricted to social care.

The issues around assessments, services, direct payments, disabled and older people, carers and outcomes are complex:

- Policy guidance (HMSO, 1990) assumes that carers should be involved in the community care assessment of the person they are supporting. Carers also have statutory rights to a separate assessment of their own ability to sustain the care-giving relationship. In practice, a carer's assessment may be carried out jointly with that of the person needing support.
- Both disabled and older people and carers may receive services and/or direct payments; these may variously aim to meet individual and/or joint needs. However, a direct payment awarded to a carer cannot be used to buy a service for the service user.
- The benefits of services or direct payments may be experienced more or less equally by the service user and the carer, depending on:
    - the focus of the initial assessment(s);
    - decision-making between carers, service users and service providers; and
    - the subsequent services or support arrangements used.
- Direct payments, whether awarded to a service user, a carer or jointly to both, cannot normally be used to employ a(nother) co-resident relative in the capacity of a personal assistant (DH, 2003).

This variability and uncertainty makes it difficult to anticipate what role carers might play in relation to IBs or how IBs might affect carers. It is not clear, for example, how far carers' needs might be assessed separately from or as part of the (self-) assessment carried out for an IB. It is also not clear how far the help given by informal carers will be discounted in service users' (self)-assessments for IBs and therefore not covered by the resources allocated to individual service users through the RAS. How far will the potential benefits of IBs be experienced by carers as well as by disabled and older people? Would resources for meeting carers' needs be allocated as part of an IB for a service user or would carers be awarded separate IBs in their own right; and what impact would these different methods of allocating resources have on relationships between carers and service users and on outcomes for each? What impact would the additional flexibility offered by IBs have on those carers who can now be paid for (some of) the support they provide, and what impact would this have on care-giving relationships? And would the impacts of IBs be different for different groups of carers, or for carers of different groups of service users?

In addition, it is not clear how far the success of IBs overall depends upon the availability of family carers to support service users in designing their own support arrangements and managing these on an on-going basis. Well-publicised cases of successful IBs involve carers playing a key role in managing both the IB resources themselves and the on-going support purchased with an IB (Duffy, 2005). If this is the case, IB users without a carer to help risk being worse off than those that do, in relation to both the planning of support and its on-going management. On the other hand, carers of IB users may find that their willingness to continue providing care taken for granted and their ability to continue in paid employment compromised, particularly if their role in the on-going management of the IB is taken for granted.

1.4 Research evidence on direct payments, individual budgets and carers

1.4.1 Direct payments and carers

Few answers to the above questions are suggested by research to date. While there is considerable evidence (albeit mainly small scale and qualitative) of the beneficial impact of direct payments on the quality of life of younger disabled (and, to a lesser extent, older) people, there has been relatively little research into the impact on carers. There is, for example, little evidence on whether assessments of the needs of service users who might use direct payments are carried out separately or together with carers' assessments; on whether direct payments are allocated separately to carers and those they care for, or as a single, joint sum; on the roles of carers in managing direct payments allocated to the person they support; and, particularly important, on the outcomes of direct payments that are experienced by service users and their carers respectively.

Most of the available English research focuses on carers with responsibility for a disabled son or daughter (either child or adult). One study, based on interviews with 29 family carers of people with intellectual disabilities, found that parents played significant roles as initiators, managers and supporters of direct payments for their disabled son or daughter. However the additional responsibilities that parents undertook in helping their child get a direct payment, recruit personal assistants and manage the paperwork for the direct payment were counteracted by the benefits of increased independence for their son or daughter and a corresponding opportunity for parents to let go of some of their own direct care-giving responsibilities (Williams *et al*., 2003). Another study of families with disabled children receiving direct payments found that parents valued being able to arrange support flexibly to meet the needs of both the disabled child and the family. Parents particularly valued the opportunity to employ a relative or friend who they already knew and trusted. However, these findings were based on a low response rate to a questionnaire survey, from which only seven families were selected for in-depth interview (Blyth and Gardner, 2007). A third, very small unpublished study focused more specifically on the impact and outcomes of direct payments for people caring for a disabled spouse as well as adult children with learning disabilities. Carers valued the increased flexibility offered by direct payments; the quality of the relationships that developed between themselves, the person they supported and the personal assistants employed through direct payments; and the positive impacts on the disabled person themselves. Reported outcomes included better relationships with the person supported; opportunities to spend more time with spouses and other family members; and improvements in carers' leisure and social lives (Littlejohns, 2006).

A recent study conducted by Carers UK reported that direct payments could have a positive impact on carers. The care they purchased with direct payments was better at meeting the needs of the disabled person; was more flexible; and gave carers more free time. Just over half the carers in the study said their overall experience of direct payments was positive. However, no details were given of the number of carers involved in the study or how they were recruited (Carers UK, 2008).

As well as being based on very small samples, it is important to note that all these studies drew on samples of carers and their families who had made a positive decision to opt for direct payments. Different patterns might be anticipated among the carers of IB holders where IBs are being systematically rolled out across a local authority.

However, a large scale Canadian study of employed working aged people providing care to an older person (Rosenthal *et al*., 2007) suggests one potential implication of

IBs for carers. Over and above the provision of direct, hands-on care, over four-fifths of the sample of employed adult carers provided ‘managerial’ care – obtaining information about services, organising services, managing finance and discussing care arrangements with the older person or with other family members. This ‘managerial care’ had additional personal and employment-related costs for carers, over and above the impact of direct hands-on care provision. This study suggests that, if carers are involved in recruiting and managing employed personal assistants and dealing with the accounts and paperwork associated with an IB, they risk experiencing increased stress.

1.4.2 Individual budgets and carers

Interviews were conducted during late summer 2006 with a small sample of very early IB users (Rabiee *et al*., 2008). This sample had been recruited to and randomised within the IBSEN evaluation (see Chapter 2) and were therefore less self-selecting than participants in the direct payment studies noted above. The interviews suggested that IBs might have a number of possible impacts on carers. Some IB holders reported that an IB had relieved them of having to depend on informal carers, with consequent improvements in the quality of family relationships. Other IB holders were now able to pay carers for the help they gave and therefore felt less dependent on them. Some carers who were interviewed as proxy respondents for severely disabled IB users were also reported to have experienced greater independence as a result of the IB user being able to access alternative sources of support. However other carers, particularly those who were interviewed as proxies for IB holders with severe cognitive or communication impairments, had experienced increased responsibilities for managing and co-ordinating the disabled person’s support arrangements. For a few carers, this potentially adverse impact was exacerbated because the RAS used to calculate the level of the service user’s IB had led to a reduction in the funding available for formal services and therefore necessitated an increased reliance on informal care.

1.4.3 Using individual budgets to pay carers

Restrictions on direct payments have hitherto largely prevented their use to employ close, co-resident relatives as personal assistants and these restrictions also apply to IBs. However, the greater flexibility of individual budgets opens up the possibility of close relatives, including spouses, parents and adult children, receiving some reimbursement for the support they provide or for the extra costs they might incur in providing care. This is an issue of considerable national and international policy interest and one where empirical research does exist. An international study of ‘cash for care’ schemes (Ungerson and Yeandle, 2007) found considerable variations between countries depending, amongst other factors, on how far relationships between service users and their paid carer relatives are regulated by contractual relationships. Such payments are in stark contrast to 'notions of family solidarity and shared norms of obligation' (Ungerson and Yeandle, 2007: 197).

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. Paid relatives were therefore very dependent on the person they were supporting, particularly so far as the duration and termination of their paid work was concerned. They also felt they had less freedom to quit the job should they become dissatisfied with it; they carried greater physical and psychological burdens; they were more likely to be called upon at unsocial hours (for which they were not remunerated); and their social lives were adversely affected. This research suggests that, despite the potential protection that could be offered by formal employment contracts, carers paid from IBs may experience some disadvantages.

1.5 Aims of the study

These issues helped to shape the aims of this present study. The study aimed to identify the impact and outcomes of IBs on (hitherto) unpaid relatives and other informal carers. Specific questions addressed by the research are:

- 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?

The next chapter describes the design and methods used for the study.

Chapter 2 Study Design and Methods

2.1 Introduction

The IBSEN Carers study built on both the design and the data collected during the main IBSEN evaluation. Table 2.1 summarises the sources and timing of the data collected that were used for the purposes of the carer study. The first section of the chapter sets out the relevant features of the main IBSEN evaluation. We then describe the overall design and conduct of the carer study, identifying key challenges in the data collection and the implications of these for the samples of carers included in this study. We report on response rates and end by describing and considering the robustness and generalisability of the study in the light of the achieved samples.

2.2 The IBSEN evaluation

At the heart of the main IBSEN evaluation was a randomised controlled trial. Those eligible for the study (new social care referrals and/or existing service users undergoing review) were identified by IB pilot sites and registered with the IBSEN website; at this point the presence (or otherwise) of a carer was also recorded. Registered people were then randomised into two groups: one group was to be offered an IB immediately; for the other group, the offer of an IB was to be delayed by six months. Baseline data were collected from local authority records on members of both groups; if the (potential) IB holder had an informal carer, data on the carer’s socio-economic characteristics and service use were also collected.

Both groups were interviewed approximately six months after registration, so that outcomes with and without an IB could be compared. In addition, information was collected from local authority staff on the plans made by those in the IB group for how they intended to use their IBs. This support plan data included details of whether carers were involved in helping an IB holder to manage the IB, either jointly with the IB holder or on behalf of the IB holder. Where a carer was also offered an IB, either separately or jointly with the service user, local authority staff were asked to complete details of the carer’s support plan as well. While considerable encouragement was given to local authority staff by the IBSEN evaluation team and by the Care Services Improvement Partnership (CSIP) staff supporting local implementation, the amount of data that local authority staff were required to return within a very short timescale for the main evaluation meant that collecting information on carers was not always accorded as high a priority.

Interviews were conducted with the lead officers responsible for implementing IBs in all 13 pilot sites about their experiences of implementation. These interviews were conducted during summer 2006 and again in late 2007. The interviews covered all aspects of the implementation process, including the development of the RAS and the interactions between the IB pilot and existing policies and practices for carers in each pilot site.

2.3 The carer study

2.3.1 Overall design

The carer study was designed as an add-on to the main evaluation. It had four strands:

- Structured outcome interviews with carers of people randomised to the IB group and comparison group respectively, to compare outcomes for carers of people with and without an IB. These interviews used the same standardised outcome measures 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.
- Semi-structured interviews with a small number of carers of people in the IB group to explore in more depth their involvement in supporting an IB holder and the outcomes of IBs for carers. These interviews were conducted between January and June 2008.
- Extraction and reanalysis of data from the two sets of interviews with IB project leads in each of the pilot sites that had been conducted as part of the main IBSEN evaluation, about how carers' issues were dealt with in implementing IBs.
- Telephone interviews with officers responsible for carers' issues in 12 of the 13 pilot sites about their involvement in the IB pilot.

2.3.2 Carer samples

Carers are a highly heterogenous group whose characteristics vary independently of those they support. It was therefore decided to focus the study primarily on the two largest groups of carers likely to be affected by IBs: carers of older people and carers of people with learning disabilities. As a result of this decision and other practical factors (see Appendix A), only nine of the 13 IB pilot sites were included in this study. The aim was to recruit 100 carers of service users who had been randomised into the IB group and 100 who had been randomised to the comparison group in the main evaluation. In addition we wanted to conduct semi-structured interviews with a further 40 carers of service users in the IB group.

In practice a number of problems arose (see Appendix A) and the sample sizes were much smaller. Carers providing assistance to all of the four main groups of service users were included in the structured interview sample. A total of 208 carers were invited to participate in the study; 163 carers agreed, yielding an overall response rate of 78 per cent. Twenty-four carers from six of the sites taking part in the study took part in semi-structured interviews and 139 carers from all nine sites took part in structured outcome interviews. For a variety of reasons (see Appendix A) it was not possible to use some of the latter interviews for the quantitative analysis and therefore the structured outcome sample size was reduced to 129.

2.3.3 Interviews with carers

The structured outcome interviews collected information about service use and needs of carers. The interview included four main outcome measures:

- The 12-item version of the General Health Questionnaire (GHQ-12; Goldberg, 1992);
- A single quality of life question using a seven-point scale (Bowling, 1995);
- An adapted version of the Adult Social Care Outcome Toolkit (ASCOT) (Netten *et al*., 2006); and
- The Carers of Older People in Europe scale (COPE index) (McKee *et al*., 2003).

The interview also identified self perceived health using a five point scale, (Robine *et al*., 2003) and measures of satisfaction with services and quality of care (Jones *et al*., 2007; Malley *et al*., 2006). See Appendix A for a description of the measures used.

The majority of structured outcome interviews were conducted face-to-face although 25 of the 129 were conducted over the telephone, 15 in the IB group and ten in the comparison group.

The semi-structured interviews 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.

Twenty interviews were conducted face-to-face and four interviews were conducted over the telephone.

Table 2.1 Sources and timing of data collections

Data collection	*Data used in carer study*	*Timing*	*Dates*
IBSEN			
Baseline data	Whether a carer present and if lived with service user Primary service user group Service user demographics Previous support packages, Activities of daily living	At assessment/ review	June 2006-June 2007
Support Plans	Level of IB Services purchased with IB	Once support plan agreed	June 2006-Dec 2007
Interviews with service users	Service use	Six months after registration[1]	June 2006-Dec 2007
Interviews with IB leads	Approach towards carers during implementation	Beginning and end of IB pilots	Summer 2006 and 2007
Carer study			
Structured interviews with carer	Carer demographics Use of carer specific services Caring activities and time Experience of IBs Outcomes	Between one and 10 months after interview with service user	Dec 2007-May 2008
Semi structured interviews with carers	Views and experiences of IB and support planning process	Between one and 10 months after interview with service user	Jan 2008-June 2008
Telephone interviews with carer leads	Involvement and council approach towards carers and IBs	During the carer interview fieldwork period	Jan 2008-June 2008

[1] Registered as allocated to IB or comparison group

2.3.4 Interviews with IB lead officers

IB project lead officers and other senior managers responsible for implementing IBs in each of the 13 pilot sites participated in semi-structured face-to-face interviews during the summer of 2006 and again during autumn 2007, as part of the main evaluation of IBs. The topic guides covered a wide range of issues, including the local context in which IBs were implemented. Data that related most specifically to the (potential) impact of IBs on carers were identified, extracted and reanalysed for this study. There were two principal issues of interest:

- The extent to which the design and development of the IB resource allocation systems took account of the support currently provided by informal carers and/or took account of carers' own needs.
- Current policy and practice relating to the potential to pay informal carers from an IB.

2.3.5 Telephone interviews with carer lead officers

Individuals with responsibility for carers' issues in all 13 pilot sites were identified and approached to take part in a telephone interview. With one exception, all carers' leads agreed to this request. In two instances, at their request, a joint interview was conducted with the carers' lead together with a colleague from the IB team. These interviews were conducted between January and March 2008.

An outline topic guide was sent to the interviewees beforehand, which helped them prepare for the interview. The following topic areas were covered:

- The interviewee's involvement in the IB implementation process.
- The local authority context for the implementation of IBs.
- Assessment processes and support planning.
- Using IBs to pay informal carers.
- IBs and the wider context of policies/provisions for carers.

2.3.6 Analyses

The quantitative analysis drew on data from the structured outcome interviews with carers; data collected at baseline in the main IBSEN evaluation about service users and their carers; and the IBs and support plans (see Appendix A for details). Unit cost and support package cost information was drawn from the main IBSEN evaluation for service users, with additional estimates for carer-specific support services and for the opportunity costs of the care they provided (see Appendix A and Chapter 4).

As in the main IBSEN evaluation, comparisons were made between the IB and comparison groups using parametric statistical tests.[1] The groups followed the initial random allocation reflecting the same approach as the main evaluation, including the retention of those who had refused an IB within the IB group. However, in two

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[1] A chi-square test of association was used to explore the relationship between two discrete variables (for example, between the IB and comparison groups on the dichotomous GHQ-12 indicator). When the outcome measure was based on a Likert scale (for example running from one to seven), a t-test was used to explore mean differences between groups (for example, quality of life and satisfaction).

instances exceptions were made; where service users initially allocated to the comparison group had since been allocated an IB, they were included in the IB group for this study. Although drawn from randomly allocated groups, the basis for the sample was not random; however, as we will show below, the groups were very similar. It was important therefore, to explore the relationship between outcomes and other factors using multivariate analyses (see Chapter 6). The software package STATA was used for the regression analyses.

The qualitative analyses drew on data from the semi-structured interviews with the carers, the IB lead officers and the carers' lead officers. All three sets of interviews were tape recorded (with the interviewee's permission), fully transcribed and anonymised. Systematic coding using MaxQDA software and qualitative analysis using the framework approach (Ritchie and Spencer, 1994) were carried out by one of the researchers who had conducted the interviews. The coded data were summarised onto a series of charts and recorded separately for each set of interviewees and, among the carer interviewees, by user group to allow comparisons to be made between their experiences. Data were analysed thematically and recorded separately for each site so that differences in policy or operational issues between the IB pilot sites could be identified. Conclusions were verified by returning to the transcripts and through on-going discussions within the research team.

2.4 Robustness and generalisability of the study

The main IBSEN evaluation examined the representativeness of the sample of service users that were randomised to the IB and comparison groups (Glendinning *et al*., 2008). This analysis concluded that, given the limitations of data about service users in general, the sample appeared to be nationally representative of the main social care service user groups, apart from the fact that both the IB and comparison groups contained higher proportions of people receiving direct payments than among service users in general. Given this, and with the same caveat, we would expect carers of service users in the main evaluation also to be nationally representative of carers of social care service users in general.

For the main IBSEN evaluation service users were randomly allocated to the IB and comparison groups. The two groups proved to be similar as a result,[2] giving us confidence that any difference between the groups at six months was the result of the intervention (the offer and receipt of an IB). However, as described above, the carers in this study had not been randomised into IB and comparison groups, so we therefore cannot assume that the carers in the two groups will be similar in terms of basic demographic characteristics.

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[2] No statistically significant baseline differences between service users in the IB and comparison groups.

The two questions we need to address therefore are:

- Are the carers in the structured outcome interview samples for this study similar to carers in the main IB evaluation?
- Are the carers in the structured outcome interview comparison group sample similar to those in the IB group?

To answer these questions we considered the distribution of carers in relation to the service user groups they were supporting; demographic characteristics and household composition; the level of disability of the people they were supporting; and their receipt of services prior to randomisation to the IB or comparison group.

During the main IBSEN evaluation, data on whether the service user had an informal carer was collected at baseline. In the carer sub-sample for the present study, 100 per cent (129) of records contained information about the informal carer at baseline compared with 56 per cent (533) in the main IBSEN study sample. We drew on this baseline data to compare the main IBSEN sample with the carer sub-sample.

2.4.1 The sample, randomisation and primary user groups

We had baseline information from the main IBSEN evaluation for 129 carers who participated in the structured outcome interviews and for the 24 carers participating in the semi-structured interviews for this study. 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. In total, our sample represented over a quarter (29 per cent) of carers identified in the main study, where carers were identified for just over half (n=533) of the service users in the overall sample.[3]

As described above, we originally aimed to reduce potential sources of variation in carers' experiences by restricting the sample to carers of two service user groups – older people and people with learning disabilities. In practice, we had to relax these criteria and include in the structured interview sample carers supporting people from all the user groups represented in the main IB evaluation. Table 2.2 shows that as a result of the sampling procedure for the carers in our structured sample, over half (54 per cent) were supporting service users with learning disabilities and about a quarter (26 per cent) were supporting older service users.

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[3] When informal carer information was not reported at baseline for service users receiving assistance from carers in the present study, information from the structured outcome interviews was used to supplement the missing data.

This represented a significantly higher proportion of people caring for service users with learning disabilities in the present study compared with members of the main IBSEN sample who had a carer identified at baseline (32 per cent, p<0.001), but a lower proportion of older people with a carer in the main IBSEN evaluation (31 per cent), although the latter difference did not reach statistical significance. As we would expect, lower proportions of the carer sample were caring for people with a physical disability or mental health problem.

Table 2.2 Distribution of the structured interview sample between primary user groups

	IBSEN sample with informal carer	*Carer study sample*		
		Total	IB group	Comparison group
	% (n)	% (n)	% (n)	% (n)
Randomisation	56 (533)	93 (129)	47 (60)	53 (69)
User Group[4]				
Physical disability	28 (150)[4]	15 (19)	13 (8)	16 (11)
Older people	31 (163)	26 (33)	27 (16)	25 (17)
Learning disability	32 (172)	54 (70)	53 (32)	55 (38)
Mental health	9 (46)	5 (7)	7 (4)	4 (3)

2.4.2 Demographics and household characteristics

Carers in our structured interview sample provided assistance to a significantly younger group of service users (mean age 47 years) compared with the average age of service users with a carer in the overall IBSEN sample (mean age 55 years) (p<.001). This was due to the higher proportion of younger people with learning disabilities being cared for by carers participating in the present carer study, compared with the main IBSEN evaluation. Within the carer study, the age of the service users in the IB group was similar and not significantly different to those in the comparison group (mean age 45 years in IB group; 48 years in comparison group).

Table 2.3 shows that in the structured interview carer sample, a significantly higher proportion of service users lived with the carer (82 per cent; p< 0.01) compared with service users in the overall IBSEN sample (70 per cent). This table also shows that, where details of housing tenure were available, a significantly higher proportion of

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[4] There was missing user group information for two service users identified as having an informal carer at baseline in the main IBSEN evaluation.

service users in the carer study were private home owners (64 per cent; $p< 0.01$) compared with service users with carers in the main IBSEN evaluation sample (52 per cent). Both factors may have a significant impact on carers' responses on outcomes, which are examined in Chapter 6.

Within the structured interview carer sample, there were no significant differences between the IB and comparison groups on each of four demographic variables.

Table 2.3 Demographic comparisons between the overall IBSEN service user sample and the carer study sample

	IBSEN sample with informal carer	*Carer study sample*		
		Total	IB group	Comparison group
	% (n)	% (n)	% (n)	% (n)
Service users living with carer	70 (373)	82 (105)**	78 (46)	86 (59)
Female service user	56 (293)	50 (64)	45 (27)	54 (37)
BME service user	8 (43)	11 (14)	13 (8)	9 (6)
Service users living in a privately owned household	52 (254)	64 (78)**	63 (35)	66 (43)

Significance Levels: ** $p< 0.01$.

Table 2.4 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.[5] 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 groups the largest single group of carers was those caring for an adult child, which is what we would expect, given the distribution of the service user groups that people were caring for.

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[5] There was insufficient baseline data about carers available from the main IBSEN study for us to be able to compare with the main IB evaluation sample.

From the perspective of the analysis the most important comparison is between carers in the structured interview IB and comparison groups. As we would hope, 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.

Table 2.4 Carer characteristics

	Structured interviews		*Semi-structured interviews*	*Total*
	IB group	Comparison group		
	% (n)	% (n)	% (n)	%(n)
Female carer	77 (46)	73 (50)	75 (18)[6]	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)

2.4.3 Activities of Daily Living (ADLs)

During the main IBSEN evaluation, data on the severity of need for help from services across 12 activities of daily living was collected at baseline. FACS criteria mean that those people without informal support – particularly co-resident carers – are more likely to receive services at lower levels of need, so those people with identified informal carers tend to be more dependent (see Appendix A). Table 2.5 shows that dependency levels of service users with identified carers in the main IBSEN evaluation were similar to those in our structured interview sample, although there is some evidence that our sample may be caring for slightly more dependent people. In the carer sample, significantly higher dependency levels for three activities of daily living were found for those included in our sample compared with those with carers in the main IBSEN evaluation not included in the carer sample; these activities of daily living were getting out of doors ($p< 0.01$), washing their face and hands ($p< 0.01$) and washing their hair ($p< 0.01$). 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.

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[6] One interview was carried out with both parents and so gender was not reported.

Table 2.5 Activities of Daily Living (ADLs)

	IBSEN sample with informal carer	*Carer study sample*		
		Total	IB group	Comparison group
	% (n)	% (n)	% (n)	% (n)
Getting up/down stairs	50 (221)	52 (56)	43 (22)	59 (34)
Going out of doors and walking down the road	66 (319)	76 (93)**	69 (37)	82 (56)
Getting around the house	29 (147)	35 (43)	36 (20)	34 (23)
Getting in/out of bed or chair	32 (163)	33 (41)	32 (18)	34 (23)
Using the toilet	33 (168)	39 (48)	37 (20)	41 (28)
Washing face and hands	31 (156)	42 (52)**	35 (20)	46 (32)
Using bath, shower or washing all over	66 (343)	71 (89)	38 (39)	73 (50)
Getting dressed/undressed	52 (267)	57 (71)	56 (32)	57 (39)
Washing hair	60 (304)	70 (87)**	66 (37)	73 (50)
Feeding themselves	18 (88)	24 (28)	20 (11)	26 (17)
Cooking/food preparation	77 (393)	83 (104)	83 (47)	84 (57)
Housework	83 (421)	86 (108)	84 (48)	87 (60)
Shopping	86 (436)	89 (109)	88 (49)	90 (60)

Significance Levels: ** $p < 0.01$.

2.4.4 Previous social services support packages

There were very similar patterns of previous service receipt when we compared both our structured interview sample with the main IBSEN evaluation sample (that had carers) and the IB and comparison groups within our carer sample.

In the carer sample, 27 per cent (n=35) of service users were new to services, compared with 29 per cent (n=153) of service users with carers in the main IBSEN evaluation. Where people had previously been receiving services, we had information about the previous social services support package for 71 per cent (n=380) of service users with a carer in the main IBSEN sample and compared with 73 per cent (n=94) of service users in the structured interview carer subsample. Within the carer subsample, we had information on previous support arrangements from 75 per cent of service users in the IB group (n=45) and 71 per cent (n=49) of the comparison group. Table 2.6 shows that there was only one statistically significant difference between carers in the main IBSEN sample and those in our carer study sub-sample. Service users in the carer study were significantly more likely to have received breaks (26 per cent; n=24) compared with those with carers in the main IBSEN sample (14 per cent; n=53).

Within the carer sample, there were no significant differences between the comparison and IB groups in terms of previous support packages.

Table 2.6 Previous receipt of services

	IBSEN sample with informal carer	*Carer study sample*		
	n=380	n=94 Total	n=45 IB group	n=49 Comparison group
	% (n)	% (n)	% (n)	% (n)
Direct payment	24 (91)	27 (25)	22 (10)	31 (15)
Home care	40 (150)	33 (31)	38 (17)	29 (14)
Day care	29 (108)	34 (32)	36 (16)	33 (16)
Sheltered employment	<1 (2)	1 (1)	0	2 (1)
Meals on wheels	1 (5)	0	0	0
Carer support services	17 (65)	18 (17)	20 (9)	16 (8)
Care home (with nursing)	<1 (2)	0	0	0
Care home (personal care only)	2 (9)	1	2 (1)	0
Breaks	14 (53)	26 (24)***	22 (10)	29 (14)
Equipment	11 (42)	6 (6)	7 (3)	6 (3)
Childcare	2 (6)	4 (4)	7 (3)	2 (1)
Total social service expenditure p.a.	£9,920 Range £200 - £72,600	£10,530 Range £200 - £45,900	£10,400 Range £200 - £27,100	£10,650 Range £930 - £45,920

Significance Levels: *** $p < 0.001$.

2.5 Conclusions

- This study was designed to build on the main IBSEN evaluation, at the heart of which was a randomised controlled trial design. This study drew on data obtained in the course of the main IBSEN evaluation and also collected new data from a sample of carers, carer leads and IB leads in the pilot authorities.

- Randomisation into the IB and comparison groups in this study was based on the initial random allocation for the main IBSEN evaluation. Randomisation information was available for 129 carers who participated in the structured outcome interview; 60 carers were assisting service users in the IB group and 69 in the comparison group.
- Information was also available for an additional 24 carers who participated in the semi-structured interviews (22 carers assisting service users in the IB group and two who had originally been randomised to the comparison group but where the service user was in receipt of an IB by the time of the carer study interview).
- By design, the majority of carers were caring for people with learning disabilities or older people. There was some evidence that the service users that they cared for were more dependent and that they were more likely to have had short breaks than those service users in the main IBSEN evaluation where carers had been identified. Other than this, the sample appeared representative of carers in the main evaluation.
- There were no significant differences between the circumstances of the carers in the IB and comparison groups in terms of demographic characteristics or circumstances; the service user’s ability to perform activities of daily living; and the service user’s use of services prior to allocation to the IB or comparison group. This gives us some confidence in comparing costs and outcomes between the two groups.

Chapter 3 Individual Budgets and Carers: Experiences of Implementation

3.1 Introduction and context

This chapter reports how the IB pilot sites took into account policy and practice issues relating to carers in their planning and implementation of IBs. It draws on data obtained through face-to-face interviews with IB project leads and senior managers (conducted during the main IBSEN evaluation); and telephone interviews with carers' lead officers in the pilot sites conducted as part of this linked add-on study. Topics covered in both sets of interviews include the involvement of carers' lead officers in the design and development of IBs; the involvement of carers' organisations in the implementation process; how carers were accounted for in the IB assessment and RAS processes; the types of IBs awarded; carers' involvement in support planning with potential IB holders; the impact of IBs on budgets, assessments, training and outcomes for carers; the perceived knowledge, training and monitoring of care managers' responses to carers as part of the IB process; and views on the payment of carers from an IB. As well as examining the integration of personalisation policies and practices with those for carers, the chapter provides important contextual information within which the outcome data, reported in Chapters 4 to 6, can be understood.

3.1.1 Carers and earlier personalisation initiatives

As background, carers' lead officers were asked about the implications for carers of earlier personalisation initiatives prior to the implementation of IBs. Interviewees considered that carers were not likely to have been a focus for, or benefited from, *In Control* schemes (see Chapter 1). For example, one interviewee believed that in their local authority, even though the *In Control* RAS might have included funding to support carers, nonetheless the *In Control* assessment questionnaire was focused on the service user and did not explicitly or transparently address the needs of carers.

In contrast, carers' leads officers were more positive about the potential of direct payments to accommodate carers' needs. Access routes to direct payments varied: in one or two local authorities carers' needs were identified through the service user's assessment and were then reflected in the latter's cash payment; in other sites carers themselves were allocated a direct payment which then counted as a carer's direct service. The latter could either be in the form of a one-off payment, for example for equipment or driving lessons; or as a regular payment, for example to be used for regular relaxation sessions. However, carers' leads raised a number of concerns that could affect offers and/or uptake of direct payments. These included the approach of social services teams towards carers; the extent to which practitioners promoted direct payments; and carers who preferred traditional services and were disinclined to encourage service users to engage in new activities or opportunities.

Carers' leads identified a range of priorities for carers in their respective local authorities before the introduction of IBs. The most common priorities related to improving access to, and increasing the number of, carer assessments. Developing innovative, flexible services for carers, providing lower level support and/or information at an early stage, developing breaks services for carers and developing a (local) carers strategy were also cited.

3.2 Carers' lead officer involvement in implementing Individual Budgets

3.2.1 Carers' lead officers' perspectives

Carers' lead officers were asked about their contribution to the initial planning and implementation of individual budgets. Their levels of involvement varied across the pilot sites, but very few carers' leads played an active role in the early stages. This mattered less, however, in the few local authorities where other senior adult social care officers and/or IB pilot team themselves had previous knowledge and experience of carers' issues which could inform the IB pilot.

Exceptionally, the IB project lead in one site approached the carers' lead officer when the local authority first bid to be a pilot site and as a result carers were included as one of the target groups for IBs. This was the only site that had developed a separate RAS for carers needs. The carers' lead in this site had since been involved continually with the IB pilot team to give the professional lead on the requirements for carers:

> I was very concerned that if we were using a self-assessment or a supported self-assessment that we were able to incorporate all the components of a carer's assessment.
> (Carers' lead 06)

In contrast, the majority of carers' leads had limited, if any, input to planning the IB pilot. This meant, for example, that some sites had only limited prompts or questions about care-giving in the self-assessment process (see below):

> I think they're, at the moment, concentrating mainly on service users, and trying to establish Individual Budgets with service users ... but carers hasn't been highlighted at the moment. I am not involved in it. ... I had approached them and said it would be important for me to be part of it, as

> a strategic and operational issue, so that carers then will from the start ... but that's the way it is at the moment. ... I don't think carers was a priority.
> (Carers' lead 04)

A number of carers' leads explained how they had become involved later in the implementation process, for example by attending presentations from the IB project teams to see how IBs might impact on carers or by organising workshops or awareness-raising events with carers to promote IBs and listen to carers' views on IBs. In these ways, carers' leads tried to ensure that carers' perspectives were not excluded from the IB implementation process. It was via a workshop on IBs for carers that one carers' lead discovered that information leaflets and assessment forms were only available in English. This prompted the interviewee to ask the IB team for the necessary documentation to be translated into appropriate languages. Some carers' leads thought it would have been helpful to have been involved earlier, to help get carers' issues on the agenda of the IB team sooner.

In a very small number of pilot sites, carers' lead officers' involvement increased over time, partly because IB teams had begun to ask their views, for example, on the assessment and resource allocation documentation. This growing involvement seemed to reflect increasing recognition of the issues involved, combined with carers' leads themselves adopting a more proactive approach so that the IB pilots began to adopt a wider perspective on carers within the service user's self-assessment and RAS.

There could be tensions between carers' leads and the IB Team. For example, one carers' lead felt sidelined for making clear her/his concerns about how carers' issues were addressed in the IB assessment and RAS:

> I've been more or less, to be honest, completely left out of the project altogether. ... There was a great deal of enthusiasm and pride that we'd been selected as a pilot authority and we were getting money to do it and people were being appointed and I think that, you know, that I was considered not to be playing the game and therefore was more or less just left out of the loop really.
> (Carers' lead 09)

3.2.2 IB lead officers' perspectives

During the second round of interviews with IB lead officers and senior managers in November 2007, they were asked how far they had worked with carers' lead officers during the design and development of IBs. IB leads in five sites reported that carers' leads had been involved in certain aspects of design or development, including:

- Developing carers' self-assessment questionnaires (two sites).

- Running events or workshops aimed at helping carers or carers groups understand the potential implications of Individual Budgets for carers and service users (one site).
- Attending events (for example, national workshops or conferences) on IBs (one site).
- Commenting on proposals or suggestions made by the IB team (one site).
- Representing carers' interests on the IB project board (one site).
- Contributing to the design of the service user self-assessment questionnaire and RAS (one site).
- Liason with carers' leads in other pilot sites (one site).
- Working to involve voluntary and community sector organisations in support planning (one site).

A further three sites reported that carers' leads had been involved in IB-related issues that were separate from or additional to the main IB pilot implementation. These included developing a carers' RAS and developing an IB model for carer-specific services to be funded from the Carers Grant.

In other sites, IB leads reported that carers' leads had had no involvement with Individual Budgets: one IB lead reported keeping the carers' lead officer informed about developments, while four other IB leads reported that they had had no contact whatsoever with the carers' lead. In two of the latter instances this was justified on the grounds that the IB team had spent so much time and effort developing and implementing IBs for service users that there was no time to consider carers' issues and in any case it was expected that IBs would have no impact on carers:

> I think because there was nothing in there that was any different, you know, carers are still entitled to an assessment, so I don't think there was actually any impact on the Carers' Team. I don't think there's been particularly any impact on carers, apart from, maybe, about outcomes, which have been better for carers, so I don't think there was probably any great need to, to be fair, because we weren't attaching any money for carers.
> (IB project lead 07)

However, this perspective overlooks the fact the IB RAS could add 'points' to a service user's allocation on the basis of the needs of their carer(s) or, more typically, could deduct 'points' on the basis that informal carers currently provided some of the support needed (see below). This was illustrated by a reported disagreement between the carers' lead and care managers:

> … when care managers do an assessment they say ‘Oh, so your husband’s at home?’, informal carer … but the carers’ lead says ‘Oh, you should discount him, you know, pretend he’s not there’.
> (IB project lead 03)

Two IB leads also noted difficulties in knowing which carers’ lead officer to involve, as there were different carers’ leads for different user groups (for example, adult social care, children and young people, substance misusers) and/or additional carers’ leads within the PCT and in service commissioning divisions. In other sites, IB leads reported that a carers’ lead officer had not been in post during the implementation of IBs; the IB lead in one site argued that all staff had an interest in carers’ issues and thus there was no need to involve a dedicated carers’ lead.

Four IB leads reported that work that had been undertaken in relation to carers had been conducted by a member of the IB team, often the IB lead themselves; while one IB lead reported that the carers’ lead sat on the IB project advisory board.

3.3 Involvement of carers’ organisations in implementing IBs

Carers’ leads from the majority of pilot sites reported that local carers’ organisations were involved in the IB implementation. The levels of input varied from direct, by virtue of being a member of an IB Project Board (two IB leads reported that carers or representatives of carer organisations were members of the IB steering group/advisory board); to indirect via Partnership Boards, a local multi-agency carers’ strategy group or wider networking forums. The extent of knowledge and understanding of some carers’ organisations about IBs surprised carer lead officers.

> It wasn’t just a scarce bit of knowledge, they knew an awful lot about the RAS, so you could tell they had known about it from the start and had really been able to inform the processes, which has been very helpful.
> (Carers’ lead 01)

However, there was potential for complex relationships to develop. In one pilot site, for instance, carers’ organisations were also on the local authority’s list of service providers and could provide support with using IBs and direct payments. This allowed them to generate an income whilst at the same time helping the local authority to sustain service users and carers in a cost-effective way.

The carers’ lead in a different pilot site drew attention to the fact that some carer organisations were very anxious about the sustainability of their own funding, as service users might in future opt out of the carer organisation services that the local authority currently funded (luncheon clubs, for example).

3.4 Carers, user (self-) assessments for IBs and the RAS

3.4.1 Service user assessments

With the exception of the one IB pilot site that had developed a separate carer RAS, the interviews with carers' leads and IB leads revealed that sites had adopted different approaches to the treatment of carers' needs within the main service user (self-) assessment process and RAS. A handful of sites had included a set of questions in the user's self-assessment aimed at determining what support carers provided; whether or not they were willing and able to continue providing that level of support; and if they were in need of support themselves. A smaller number of sites had included questions in the main service user self-assessment form that specifically addressed carers' wishes in relation to employment, training/education and leisure activities, as required under the Carers (Equal Opportunities) Act 2004. In some instances, this had been a gradual process. For example, according to one carers' lead the first version of the RAS did not include any reference to carers. While the second version did include carers' needs, this was predominantly to identify potential respite care needs. The third version took a much more rounded view of carers' needs and reflected the 2004 legislation by addressing participation in paid work, training, education and leisure activities The carers' lead considered that her/his increasing input was instrumental in developing this broader carer perspective within the service users' RAS.

Sites also had different approaches to the links between service user (self-) assessments for IBs and carers' assessments. These included running the two procedures in parallel and not allowing a case to be closed without a satisfactory explanation of why a carer's assessment had not taken place. The carers' lead from one site described two examples of rejecting support plans (for young men with learning disabilities) because they did not consider their carers' needs for a break. As a result of the carers' lead's intervention, each IB user now saved £50 per week to pay for short respite stays to give their carer a break.

Carers' leads raised a range of concerns about IB service user assessments:

- Self-assessment forms not including 'trigger points' to prompt service users and/or social services practitioners to think about carers' needs. This risked the latter being overlooked, and/or, in the words of one interviewee, carers' support needs somehow 'popping out of the resource allocation machine'.
- Carers' support being treated as an additional service for the service user, rather than services aimed specifically at the carer.
- Not enough emphasis in the IB process to the 1990 NHS and Community Care Act and Fair Access to Care criteria, with the risk that councils might begin

providing support for carers who, strictly speaking, did not meet local eligibility criteria, with subsequent large financial implications for the council.

- Carers' needs and rights to help in relation to education, training, leisure and work being much more difficult to address within the service user RAS compared with carer breaks.

To address these concerns, a number of carers' lead officers considered there was now a need to develop a separate RAS for carers, following the precedent of one IB pilot site. This would help to determine a carer's willingness to continue care-giving and any associated needs; and ensure that appropriate support was in place. Some pilot sites had already made a start on this, with carers' lead officers helping to develop self-assessment forms for carers. A key concern of these carers' lead officers was to ensure that the impact of care-giving on a carer, and carers' commitments and aspirations relating to employment or training, for example, were made far more explicit than they currently were within a carer section of the service user RAS. To that end, carers' leads indicated they were keen to build the key elements of carers' assessments into a separate carer RAS.

3.4.2 Accounting for carers in the service user RAS

In the majority of IB pilot sites, the main way that carers' needs were addressed was through the service user RAS. Typically service user (self-) assessment questionnaires sought information about the extent of existing informal care; any additional sources of support required by the service user; and whether existing informal carers were able and willing to continue undertaking the same – or more – care. Responses to these questions affected the level of the service user's IB as determined by the RAS. In principle, the presence of an informal carer could effectively 'deduct' points from a service user's RAS on the grounds that resources were not needed to fund external support arrangements that informal carers were already undertaking. Conversely, if informal carers were unable or unwilling to continue providing this level of care (or more), or if unmet carer needs were identified, points could be added to the service user's RAS to enable more formal support to be bought for the service user and/or the carer.

IB lead officers reported different views on such adjustments. For some, it was perfectly acceptable that, for example, a co-resident family member who was cooking their own meal or doing their own laundry could reasonably be expected to cook or wash for the service user at the same time. Others felt that this could generate perverse incentives for service users not to live with their families and effectively penalise informal carers/families for all the care and support they had provided over many years. However there was a consensus among IB leads that their local authority's adult social care budget could not stretch to pay all informal carers for the care that they provide; nor could it afford not to discount certain IB packages where informal carers were able to continue care-giving.

3.5 IBs awarded to carers

In the majority of pilot sites, IBs were awarded to service users only. Carers' leads in some sites thought that a very small number of joint user-carer IBs had been awarded. Interviewees also referred to instances where there was an allocation for respite care within a service user's IB and one interviewee suggested that could be viewed as a *de facto* joint user-carer IB. However, including respite care for a carer in a service user's IB could be complicated, as it was difficult to work out which party the payment should go to:

> Having said that, for this individual it was important that respite could not be provided for the carer without an assessment of the service user, which meant in turn that the money would have to be in the name of the service user even if it was managed by the carer.
> (Carers' lead 09)

Only one pilot site awarded IBs to carers in their own right through a completely separate carer RAS (although because respite care was seen as a provision to the service user that also benefited the carer, respite care was funded through the service user's RAS). This site resourced its carer IB pilot project from its Carers Grant budget. About 45 carers of older people had received one-off payments, ranging from £100 to £1,000. At the time of the telephone interview for the present study a second pilot had just started, to award IBs to carers of people with learning disabilities; the new maximum IB was now £2,200.

In contrast, some sites offered carers a one-off payment (not necessarily linked to the service user's IB), funded from the Carers Grant. While this did not involve a carer RAS and was not labelled an IB, one or two carer lead officers suggested that it could be considered a form of IB (or direct payment), even though one-off payments to carers preceded the piloting of IBs.

3.6 Carers and support planning

With just two exceptions, carers' leads confirmed that carers were strongly encouraged to become involved in developing support plans for the service user. Carers were perceived to be the people who knew the potential IB holder best: 'Carers will always be integral to what people are thinking and what's involved. I mean, you couldn't – let's be realistic about it, you couldn't exclude the carers from the IBs'. However, in one pilot site where carers were asked or consulted but not fully involved with the IB implementation process, the resulting IBs were considered by the carer lead officer to be not fit for purpose. The carer lead reported having ‘to fight tooth and nail’ to change the support planning process to encourage care managers to make every effort to involve carers in a ‘family meeting’ as part of the (self-) assessment and support planning process. It was acknowledged that developing support plans could create extra work for carers. Indeed, one carers’ lead understood that a carer had become so involved that she actually gave up paid employment in order to have sufficient time to plan and manage the service user’s IB.

In contrast, several IB leads expressed relatively strong concerns about the involvement of carers in support planning for and with the service user. They feared that carers’ choices could over-ride choices made by the service user and they questioned whether informal carers (typically family members) were actually best placed to promote the independence of an older or disabled person. Some IB leads suggested that independent support planners (for example, from voluntary organisations) and/or advocates should be involved.

Indeed, in many sites, in-house support facilities and/or external agencies were being commissioned to take on this role. In some instances, the latter were the same organisations who helped direct payments users. In other cases, they were voluntary organisations such as Age Concern, Anchor, Crossroads Caring for Carers and/or other local carers organisations. Carers’ leads held differing views about who was best placed to support carers; as one interviewee said ‘It depends really on what the person wants, and what their families want’. One or two carers’ leads questioned the benefits of external support planning organisations, especially as they could be expensive to commission. One interviewee reported anecdotal evidence that some people who had used external support planning agencies said that with hindsight they would have preferred to maintain continuity with the staff they had been working with during the assessment process.

Several carers’ leads reported that helping carers with support planning was not part of their role, but was the care manager’s responsibility. Similarly, IB leads did not report any expectation that carers’ leads would or should be involved with support planning.

3.7 The reported impact of IBs on carers

3.7.1 The impact of IBs on local authority carers’ services budgets

At the time of the telephone interviews, most carers’ leads were confident that the introduction of IBs had not affected their local authority’s budget for carers’ services.

Just one interviewee reported having had to take action to ‘ring fence’ the Carers Grant budget:

> As soon as ... questions about carers getting individual budgets were raised, all of the financial fingers were pointing at my budgets ... and I basically had to clear up the information by going to the Department of Health and getting the guidance notes ... and at long last it was agreed that, yes, the budget will come from the allocated monies rather than the Carers Grant ... I won the battle by making loads of enemies!
> (Carers’ lead 04)

However, a number of IB leads reported that since services and support for carers often came in the form of support or services for the service user, then it was possible that in the longer-term at least a portion of the Carers Grant could become one source of funding to contribute to a service user’s IB. Moreover a few IB lead officers commented that, should IBs for carers be developed at a later date, the Carers Grant would be one of the key sources of funding for carers’ IBs.

3.7.2 The impact of IBs on carers’ assessments

In general, carers’ leads did not think that IBs had had any impact on the number of carers’ assessments undertaken. One interviewee commented that this would have been surprising, given that it was a pilot scheme, with limited numbers, operating in a few teams rather than across the local authority as a whole. However, this interviewee was aware that if IBs were rolled out across the authority, then it would be important to monitor the number of carers’ assessments carried out.

As far as the processes of undertaking carers’ assessments were concerned, the interviews with carers’ leads suggested that the introduction of IBs had prompted some changes. These included: triggering a self-assessment process for carers, in addition to the standard face-to-face carer’s assessment; and increased attention to the details of carers’ roles within the service user’s support plan. It was also suggested that there was potential for greater breadth in capturing carers’ care-giving activities and consequent needs for support, but to date there was no evidence that this change had actually happened.

3.7.3 The impact of IBs on services and outcomes for carers

Carers’ leads were asked about the impact of IBs on services and outcomes for carers. Impacts might be expected to vary because pilot sites had adopted different approaches to the capture and use of information about carers within the service user’s (self-) assessment and RAS. Not surprisingly, in the site that had developed a carer RAS and allocated carers IBs in their own right, the carer lead officer took the view that personalisation and IBs offered carers more flexibility, choice and control than was the case with direct payments. In this site, IBs had been piloted by the carers team, which did nothing apart from work with carers and so had specialist insights into carers' needs and attaining good outcomes for carers. Carers in this site were reported to use their IBs to buy practical help such as gardening, decorating and housework, or to purchase household goods such as a tumble dryers or bedding. However, one concern that had arisen was that some carers were not using the money as specified on agreed planning forms. This issue of controlling for these sorts of situations was currently under discussion.

The general feeling from carers' leads was that in principle carers should be able to realise better outcomes from IBs because of greater choice, increased flexibility, less pressure and greater peace of mind. Yet the majority of interviewees acknowledged that they did not have enough evidence to be confident that carers were achieving better outcomes. Nevertheless, a few examples were given of how carers could gain from the introduction of IBs:

- At the level of individual IB holders and carers, there were instances of innovative support plans. In one site a terminally ill woman with a husband and two young children had used an IB to buy a funeral bond rather than purchase respite care. This meant that the whole family could be together for the mother's last few weeks of life, without financial anxieties.
- Indirectly related to IBs, some sites were introducing new services from which all carers could benefit. For example, one site was in the process of commissioning a new type of carer break scheme, where the carer and the service user could go on trips together with the aid of a support worker. Another site had developed a one-off payment panel to which carers could apply for funding for a break; it was hoped to extend the scheme to other types of services.

Carers' leads were aware of the tensions that could arise in relation to the competing interests of carers and service users. Reflecting on why it was hard to know if carers were achieving better outcomes through IBs, one interviewee was of the opinion that:

> I think probably in some cases they do, because they're getting more of a bespoke service to what [the service user] needs, but I suppose that that's really hard to say because if they have a service that, you know, that maybe they had four days in a day centre and now they get two days going out, and from the point of view of the carer, they might have quite liked the four days where they had the break. So, you know, it's difficult to say.
> (Carers' lead 03)

Carers' leads also raised questions about the limitations of traditional commissioning arrangements and market capacity in meeting carers' needs. The advantages of block contracts for sitting services, for instance, were now being questioned because of the constraints on commissioning new, more individualised services: ‘The market just isn’t out there at the moment, for everybody to just go out and purchase, kind of, whatever care that they want as and when they need it’. Carers’ leads also noted that it was not just IBs that could generate good outcomes for carers; a range of flexible, individualised service options was also important, whether or not these were funded through IBs:

> Some people would really, really benefit from IBs 100 per cent, they’d benefit 100 per cent but some people wouldn’t want an IB and would want to have the conventional services.
> (Carers’ lead 05)

Another carers’ lead insisted that ‘Carers don’t have to have IBs to think they’ve had a good outcome in terms of carers’ services’ and that ‘Individual Budgets is just one part of a large whole really’. Some years ago, this particular pilot site had adopted outcomes-focused practice, an approach that the carers’ lead believed was a key factor in carers reporting good outcomes prior to the introduction of IBs. However, the control that came with IBs was acknowledged to be important, whether or not the IB was held as a direct payment or a ‘virtual budget’:

> If you can control the money, whether you buy a traditional service or whether you do something, you know, a bit more, off the wall with it, you still influence how that’s delivered, because you can control that and ultimately, you can take your money away.
> (Carers’ lead 08)

3.8 Front-line practitioners, IBs and carers

3.8.1 Care manager awareness of carers’ needs, information and training

The interviews with carers’ leads suggested that the extent to which care management teams in the pilot sites were aware of carers and conducted carers’ assessments as part of the IB process varied. These variations and inconsistencies partly reflected historical patterns of how ‘carer-aware’ team managers and individual workers were, and partly variations between staff working with specific user groups. For instance, practitioners working with people with mental health problems were reported to be less carer-focused because of concerns about confidentiality issues between the person with mental health problems and a carer.

Whilst interviewees were under no illusions about the priorities of some of their colleagues, at the same time they were sympathetic to the demands made upon them:

> It is a bit of a cultural shift, you know. I think there’s still the belief that they’re there for the service user and actually, saying that they’ve got to do carers’ assessments doubles their workload, whereas in fact to be fair to care managers, a lot of them are under a great deal of pressure for so much. All of these, like doing Individual Budgets has had an impact on their workload, because where they’ve gone once, they might have to go a couple of times to complete the forms that they need to complete.
> (Carers’ lead 03)

Carers’ lead officers considered that teams that worked well with carers would see the connection between the IB (self-) assessment and support planning and a carer’s assessment. Conversely, teams or individual practitioners who were not strong on carers’ issues were more likely to promote a service user’s focus to the exclusion of carers, unless they were also encouraged to undertake a separate carer assessment. Moreover, even when practitioners had a reasonable grasp of carers’ issues, they might lack knowledge about available support and services.

Carers’ leads identified a range of ways in which awareness-raising about carers’ issues in general, and in relation to IBs in particular, had been developed amongst social services colleagues:

- Training through team meetings, drama groups, DVDs, people’s stories (either on a DVD or told by carers in person), and sharing experiences at presentation events.
- Information packs containing material about available services, relevant legislation, and information about other agencies.
- Identifying a ‘carer’s champion’ in each team with whom the carers’ lead met on a regular basis to facilitate information flows.

3.8.2 Monitoring how practitioners deal with carers in the IB process

Carers’ leads were asked what, if any, monitoring procedures were in place to check how practitioners dealt with carers’ issues within the IB process. Responses were mixed; in some sites, carers’ leads were not aware of any procedures and at least one interviewee queried whether it was too soon for this sort of auditing. In contrast, one carers’ lead explained that in their local authority monitoring took place at two different levels; individual supervision with workers on a monthly basis and monitoring outcomes at the review stage.

A ‘good practice’ example cited by another carers’ lead was for the carers’ team to sit with team managers and senior practitioners every week and go through every new (self-) assessment – a system which, according to the interviewee, ‘will only stop ... when we think it’s of a particular standard’. Because further changes were planned in this particular site relating to the introduction of a carer RAS, the carers' lead envisaged monitoring 'going on, sadly, for at least another year'.

3.9 Paying carers from an IB

As noted in Chapter 1, under current policy and practice guidance for direct payments, unless there are exceptional circumstances service users in receipt of direct payments are not allowed to employ co-resident close family members as personal assistants. IB sites were encouraged to be more flexible about how IBs were used, but the interviews with carer leads and IB lead officers revealed considerable concern and confusion.

3.9.1 Perspectives of carers' leads

The interviews with carers' leads revealed mixed understanding about whether carers could be paid through an IB, with a handful of interviewees acknowledging that they did not know what the policy was in their own local authority. One carers' lead stated that as the IB pilot was following the direct payment guidelines, it was not normally possible for IB holders to pay carers living in the same house. In contrast, carers' leads in four other pilot sites said that co-resident carers could be paid for (part or all of) their care-giving activities from an IB. This was seen as helpful for a range of different reasons; in particular IB users from black and minority ethnic communities could employ relatives who would provide culturally appropriate care.

3.9.2 Perspectives of IB leads

IB leads affirmed that they were constrained by the direct payment guidance; however, interpretation of the guidance again differed between sites. In seven sites, IB leads reported strict adherence to the guidance so that co-resident carers could only be paid from an IB if there was absolutely no feasible alternative, for example if the service user and carer lived in a remote rural area where there was nobody else available to provide care and support.

In contrast, in six sites IB leads interpreted the regulations more flexibly and allowed co-resident carers to be paid if, for example, they were deemed to be the most suitable person to undertake the caring role or if they had already terminated paid employment in order to care for the IB user. One of these sites reported having adopted this less rigid interpretation in order to ensure a sufficient supply of potential personal assistants. Another IB lead officer suggested that adult social care policies needed to face up to the reality that, given a choice, many people would prefer to pay a co-resident family member; prohibiting this option effectively deterred service users from taking up either direct payments or IBs. Two IB leads argued that IBs should be less prescriptive and should put the rhetoric of choice and control into practice to the extent of allowing the payment of co-resident relatives, where this was preferred.

The majority of IB leads argued that any and all payments to informal carers would need to be properly regulated: contracts of employment would be necessary; and payroll records, tax and national insurance contributions would be required. IB leads argued that as ‘protectors of the public purse’ they were obliged to ensure that all monies paid out from IBs were fully accountable:

> I think there’s an assumption abroad that because the principle of IBs is that it’s freeing people up to exercise more control, that that choice and control extends to not observing the law and we have to scotch that one from time to time. I mean, the fact of the matter is, whether you call your money an IB or whatever, if you’re going to employ someone there are employment laws to observe and insurance laws to observe and we can’t dispense with those. The person can’t dispense with those simply because the Council has decided to call that lump of money an Individual Budget.
> (IB project lead 10)

However, six IB lead officers argued that, for certain types or amounts of caring work, such bureaucracy was unnecessary, confusing and time-consuming and they therefore allowed small cash-in-hand payments to be made to co-resident carers. This typically involved, for example, paying for cleaning or for a relative to undertake a small number of hours of care. In such cases IB leads argued that contracts of employment, national insurance contributions or tax payments would not normally be expected from the employer so why should this be different for an older or disabled person? Indeed, the ability to make some cash-in-hand payments was argued by one IB lead to symbolise the freedom and choice at the heart of IBs:

> I think obviously local authorities would, if they had the opportunity, would like to back off when it comes to monitoring those kind of detailed arrangements because it’s against the spirit, feels against the spirit, and it’s intensive to be able to, to want to do that. And then, if you find out that someone’s done it, what are you going to do? Are you going to pull the money from them? It undermines the kind of, their relationship a bit. … There are tensions there between what’s illegal, legal, what’s protection and there’s safety and those sort of things, and what’s freedom of choice. And those agendas will continue to be tensions that we tackle really.
> (IB project lead 11)

As a kind of half-way measure, one IB lead reported that informal carers could be paid small sums cash-in-hand so long as the IB holder kept a record of dates and payment amounts so that minimal accountability was retained.

A few IB leads expressed concern that relatively small payments to informal carers could push them over the threshold for entitlement to particular benefits and suggested instead that informal carers could be paid in kind, for example by being taken out for meals or having their car tax or a weekend break paid for by the IB holder.

Irrespective of their position on cash-in-hand payments, IB leads tended to agree that support and advice about employment responsibilities was necessary for all IB holders who chose to employ either a formal or informal carer, as such IB holders could be taken to an Employment Tribunal if the employment relationship was not handled within legal regulations.

3.9.3 Examples of carers being paid through an IB

Carers’ leads identified a number of carers who were paid through the service user’s IB. These included carers providing regular personal care, company or practical help such as cooking or shopping. Within South Asian communities, paid informal carers might take the IB holder to temple or read to them.

One example was that of a terminally ill IB holder in a large extended family from a minority ethnic community. A nephew living in the family home was keen to take on a full-time caring role and it was agreed that he could be paid from the IB. In this IB pilot site, carers wishing to be paid in this way were advised to register with a home care provider agency to make it easier to manage the associated administrative and payroll paperwork. Paid carers could also take advantage of health and safety training provided in-house by the local authority. Informal carers employed through an IB were expected to undergo Criminal Records Bureau checks in exactly the same way as unrelated carers. They were also required to have a national insurance number and a contractual agreement stating how many hours they were providing services for.

3.9.4 Perceived advantages and disadvantages of employing carers through an IB

Both carers’ and IB lead officers had strong opinions about the perceived advantages and disadvantages of employing co-resident close relatives through an IB. A common theme that emerged across the whole series of interviews related to ‘duties’ and ‘obligations’ to care; however, there were radically different views on these. At one end of the spectrum, one carers’ lead said:

> Obvious advantages are that the person is going to feel that they’re going to get paid so they’re valued and they’re also going to feel that well, I don’t

> need to. Maybe that's what they like to do, they want to do ... up to now, it's sort of all duty, isn't it? All want. This is just a little bit of something special for them.
> (Carers' lead 02)

At the other end of the spectrum, another carers' lead questioned the impact that being paid for care-giving activities might have on carers:

> Once you start employing, and certainly resident members of the family, what is the point in anybody being a carer ... if the person next door who's a carer is getting paid by the hour? ... I mean, there's no legal obligation to care, but people do it under a sense of duty, but I think that would start to break down if there was widespread paying of family members to care. Why would – you'd be a fool, wouldn't you? I mean, you know, people give up jobs, severely disadvantage themselves financially, you know, in order to care for loved ones.
> (Carers' lead 09)

Allowing carers to be paid through IBs was giving rise to difficult situations. One example given by a carers' lead was that of a carer who had requested payment of £35 per hour to look after a relative. This was because he was a qualified social worker and argued that he would receive that pay rate if he was working for a social work agency.

Table 3.1 summarises what carers' leads and IB leads said about the potential advantages and disadvantages of paying informal carers through an IB (these are in no particular order).

Table 3.1 Perceived advantages and disadvantages of paying informal carers through IBs

Advantages	*Disadvantages*
Choice for IB holder: care is delivered by an individual chosen by the IB holder who they can trust and who knows them well; this increases the potential for person-centred care. The service user can choose what support they feel they need rather than having to accept what is available from the local authority.	**Fraud and exploitation:** there is potential for fraud, misuse of funds and exploitation. A carer may report they are meeting the service user's needs but in reality are not; the main carer might be getting paid but someone else was providing the care instead. Careful monitoring is needed as the local authority is accountable for public monies. One IB lead expressed concern that an IB holder needing round-the-clock care could end up paying their informal carer simply for living in the same house 24/7: '… otherwise you know it's not really about paid care, it's about … just by being present and being in the household they're triggering, you know, payment equivalent of 160 hours a week which is nonsense isn't it really?' (IB project lead 04)

Advantages	*Disadvantages*
Recognition for carers: carers who are paid are more likely to feel valued, that they are caring by choice rather than obligation. Carers' rights and needs are recognised (although it might be difficult for individuals who do not see themselves as carers to make this cultural shift).	**Equity and fairness**: many individuals provide care for little if any monetary gain; others might start to demand full financial rewards. Over time, such circumstances could undermine voluntary care-giving, as individuals who see others being paid to care become reluctant to give up work to care on an unpaid basis.
Financial rewards for carers: carers' income is increased, and they have some security. Carers who give up paid work to care can still receive some income.	**Increased financial strain on LA**: carers who previously provided care on a voluntary basis may in future only do so for financial reward which would cause great financial strain on local authorities.
Access to training: carers may have greater access to training opportunities and other activities that might benefit them in the caring role.	**Social security benefits**: carers in receipt of social security benefits such as Carer's Allowance risk losing their entitlement to benefits so could be financially worse off.
Ownership: employing carers through IBs can give ownership to carers and disabled/ older people.	**Relationships**: being paid for care-giving might change the relationship between the carer and the person they look after by "turning a family relationship into an employment relationship". There is potential for breakdown in the caring relationship if there are disagreements between the two parties.
Improvements in care agencies: the potential to employ informal carers poses a threat to care agencies, which could lose business if IB holders choose to hire informal carers instead. However this threat could also push care agencies to improve the service that they offer, thus potentially raising standards and flexibility for all service users.	**Maintaining boundaries**: boundaries can become blurred over the extent and intensity of carers' care-giving activities if they are paid, and they may feel obliged to do things they do not wish to do. It could be difficult to distinguish between the activities carers undertake within their paid care work, and additional ones they might do as goodwill.
	LA support for carers: paid carers would no longer fit the LA definition of a carer, which raises questions about whether they could still be supported with a carer's assessment, service or one-off payment. LAs would have to decide whether a 'paid' informal carer is different from, or the same as, a paid care worker.
	Bad publicity: Local press could (mis)represent a case.

Advantages	*Disadvantages*
	Sustainability: the care-giving relationship might not be any more sustainable if the carer was paid for some hours of care but not all. The carer would still have all the caring responsibilities and might prefer to have a break rather than to be paid. Whose responsibility is it if a paid carer's health broke down?
	Safeguarding and protection: there was some uncertainty about whether carers could or should undergo Criminal Records Bureau (CRB) checks. Several IB leads expressed concern that informal carers are highly unlikely to have been through a CRB check, leaving the IB user at risk of financial, physical or mental abuse or exploitation. An informal carer may not be the most appropriate person to promote the independence of the IB user, presenting further risk for the IB user. One IB lead argued that this risk would be minimised if care managers could check service users' capacity to identify a suitable carer, take decisions to enhance their own independence and recognise abuse or exploitation; check for any previous history of protection of vulnerable adults (POVA) issues; and have the power and authority to disallow IB holders from employing (certain) informal carers.
	Health and safety issues: if carers have less time off (for example to earn more money from paid caring), then they may not have adequate breaks from care-giving, putting their health at risk. Health problems stand to be exacerbated if carers do not have training in, for example, lifting and handling.
	Employment agreements: it could be difficult to have stringent agreements between the carer and the person they look after, which could cause difficulties in the long term.
	Impact on care agencies and reduction in choice: existing care agencies could lose business if IB holders choose to employ informal carers. This could lead to the demise of some care agencies and hence a reduction in choice for other service users and carers.

3.10 Conclusions

- Carers' leads had limited involvement in the planning and implementation of IBs, but in some sites they did have have gradually more involvement over time. This enabled them to integrate carers' issues better into the IB assessment procedures and the service user's RAS.

- Carers’ leads thought the focus of the IB team was on service users rather than carers. IB leads concurred with this; the pressures of implementing IBs for IBs for service users had left little time to fully consider carers’ issues within the IB process.
- There was a danger that carers’ needs for support could be overlooked in the (self-) assessment for service users.
- IB pilot sites varied in the extent to which the service user RAS accounted for the needs of the carer. In some sites ‘points’ could be deducted from the service user RAS if an informal carer was currently providing care and was willing to continue doing so; in other sites ‘points’ could be added if an assessment indicated unmet needs on the part of the carer.
- Carers’ leads and IB leads felt at this early stage there was too little evidence for them to comment with any authority on the impact of IBs on carers’ assessments, services and outcomes.
- Carers’ leads, and to a lesser extent IB leads[7], were sympathetic to the additional demands on care managers arising from the implementation of IBs.
- Whilst carers’ leads and IB leads could see many significant advantages in paying carers for their care-giving activities from IBs, they also expressed serious and numerous concerns about the potential disadvantages for carers.

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[7] See the report on the main evaluation of Individual Budgets (Glendinning *et al.*, 2008) for an in-depth examination of the impact of IBs on care managers and social workers.

Chapter 4 Carers' Receipt of Support and Services, Care-giving Activities and Costs

4.1 Introduction

A key question to be answered by the main IBSEN evaluation was whether IBs cost more or less than conventional arrangements, and how the costs compare across different user groups. The main IBSEN evaluation concluded that there were no significant differences between the costs of conventional service packages and IBs (Glendinning *et al*., 2008). However, this comparison only showed part of the picture. The analysis of patterns of expenditure on services showed that those service users who had a principal carer living in the same household received significantly lower levels of formal resources (Glendinning *et al*., 2008). We know that, where there is a co-resident carer, the majority of care is likely to be provided by that carer, so ideally the opportunity cost of this care should also be incorporated in any comparative measurement of the costs of support received by IB users and those using conventional services.

Moreover, IBs are likely to have an impact on informal carers' behaviour and we also need to understand this if we are to appreciate the full impact of IBs on resource use. It is possible that IBs will allow some IB holders to access alternative sources of support and reduce their reliance on informal carers. Alternatively, other people may use their IB to pay family members for at least some of the care they have previously provided on an unpaid basis. However, paying a carer from an IB could have a negative impact by encouraging carers to provide more care, with consequent damage to their health and knock-on cost implications.

In this chapter we draw together the evidence about the impact of IBs on carers' activities and use of resources, by comparing the IB and comparison groups. We start by outlining the methods of analysis and identifying the stage of the IB process reached by service users by the time of the carer interviews. We then estimate the costs of social care support for service users and carers in this sample, payments for carers, their receipt of benefits and use of health care services. We discuss the evidence of the impact of IBs on the activities and opportunity costs incurred by carers and consider the implications for estimating the total cost of care.

4.2 Methods

In order to explore the resource implications of IBs, we draw on information provided by carers in this study and on the costs estimated from the main IBSEN evaluation for our sample of carers. In the main IBSEN evaluation, the cost of IB support plans was based on the budget allocated through the RAS (see Chapter 1) for the IB group; in the comparison group, the cost of packages of care was derived from data on the level of use and the unit costs of the mainstream services they received. Information about services for carers (for example, training courses and carer group attendance), carer-related benefits and opportunity costs such as hours spent caring were all obtained from the structured interviews with carers. The semi-structured interviews with 24 carers also explored in depth their experiences of the IB process and of the support purchased with the IB.

4.3 Progress through IB process

The carer interviews took place some time after the main IBSEN evaluation interviews with service users, in some cases up to a year later. In the main evaluation, only 68 per cent of service users with an informal carer had their support plan agreed and only half of the sample had IB-funded support in place at the time of the six-month outcome interview. We would expect that the amount of time support has been in place would have an impact on responses, so it is important to understand the situation at the time of the carer interviews carried out for the present study.

Table 4.1 shows that, in the structured interview sample, a significantly higher proportion of service users had their support plan agreed by the time of the carer interview than by the time of the six month outcome interview in the main IBSEN evaluation. By the time of the structured interviews for this study, a higher proportion of service users were reported by carers to have support and services in place and to be receiving services paid for by the IB (58 per cent; n=33) compared with those in the main IBSEN sample with an informal carer (51 per cent; n=137). The relatively low proportion of carers who, even now, reported that the person they cared for was receiving services paid for by the IB 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.

Table 4.1 Stage of the IB process that service users had reached at the time of interviews for the main IBSEN evaluation and structured carer study interview

	IBSEN sample with informal carer		*Carer study sample*	
	Count	%	Count	%
Total randomised into IB group	289	100	60	100
IB-accepted group	269	93	57	95
Support plan agreed at time of service user interview[8]*	183	68	43	75
IB support and services in place at time of interview	137[9]	51	33[10]	58

Significance Level: * $p < 0.05$.

For those in the IB group who had said that new support arrangements were in place, Table 4.2 shows how long these had been in place at the time of the service user interview for the main IBSEN evaluation and the structured interviews for the present study. Not surprisingly, a higher proportion of carers (81 per cent; n=27) reported that the service user was in receipt of support paid for by the IB for more than three months, compared with 56 per cent (n=77) at the time of in the main IBSEN evaluation.

Table 4.2 Length of time IB funded support had been in place for at the time of interview

	Main IBSEN study with informal carer		*Carer study sample*	
	Count	%	Count	%
Less than one month	11	8	0	0
Between one month and three months	38	28	5	15
More than three months	77	56	27	81
In place, but don't know how long	2	1	1	3
Not all in place yet	9	7	0	0
Total	137	100	33[11]	100

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

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[8] A further four IB 'refusers' had returned support plans (presumably refusing to proceed only after the support plan was complete). These are excluded from this figure.

[9] Based on the overall IBSEN sample including the carer subsample.

[10] Based on carer responses in the structured interview.

[11] There was missing information for eight carers.

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.

4.4 Service and support costs

4.4.1 Service use and support costs – structured interview sample

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[12]. 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 evaluation, the difference in overall weekly costs between the IB and comparison group was not as marked, either overall (mean £280 (median £180; range £2.00 to £1,640) and £300 (median £150; range £1.00 to £3,160) respectively) or 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 £3,160) respectively).

Cost and funding comparisons need to be made with caution as the sample sizes are very small and exclude purchases of non-mainstream services, as there is no equivalent of such IB expenditure for the comparison group. Levels of expenditure on personal assistants were broadly comparable, with £71 being spent per week by the IB group and £65 by the comparison group. The overall difference in total costs appears to be associated with higher levels of expenditure on home care (£29 per week compared with £59 in the comparison group) and apparently higher levels of receipt of Independent Living Fund money in the comparison group (£6 per week in the IB group compared with £68 in the comparison group). These findings are consistent with those of the main IBSEN evaluation, as was higher local authority social worker/care manager weekly costs for the IB group (£17 compared with £7 in the comparison group).

Day care and short breaks are often the principal source of a break or respite for the carer. There was evidence that this type of support was more prevalent in the IB group. In the main IBSEN evaluation, at six months a third (31 per cent; n=72) of service users with an identified informal carer in the comparison group were

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[12] Due to the small sample size, any firm conclusions need to be made with caution.

attending a day centre, compared with 50 per cent (n=35) of IB users who either reported that they spent their budget on day centres or day care in the six month outcome interview or had this identified on their support plan record.

More was being spent on short breaks among IB users with an informal carer in the main IBSEN evaluation compared with service users in the comparison group. Just over a third, 36 per cent (n=86), of service users with an informal carer in the comparison group reported that they had a break in the previous six months at the time of the main IBSEN evaluation outcome interview. The average annual cost of these breaks was £842, an average weekly cost of £16 (n=58). While a similar proportion of IB users with an informal carer reported that they had a break in the previous six months (29 per cent, n=80) in the outcome interview, on average more resources were devoted to these breaks: support plan records included on average £57 per week for planned short breaks for IB users with an informal carer (n=47).

In addition to these more formal types of break or respite, innovative uses of IBs tended primarily to be in the areas of occupation and leisure activities for the service user. These potentially could also provide some respite, although they could potentially involve carers more, rather than providing a break from caring.

In the structured interviews with carers we focused on support for the carers themselves. The costs of this were in addition to the costs of the service users' IB or mainstream service package for the comparison group that we report above.

There was little evidence of use of these carer specific support services and no significant difference between the IB and comparison groups. Thirteen per cent (n=8) of carers in the IB group and ten per cent (n=7) in the comparison group had attended a carer support group in the previous six months. Five per cent of carers in the IB group (n=3) and in the comparison group (n=4) had attended a carer training course in the previous six months. About half of those that had been to carers' groups (n=8) attended on a monthly basis.

We estimated that the unit cost of carer group sessions was about £8 per attendance.[13] Based on how frequently they had attended, the average costs of those using carer groups was about £3 per week. Training included day-long courses, courses of three or more sessions, and various unrelated sessions during the previous six months. The estimated cost of these was about £24 per carer over the six month period in total, that is less than £1 per week.

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[13] Carer support groups and training are provided in a wide variety of contexts, quite frequently as part of block contracted arrangements with voluntary organisations. We estimated the costs of these assuming that the groups of training sessions were run by social workers and lasted two hours with 12 people attending on average.

Excessive strain caused by the demands of caring can have health implications, either directly or because of a lack of access to timely health care when needed. This has potential knock-on costs for health services. Carers' use of health care services and the associated costs are reported in Table 4.3. The total mean costs of health service use per week for carers in the IB group (£12) and carers in the comparison group (£14) were very similar. Table 4.3 shows that patterns of health service use were very similar in the IB and comparison groups, suggesting that there were no major impacts from IBs either in terms of accessing or needing health services.

Table 4.3 Carer health service use and costs

Health Resource	*IB group*	*Comparison group*
District nurse in the last month		
Mean number of times (at home and elsewhere)	0.22	0.31
Mean cost	£12	£19
Mean cost per week	£3	£5
Practice nurse in the last month		
Mean number of times (at home and elsewhere)	0.31	0.29
Mean cost	£9	£8
Mean cost per week	£2	£2
Therapist in the last 3 months		
Mean number of times (combined at home and elsewhere)	0.06	0.19
Mean cost	£2	£5
Mean cost per week	<£1	£1
GP in the last 3 months		
Mean number of times (combined at home and elsewhere)	1.31	1.26
Mean cost	£41	£41
Mean cost per week	£3	£3
A&E department in the last 3 months		
Mean number of times	0.10	0.06
Mean cost	£3	£2
Mean cost per week	<£0.27	<£1
Chiropodist in the last 3 months		
Mean number of times (combined at home and elsewhere)	0.07	0.13
Mean cost	<£1	£2
Mean cost per week	<£1	<£1
In patient service in the last 6 months		
Mean number of days in hospital	0.25	0.25
Mean cost	£59	£58
Mean cost per week	£2	£2

4.4.2 Service use before and after the IB – evidence from the semi-structured interviews

Data from the semi-structured interviews with carers in this study was used to compare the levels and types of formal support that IB users received before and after award of the IB, to help understand the likely impact of the IB on the experiences of carers. All the carers felt that they had, or expected to have, more support for the person they cared for, following receipt of the IB. Five carers (four supporting older people and one supporting a person with a learning disability) reported that the IB holder had received no formal support prior to the IB. This was said to be either because the person did not need the support at that time (for example where the IB had been prompted by recent onset support needs arising from a stroke) or because they were not previously considered by social services to be eligible for support. Other carers reported that the formal services and support they and/or the service user were receiving or were due to receive had increased as a consequence of the IB. For older people, carers reported this increase ranged from an extra day at a day centre or care home; one or two extra hours of home care a week; and funding to cover the cost of general household tasks like cleaning and gardening. For people with learning disabilities, the increase in support was mainly due to being able to pay people to spend time helping the IB user access social activities. Six carers reported that they were receiving some payment from the service user's IB for part of the care they provided (see below for further details).

4.5 Carers' assessments and payments for carers

4.5.1 Carers' assessments and carer payments

During the structured interviews for this study, over 40 per cent of carers in both the comparison group (44 per cent, n=26) and the IB group (46 per cent, n=27) reported that they had had an assessment. While half the samples reported this had occurred more than a year ago, 65 per cent of carers in the IB group (n=17) and 88 per cent of carers in the comparison group (n=24) reported that they had received additional information or services as a result.

None of the carers in the structured interview sample received an IB in their own right because of their own support needs or officially jointly with the care recipient. However, about a quarter were in receipt of direct payments in their own right or a carer's grant. Although the difference was not statistically significant, more carers in the comparison group received this type of payment (32 per cent; n=22) compared with those in the IB group (18 per cent; n=11).

4.5.2 Paying carers from the IB

The previous chapter reported the policies guiding local authorities and their somewhat variable interpretations of the relevant policy guidance on employing and paying carers from direct payments or IBs. Table 4.4 shows that, according to the structured carer interviews, only six of the carer interviewees and five other family or friends providing care 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 this difference was not statistically significant.

Table 4.4 Payment of carers from the IB, structured interview sample

	Carer interviewed		*Other informal carers supporting service user*	
Source of payment	IB group % (n)	Comparison group % (n)	IB group % (n)	Comparison group % (n)
Direct payment or a carer's grant	18 (11)	32 (22)	3 (2)	1 (1)
Care recipient's IB	14 (6)	-	11 (5)	-
Care recipient's direct payment	0	3 (2)	0	3 (2)
Care recipient's *In Control* Independent Living Fund	0	2 (1)	0	6 (4)
Care recipient's own (private) money	4 (1)	5 (3)	8 (2)	1 (1)
Payment in kind (any source)	8 (2)	3 (2)	0	2 (1)

Six of the 24 carers who participated in the semi-structured interviews reported that they, or another relative or friend, were receiving some payment from the service user's IB. In two cases, the payment was minimal (about £5 a month) and was made either to cover petrol costs or for managing the service user's IB account. In the other four cases the payment was made directly for the care that the carers provided. Of these, one carer had left her part-time job to become a paid carer; the other three carers were each receiving payment for providing two to three hours of care a day. None of these carers said they were able to make a clear distinction between the hours they worked as a paid carer and the hours they worked as an unpaid carer. In addition to the carers who were interviewed, four other relatives and friends were also reported to receive payment for the support they were providing, including taking the service user out or cooking for them.

All six carers taking part in the semi-structured interviews who received a payment from the service user's IB considered themselves to be employed by the person they supported and they treated the money they received as a wage. However, none of them felt there was any security in the job. Only two of the six carers reported that they had formal contracts of employment. They both felt having a formal contract had given their caring job more structure.

None of the six carers who were paid from the IB reported that they were motivated to care by the money they were receiving. They said they would carry on providing the care for their relative or friend irrespective of the IB. In fact they all felt that the payment had made no significant changes either to their financial circumstances or to the range or types of tasks they undertook in their caring role following the award of the IB. One carer, who had given up her part-time job, explained her motivation:

> I'm happy, you know, because at the end of the day, it's [service user] … that counts. You know, and I'm happy with what I get 'cause it's as much – it's a little bit more than what I got at [supermarket] anyway ... I don't need much. It's not all about money for me ... I needed to be able to give up work to do it better and that's what it's done for me.
> (LD5)

However, others were not as satisfied with the payment they received and felt that the time, effort and money they were putting into caring was not adequately rewarded:

> ... I feel like I'm working for free, but the only thing they can offer me is that four hours [payment from the IB] per day ... but still I'm doing the job … but really … I need more than that. If she is not there I can go out and get more hours [paid work] ... I can work from nine 'til three or four or five ... [but the IB payment is] better than nothing.
> (OP6)

One carer said she was still happier to be paid for the job she did through the IB rather than receive money from the person she cared for on an informal basis as a gift (which had happened before the IB), as it felt more like an earned income.

4.5.3 The impact of IBs on carers' receipt of benefits

The most frequently reported source of income associated with the caring role was the Carer's Allowance, which is currently £50.55 per week (www.direct.gov.uk). Table 4.5 shows that over half the carers in the structured interview sample were receiving this. Some carers were also receiving other benefits related to providing care; just under a fifth received the Carer Premium top-up to Income Support or Pension Credit, under which they can receive up to £27.15 per week (www.carers.org). There was no evidence that receipt of these benefits was associated with whether or not the service user received an IB.

While there was no evidence from the structured interviews of lower take-up of benefits, two carers taking part in the semi-structured interviews reported that their social security benefits had been reduced or cut as the result of receiving money from the service user's IB. One carer said she lost her Carer's Allowance because the payment she received from the IB had taken her over the earnings limit for the benefit. The other carer was on Incapacity Benefit and said the payment she received from the IB had been deducted from her benefit.

Table 4.5 Carers' receipt of benefits, structured interview sample

	Carer/Interviewee		*Other informal carers*	
	IB group % (n)	Comparison group % (n)	IB group % (n)	Comparison group % (n)
Carers Allowance[14]	56 (30)	55 (29)	2 (1)	4 (2)
Home Responsibility Protection[15]	20 (11)	9 (5)	6 (3)	4 (2)
Carer premium on Income Support/Pension[16]	19 (10)	17 (9)	1 (1)	2 (1)
Working/child tax credit	15 (8)	9 (5)	3 (2)	4 (2)

4.6 The impact of IBs on carers' time and care-giving activities

The principal cost to the carer is the opportunity cost of the time spent on caring.[17] A key question was whether this is affected by the use of an IB. Table 4.6 shows that, on average, carers of IB group service users 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 people were reported to spend on average over 21 hours per week on caring. This needs to be put in the context that, as we reported above, although the difference was not statistically significant, the cost of the support plan was lower in the IB group than the service

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[14] Carers may be eligible if they are aged 16 or over and spend at least 35 hours a week caring for a person getting Attendance Allowance or Disability Living Allowance at the middle or higher rate for personal care or Constant Attendance Allowance (at or above the normal maximum rate with an Industrial Injuries Disablement Benefit or basic (full day) rate with a War Disablement Pension).

[15] Home Responsibility Protection is a scheme which helps protect the State Pension (www.direct.gov.uk).

[16] If a carer receives Carers Allowance and is eligible to claim Income Support or Pension credit.

[17] Other costs include costs to their health and financial costs in the shorter and longer terms.

package for the comparison group. This was reflected in part by the higher number of hours that were reported as being spent by paid carers in the comparison group.

Table 4.6 Time spent on caring tasks, structured interview sample

	IB group	*Comparison group*
Average hours per week spent caring by carer interviewed (standard deviation)	81 hrs (53) n=56	72 hrs (52) n=62
Average hours per week other informal carers spent caring (standard deviation)	23 hrs (45) n=36	21 hrs (33) n=38
Average hours per week paid carers spend caring (standard deviation)	20 hrs (16) n=47	22 hrs (27) n=51

Table 4.7 shows that carers were involved in a whole array of caring activities, ranging from personal care to looking after pets, DIY and gardening. There was very little difference between the two groups in patterns of care-giving activities.

Table 4.7 Caring activities, structured interview sample

Caring tasks	*IB group* % (n)	*Comparison group* % (n)
Personal care	80 (48)	78 (54)
Housework/laundry	83 (50)	80 (55)
Providing transport/going out	72 (43)	78 (54)
Preparing meals	92 (55)	86 (59)
Gardening	45 (27)	52 (36)
Shopping	95 (57)	87 (60)
Looking after pets	38 (23)	38 (26)
DIY/home improvements	42 (25)	45 (31)
General finances	83 (50)	84 (58)
Managing care arrangements	68 (41)	74 (51)
Managing/reminding about medication	68 (41)	65 (45)
Other health-related tasks	30 (18)	25 (17)

To get a better picture of how an IB affected the role played by the informal carers, the semi-structured interviews explored the time that carers spent on caring and the types of caring tasks they undertook before and after receipt of the IB. Prior to receipt of the IB, the majority of the carers were involved in a range of practical tasks for the service user (including laundry, cooking, shopping, cleaning and cooking); health-related tasks such as looking after medication, escorting to and from appointments with a GP, dentist and chiropodist and collecting prescriptions; and organising and managing the service user's finances. However, more than twice as many carers supporting someone with a learning disability, compared to carers supporting an older person, reported that the person they cared for was totally dependent on them. As well as providing practical support these carers also provided personal care (for example, bathing, toileting, and dressing). While most carers of people with disabilities said that they had been providing the same level of care for a long time, the majority of the carers looking after an older IB user reported that they had either started caring more recently after an illness or that the amount of care they provided had increased significantly following a recent illness.

Four carers (three of older people and one of a learning disabled service user) reported that the IB had helped reduce the time they used to spend on caring. The carers supporting older service users said that with the IB money they were able to pay a cleaner or a gardener to do some of the tasks they did before, or pay someone to provide meals for the person they cared for or take them to doctor’s appointments. The carer supporting a person with a learning disability reported that she was spending less time on caring tasks because the latter was now receiving extra formal support during the week and some weekends.

In contrast, a number of carers of people with learning disabilities said that the IB had created additional work for them. For example, a single mother with three children explained that the IB had enabled her adult son to move out and live independently. However, because there was not enough formal support in place for him, he had found it hard to cope on his own in the evenings for the first couple of months. His mother had therefore had to spend a lot of time with him, leaving her other children with her own mother. After a couple of months of independent living, her son was hospitalised for three months. When he came out of the hospital, he had unexpectedly lost the support he had before going into hospital and she had no option but to take her son back to live at home. Two other carers of learning disabled service users reported that even though they were spending more time caring, they found it less stressful. For example, one carer explained that the IB had enabled her to give up her part-time job and be paid by the IB to do all the unpaid caring work she had already been providing but without such a tight timetable.

A number of carers of both older people and people with learning disabilities reported that the amount of time they spent caring had not changed as a result of the IB but the types of tasks they undertook had done. They reported spending more time organising and managing the care and less time doing shopping and taking the person they supported to appointments. Four carers of people with learning disabilities felt that the IB had made no difference to either the type or the amount of care they provided. This was because the IB was only paying for the formal carers to take the child out to help develop his/her independence and social life and the carer still had to provide all the personal and practical support.

Most carers taking part in the semi-structured interviews said that they relied on help from another family member or a friend. For the carers of older people, this additional help consisted mainly of help with shopping, transport to and from doctors/hospitals, filling in forms and doing odd jobs around the house. For carers of people with learning disabilities, additional support was more likely to be in the form of spending time with the service user to give the main informal carer a break. Carers of learning disabled IB users were more likely to receive additional informal help on a regular basis, unlike the carers of older IB users who said they knew they could ask for help if they needed it. In four cases the carer interviewees were able to pay another family member or friend from the IB for some of the help they provided. No other changes were reported in the amount or type of the care that was provided after the IB was in place.

4.7 Total costs

It is far from straightforward to compare the total cost of the support provided to service users and the support provided to and by their carers under IBs and conventional service arrangements. We have identified the costs of social care support provided through IBs or conventional service packages; the minimal costs associated with services specifically aimed at supporting and training carers; carers' receipt of direct payments and financial benefits; health service use by carers; and time spent by carers on care-giving activities.

It makes little sense to identify the costs of the support provided to carers separately from that provided to the service user, as the type and extent of support provided to the service user plays a fundamental role in the support needed by the carer and what the carer is able to do for him/herself and the person that s/he cares for. So-called 'respite' services may be intended to benefit the carer but are provided for the service user and will have important effects on his/her welfare.

In the main IBSEN evaluation there was evidence of lower levels of formal expenditure on social care support where there was a co-resident carer. Including other forms of formal support that carers are accessing will have little impact on this difference. As we would expect, the difference is more than made up by the high levels of care provided by the informal carers.

The argument is often made that the impact on informal carers should be incorporated in economic evaluation (for example, Werner *et al*., 1999). This includes the cost to carers, but it is debatable how such costs should be calculated (Van den Berg *et al*., 2004). One approach is to estimate opportunity costs by multiplying the hours spent on caring by the principal carer by a shadow price for the time spent on other unpaid work in the home – the national domestic wage rate – to reflect the opportunity cost of time spent by the carer[18] (Van den Berg *et al*., 2004; Netten, 1993). This calculation results in an additional £579 per week for the unpaid hours spent by carers supporting service users in the IB group, compared with £508 in the comparison group.

None of the differences between the IB and comparison groups in the various cost elements that we have identified have been statistically significant. This is partly because of small sample sizes, a particular issue in the measurement of costs which tend to vary widely and often have very skewed distributions. It is clear, however, that the opportunity costs to the informal carers in this study are substantial and, in many instances, dominate the costs of formal care services or support. If we sum the support costs for the service user with the opportunity costs to informal carers we can estimate the proportion of the overall cost of care represented by the opportunity costs for carers. For our sample, opportunity costs accounted for 69 per cent of the total cost, compared with 57 per cent for the comparison group. While small sample sizes mean that firm conclusions need to be made with caution, this result does suggest that to some extent having an IB results in carers having the opportunity, or feeling an obligation, to spend more time with the service user.

Sample sizes are too small for us to be able to investigate causes of variation in these costs. However, unsurprisingly, carers living with service users were significantly more likely to report spending more hours a week caring (86 hours per week; $p<0.001$) than those who lived in a separate household (33 hours per week). In addition, male carers reported that they spent more hours per week caring (mean 84 hours per week) than female carers (74 hours) – this difference was not statistically significant.

4.8 Conclusions

- The principal mode of formal support for carers is through the services and support provided to the service user. The average value of funding through IBs for the service users whose carers took part in this study was £270 (median £170) per week, compared with the costs of conventional service packages of £390 (median £350) in the comparison group. The difference did not reach statistical significance but was more marked than the difference in the main IBSEN study sample.

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[18] Reflected by the hourly rate for elementary administration and service occupation (New Earnings for England, 2007). This is just one of a variety of possible approaches. It is arguable, for example, that those who would otherwise have spent the time in waged work should have the opportunity cost of caring reflected through their lost wage rate. Further research could investigate the impact of alternative approaches to valuing the cost of carer time.

- While direct comparisons are not straightforward, it appeared that expenditure on services that could provide respite for carers was higher in the IB group than in the comparison group.
- There was minimal use of carer groups or training for carers in either the IB or comparison group. These services added less than £3 per week to the costs of support for those carers that were making use of them.
- None of the carers in either of our samples received an IB in their own right because of their own support needs or officially jointly with the service user.
- Only 14 per cent (six) carers and five other friends and relatives in the structured interview sample were identified as receiving payments from the service user's IB. In part this reflected carers own attitudes; over 50 per cent of carers reported that payment for the care they provided would be inappropriate. However, carer-related benefits, particularly Carer's Allowance, were taken up by over half the sample.
- Six carers who took part in the semi-structured interviews were paid through the IB, although amounts were often small. None of the carers felt motivated by this type of income incentive and they all thought that the caring they provided was not adequately reflected in the payment they received.
- Evidence from the semi-structured interviews also suggests that the carers of people with learning disabilities were more likely to support people who were totally dependent on them; had done so for a longer period of time; and were less likely to have experienced a reduction in the time they spend on caring as the result of the IB.
- There were no statistically significant differences between the IB and comparison groups but this is to be expected with the size of the samples. If there are any underlying differences, the directions of effect suggest higher levels of formal sources of support in the comparison group and higher levels of input from informal carers in the IB group.

Chapter 5 Carers' Involvement in Assessment and Support Planning for IBs

5.1 Introduction

In this chapter, we draw on both the structured and semi-structured interviews with carers to report their experiences of the IB assessment and support planning processes.

5.2 Assessment, planning and management of care

5.2.1 Evidence from the structured interviews

In the structured interviews, carers in the IB group were asked for their views about the overall value of the budget; arrangements for paying the IB; and the associated paperwork[19]. Table 5.1 shows that 83 per cent (33) of the carers were satisfied with the value of the IB. In terms of the financial arrangements, 88 per cent (35) were satisfied with the way that the IB was paid and 57 per cent (20) were satisfied with the amount of paperwork involved. The particular client group of the service users who had assistance from the carers in this study did not have a significant impact on responses; however the small sample sizes may have influenced this result.

Table 5.1 Levels of satisfaction with the IB

	Value of the IB n=40 % (n)	*How the IB is paid* n=40 % (n)	*Paperwork required for financial arrangements* n=35 % (n)
Extremely satisfied	10 (4)	10 (4)	9 (3)
Very satisfied	33 (13)	35 (14)	17 (6)
Quite satisfied	40 (16)	43 (17)	31 (11)
Neither satisfied not dissatisfied	8 (3)	8 (3)	29 (10)
Quite dissatisfied	8 (3)	3 (1)	11 (4)
Very dissatisfied	2 (1)	0	3 (1)
Extremely dissatisfied	0	3 (1)	0

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[19] For valid comparisons we used the randomisation group that the service users were allocated to in the main IBSEN evaluation. For the IB group, there were occasions when the carer did not think that an IB existed and therefore a comparison group questionnaire was used at the time of the interview, resulting in a smaller sample for IB-specific questions highlighted in Table 4.1.

Table 5.2 shows that 64 per cent (n=25) of the carers reported that the IB process changed their view on what could be achieved in their life either a lot or a little. The client group of the service users being supported by the carers in this study did not have a significant impact on responses.

Table 5.2 Aspirations of carers of service users accepting the offer of an IB

	IB group n=39 % (n)
Has the IB process changed your view on what can be achieved in your life?	
A lot	18 (7)
A little	46 (18)
Not at all	36 (14)

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 5.3 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. As we discuss in Chapter 6, satisfaction with the support planning process has important implications for the impact of the support provided for carers.

Table 5.3 Overall satisfaction with the support planning process

	IB group n=58 % (n)	*Comparison group* n=67 % (n)
Extremely satisfied	7 (4)	9 (6)
Very satisfied	29 (17)	13 (9)
Quite satisfied	38 (22)	40 (27)
Neither satisfied not dissatisfied	5 (3)	9 (6)
Quite dissatisfied	5 (3)	9 (6)
Very dissatisfied	10 (6)	9 (6)
Extremely dissatisfied	5 (3)	10 (7)

Table 5.4 shows that 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).

Table 5.4 Involvement in support planning

	IB group n=58 % (n)	*Comparison group* 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.

5.2.2 Evidence from the semi-structured interviews

To recap, semi-structured interviews were conducted with 11 carers supporting older service users and 13 carers supporting people with learning disabilities, from six of the 13 IB pilot sites.

5.2.3 The level and nature of carers' involvement in IB assessments

In most cases, the IB assessment involved the carer, a social services practitioner (social worker, care manager, council broker or IB support worker) and another close member of the family. In a number of cases, a hospital worker was also present. While in most cases the service user was reported to have been present during the assessment session/s, only a few carers reported that the service user had been able to participate effectively in the assessment. In all other cases, carers acted as proxies reporting the service user's needs.

Most carers, particularly carers of people with learning disabilities, understood that the aim of the assessment was to identify the service user's needs and look at the areas of his/her life that could be changed or improved. Others said that the assessment was also intended to look at carers' circumstances and needs for help.

Most carers thought the assessment was not lengthy, lasting up to a couple of hours. However a few carers reported that the assessment was long drawn-out, involving several interviews. This was mostly the case where the service user required a lot of support and where carers had been given a blank assessment form to fill in on their own for the service user and have a discussion about it with a practitioner afterwards. Sometimes the assessment process was said to have been delayed because practitioners who were helping with the form filling were themselves not clear about what to do.

A number of carers had not been involved in any previous assessments and therefore had nothing to compare the IB assessment with. Most of the carers who had experienced previous assessments found that the IB assessment was simpler and more thorough than their previous experiences (for example, of assessments for Disability Living Allowance) and reported that they had received more support in completing the assessment form. A few carers supporting people with learning disabilities reported they had difficulties filling in the assessment form, because the needs of the people they supported did not easily fit into its tick boxes. However, others felt that the IB assessment gave them more of a say about what they thought was important for the person they cared for; moreover it asked about what people could and wanted to do, rather than fitting people into services. One parent caring for an adult child with a learning disability explained that her main concern was her child's future independence but she thought social services were only interested in situations when they reached a crisis point. She found the IB assessment a new and fulfilling experience for her, because it gave her a chance to think beyond day-to-day routines to what her child might want for the future

> Whereas usually, social services would come in and they would say, 'Right, you need some more help. Okay, what can we offer you? Well actually, there's not a lot out there. You can go to this place or that place, but they don't cope with people with epilepsy and they don't cope with people with challenging behaviour, so actually there's not a lot we can give you,' and they'd go away again. So rather than it being quite a negative reaction and quite a stressful situation, we actually quite liked doing it, and it was quite an eye-opening sort of experience, an enlightening experience to sort of look at everything from [service user]'s view, rather than what she might fit in to.
> (LD1)

However, there were a few carers who thought the IB assessment did not reflect their concerns for the person they supported. For example, a wife caring for her husband who had a stroke wanted someone to help her husband to learn how to read again. She said the social worker did not support the idea and told her 'He's had a stroke, he can't read, tough, get on with it'.

Many carers mentioned that this was the first time they had been able to see an assessment document before it was completed or make amendments to it. Some carers strongly believed that their involvement in the assessment was crucial to the success of the IB.

5.2.4 Assessments and recognition of carers' own needs

Although some of the carers taking part in the structured interviews reported having had an assessment (see 4.2.1), none of the carers in the semi-structured interviews reported having had a separate assessment of their own needs at the time of the IB user's assessment. However, many carers – particularly carers of older people – thought that one of the advantages of IBs was their holistic approach; this encouraged carers to give a broad view of the situation and think about the needs of the family as a whole. Nine carers – seven caring for older people and two caring for a service user with a learning disability – reported that the IB assessment had given them the opportunity to describe the care they provided; whether or not they felt they could cope with providing that amount of care; and the help they needed in their caring role. In fact a number of carers thought the IB was mainly to help carers maintain their level of commitment and involvement. For example, one carer mentioned that social workers were worried she was not getting a good night's sleep as her husband was doubly incontinent and woke up three or four times a night. As the result of the IB assessment she was able to get one extra day respite care for her husband. Another carer said having someone from the hospital involved in the assessment was important because: 'he were looking at it in the light that, if I didn't get any relaxation or relief from full-time care, they would have two patients not one'.

Other carers understood that the assessment only covered the service user's needs. While some carers did not see a problem with this, others felt that the care they provided was taken for granted. One parent said she was made to feel guilty because she was working:

> … I do feel bad and I do feel terribly guilty … I did say to her [social worker], 'I feel you're criticising me. I feel that anything I'm doing is not enough and I feel as though you think that I'm having a fantastic time, and anybody can tell you, if I didn't go to work, I wouldn't have a social life at all.'
> (LD3)

5.2.5 Carers' experiences of support planning

In most cases, devising the support plan was reported to have been a joint effort between the carer; the service user (where this was possible); the social worker or support broker; other family members; and, in a number of cases, a member of hospital staff and/or a local independent living association. Carers of people with learning disabilities reported more involvement in developing the support plan for the service user than those caring for an older person. Two carers said that they had approached voluntary organisations such as Mencap for information and support. A few parents reported attending training sessions to help them with support planning, which they found very helpful as it provided an opportunity to meet other parents going through the same process and share their ideas. One parent had put together the views of close family and friends who knew her child well about what they thought the child would like to do.

Very few carers reported experiencing trade-offs between their own needs or aspirations and those of the service user in developing the support plan. However, a few carers reported differences of opinion between themselves and a practitioner. In one case, a mother caring for a child with a learning disability was quite upset that the local authority broker tried to impose her own views of what was best for the child and criticised her for not allowing her child to do certain things such as going away with a paid carer for a week:

> I didn't like her. I told her not to come no more, 'cause I didn't like her … Ooh, I couldn't stand her. It were things she were throwing at me, as though I weren't doing my job … I says to her, I says, If you're any better than me, love … and give my kids, what I've given them, you're welcome to do it.'
> (LD11)

None of the carers felt under pressure during the support planning process to provide more care than they were willing or able to provide. Most carers of older people felt that their circumstances were taken into account when planning the service user's support. Two carers said the IB was to give the carer a break by allocating money to pay someone to carry out some general household tasks. Another carer looking after her elderly parent said she was very happy with the IB and even though she received no actual payment it had made a big difference to her. Before the IB she felt she had no backup as none of her family lived near her. With the IB she felt there was somebody there to help her. One carer explained she was able to get an electric bath lift to help her bathe the person she supported.

In comparison, 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. One parent worked part-time and relied on her own parents (who were also working part- time) to look after her child after school and part of the weekends. The IB paid for help from a paid carer in the evenings and weekends. This reduced some of the pressure on her parents, but did not help her reconcile the demands of her job and care.

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; moreover a large proportion of the IB had to go on paying for 24 hour care. Some carers preferred to use the IB as a cash incentive to get a family member or a friend who knew the service user well to take him/her out. However, they reported that the IB would only pay the paid carer's expenses (like lunch and a cinema ticket); informal carers' expenses could not be paid in the same way:

> I feel that's a slur on the families that care for them … why not … pay me and my child … I would say I'm not bothered about the hourly rate of the time that I've spent there, just give us the entrance fee to these places, so I can have quality time with him.
> (LD3)

Many carers thought that the support plan devised for the service user looked fantastic and very promising, but what people received in reality was very different from that and often not dissimilar to what they had experienced before the IB. One parent had a more positive view of the IB, saying she felt valued by the way everybody's needs in the family were incorporated into the planning of her child's support. Her family's biggest concern, she said, was to have the child within their home environment rather than having her in residential care. The IB supported the family in that aim by providing the resources needed for the necessary housing adaptations.

5.2.6 Understanding the IB and what it could be used for

Most interviewees seemed to be quite clear about how the IB had been calculated, but they did not have a clear understanding of what the IB could and could not be used for. One carer, for example, said he paid for the theatre ticket for a relative to take his wife out from the IB, but he was not sure if he could use the IB to pay for his own ticket if he took her out himself. Another carer reported that she had been given the impression that carers would have the freedom to spend the money more flexibly, but this was not what she had experienced. For example, she said that she was told she could spend the IB money on the garden. She did that only to find out later that the IB would not cover any gardening jobs, whereas it did cover the cost of decorating the house; she found this very confusing. Such restrictions reflected local policies. Advice to pilot sites had been that as long as something was safe and legal and met the outcomes of the user or carers, nothing was ruled out.

Only two carers had any knowledge of the different funding streams that made up the service user's IB; others assumed that the money they had been allocated had all come from the social services. Two of the carers felt it would make no difference to them knowing where the money had come from.

Most carer interviewees had no idea what would happen if the IB was not all used during the period it had been allocated for. Some carers reported that the money was accumulating in the bank and they could not use it because the new care arrangements had not yet been finalised. One parent reported that she had been waiting for almost a year for an agency to recruit a suitable personal assistant for her child. A few carers reported they were underspending the IB because of the fear of overspending – these carers were all concerned about losing the money that had not been spent. While some carers reported that they knew who to approach for more information, a number said that they had asked the practitioner involved in their case to clarify some of the restrictions on the budget but they did not seem to have a clear answer.

5.3 Carers' involvement in managing the IB

5.3.1 Carers' involvement in managing the IB accounts

Over half the carers, supporting both older and learning disabled people reported that they were not prepared to manage the IB accounts as they thought this would be too daunting; instead they used a local direct payment support service. Carers explained that they were anxious about the responsibility of managing a large sum of money; were concerned they might make mistakes; or were already too busy to take on additional commitments:

> No, I couldn't because it's bad enough getting myself up and [laughs] working out what hours I'm working and who's going to look after [service user] and where he's going to be and telling the taxis where to drop them, no, I couldn't possibly do anymore.
> (LD3)

Some carers were concerned that they could be pushed to take on managing the IB accounts in the future; indeed a few carers reported that they were already making arrangements to open a bank account to do this at the time of the interview. Other carers were concerned about the possibility of having to pay for the IB support service in the future.

Eleven people, spread almost equally across carers of older and learning disabled people were managing the IB in the form of a direct payment. This involved opening a bank account, keeping timesheets, getting pay slips and paying personal assistants, agencies or service providers themselves. However, all these carers reported that tax and national insurance matters were handled by an external agency. Five carers said they did not think they had a choice over whether to manage the IB; of these, three people felt it was the carers' responsibility and two thought an external agency should have been responsible.

In line with the structured interviews, all the carers in the semi-structured interviews who had taken on the responsibility of managing the accounts said that the IB had created more paperwork. Most said that at first this was quite stressful but became less of a burden when they got used to it. Carers who had had previous relevant experience, either through direct payments or their own employment, said that they found this very helpful. One parent had appointed a personal assistant to manage the IB in order to give her child more independence. The parent's concern was that she might make decisions that were good for herself but not for her child.

However, some carers who were managing IB accounts reported challenges. For example, one person supporting three members of her family, all with learning disabilities, reported that she struggled with the paperwork for some time and passed it on to an agency as soon as she realised she could do so. She had already opened separate bank accounts for each of them and found it particularly stressful setting up additional bank accounts; the bank did not understand why she had to open so many bank accounts. She also felt uncomfortable managing the accounts as she was also being paid from the IB and she was unsure how to manage any conflict of interest.

In general, non-resident carers seemed to find managing the IB more difficult than those living with the service user. One non-resident carer said she would find managing the IB a burden as she already had the added responsibility of paying two sets of bills. Another non-resident carer reported that she was thinking about moving to a bigger house which could accommodate the person she supported, but she was not sure whether the IB would be affected if the service user was living in the same household as the carer.

There was also some concern about a lack of flexibility in using the money. For example, a non-resident carer was paying someone to prepare food for her father and give him a shower; she did everything else for him. Having had an operation, she decided to take her father to her own house while she was recovering. She asked social services if she could keep her father's dinner money and get somebody else who lived closer to her to give him a shower. They refused on the grounds that the money was from a different authority to where she lived.

How paid carers/personal assistants were paid from the IB was an issue for many carers who were managing the IB; some personal assistants were paid in cash, others by cheque. The carer interviewees often did not know whether they had a choice in this. Most of them preferred to pay personal assistants in cash because they thought that was what the latter preferred. They also thought paying cash would make the management of the IB accounts easier because they would not have to wait for the formal carers to cash their cheque before they could sort out their accounts.

5.3.2 Carers' involvement in co-ordinating support

As discussed in Chapter 4, many carers, whether caring for older or learning disabled people, reported having greater choice over how they spent their time because of the flexibility of the IB. However, a number of carers reported having increased responsibilities for co-ordinating the service user's support arrangements. Some carers seemed to be happier about this than others. One carer who had managed the IB for a few months reported that, even though she had arranged the service user's support which involved many phone calls and letters, she found the experience productive. The fact that she was controlling the budget, she said, meant that she could get things done, in contrast to previous experiences:

> … it is more work for me. But … it's positive work most of the time. I, I'm in control … it's positive because I, I can get what I know wants done … because I'm valued as a carer, I'm part of the team. I can get things done for [service user] whereas I couldn't before.
> (LD9)

There was some confusion and concern among some carers about who they could employ. A few carers said they had carried on using the same agency carers as before the IB because they did not know what other options were available. Some felt having to pay their carers by cheque had limited their choice of who they could employ; one carer explained that the agency carers they had used for a long time had left the agency to work privately. He would have liked to employ the same people but could not do so because they did not want to be paid by cheque. Another carer queried why she had to employ someone from an agency costing £35 an hour when she could employ someone privately for only £14 an hour. A few carers wanted to employ a family member or friend for a few hours each week, but thought that was not worth the hassle because it would involve a great amount of paperwork and it would reduce the other person's chance of earning their full potential. Another carer reported that at first she employed a friend, someone her child knew, but she was concerned about their safety. She decided to approach an agency to 'have it set up properly' so that the paid carer would be vetted and covered by insurance. This carer expressed a lot of disappointment because, she said, almost a year had gone by and she was still waiting for something to happen.

5.4 Conclusions

- There were high levels of satisfaction among carers with the value of the IB and how it was paid; and a suggestion of higher levels of satisfaction with support planning compared to conventional care planning.
- IB group carers were significantly more likely to have planned support together with the service user than comparison group carers.
- None of the carers taking part in the semi-structured interviews had had a separate assessment of their own needs. Nevertheless they reported that in the service user's IB assessment their own needs and circumstances were more likely to be recognised and taken into account, compared to their previous experiences of assessment for benefits and services for the service user. This was more apparent in the case of carers of older people than those supporting adults with learning disabilities.
- However, carers of people with learning disabilities appeared more likely to make a greater contribution to the assessment of the service user's needs and support planning processes than carers of older people.
- For many carers, the IB had created more paperwork and management responsibilities. However, any disadvantages experienced by carers appeared to be related to apparent restrictions or lack of clarity over how the IB could be used; or to support plans that failed to materialise.

Chapter 6 The Outcomes of IBs for Carers

6.1 Introduction

IBs could have both positive and negative effects on carers. On the one hand, planning and organising support through an IB could impose (further) burdens on carers. Indeed, the evidence in Chapter 4 suggested that carers of people with IBs may be spending more time on care than those caring for people receiving mainstream services. Alternatively, the greater flexibility of IBs could offer opportunities to use IBs to secure the types of support that benefit and relieve carers as well as service users, and thus result in improved outcomes.

Although the IB and comparison groups for this study were selected from the randomised groups in the main IB evaluation and were not randomly allocated *per se*, there was no evidence of any difference in the demographic characteristics of carers in the two groups (see Chapter 2), giving us some confidence that any differences in outcomes between the groups are due to the IB. However, even though they might not be statistically significant, any differences between the IB and comparison groups could nevertheless still have an impact on outcomes. In order to allow for other effects on outcomes, and to explore the importance of these, we use multivariate analyses to explore the impact of IBs and other factors on our outcome measures. Finally we draw on the semi-structured interviews to provide insights into our quantitative findings on outcomes.

6.2 Overall outcome measures

Table 6.1 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. There was evidence of improved outcomes as a result of IBs and no evidence of poorer outcomes for carers. 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). While there was no statistical difference between the IB and comparison groups, outcomes measured by GHQ-12, social care outcomes reflected through current levels of met need (ASCOT) and the COPE index also appeared better for carers in the IB group compared with those in the comparison group. The client group of service users who had assistance from the carers in this study was not associated with a significant impact on responses.

Table 6.1 Quality of life, well-being and met needs

	IB group	*Comparison group*
Quality of life *	**n=60**	**n=69**
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)
GHQ-12	**n=59**	**n=69**
Mean score[1] (sd)	12.59 (5.42)	14.17 (6.45)
Percentage[2] scoring 4+	29%	42%
ASCOT[3]	n=58	n=66
Current met needs mean score (sd)	1.90 (0.65)	1.66 (0.76)
Self-perceived health	**n=58**	**n=69**
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)
COPE index	**n=55**	**n=62**
Negative impact[4] (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)

[1] GHQ item scoring 0-3, higher GHQ scores indicate poorer outcomes.
[2] Using GHQ 12 item scoring 0-1.
[3] Higher scores indicate lower levels of need.
[4] Higher scores indicate fewer negative responses.

6.2.1 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 6.2; carers in the IB group were significantly more likely to report that they were fully occupied in activities of their choice (38 per cent; $p< 0.05$)[20] 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 6.2 ASCOT outcome domains for all service user groups combined

	IB group % (n)	*Comparison group* % (n)	*Overall* % (n)
Social participation and involvement			
No needs	33 (19)	33 (22)	33 (41)
Low needs	47 (27)	39 (26)	43 (53)
High needs	21 (12)	27 (18)	24 (30)
Control over daily life			
No needs	42 (25)	32 (22)	36 (47)
Low needs	55 (33)	55 (38)	55 (71)
High needs	3 (2)	13 (9)	9 (11)
Safety			
No needs	73 (44)	75 (52)	74 (96)
Low needs	27 (14)	20 (14)	23 (28)
High needs	3 (2)	4 (3)	4 (5)
Occupation and employment *			
No needs	38 (23)	20 (14)	29 (37)
Low needs	58 (35)	67 (46)	63 (81)
High needs	3 (2)	13 (9)	9 (11)
Caring role			
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: * $p< 0.05$.

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[20] A four point scale was used for this domain which could have affected carers’ responses. For the purposes 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.

6.2.2 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 6.3 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. However, there was no evidence from this measure that carers in the IB group felt more supported.

Table 6.3 COPE index

	IB group Mean (SD)	*Comparison group* Mean (SD)
Negative impact of caregiving[21]		
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)
Positive aspects of caregiving[22]		
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)
Quality of support?[23]		
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)

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[21] Lower scores represents a negative appraisal.
[22] Higher scores represent a positive appraisal.
[23] Lower scores represent higher perceptions of quality.

6.2.3 Satisfaction with services

We might expect that, in the majority of cases when there is the flexibility for people to organise their own support, joint planning with carers or taking into consideration carers circumstances, 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 6.4)[24].

Table 6.4 Satisfaction with help paid for from IB or from Social Services

	IB group n=60 % (n)	*Comparison group* n=68 % (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 satisfied	10 (6)	4 (3)
Very dissatisfied	8 (5)	6 (4)
Extremely dissatisfied	5 (3)	9 (6)

6.3 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;

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[24] People who were interviewed by telephone were significantly more likely to report being satisfied than people interviewed face-to-face.

secondly, differences that are not statistically significant because of the relatively small sample sizes can sometimes be identified.

The results of the multivariate analyses are described below. The equations show the influence of each factor, after taking into account the effects of all other included variables.[25] There was very little variation for the COPE index, as shown in Table 6.3. This meant that it was not possible to identify a satisfactory statistical model for this outcome measure.

6.3.1 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 6.5 Predicting quality of life

	Coefficient	*P*
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

Note: Model estimated using a linear multiple regression. Positive effects denote improvements in the outcome. R^2=0.28; n=114.
RESET test 0.31.
Prob > chi^2 0.80.

6.3.2 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

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[25] Tests of interaction were also conducted (for example IB effects by user group for each outcome domain, interactions with pilot site models and so on) but none was found to be significant.

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 6.6 Predicting social care outcome (ASCOT)[1]

	Coefficient	*P*
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

[1] Model estimated using a linear multiple regression. R^2=0.40; n=111.
RESET test 0.71.
Prob > chi^2 0.40.

6.3.3 GHQ-12

For ease of interpretation, we recoded GHQ-12 so that positive outcomes were associated with positive values. 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 ($p < 0.05$).[26]

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 ($p < 0.001$).

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[26] This is not shown in table 6.7 as the number of observations was reduced considerably because of missing data.

Table 6.7 Predicting GHQ-12[27]

	Coefficient	*P*
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

Note: Model estimated using linear multiple regression. R^2=0.34; n=120.
RESET test 0.19.
Prob > chi^2 0.18.

6.4 Cost effectiveness

In Chapter 5 we identified the problems associated with estimating total costs. Our sample size is very small once we include only those cases for which we have full cost information. While imputation techniques can be used to address such problems, we did not feel it necessary in this instance and no separate cost-effectiveness analyses were conducted. This was because all the evidence here and in Chapter 5 suggests that costs to the formal sector in our IB group were the same as or lower than those in the comparison group. Despite a suggestion that the costs to the carer may have been higher, with carers bearing a higher proportion of the overall cost, all evidence in this chapter suggests that this was not at the expense of carers' well-being – indeed, carers in the IB group were reporting better outcomes. Any intervention with the same or lower costs and better outcomes is clearly cost-effective.

This is a welcome finding, but then raises further questions. We turn to the results of the semi-structured interviews for insights into what lies behind these effects.

6.5 Understanding the impact of IBs on carers

The IB intervention was not primarily targeted at carers. None of the carers in our sample had IBs that were intended for them, either individually or jointly. This raises the questions of what lies behind the positive impact IBs appeared to have and what this positive impact depended on. We draw on the semi-structured interviews with 24 carers to gain some insight into carers' experiences and what lies behind the carer outcomes.

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[27] GHQ item scoring 0-3, lower GHQ scores indicate poorer outcomes.

While no association was found between service user group and carer outcomes in the multivariate analysis, responses in the semi-structured interviews suggested that the carers of older people tended to be more satisfied with the IB than those caring for people with learning disabilities. The majority of the carers in the former group said that the IB was fantastic and a real bonus because they had had no or very little support before the IB was offered. Two carers thought the IB was too good to be true:

> My instant thing was OK, what's the catch? I couldn't believe something happens without there being a catch in it. My head still goes … you don't get this much help without there being a catch, and so far I haven't found it. (OP1)

Among the carers supporting people with learning disabilities, some had a more positive view of the IB than others and drew attention to what the IB had helped the service user to achieve. Others were more sceptical, arguing that at first the IB sounded like a brilliant idea by promising to give their child more of a social life as well as supporting carers. However, in reality these promises had not been realised. A couple of parents thought social services had become interested in their families only because they wanted to encourage more people to move onto an IB in order to meet their target for the evaluation and they had no choice but to take an IB.

Nevertheless, the majority of carers who were interviewed were positive about IBs and the reasons for this provide some insight into why we found no reduction – indeed, even found increases – in time spent caring (Chapter 4), alongside better perceived quality of life and social care outcomes. In the semi-structured interviews carers identified the benefits of IBs as including greater flexibility, choice and control; this positively affected how they spent their time, improved the quality of life of the service user and enhanced family relationships.

6.5.1 Choice, control and use of time

The majority of carers reported that the biggest advantage of the IB for the carer was that it gave them choice. Whereas previously they personally had had to do everything for the service user, the IB allowed them to decide whether to pay someone else to do some of these tasks, such as take the service user to football matches, give them a shower or do some household chores. Most carers said that they used the extra free time to visit relatives and friends, go shopping and attend doctors' appointments. One carer of an older person joined a health club and another was using the additional free time to help her neighbours and friends and do more voluntary work. For one parent sometimes just doing nothing was 'fabulous'.

Most carers said that they valued having the opportunity created by the IB to go out without having to take the service user with them or without worrying about them. A number of parents reported that the IB had taken away the feeling of guilt they had previously experienced when they did something for themselves. They used to think that the caring they did for the service user was their duty and that they did not deserve to have a break:

> I think when [daughter] used to go away to respite and she hated it, there was a guilt element to sending her … because I was tired, or because I needed a break. Whereas now, if she goes away to CenterParcs for three days, and I recharge and I have a fantastic time, but I know that she's also having a fantastic time, it also takes that guilt element, so you're more likely to do it.
> (LD1)

A number of carer interviewees expected the IB to increase their employment opportunities. One carer who was working part-time hoped that, once she started to fully access the IB, it would give her the opportunity to commit herself to a full-time job. However, at the time of the interview, only four carers reported that the IB had already given them chance to use their time differently. A self-employed carer said that she had already started putting more time into her work. The IB had enabled another carer to give up her job to become 'a better carer'. A third carer said the IB had given her the opportunity to go back to work but her own ill-health was preventing her doing so at the time of the interview.

One carer who had given up her part-time job to care with payment from the IB explained that she was less tired and stressed than before (even though she was doing more caring work). This meant that she could have more quality time with the people she supported. Another carer who had been receiving Income Support and was under pressure from Jobcentre Plus to find paid work was paid from the IB to look after her mother instead and was able to stop claiming Income Support and avoid these competing pressures.

Although the flexibility of IBs had enabled many of the interviewees to exercise greater choice over how they spent their time, a few were disappointed with the way the IB had worked out and had experienced a lack of flexibility in the service user's support arrangements which was restricting their employment opportunities.

6.5.2 Quality of life for service users

About half of the carers said that they thought the IB was good because the person they were supporting was happier and the IB had improved his/her quality of life. A couple of carers said that the service users were actually happier because they were able to use their IB to pay the carer for the support they provided.

Carers of people with learning disabilities in particular felt that it was difficult to separate their own interests from those of the person they supported, because their lives were so interwoven. One parent said her child's challenging behaviour had subsided tremendously with the new IB-funded support arrangements and this was an indication that her child was happier. A number of parents were particularly concerned about their child's independence and felt the IB was supporting them in their desire to help their child develop more independent living skills. Some parents said they were pleased because the IB had enabled their son or daughter to have paid carers of their own age:

> … it's wonderful to see [brother] living the life he wants. I mean, before he used to have a carer that would sit with him all the while, she'd be sitting downstairs watching television, Asian television, and [brother] would be upstairs watching his television in his bedroom. Now he, he goes out … I really, really do think it is fantastic for [brother]. Because my brother's happy, my brother's saying what he wants now, whereas he's never been able to before. I've had to sort of guess at it before, whereas now he's actually coming out and saying things. He's become an individual.
> (LD9)

However, not everybody felt that the quality of life of the person they supported had improved. For example, one parent reported that she had expected the IB to create new opportunities for her daughter. She said that she had spent a long time putting together a support plan that included activities her child enjoyed. Instead, all the formal carer did was take him for rides, out for a coffee, to a garden centre and to her own house; these activities were no different to what they did anyway as a family. Another parent said the paid carers often had no plans and spent a lot of time driving around with the service user to look for activities. Both of these parents felt that part of the problem was that the agency carers, who were arranged by social services, kept changing.

6.5.3 Family relationships

Carers of older people and learning disabled people who had used the IB for a relatively longer period reported that the IB enabled them to spend more quality time with the person they supported. A number of carers of learning disabled service users said that because they were not with the person they supported 24 hours a day, they felt closer to each other:

> ... in the same way as, like, with her older sister, if we go out and we do stuff, we have a nice relationship there, it's the same with [IB user] now and it's more fun and, you know, to go out and go shopping and that's not such a chore, and I can actually say to one of the carers, 'Look, I'm going shopping with [IB user] tonight, will you come to help?' So it means that the burden of the care isn't so much there, so I can enjoy it and, you know,

> if she wants to go off and go to toilet or anything, she can go with her carer, it doesn't immediately have to be me.
> (LD1)

Some parents reported that the IB had also given them a chance to spend quality time with their other children, which they had not had much time for previously. However, one carer reported a change in her relationship with her father as a result of being paid from the IB to support him:

> … before he [father] had the Individual Budget … I felt he was very generous. I felt since he had the Individual Budget he's become, he's seemed to become quite mean … he didn't give me any extra money. I got the [amount] for the cleaning and so he didn't give me anything [else] … and I began to wonder what was happening.
> (OP5)

Most carers did not report any significant changes in their relationship with their own partners (where the partner was not the IB user) as a result of the IB. However, two carers said that the IB had a negative impact on their relationship with their partners. For one carer, this was because she was busy managing the IB and co-ordinating the service user's support and so had less time to spend with her partner. The other carer explained that this was because her mental health had suffered considerably after the IB because she felt her life had been taken over by social workers and community nurses. Both carers expected their relationship with their partners to improve in the longer term, once their respective support arrangements were more settled.

6.6 Conclusions

- IBs are associated with a positive effect on carer outcomes in terms of quality of life and, when we allow for other factors, social care outcomes. There was no evidence of negative impacts on outcomes from the analysis of the data from the structured interviews.
- 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.
- Psychological well-being of carers was not associated with receipt of IBs but was associated with higher costs of formal support once other influences had been allowed for.
- While there was no association between outcomes and the client group of the service user in the multivariate analysis, among those who took part in the semi-

structured interviews the carers of older people were more positive; some parents of people with learning disabilities expressed some reservations.

- From the semi-structured interviews, improved outcomes appeared to be primarily the result of carers having more choice and control over how they spent their time. This was also reflected in significantly better outcomes in the ‘occupation’ domain in the structured interview outcomes.
- Both the benefits and the limitations of IBs appeared to be associated with the level of flexibility that was afforded to carers.

Chapter 7 Conclusions, Discussion and Recommendations

7.1 Introduction: aims and design of the study

This study aimed to examine the impact of Individual Budgets (IBs) on the family and informal carers of IB recipients. The main research questions 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 social care services? If so, in what ways, for which groups of carers?

The study has also examined how the implementation of IBs in the 13 pilot sites took into account the needs of carers. This contextual information helps in understanding and explaining the experiences of carers as reported in the study. It also raises some important issues for policy and practice.

The study built on the main, large-scale national evaluation of IBs (IBSEN) (Glendinning *et al*., 2008). It used data from several different sources:

- Structured interviews, using a range of standardised outcome measures, with subsamples of carers of people who had been randomised to the IB and comparison groups in the main IB evaluation.
- Semi-structured interviews with a subsample of carers of people who had been randomised to the IB group in the main study, about their experiences of supporting an IB user.
- Baseline socio-demographic data and information on the types and costs of services used by IB holders and comparison group members in the main IB evaluation study.
- Extraction and reanalysis of data obtained for the main IB evaluation from interviews with senior local authority officers responsible for implementing IBs.
- Telephone interviews with officers responsible for carers' services and support needs in the IB pilot sites, about their roles and experiences in implementing IBs.

By triangulating data from these different sources, the study has identified important effects of IBs on carers; explored explanations for these findings; and identified some important issues that need addressing in policy and practice.

Problems in tracking down the carers of the original IBSEN study participants had an impact on sample sizes, which were smaller than had been planned. It also resulted in a more diverse sample of carers than originally intended. 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.

Because the majority of carers in this follow-up study were supporting adults with learning disabilities or older people, the carers in this study were more likely than in the main IBSEN evaluation to be 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. The structured and semi-structured interviews with carers were therefore held some time after those in the IB group had first been offered an IB. 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.

7.2 Main findings from the study

7.2.1 The balance between formal support and informal care

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 (see below). 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. There was also no evidence from the interviews with the IB implementation lead officers or the carer lead officers that IBs were leading to some substitution of informal for formal care – that the IB assessment and resource allocation processes were leading to an increase in the help given by informal carers.

7.2.2 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. 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.

Two-thirds of carers reported having changed their views on what could be achieved in their lives following the offer of an IB to the person they were supporting. On balance, carers of IB users also tended to express satisfaction with the level of the IB; the IB deployment arrangements; and the amount of paperwork the IB involved.

However, the findings in relation to carers' satisfaction with the IB assessment and support planning processes – how an IB was to be used or what standard social care support was to be provided for the service user – were more difficult to interpret. 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.

These findings need unpacking a little further and the qualitative interview data helps us to do this. First, there is the **level** of carers' involvement in assessment and support planning. Carers reported that they were more likely to have been involved in the processes of assessment and support planning for the service user's IB, compared with their previous experiences of assessment, for example for disability benefits. Carers of learning disabled IB users were particularly likely to report high levels of involvement in planning how their son or daughter would use the IB and had also had more help from social workers or external agencies with this role.

Secondly, there is the nature of the **role** that carers played in assessment and support planning; here the evidence is not wholly conclusive. 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. Similarly, 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. 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.

A third issue is the **scope** of the IB assessment and support planning processes. Legislation now affords carers the right to an assessment of their own needs. Although none of the carers taking part in the semi-structured interviews had had a separate assessment of their own, carer-related needs (see section 7.4 below), several of these interviewees reported that the IB assessment and support planning processes had been more holistic than their previous experiences, offering a broader perspective on the support needed by the disabled person within his/her wider family context. Carers of older people who had been offered an IB were more likely to report this wider perspective which, amongst other things, was also likely to take into account the support they needed as carers. In contrast, carers of people with learning disabilities were more likely to report that their own support needs were not taken into account in the service user's assessment and support plan.

It seems, therefore, that the nature, level and scope of carers' involvement in these processes may all contribute to carers' overall satisfaction. Potentially, therefore, some of the benefits that carers appeared to derive from IBs were due to the fact that the IB assessment and support planning processes have more capacity than standard practice to reflect their perspectives. The variability in satisfaction levels in the larger sample and the very variable experiences of carers who took part in the semi-structured interviews suggests that there is potential for more widespread benefits. From the interviews with carer leads it would appear that this variation in experience partly reflected historical patterns of how 'carer-aware' team managers and individual workers were, and partly variations between staff working with specific user groups. The latter will be associated with attitudes to carers and their perceived role and with assessment of risk across health and social care and the importance put on ensuring that information that carers have access to what they need to know about someone's treatment. Carers in the semi-structured interviews who expressed dissatisfaction with IBs tended to be those who felt their own views on the service user's needs had been ignored in assessment and support planning. The contrasting experiences of carers supporting an older person and those supporting a learning disabled service user were particularly noticeable. They 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.

Beyond the processes of assessment and support planning, to what extent did carers feel that they benefited from the new support arrangements that were put in place with the IB? Clearly, the extent to which carers' own support needs were taken into account in wider, more holistic assessments will have some impact here, at least insofar as the IB support plan subsequently addressed those needs. Again, 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. However, this was not the only source of benefit for carers. IBs also gave at least some carers new choices and opportunities. These 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. Significantly, many carers had also taken on the additional responsibilities of managing the IB, paying staff and co-ordinating the IB holder’s support arrangements. These responsibilities were particularly burdensome for carers who lived in a separate household and for those supporting more than one disabled person. However, so long as the expectations of the support plan were met and benefits to the IB user were apparent, carers appeared to regard this extra work as worthwhile.

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 that their carers were interviewed. 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. This is discussed below.

7.3 IBs, carers, policy and practice

As the introduction to this report described, since the mid 1990s, policies and practice relating to carers have developed along largely separate lines from those for disabled and older people. Carers have rights to an assessment of their own needs, independently of the wishes or circumstances of the person receiving care; this must now take into account their employment, lifelong learning and leisure needs. Carers can also receive direct payments in their own right. According to the interviews with IB and carer lead officers, the IB pilot projects were initially implemented largely independently of these arrangements; only later in the pilot projects did sites begin to consider how emerging IB policies and practices might be integrated or aligned with carers’ assessments and support.

The fact that none of the carers taking part in the semi-structured interviews reported having a separate assessment of their own, carer-related needs indicates a possible failing in the application of IBs to these carers. The law requires an assessment to have been offered. Of course, people sometimes do not realise that they have been offered or indeed received an assessment and some of them may have declined one. However, if the offer is routinely not made, this is a serious problem that needs to be addressed.

It was clear from the interviews with senior managers responsible for implementing IBs and those responsible for carers' services in the pilot sites that relationships between the two sets of arrangements were far from clear and unproblematic. Carer lead managers had rarely been involved in the early development of IB processes. There was a lack of clarity and consistency between authorities over how carers' support needs were treated within the IB assessment and resource allocation processes; over the relationship between IB assessments and local authorities' statutory duties in relation to carers' assessments; and over whether the resources currently allocated within local authorities for carer support (particularly for the funding of short-term breaks for carers) should be included within the resources to be allocated through the IB RAS. Some carer lead officers argued for a separate RAS for carers because the IB assessment and RAS paid insufficient attention to carers' needs. The IB assessment and RAS was also not an adequate or appropriate basis for local authorities to meet their new statutory obligations in relation to carers' employment, training and leisure needs. However, only one site had so far used its carer support budget to develop a separate RAS and IB process for carers. In other cases, local authorities continued to operate separate IB and carer assessment and resource allocation processes (in the form of grants and direct payments for carers).

There was also confusion about what role carers should play in planning an IB user's support arrangements. On the one hand, there were strong arguments that carers should be actively and fully involved – although there was no agreement on who should be responsible for helping carers in carrying out this support planning role. The discussion above, on the contribution of satisfactory assessment and support planning process to positive outcomes for carers, would tend to support the argument in favour of carers' involvement. On the other hand, there were concerns that involving carers risked compromising choice and control for IB users. To the extent that this concern informed local practice, it was reflected in the feelings of some carers taking part in the semi-structured interviews that their opinions had been side-lined in the development of the service user's assessment and support plan.

Other uncertainties and inconsistencies about the role of carers characterised the IB implementation process. Both carers themselves and senior officers responsible for carer services reported a lack of clarity over how and what the IB could be used for. Carers were particularly unclear about how underspends in an IB that they were managing for the person they supported would be treated – would they lose some of the IB if it was unspent? This issue reflects the longer experience of some of the carers in managing an IB – it is possible that such concerns might have been reported by IB users themselves had a longer follow-up period been possible in the main IBSEN evaluation. Carers also reported a need for guidance on how payments from the IB should be made – in cash or by cheque; and on who they or the service user could employ. Again, these are concerns which are not peculiar to carers and would probably have arisen in the main IBSEN evaluation study had a longer period elapsed before the follow-up outcome interviews.

As in the main IBSEN evaluation, there was widespread uncertainty about the boundaries of what IBs could legitimately be used for. Carer lead officers, IB lead officers and carer interviewees themselves reported widely inconsistent practice with regard to paying carers from a service user's IB. Only a small minority of carers in this study were receiving payments from the service user's IB; here carers reported that a service user's ability to pay a carer could contribute to positive outcomes for the IB user by reducing feelings of dependency and indebtedness. Levels of payments to carers varied from that equivalent to a part-time job to small payments to cover carers' expenses. However, there were drawbacks. Carers who were responsible for managing an IB on behalf of a user were aware of the potential conflict of interest in paying themselves from the budget. Only six carers taking part in the semi-structured interviews considered themselves employed by the IB holder; only two had a contract of employment; some felt the payment they received did not reflect the actual extent of their care-giving work; and all considered their situation to be very insecure. Two carers had had their own social security benefit entitlements reduced because of the IB payments they were now receiving.

7.4 Recommendations for policy and practice

As with the main IBSEN evaluation, this study has shown that IBs can have positive impacts. Indeed, despite the potential for IBs to have negative impacts on carers, the evidence of positive outcomes in this study is clearer and more consistent than the evidence of positive outcomes for IB users in the main evaluation. This may simply reflect the relative timing of the two studies and the fact that the service users and carers who took part in this study had had more opportunity to experience their new support arrangements. Nevertheless, the evidence of positive outcomes is striking, given the relatively small samples involved in this study. 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. There is a need for clearer guidance for carers who take responsibility for managing an IB on how and what this can be used for. And 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.

At a policy level, the study has revealed the complexities and contradictions that arise from the intersection of a user-focused personalisation agenda and England's strong tradition of recognising carers' independent rights and support needs. Across the 13 IB pilot sites, there appears to be a lack of clarity about how carers' needs are to be assessed; the extent to which support for carers should be built into an IB; and the implications for local authorities' other statutory duties, particularly those imposed by the 2004 Carers (Equal Opportunities) Act. The resolution of these tensions is not straightforward and may require wide-ranging reconsideration of current policy assumptions that treat disabled and older people and their carers separately. This study suggests that for some service users and carers these assumptions may indeed be appropriate; however the quantitative analyses presented in this study suggest that, even without separate treatment, carers may nevertheless benefit from IBs.

The findings suggest that personal budgets have the potential to deliver core outcomes of the revised National Carer Strategy (Department of Health, 2008). There was evidence that IBs involved carers as 'expert care partners' and can facilitate access to 'integrated and personalised services they need to support them in their caring role'. The finding that occupation was the social care outcome domain suggests they could support carers having a 'life of their own'. There at least is the potential, although not demonstrated here, of 'financial support' through IBs and the overall quality of life finding suggest IBs helped keep them 'mentally and physically well'. Personal budgets are likely to be even more successful if some of the caveats identified above about the implementation process were addressed. 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, ASCOT outcome indicator and satisfaction with the care planning process are all relatively low burden measures that should reflect change where there are improvements in performance.

7.5 Further research

The study raises a number of questions that warrant further investigation. Limitations on what was possible in the scope of this study mean that the conclusions drawn about the costs to the public purse and the impact on costs to carers have had to be drawn 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 and 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.

A clear message that has emerged is the importance of carers’ satisfaction with care planning process and some indications that this varies depending on the service user group that the person they care for belongs to. This is likely to depend on other factors: 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, provider market and the professionalisation of social care. 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. What are the implications of personal budgets on other family income sources such as employment and welfare benefits? What are the implications for the care workforce and the professional development of that workforce?

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Appendix A

A.1 Selecting the study sites

Only ten of the 13 IB pilot sites in the main IBSEN evaluation were included in the IBSEN carers study for a number of reasons. Originally, the carer study restricted recruitment only to carers providing assistance to people with learning disabilities and older people. Due to problems with recruitment it was decided to widen the criteria to include carers helping people with mental health problems and people with physical disabilities. It was too late in the study to begin new research governance procedures, which resulted in one site not being approached which had concentrated in the main IBSEN evaluation on offering IBs only to people using mental health services. A second site was rolling out IBs to all its adult social care service users so that by the time the interviews for the carers study were due to be conducted, it was expected that all the members of the former comparison group in that site would be in receipt of IBs. The third site not included in this study had focused its IB pilot project on people in transition between services and had therefore not been included in the randomisation process for the main IB evaluation. In one of the remaining ten sites there were no carers registered as having given consent. This meant that effectively nine (rather than ten) pilot sites took part in the study.

A.2 Recruitment of the carer sample

In principle, all carers who had given consent to take part in the main IB evaluation at the point of registration in each of the (nine) IB pilot sites collaborating with the study were eligible to take part in the study. The numbers of carers registered in the different sites varied from less than ten to over 70.

The research team checked all carer consents against the recorded details for service users in the main IBSEN evaluation in both the IB and comparison groups. After identifying those individuals who were eligible for this study and it was still appropriate to contact, letters were sent out to all carers reminding them that they had given consent to participate in the study and inviting them to take part in an interview focusing specifically on their views about the impact and outcomes of IBs on their role as a carer. Carers were given the opportunity to ‘opt out’ by contacting the research team within seven days of receipt of the letter. Interviews (either structured outcome interviews conducted by experienced sessional interviewers, or semi-structured qualitative interviews conducted by SPRU researchers) were then arranged with those carers willing to take part in the study.

Timing was an important issue; carers were not contacted until after the service user (or their proxy) had undertaken the six-month outcome interview for the main IBSEN evaluation. This slight delay in conducting the interviews had several consequences. First, it may have contributed to the difficulties in recruiting carers to the study as, over time, there were increased risks of contacts with carers being lost or of changes in the circumstances of carers or service users that made further interviews inappropriate. Second, there were a few service users who had been allocated to the comparison group for the main IBSEN evaluation, who were in receipt of an IB by the time their carer was interviewed for this study. To be consistent with the main IBSEN evaluation, the allocation group that service users had originally been randomised into had to remain the same for the carer. However, two of these were in fact reassigned to the IB group and semi-structured interviews with their carers carried out. Third, by the time of the interviews for this study, some members of the IB group had been in receipt of an IB for up to a year. The interviews with their carers therefore reflected this longer term experience. A further complication related to the need to contact care managers in respect of those carers who did not live with the service user and for whom information on safety issues, essential before an interviewer visited, has not been collected in the main IBSEN study.

As noted above, it was intended to restrict recruitment to carers of older people and carers of people with learning disabilities only. However, attrition rates were high. Carers refused to take part in an interview for the study for a range of reasons: the service user had died or entered long term care; or the carer had taken part in a previous interview(s) for the main IBSEN evaluation as a proxy respondent and was unwilling to take part in another. In addition, there were instances of contact details being incorrect and the research team being unable to obtain accurate contact information, and interviewers not being able to make contact with carers despite persistent attempts for up to two months.

Various strategies were adopted to try to boost the size of the study sample, including approaching carers of all user groups. In addition, two further sources of carers were pursued: (a) carers who did not give consent to participate in the main IBSEN evaluation but had been interviewed as a proxy interviewee at the two-month stage and had agreed at the end of that interview that they were willing to be contacted about taking part in further research; (b) carers interviewed as proxies in the main IBSEN evaluation who said they would be willing to take part in further research.

The majority of carers who agreed to take part in the study were interviewed using the structured outcome questionnaire. However, a sub-sample of carers were selected to take part in a semi-structured qualitative interview.

A.3 The sample

Not all the people interviewed were included in the analysis. Among the structured outcome interviews, three carers were removed from the sample as the service user had not been randomly allocated within the overall IBSEN evaluation, and a further eight records were excluded as they could not be matched to a randomised record in the full IBSEN sample or to a six month outcome interview with the service user. Carers were providing assistance to three service users who had declined the offer of an IB in the main IBSEN evaluation. To follow the methodology in the main IBSEN evaluation, this small sample was included in the IB group.

A.4 Structured outcome interviews

A number of outcome indicators and instruments were included covering psychological well-being, self perceived health, social care outcomes, quality of life and indicators of satisfaction and quality of care:

- *Psychological well-being*

The psychological well being of service users was measured by the 12-item version of the General Health Questionnaire (Goldberg, 1992). This scale comprises 12 items that explore 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 to 3) which generates a total score ranging form 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 designated cut-off score of 4 or more. The GHQ-12 has been extensively used in national studies including the British Household Panel Survey and the Health Survey for England providing the scope for comparative analysis in the future. In our sample Cronbach's Alpha for the scale was 0.92, demonstrating that it had good internal reliability.

- *Self Perceived Health*

A person's perception of his/her own health has been found to be a reliable predictor of functional decline (Ferraro, 1980), chronic disease (Shadbolt, 1997) and even mortality (Idler and Benyamini, 1997). 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'.

- *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 item was measured using 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 preference weighted indicator that reflects need for help and outcome gain from services across 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 ask respondents to choose, from a series of three deteriorating situations, which of the options best describes their situation. In this way, the questions aim to capture no needs, low level needs and high level needs in each domain. Table A.1 below shows the responses actually used in the interview for each of the five domains. Using the same format, carers were asked to best describe their situation in the absence of services or the support purchased through the IB. Rather than assuming that each domain and level is of equivalent importance, the measure is weighted using population based preferences (see Burge *et al.*, 2006). Outcomes can be reported in terms of both current levels (a score ranging from 0 to 2.80) and a difference measure that reflects the difference between expected needs in the absence of services and current levels. The focus in the study was on current need, which had a Cronbach’s Alpha of 0.80, demonstrating that it had good internal reliability.

Table A.1 Options provided for ASCOT domains to reflect individual levels of need

Domain	*Need level*	*Description*
Control	No	I feel in control of my daily life
	Low	I have some control over my daily life but not enough
	High	I have no control over my daily life
Safety	No	I have no worries about my personal safety
	Low	I have some worries about my personal safety
	High	I am extremely worried about my personal safety
Social participation	No	I have a good social life
	Low	I have a social life but sometimes I feel lonely
	High	I feel socially isolated and often feel lonely
Occupation[1]	No	I do the things I want to do
	Low	With help from services I do the things I want to do
	Low	I don't do many of the things I want to do
	High	I don't do any of the things I want to do
Caring role	No	I provide X with the kind of support that I want to provide
	Low	At times I find it difficult to provide X with the kind of support that I want to provide
	High	I am not able to provide X with the kind of support I want to provide

[1] Four levels were presented to respondents in these domains but reduced to three as shown here for the purpose of scoring the measure.

- *Satisfaction and quality of services*

Measures of satisfaction and perceived quality of services 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). For transparency reasons, the raw scores of each item underlying the quality of care measure should be transformed into dichotomous scores to ensure that each element of the measure is weighted equally. It is likely that the most important difference will be between service users who respond at the extreme end of each scale and the other codes. However, as well as the overall small sample in this study, only small proportions of carers responded at the extreme end of each scale, so to use these items to compare responses between the carers of individuals in the IB and comparison groups would be misleading.

- *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). Good internal reliability was found for all three subscales (0.62 for the positive value of caregiving scale; 0.84 for the negative impact of caregiving scale and 0.73 for quality of support).

A.5 Semi-structured interviews

Particular groups of carers were targeted to take part in the semi-structured interviews. Priority was given to carers of older people, carers of people with learning disabilities, and carers from minority ethnic populations. Selection of interviewees also aimed to identify those with longer experience of the service user's IB. Efforts were made to recruit carers living in different pilot sites, as well as both co-resident and extra-resident carers. The interviews were conducted between October 2007 and June 2008, with most conducted during 2008. Three pilot interviews were carried out to test out the topic guide. Since there were only minor changes that had to be made to the original version, it was decided to use the three pilot transcripts and analyse them alongside the other 21 transcripts.

As well as the semi-structured interviews with carers, telephone interviews were carried out with officers responsible for carers' assessments and services in 12 of the 13 IB pilot sites (the officer in the thirteenth pilot site could not be contacted for interview, despite numerous attempts). In addition, two rounds of semi-structured interviews with officers with lead responsibility for implementing IBs in all 13 pilot sites had been conducted during the main IBSEN evaluation. Data from these interviews relating to carers was identified and extracted for further analysis.

A.6 Other data

For service users in the main IBSEN evaluation, there were three sources of data: baseline returns; support plan records; and six month interviews (Glendinning *et al*., 2008). Information about service use and needs were collected both at baseline from local authorities and at six months from the individuals in the comparison group. For the IB group, support plan data, which included the costs of different elements of the plan, were collected from the pilot sites. Due to time constraints in the main IBSEN evaluation, baseline and support plan data for carers was not consistently collected. All relevant data for carers that was later used in this study was collected during the structured outcome interviews.

A.6.1 Baseline data

For the service user, baseline administrative information was collected about whether the person was a new referral, their primary service user group, FACS level, basic demographic information (ethnicity, age, gender and so on), and information about their current circumstances (previous support packages, household composition, receipt of benefits, employment status, activities of daily living, presence of carer and so on). As reported in Chapter 2, it was expected that service users with identified carers would be more dependent compared with those without informal support. Table A.2 reports the proportion of service users with and without an identified carer requiring regular help to perform 12 activities of daily living, according to the baseline data collection instrument.

Table A.2 Activities of Daily Living (ADLs)

	Overall IBSEN sample (without informal carer) % (n)	*Overall IBSEN sample (with an informal carer)* % (n)	*Overall IBSEN sample* % (n)
Getting up/down stairs	41 (139)	50 (221)*	46 (360)
Going out of doors and walking down the road	44 (161)	66 (319)***	56 (40)
Getting around the house	14 (52)	29 (147)***	22 (199)
Getting in/out of bed or chair	25 (97)	32 (163)*	29 (260)
Using the toilet	21 (81)	33 (168)***	28 (249)
Washing face and hands	22 (85)	31 (156)**	27 (241)
Using bath, shower or washing all over	52 (203)	66 (343)***	60 (546)
Getting dressed/undressed	40 (155)	52 (267)***	46 (422)
Washing hair	44 (165)	60 (304)***	53 (469)
Feeding themselves	14 (53)	18 (88)	16 (141)
Cooking/food preparation	51 (197)	77 (393)***	66 (590)
Housework	67 (259)	83 (421)***	76 (680)
Shopping	68 (268)	86 (436)***	78 (704)

Significance Levels: * $p< 0.05$ ** $p< 0.01$ *** $p< 0.001$.

Where there was carer baseline data, information was collected about basic demographic characteristics (ethnicity, age, gender and so on), and current circumstances (household composition, previous service package, employment status, relationship to service user).

A.6.2 Support plans

For IB holders, pilot sites were asked to complete a support plan record designed to capture the content of the agreed plan. Support plan records also included information on:

- Who held the budget and who was involved in the support planning and support management.

- Activities included in the support plan; the budget per year and the frequency of activity; and whether services were commissioned by the budget-holder/nominated person or by the local authority.
- The formal organisation of the budget in terms of who held the budget.
- Activities included in the support plan, the budget per year and the frequency of activity.

A.7 Estimating costs

There were two principal sources of data in the main IBSEN evaluation: local authorities, and service users participating in the six month outcome interview.

A.7.1 Cost of packages for service users

During the main IBSEN evaluation, as we did not interview individuals and their carers at baseline, we asked local authorities for the components and costs of service packages for those already in receipt of services. Although there was a substantial amount of missing data, authorities were able to provide sufficient data to provide a good picture of the costs of packages prior to the introduction of IBs, as described in Chapter 4.

As described above, we had intended to collect information about service use in a structured way as part of the six month interview for both IB holders and the comparison group. This was done for the comparison group but did not prove practical for the IB group so we drew on the support plan record instead. The total cost of the IB was estimated by summing the total costs of the services and support identified on the support plan record. We included funding within the IB for the following activities: personal assistance, home care (from a registered external agency), home care (through in-house services), telecare equipment, other equipment, other one-off purchases, leisure activities, transport, accommodation, planned short breaks, payment in lieu of services, support with managing a direct payment, payroll support for direct payment users, child care, health and dental services, meal services and all other services that were reported on the support plan record.

Information about service use supplied by individuals (or their proxies) in the comparison group at six months provided us with their overall pattern of resource use. In order to compare like with like, it was important to reflect unit costs within the same sites as these would best reflect what IB holders would be able to purchase with their budgets. The pilot authorities were asked to provide unit costs for all services used by people in the comparison group in their area. Each unit cost was multiplied by the appropriate frequency of use and summed to produce an overall social care cost for each member of the comparison group.

The social care resources identified along with the unit costs supplied by the pilot local authorities are listed in Table A.3. To provide a comparison, data were extracted from the PSS EX1 2006-2007 and from Curtis (2007) (where necessary inflated[28] to 2007/2008 prices). Table A.3 shows the variation in unit costs between local authorities which will have an impact on the calculated social care cost for people who had not been offered an IB.

A.7.2 Carers' health service use

During the structured outcome interviews for this study, carers were asked about their own contacts with their GP, health visitor, district nurse, practice nurse, occupational therapist, chiropodist, day hospitals, accident and emergency units and inpatient hospital stays. National unit costs were used for these services (Curtis, 2007) inflated to 2007/2008 prices. The service resources identified along with their unit costs are listed in Table A.4.

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[28] The PSS inflator was used which was 3.6 per cent for converting 2006/2007 prices to 2007/2008.

Table A.3 Average social care costs

Social care resource	*Average unit cost (supplied by pilot sites) 2007/2008*	*National average - PSS EX1 (2006-07)*	*Other sources*
Home care			
Mean	£15.54	£17.70	
Minimum	£10.50		
Maximum	£21.68		
Day centre per attendance			
Mean	£39.75		£28.14[29]
Minimum	£24.72		
Maximum	£56.00		
Lunch club per session			
Mean	£2.76[30]		
Minimum			
Maximum			
Meals on wheels (per meal)			
Mean	£4.62	£3.50	
Minimum	£3.20		
Maximum	£5.25		
Supported employment service			
Mean	£12.99[31]		
Minimum			
Maximum			
Average gross weekly expenditure on supporting adults in residential and nursing care [32]			
Kensington – Learning disability		£910	
Essex – Physical disability		£893	
Oldham – Older		£403	
Oldham – Learning disability		£383	
Norfolk – Mental health		£486	
Lincolnshire – Older		£415	
West Sussex – Older		£788	
Bath – Learning disability		£864	
Bath – Physical disability		£918	
Gateshead – Physical disability		£726	
Gateshead – Older		£402	
Local authority social worker[33]			£131

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[29] Data from Curtis (2007).

[30] Only one local authority supplied a figure.

[31] Only one local authority supplied a figure.

[32] The PSS EX1 2006-07 data were inflated by 3.6 per cent to reflect 2007-2008 expenditure.

[33] Based on an hour of face to face contact.

Table A.4 Summary of main service resources and unit costs

Service resource[34]	*Unit cost 2007/2008*
Day Hospital per visit	£142[35]
District nurse, health visitor or other kind of nurse [36]	
Home	£77
Clinic	£55
Home and clinic	£68
Practice nurse	
Home	£34
Clinic	£28
Home and clinic	£28
Occupation therapist, physiotherapist, speech therapist or any other kind of therapist[37]	
Home	£38
Clinic	£29
Home and clinic	£36
General Practitioner	
Surgery	£31
Home	£50
Hospital accident and emergency department	£32[38]
Chiropodist	
Home	£17
Clinic	£9
Home and clinic	£19
Inpatient service – per bed day	£231[39]

A.8 The impact of service user related variables on outcomes

Table A.5 lists all the service user-related variables that were used in the multivariate analysis when exploring what factors had an impact on outcomes. As reported in Chapter 6, among the service-user related variables, allocation to the IB or comparison group, tenure and social care costs all had a significant impact on outcomes.

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[34] Seeing a health professional at home - the unit cost was based on an hour spent on a home visit. Seeing a health professional in the clinic - the unit cost was based on an hour of clinic contact. For home and clinic, the unit cost was based on an hour of client contact.

[35] General inpatient cost – weighted average of all day care attendances in a hospital.

[36] Based on an average unit cost between a community nurse (including a district nursing sister and district nurse) and health visitor.

[37] Based on an average unit cost between a hospital physiotherapist, community physiotherapist, community occupational therapist and a community speech and language therapist.

[38] Based on an average between cost of walk-in, follow attendance and non 24 hour A&E department.

[39] Based on the weighted average of all patient rehabilitation stays excluding patients with brain injuries.

Table A.6 shows the carer and caring task-related variables that were investigated in the multivariate analysis. As reported in Chapter 6, average hours per week caring, satisfaction with the support planning process, being able to go on holiday with the care recipient were significantly associated with outcome variation. All the questions comprising the COPE index were included in the initial models of outcome variation. Three items had a significant impact on outcomes:

- Do you have a good relationship with X?
- Does caregiving cause you financial difficulties?
- Does caregiving cause difficulties in your relationship with your family?

Table A.5: Service user related variables tested for their impact on outcomes

Service user variables	
Baseline	*Support plan record*
Allocation Group[40]	Support plan agreed
User groups	Services paid for by IB in place
Age	IB deployment
Gender	Involvement with support planning
FACS	
New referral	*6 month interview*
Previous support package	Social care costs[41]
Previous non social service package	Satisfaction with financial arrangements
Gross cost of previous support package	Satisfaction with support planning process
Service user savings	
Financial contributions for care services	
Dependency levels	
Get up and down stairs or steps	
Go out of doors and walk down the road	
Get around indoors (except steps)	
Get in and out of bed (or chair)	
Use WC/toilet	
Wash hands and face	
Bath, shower or wash all over	
Get dressed and undressed	
Grooming (i.e. washing own hair)	
Feed him/herself	
Cooking/food preparation	
Housework	
Shopping	
Service user employment status	
Risk to/from other	
Evidence of cognitive impairment	
Household composition	
Tenure[42]	
Marital status	
Accommodation	
Benefits	

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[40] IB significant impact on quality of life and social care outcome (ASCOT).
[41] Significant impact on GHQ-12.
[42] Significant impact on GHQ-12.

Table A.6 Care-related variables included in outcomes' analysis

Carer outcome interview

- Age
- Gender
- Marital status
- Household composition
- Tenure
- Employment status
- Living with care recipient
- Involvement with support planning
- Who carer provides care to
- If interviewee was the main carer
- Caring tasks that carer perform;
  - Personal care
  - Housework
  - Providing transport
  - Preparing meals
  - Gardening
  - Shopping
  - Looking after pets
  - DIY
  - General finances/paperwork
  - Managing care arrangements
  - Medicine management
  - Other health tasks
- Average number of hours a week caring [48]
- Average hours a week do other informal carers spend caring
- Average hours a week do paid carers spend caring

- Length of time IB has been in place
- Support plan agreed
- Understanding of how IB amount was decided
- Satisfaction with:
  - The amount of the IB
  - Financial arrangements – how IB is paid
  - Financial arrangements - amount of paperwork involved
  - Support planning process[43]
- Did the assessment for the IB cover the help that carer provides for service user?
- Whether carer's needs was taken into account in the assessment
- Did carer and/or service user receive enough help when deciding what to spend the IB on
- Whether the relationship between service user and carer has changed since the IB
- A regular arrangement - carer can have a break?[44]
- Did carer manage to have a break in the last 6 months
  - Not with service user
  - With service user[45]
- COPE INDEX
  - Do you have a good relationship with X? [46]
  - Does caregiving cause you financial difficulties? [47]
  - Does caregiving cause difficulties in your relationship with your family?[49]

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[43] Significant impact on quality of life outcome.
[44] Significant impact on GHQ-12.
[45] Significant impact on quality of life and social care outcome (ASCOT).
[46] Significant impact on quality of life outcome.
[47] Significant impact in GHQ-12.
[48] Significant impact on quality of life and social care outcome (ASCOT).
[49] Significant impact on social care outcome (ASCOT) and GHQ-12.