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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

[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.

[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.

[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

[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.

[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.

[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.

[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

[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

[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.

[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

[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.

[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.