Individual Budgets: Lessons from early users' experiences

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Abstract

Within the context of modernization, there has been a trend towards 'cash for care' schemes designed to bring choice and control closer to the service user. In England, Individual Budgets (IBs) are being piloted with the aim of promoting personalized support for disabled people and other users of social care services.

This paper reports on the experiences and outcomes of early IB users two to three months after first being offered an IB. The users included adults with physical/sensory impairments, learning difficulties, mental health problems and older people. Semi-structured interviews were carried out with nine service users and five proxies.

The findings suggest that IBs have the potential to be innovative and life-enhancing. However, achieving this potential in practice depends on a range of other factors, including changes in the routine practices and organizational culture of adult social care services and ensuring users have access to appropriate documentation and support. Any conclusions drawn from the experiences of these early IB users must be treated with caution. The findings nevertheless indicate some of the issues that will need to be addressed as IBs are implemented more widely to replace conventional forms of adult social care provision.

Key words: Individual Budgets, disabled people, older people, service users.

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Introduction

Current policies in England aim to modernize adult social care by promoting choice and personalized support for disabled people and other users of services. Building upon the experience of Direct Payments (DPs) in the 1990s and the model of In Control developed with people with learning difficulties in the 2000s, Individual Budgets (IBs) are being piloted between 2005 and 2007 with the aim of enhancing users' choice and control. This paper reports the findings of interviews conducted with a small sample of early IB users. Following a description of the policy background, research methodology and interviewees' previous support arrangements, the paper presents the IB users' experiences of assessment, support planning, using IBs and the actual and/or anticipated outcomes. The conclusions discuss the some of the implications for practice and implementation.

Direct payments (DPs), In Control, and IBs all reflect trends towards person-centred planning (Dowling *et al.*, 2006), individualization, and schemes that substitute 'cash' for 'care' (Glendinning and Kemp, 2006; Ungerson and Yeandle, 2007). The latter are common in parts of Europe, Australia, Canada and the United States (Glendinning and Kemp, 2006; Leece and Leece, 2006; Lord and Hutchison, 2003; Ungerson and Yeandle, 2007). In some countries, cash-based schemes are only available to older people as part of arrangements for funding long term care; elsewhere cash payments are only available to younger disabled people as part of

moves to support independent living. Small-scale studies of the impact of cash-based schemes on older people suggest that users are relatively satisfied and consider themselves to be exercising greater choice and control (Ungerson and Yeandle, 2007). However, commentators have expressed concerns about the 'commodification of care' (Ungerson, 1997); the impact of cash-for-care schemes on informal and previously unpaid family carers (Breda *et al.*, 2006; Glendinning, 2006; Ungerson and Yeandle, 2007); and the growth of grey/migrant labour markets in social care (Ungerson and Yeandle, 2007).

The development of individualized cash-for-care schemes is being influenced by the demands of the disability movement for increased independence and control (Barnes, 1993; Campbell and Oliver, 1996; Dowling *et al.*, 2006; Priestley, 1999); demographic factors, particularly population ageing; and economic pressures to contain the costs of long-term care through the use of unpaid informal care while simultaneously increasing formal labour market participation. Cash-for-care schemes challenge assumptions about dependency and the role of disabled people in society and require significant changes in both everyday practice and power relationships between service providers and users.

In England and Wales the 1996 Community Care (Direct Payments) Act empowered local authorities to offer direct payments (DPs) to people assessed as needing care services and willing and able to use cash payments to purchase their support. However, take-up of DPs has been low (CSCI 2005, Priestley *et al.*, 2006) and since April 2003 local authorities have been required to offer DPs to all social care service users.

There nevertheless remains considerable variation in take-up between different groups of service users (Leason and Sale, 2004; Spandler and Vick, 2004, 2005) and within and between different parts of the UK (Priestley *et al.*, 2006). The underlying causes of this slow and patchy growth include local differences in political culture, reluctance on the part of local councils to relinquish control, fears of job losses, concerns about cost, risk-adverse professional practice and uncertainties about the capacities of service users (Commission for Social Care Inspection, 2004; Ellis, 2007; Fernandez *et al.*, 2007; Hasler 2003; Priestley *et al.*, 2006). From the perspective of potential users, lack of information and practical support, anxieties about recruiting and employing personal assistants and 'paper work' (Spandler and Vick, 2004) are further reasons for low take-up.

The In Control programme, launched in 2003, works with local authorities to develop systems of self-directed support for people with learning difficulties. In Control helps local councils to develop a resource allocation system (RAS), through which service users are told how much money is available to them to fund their support arrangements. Service users are helped to devise tailor-made support plans to meet their self-assessed needs and desired outcomes (Poll *et al.*, 2006). However, the scheme is limited; it was developed primarily for people with learning disabilities and only includes local authority social care resources.

Building upon In Control and Direct Payments, Individual Budgets (IBs) aim to extend self-directed support to a broader range of user groups and funding streams. Individual Budgets were first proposed in the Cabinet Office Strategy Unit report

Improving the Life Chances of Disabled People (Prime Minister's Strategy Unit, 2005) and subsequently formed a key proposal in the White Paper on health and social care *Our Health, Our Care, Our Say* (DH, 2006). Like Direct Payments and In Control, IBs aim to bring choice and control closer to the end user. However, in addition:

- ➢ IBs combine resources from the different funding streams to which an individual is entitled – currently these are local authority adult social care, integrated community equipment services, Disabled Facilities Grants, Supporting People for housing-related support, Access to Work and the Independent Living Fund (ILF). Pooling the resources from these funding streams to create one user-controlled budget is intended to give IB users greater flexibility in using the resources they are eligible for, to meet their needs and achieve desired outcomes. Despite the pooling of central and local government funding streams, primary responsibility for implementing IBs and for ensuring an appropriate range of support is available for older and disabled people remains with local authorities.

- ➢ IBs aim to align assessments from the different funding streams, encourage self-assessment (where appropriate) and introduce transparent resource allocation systems (RAS), so an individual knows exactly what resources are included in her/his IB.

- ➢ IB holders are encouraged to devise support plans to help them meet desired outcomes and can purchase that support from social services, the private

sector, voluntary or community groups or family and friends. Assistance with

support planning may come from care managers, independent support

planning/brokerage agencies, or family and friends.

➢ IBs can be deployed in different ways: by the service user as a cash direct

payment; by the care manager; a Trust; as an indirect payment to a third party;

or can be held by a service provider. Local authorities piloting IBs (see below)

are encouraged to be more creative and flexible, especially when IBs are

provided in the form of a cash direct payment; this flexibility includes less

elaborate monitoring arrangements and encouraging the use of IBs for a wider

range of outcomes or support needs besides personal care.

IBs are being piloted in thirteen local authorities in England between 2005 and 2007.

The user groups being offered IBs include older people, people with learning

disabilities, mental health service users, people with physical and sensory

impairments and disabled people in transition (e.g. from residential to community

care). Service users' experiences of IBs provide a partial perspective on the success

of the pilots.

Methods

Interviews were conducted with fourteen early IB users from four of the thirteen pilot

sites. The sites were selected because they reported having made offers of IBs

during summer 2006, with the expectation that users selected for interview would be

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in receipt of an IB. Three of the four sites were in the South of England and one in the North-West of England; two were large counties with significant rural populations and two were urban metropolitan unitary councils with large minority ethnic populations.

Ethics approval was received from NHS COREC, along with local research governance bodies in each of the four IB pilot sites. Approval was also obtained from the Association of Directors of Adult Social Services (ADASS).

Interviewees were asked about their previous support arrangements; their experiences of (self)-assessment and support planning; and the (anticipated) impacts of IBs. The topic guide was semi-structured, with open-ended questions. Interviews were tape recorded, transcribed, coded and analysed using the framework approach. Qualitative interview data were analyzed by a process of data reduction, data display, and conclusion drawing and verifying (Miles and Huberman, 1994). First, the raw data were coded according to a series of analytical categories (both a priori and emergent themes), generated by the researchers based on their readings of the transcripts. Next, the coded data were summarized onto a series of charts, one for each analytical category. The charts did not contain verbatim text but rather a synthesis accompanied by a reference to where it could be found in a transcript. Data were entered on the charts so that reading across a chart provided information about a particular participant, while reading down a chart allowed comparisons to be made across the sample. The charts were used to identify overarching themes and draw conclusions. Conclusions were verified by checking with transcripts and through on-going discussions within the research team.

The interviewees

The fourteen interviewees included five with physical and/or sensory impairments, four with learning difficulties, three with mental health problems, and two older people (see Table 1). All defined themselves as White British and ranged in age from 18 to 84 years. Nine of the interviews were conducted with the service user (with some support from family, carer, or social worker); the remaining five were undertaken with a parent or partner, acting as proxy, in the presence of a learning disabled service user. At the time of the interview, seven of the fourteen interviewees were in receipt of an IB; six had completed the (self) assessment and support planning processes and were waiting for their support plan to be signed off or their IB to come through; and one interviewee had withdrawn from the IB pilot.

Table 1   Summary of interviewee characteristics

Int.	PSI	LD	MH	OP	Service user interview	Proxy interview (parent, partner)	Prev DP user	Stage of IB
1	√				√		√	In receipt
2		√				√ parent		Waiting for support plan to be approved
3		√				√ parent	√	Waiting for support plan to be approved
4		√				√ parent		Approved, now awaiting receipt
5	√				√			Waiting for support plan to be approved + finance forms
6				√	√			Approved, waiting for finance forms
7				√	√			In receipt
8	√				√		√	Waiting for support plan to be approved
9	√				√		√	In receipt
10	√					√ parent		Withdrawn from IB scheme
11		√			√		√	In receipt
12			√		√			In receipt
13			√			√ partner	√	In receipt
14			√		√			In receipt
Total	**5**	**4**	**3**	**2**	**9**	**5**	**6**	

Limitations of the study

The interviewees were selected by staff in the pilot sites, who were asked to identify people who had been offered an IB approximately two months earlier. Thus the individuals selected for interview may not be representative of other IB holders. Additionally, because the interviews were conducted at an early stage in the IB pilots, the experiences of these users may not be typical of those offered an IB later on. For example, early users may experience more delays and uncertainty compared to those offered IBs subsequently. Nevertheless, the experiences of these interviewees offer opportunities for important learning about some of the issues that need to be addressed in the wider implementation of IBs.

At the time of the interviews, only seven of the fourteen interviewees were actually receiving an IB; the remainder could only speak about how they anticipated the IB would impact upon their lives. Nevertheless, the study was able to capture their experiences of (self-)assessment and support planning and any associated benefits or difficulties.

Previous support arrangements and current support plans

Interviewees were asked to compare their previous (pre-IB) support arrangements and the new support plans setting out how they would use their IB. Two interviewees were new referrals and thus unable to make any such comparison. Six interviewees had previously received DPs. Among most of the remainder, previous support arrangements consisted largely of personal assistants or carers coming into the

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home on a regular basis. While some interviewees were reasonably happy with these arrangements, others complained about the lack of flexibility (e.g. carers not accommodating commitments such as hospital appointments); consistency (e.g. agencies sending different carers); and unreliability (e.g. carers not turning up on time).   Direct Payments were also criticized for being restrictive, as interviewees believed they could be used to pay for personal care only and not for any other support needs.

In planning how to use their IBs, interviewees' first priority was generally personal assistance, through directly employed personal assistants, agency staff or paying family/informal carers. Interviewees also planned to spend their IBs on:

- transport to get out and about, go to meetings and be more involved in their communities;

- equipment, for example tele-care equipment;

- short periods of respite care at times that suited users and their families; and

- other things that mattered to them that would not have been funded under previous support arrangements.

Early experiences of Individual Budgets

Assessment and support planning

Most interviewees had found the self-assessment forms user-centred. Previous experiences of assessments, in which professionals decided what they needed, were reported to focus on what they could not do; but IB self-assessment and support planning were felt to be more about what they could and wanted to do. The

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processes were also felt to be holistic and encouraged people to think creatively about what they wanted to achieve:

'…It was a way of me being in charge. I didn't feel like…Social Services was telling me what I should do, what they thought was best for me, I was able to say what I thought was best for me…they're [Social Services] beginning to realize that the users are the experts, they're people with the impairments who live with them every day…You're so used to this rigid narrow little box…to be able to use the money in creative ways is…fantastic.'

Interviewees with fluctuating conditions found that the flexibility of IBs allowed them to use their allocated resources over a year and this reassured them that support would be available as and when they needed them:

' …if I am well I don't want to have to use my hours [of home care] …now they've sorted it so it's like once a year I feel like there is less pressure on me to use my hours. 'Cos before I was thinking Oh God, I'm going to have to use my hours otherwise they're going to cut them off and I won't have no hours when I'm ill, 'cos I'll probably need more than the, more hours than what I've got when I'm ill but a lot less when I'm well. So I'm going to save them up and sort of like and then when I'm ill I can have someone sort of wait on me all the time then'.

Although a few interviewees found the IB self-assessment form simpler than other self-assessments such as that for Disability Living Allowance, several people reported difficulties in completing it. Some found a number of questions difficult to understand or open to interpretation – for example, 'substantial' was entirely

subjective; 'frequent' could mean once a day, once a week, or once a month. Some interviewees had found it difficult to answer certain questions as more than one answer applied to them. There was a real concern among some interviewees that giving wrong answers could have implications for the level of their IB.

Interviewees valued the involvement of other people, including other family members, friends, social workers and inclusion workers, in completing the IB self-assessment. Several people felt that without this support potential IB holders risked under-estimating their support needs because they wanted to minimize their impairment; did not think certain things were important; or, in the case of fluctuating conditions, did not want to acknowledge that their condition could sometimes get worse. People with fluctuating conditions reported problems with both self-assessment and planning their support arrangements, because they found it difficult to predict the level of support they would need at any given time - as their condition changed, sometimes quite unexpectedly, so their support needs could change significantly too. Two interviewees said they found it helpful to do two care plans – one for 'a good day' and one for 'a bad day' – in order to derive an average.

In three of the sites (two of which also had In Control schemes), interviewees' self-assessments had been completed and support plans devized with the help of friends, family, social workers, care managers or inclusion workers. Four interviewees in these sites reported having help from a broker to work out how much support they could afford to purchase from different services. The fourth site had run a series of workshops about support planning, involving representatives from most of the organizations involved with IBs: social services, housing associations, the local

Independent Living Association, the ILF, support workers, inclusion workers, advocates, support planning brokers, Access to Work staff, occupational therapists and people already using IBs who could mentor others. The interviewees from this site had attended most of these workshops and found them very useful, because they provided an opportunity to discuss their own situation one-to-one with representatives from a range of agencies and because the costs of different services were made available. Significantly, while many interviewees in the other sites said that they would have liked more help with assessment and support planning, interviewees in this site felt adequately supported.

A few interviewees, across all sites, reported that the support planning process had improved transparency in communication between themselves, their carers and professionals. One parent interviewed as a proxy for her learning disabled son said:

> '… in the previous assessments … we never actually really saw the paperwork, the social worker did it and it was, it was all a bit cloak, not quite cloak and dagger, but it wasn't, it wasn't an open process. It was a relatively short interview, they went away, they filled the paper in, they did all the paperwork and everything else and the [number of] hours came out of it … no time did they [the professionals] come back to us and say "we have done this piece of work, do you agree with this piece of work, do you need to change it?"'.

All interviewees thought that the most important aspect of IBs was that they offered more choice and control.   Unlike previous support arrangements, IBs gave users more of a say by allowing them to identify their support needs and decide how their desired outcomes could best be met. Users felt they were given chance to think 'outside the box' and use their money in ways that could enhance their quality of life,

rather than simply using it for personal care (as had been the case with DPs). For example, one parent said that she used some of her IB to take her child to a parent and toddler group. A few interviewees had decided to spend their Individual Budget on paying for support to enable them to go to college; those with previous experience of using DPs stated that they could not have spent their DP like this.

For most interviewees, the IB was, or was expected to be, more or less the same as the value of their previous support arrangements, although some interviewees said it felt as if their IB was higher because they were able to do more with it. In four cases the overall value of interviewees' support was expected to increase, as they had at the same time been made aware of other funding streams they were eligible for, particularly the ILF.

A few interviewees said they expected IBs to shift the balance of power between users and service providers and, in the long-term, they felt this would result in better quality support.   However, those interviewees who expected the level of their Individual Budget to be considerably lower than the value of the support they had received under their previous arrangements felt this would potentially reduce their choice and control over decisions and the outcomes that mattered to them.

A number of interviewees admitted they were not clear about what an Individual Budget actually was and how it differed from a direct payment or coventional support arrangements. There was also a lack of understanding about the different options for holding the budget and a few interviewees were not clear what the Individual Budget could and could not be used for. While some people said that the whole thing was

too complex to comprehend, others felt that the details had not been clearly explained. Two people reported receiving contradictory advice from care managers about what the IB could be spent on. Most interviewees were unaware which funding streams were included in their IBs and what, if any, restrictions these placed on their support planning.

Several people thought the assessment and support planning processes were unduly lengthy. However, most people expected these processes to become quicker and smoother once the scheme was established and more staff had training and experience of helping users with support planning.

Using Individual Budgets

Interviewees who had previously used DPs reported that their IB was easier to manage as it did not require such onerous record-keeping. A few interviewees said their first impression of the Individual Budget was like a dream come true:

> "… I couldn't see how Social Services could change from "We're in charge" to trusting us, you know, I really thought there was a hidden agenda … I couldn't see how they could go from wanting to know every single little thing [about how a Direct Payment was spent] to trusting us, I was very cynical."

All interviewees stated that one of the most positive aspects of IBs was their flexibility, both in terms of what IBs were spent on and also when they were spent. Interviewees gave a number of examples of how this flexibility might help them and contribute to their quality of life. For example, they were able to ask paid carers to come at times that suited the user; they could get things done more quickly and at

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more convenient times; and they could pay their carers more flexibly on the basis of what they were asked to do rather than how long it took them to do it.

The opportunity to have support as and when needed was seen as particularly important, and fundamental to the well being of people with fluctuating conditions whose support needs varied over time. A few users said they could go through periods where they needed minimal support, but needed a lot of support at other times. Two interviewees with fluctuating conditions described how the flexibility of their IB had enabled them to pursue important personal goals. For example, one interviewee who had had to leave university because her support needs could not be met described how her IB had enabled her to return:

'… I didn't think I'd be able to go back to university without it … if I hadn't have had the Individual Budget when I got ill … the only way I've been able to come back [to university] is because of this really ... 'cos I need, when I'm ill, I need the carer to come round in the morning and get me up and get me dressed and stuff before I go to lectures otherwise I wouldn't, I couldn't dress myself, couldn't brush my hair. It's amazing the amount of things you notice when you're ill that you can't do …'

The freedom to employ one's own carer(s) was appreciated by interviewees across all groups, but the significance of this varied according to individual circumstances. Several interviewees, including those who had previously used DPs, saw it as an opportunity to maintain consistency and continuity by employing the same carers, or to hire people whom they knew and trusted like a friend or a family member. Other interviewees identified opportunities to employ different carers for different tasks. For example, one young person said that she would rather pay a friend to accompany

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her on social outings and an older carer to take care of her personal care needs. However, several interviewees planned to employ care workers (sometimes their existing carer workers) through an agency, as they did not want the extra effort of advertising for and recruiting their own staff.

Interviewees were asked about any anxieties over managing and accounting for the IB. Views differed on how much extra burden this would impose on them and their families; whether they felt able to cope with it; and whether the level of their IB was adequate. Interviewees who did not anticipate needing help to manage their Individual Budget, including most of the proxy interviewees, said they expected to be able to manage both hiring their own staff and planning and accounting for the IB. This was because either they had experience of being self-employed and were familiar with tax and insurance issues or, in the case of proxy interviewees, because they had had years of experience of caring for a disabled person. However, they all emphasized that other people without this experience could struggle and some thought they might not be able to cope with these responsibilities if their condition deteriorated.

In contrast, where the disabled person had high support needs and the level of the IB was (or was going to be) lower than the value of their previous support arrangements, there were concerns that this would place additional burdens on family members because of the implicit expectation that more unpaid informal care would be required. Three such cases were reported. In one case the gap was filled by ILF funding, so the parent carer did not feel s/he was adversely affected by the new arrangement. However another family had withdrawn from the IB pilot as they felt that they could

not cope with less money; a third case was still under review at the time of the interview.   Where levels of funding were expected to be reduced, family carers felt that was because the IB assessment and resource allocation processes had failed to take into account the higher costs of providing support for people with high level support needs, including the cost of specialist staff. There were also concerns that families were expected to provide high levels of informal and unpaid care which was neither supported nor recognized. One carer commented that IBs were:

> 'designed to cut social care budgets and 'dump' more onto family/informal carers. ... If I was ... doing the work that I'm doing for [daughter] for my neighbour's disabled son or daughter, I could actually get paid for it'.

This parent felt that the pendulum had swung from 'we know it all' to 'leaving you to cope'.

Parent carers managing a son/daughter's IB were anxious about what would happen to their support arrangements if they were suddenly taken ill. One parent carer said she was happy to take on the extra work because of the benefits she anticipated to accrue, but she would 'walk away' from the scheme if an excessive burden of paper work and review processes outweighed the benefits. Another parent carer said that while she could see the value of being able to employ their own carers, she was not able to take that role on because of other demands on her time.

Interviewees who had used a broker to manage their Direct Payment or In Control accounts prior to the IB continued using the same broker because they said they would otherwise find it hard to keep track of how their money was spent. One older

person said she would find it difficult to hire her own carers and would rather keep the same agency carers that she had known for years. The interviewee who had withdrawn from the IB pilot had done so partly because he thought he was expected to hire his own paid carers and neither he nor his family wanted to take on the responsibility of recruiting and employing somebody.

Experienced and/or anticipated outcomes of using an Individual Budget

These early interviews suggest that IBs would, and in some cases already had, enable(d) users to have greater variety and opportunities for socialising, getting out and engaging in activities that promoted inclusion, freedom and independence. A few users mentioned that, prior to receiving an IB, they were virtually housebound as their care arrangements had covered personal care only. One interviewee reflected that:

> '… personal care, … is all very well … it is very needful but ... you still, if you get somebody to put you in the bath and wash you and whatever, you still need, you need, you can still be incredibly isolated because after all that's done you sit in your chair, in your house, on your own. Whereas with the Individual Budget, because there was more leeway … it's allowed me to be able to pay for a driver and all … when I need it, you know'.

She added that one of the greatest things about her IB was that she was now able to employ someone to take her to meetings and take notes for her, something that she had not previously felt able to use her Direct Payment for.

Many interviewees described how their (previous) reliance on informal carers had created a degree of dependency; sometimes this meant having to wait a long time

until a family member was free to help them. Interviewees who had previous experience of using DPs said that both schemes helped them become less reliant on family members. However, they felt that IBs gave them even more independence as they were able to use their money more flexibly, for example giving gifts to family members to say 'thank you' for the support they provided. A few interviewees noted that this had already resulted in relationships with family members reverting from predominantly care-giving to kinship relationships.

As well as promoting independence and having a positive impact on family relationships, several interviewees said that their Individual Budget had also enhanced family carers' independence by taking the pressure off them. A couple of carers said the IB had enabled them to get out and do things for themselves without worrying or feeling guilty about leaving their disabled relative.

Many interviewees talked about how using the IB had already enhanced their sense of identity and self-esteem.   Some interviewees described how, over time, their disability had dominated how they felt about themselves and how other people viewed them. They thought the IB would help them regain their identity because it was a budget for them as 'an individual' and not as 'a disabled person'. One person said: 'At first I was wary of being me, now I celebrate it, like being reborn' and went on to note:

> '... One of the things that I've been able to do ... my appearance is really important to me because I was, that, that was me, I can't put on make-up, I can't do my hair and things like that … I've been able to pay for somebody to do that for me'.

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While no interviewees reported any negative outcomes yet from having an IB, some expressed concerns about the future. For example, a few people were anxious about the sustainability of IBs. Some were scared of 'dreaming' because their aspirations and support plans might not be realized. Several people were anxious about what would happen if their circumstances changed after their support plan had been agreed – would IBs be flexible enough to accommodate those changes? A few people were worried about IBs being misused by users, their families or social care agencies and wanted to know how this risk could be prevented. One interviewee was concerned that IBs might not meet the higher costs of providing support in remote areas where local services were not available or paid carers had to travel long(er) distances.

Factors enhancing the impact of IBs

Interviewees were asked about the factors that could help them and others like them to benefit from the potential opportunities offered by IBs.

One-to-one support with the assessment and planning processes

All interviewees emphasized the importance of professional support during the assessment and support planning processes. While they all valued the freedom to think 'outside the box', some had found this a difficult task; in the past they had been told by the professionals what they could and could not have and now needed help to learn how to plan their own support. A few people highlighted the importance of one-

to-one mentoring from people who had already been through the assessment and support planning processes and the opportunity of learning from these first hand experiences. They also thought such mentoring should be extended to cover training on the financial management of IBs.

Carers of people with learning difficulties felt that it was essential to have an advocate involved in assessment and support planning, to explain the self-assessment form; ensure that the individual's views were correctly represented; and challenge users' low expectations. This reflects other findings (Beresford *et al.*, 2006) that people with learning difficulties may have difficulty imagining alternative arrangements beyond their current situations. Independent advocates therefore appear essential to ensure meaningful and equal participation in assessment and support planning by people with restricted cognitive abilities.

On-going help with managing an IB

Interviewees thought that, in practice, the effectiveness of IBs would be determined by how much they could enhance an individual's quality of life. However, several people questioned the extent to which IBs were accessible to different groups of people. Interviewees expected IBs to work well for more able people, with straightforward support needs, who did not require high levels of family assistance to plan and manage their support. Such people should be able to determine their own support plan and manage their IB independently. However, for people with high level or complex support needs and little family support (or who did not want to rely on their families), IBs would only work if free advocacy or brokerage services were available.

Interviewees were asked if they would recommend IBs to other people in similar situations and if there were any groups of people to whom they would not recommend an IB.   Those who had a view on this tended to think that the appropriateness of the IB option depended on the interplay of people's abilities; the level of support they needed; the extent of formal and informal support available to them; and, last but not least, individual priorities and preferences. For example, while making choices and being able to use money flexibly could be important to some people, others might prefer to have fewer options and more structured routines. In general, interviewees felt that IBs might not work for older people, who could find it confusing and/or difficult to use the Budget flexibly; for people without informal support; for people needing highly structured routines; and for people with cognitive impairments or low levels of mental capacity who could easily be taken advantage of.

Conclusions

This paper presents some of the key issues raised by early users of Individual Budgets; it highlights some of the benefits as well as the barriers and blockages of this new scheme. However, any conclusions drawn from this small-scale study must be treated with caution; neither these interviewees nor their early experiences may be typical of those to follow.

Evidence from these interviewees nevertheless suggests that while in principle IBs have advantages over conventional forms of support (including direct payments),

realising this potential depends on a number of factors. Individual Budgets require changes in the routine practices and organizational culture of adult social care services, from a needs- or service- led approach to an individualized and outcomes-focused approach. This can be helped by the increased use of self-assessment documents; other research (Foster *et al*., 2006) has shown how appropriate documentation can support changes in the behaviour and culture of professionals. Further, such organizational changes require professionals to have conceptual clarity about the scheme, supported by high quality training.

The research showed that where users could identify outcomes they want to achieve, positive changes could be made to their lives. However this depends on appropriate support being available. (Self-)assessment and other forms must be accessible to a wide range of people and professionals have a vital role in offering support in assessment, support planning and managing and accounting for IBs. Without this support, IB holders and/or their families risk increased administrative, employment and support co-ordination responsibilities which could outweigh any benefits of increased choice and control. Other researchers have highlighted the importance of user-led organizations, such as Centres for Independent/Integrated Living, in supporting disabled people (Barnes *et al.,* 2001). However, there was no evidence from the user interviews in the pilot areas involved in this study of the involvement of such organizations as yet in supporting IB users.

A clear finding from this small study was that service users who are more able and/or have more robust support networks may be better able to benefit from the flexibility, choice and control associated with IBs. This is similar to research on the take-up of

direct payments, which has also identified that having help with support planning and on-going management is crucially important (Clark and Spafford, 2002; Spandler and Vick, 2005; Williams *et al.*, 2003). For those less able to manage their support arrangements independently, greater choice and control is only meaningful if it is coupled with help to plan, organize and manage that support. Sites piloting IBs will therefore need to recognize when such support is needed and how to deliver it.

The research indicated that the new resource allocation systems being developed for IBs may not, as yet, be appropriate for disabled people with high, specialist support needs. The introduction of any new assessment process is likely to result in some 'losers' as well as 'winners' and this is equally true of the more transparent IB resource allocation systems. Sites piloting IBs will therefore need to ensure their assessment and resource allocation systems are appropriate for people with very high or specialist support needs as well as others. Mechanisms may also be needed to protect individual users from sudden major reductions in the value of their support without compromising equity in the longer term.

The findings also suggest that deploying IBs in the form of a cash Direct Payment may not be appropriate for those who prefer not to have responsibility for their support arrangements. A number of interviewees who were offered an IB said that they valued having been given a choice of deployment options rather than having the scheme imposed on them. There was concern among some people that such choices may not be available if the scheme is rolled out more widely. A further challenge for the IB pilot projects, therefore, is to ensure that people who prefer to receive their support in the form of council-provided or commissioned services are

able to exercize the same level of choice and control as those receiving IBs in the form of a cash payment.

Individual Budgets are a major innovation that may transform the organization and delivery of adult social care in England. Although this paper presents 'early' findings from the research and therefore has some limitations, the findings nevertheless indicate some of the issues to be addressed in the wider implementation of IBs.

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