

Individual Budgets: Impacts and outcomes for carers

Individual Budgets (IBs), piloted in 13 English local authorities, aimed to give greater flexibility, choice and control. Although primarily intended to benefit chronically sick, disabled and older people, IBs could also be expected to affect carers. This study investigated the impact of IBs on carers in terms of assessment, support planning, costs and outcomes.

- When carers of people with IBs were compared with carers of people using conventional services, IBs were significantly associated with positive impacts on carers' reported quality of life and, when other factors were taken into account, with social care outcomes. Positive outcomes for carers partly reflected being more able to engage in activities of their choice.
- Carers' satisfaction with service users' support planning was an important predictor of carer outcomes. IBs assessment and support planning offered more opportunities for carers' involvement than conventional social care practice. Compared with carers of people with learning difficulties, carers of older people were particularly likely to appreciate holistic, family-based IBs approaches that took account of their roles.
- There was no statistically significant difference between the costs of IBs and conventional services, nor in the time spent or opportunity costs of the help given by carers in either group. However, the direction of effect suggested higher opportunity costs to carers in the IBs group. Better outcomes at no higher cost suggests IBs for service users may be cost-effective for carers.
- The 13 pilot sites varied in how help from carers was treated in service users' IB assessments. Especially early in implementation, carers' own needs risked being overlooked. Where carers' needs were included in IB assessments, this did not always comply with current legislation giving carers rights to assessments of their own needs.
- Sites also varied in how help from carers was treated in calculating the monetary value of service users' IBs. Typically IB amounts were lower if help from carers was taken into account. Only one site developed separate IB assessments and payments for carers.
- Only a minority of carers received any payment from service users' IBs. This was always far lower than the value of the help they actually gave. Local authority officers had very mixed views about paying carers from service users' IBs.

Background and aims

Individual Budgets (IBs) were piloted in 13 English local authorities between 2005 and 2007. Compared with conventional social care support, IBs were intended to:

- Increase opportunities for self-assessment
- Make transparent the resources for each user
- Bring together resources from different funding streams, to reduce multiple assessments and increase flexibility
- Be deployed in different ways and used flexibly to achieve individual outcomes.

A major evaluation found that IB users as a whole were significantly more likely to report feeling in control of their daily lives and satisfied with the support they received. It concluded that IBs have the potential to be more cost-effective than standard social care (Glendinning et al., 2008). Although carers often helped with IB assessments, planning support and managing IBs, the evaluation did not examine the impact of IBs on carers.

This linked study aimed to identify the impacts and outcomes of IBs on carers; most carers in the study were supporting learning disabled or older service users. Potential outcomes investigated included:

- Changes in the levels and types of support provided by carers following award of an IB, including different patterns for different groups of carers
- The well-being and quality of life of carers of IB users, compared with carers of people receiving conventional social care.

Findings

Implementing IBs

Most local authority IB and carer lead officers agreed that carers' issues were relatively marginal to IB implementation, at least initially. However, in some sites carer lead officers became more involved as the pilot progressed. This led to the inclusion of more questions about the help given by carers and about carers' needs – particularly those highlighted by the 2004 *Carers (Equal Opportunities) Act* – in users' IB assessments. However, practice in conducting separate or joint assessments varied widely, depending partly on the awareness of care management teams about carer issues.

There were wide variations in how help given by carers was treated in calculating the value of IBs. In some sites, support for carers was treated as an additional service needed by service users rather than by carers and the service user's IB included additional resources to address carers' unmet needs. Only one site had developed separate IBs for carers, using its Carers Grant budget. Other sites continued to offer Carers Grant payments to carers alongside IBs for service users.

Carer lead officers encouraged carers to be involved in service users' IB assessment and support planning. However, some IB lead officers were concerned that carers would influence service users' wishes and inhibit their independence; this was particularly the case with carers of learning disabled people. Views on paying carers from service users' IBs were also mixed. Although, like direct payments, IBs could not normally be used to pay close co-resident relatives, some sites interpreted these regulations more flexibly in the context of IBs. However, there was a wide range of views about the advantages and drawbacks of paying carers from service users' IBs.

Carers' receipt of support and services

Information about the costs and outcomes of IBs was collected from carers of people who had taken part in the main IB evaluation. Although not statistically significant, the average weekly level of IBs received by the service users in this study

was lower (£270; median £170) than the cost of conventional services (£390; median £350); this may reflect the lower levels of services received by people with carers (the main IB evaluation sample included people with and without carers). Although again not statistically significant, carers supporting IB users appeared to spend more time on care-related tasks than carers supporting someone receiving standard social care services.

Only a small minority of carers or other relatives received payment from the service user's IB. Payments were usually small; carers did not consider these adequately reflected the actual amount of help they gave and some were unhappy about the level of payment. However, many carers did not think it was appropriate to pay them in this way.

Carers' involvement in assessment, support planning and managing IBs

Carers of IB users were significantly more likely than carers of people in receipt of conventional services to have been involved in planning the user's support arrangements. Carers were also satisfied with the value of the IB and how it was being paid. However, there was no statistically significant difference in carers' satisfaction with IB support planning than conventional service planning.

Semi-structured interviews revealed that carers of learning disabled people were more likely than carers of older people to have contributed to service users' assessments and support planning. This may reflect both the different support needs of each group and user group-related differences in social care practice. However, carers of older people were more likely to report that their own needs and circumstances had been taken into account in the service user's IB assessment and service planning, compared with previous experiences of conventional service planning.

Although there was no difference in the proportions of carers spending time on managing paperwork and on-going support arrangements, semi-structured interviews suggested that IBs generated more work for carers in managing paperwork and on-going support arrangements. Carers reported uncertainty over how the IBs could be used; the management of underspent IBs; and problems with support plans that failed to materialise.

Outcomes of IBs for carers

Compared to conventional social care, IBs were associated with statistically significant positive effects on carers' quality of life and, when other factors were controlled for, on carers' social care outcomes. These positive outcomes were achieved despite no higher public expenditure costs, suggesting that IBs for service users are cost-effective for carers. Satisfaction with the support planning process was an important predictor of outcomes. This suggests that, compared with conventional practice, carers' greater involvement in IB assessment and support planning processes might contribute to care and support arrangements that better suit carers.

In semi-structured interviews, carers of older people were more positive than carers of learning disabled people about IBs, partly because they had more choice and control over how they spent their time – for example, being able to pay someone else to do some of the tasks they had previously done. Carers also reported benefits from IBs where these had given service users better quality of life or independence – in other words, carers' outcomes partly depended on service user outcomes.

Implications and recommendations

Since 1995, carers have had rights to assessments of their own needs and can receive services, direct payments and grants in their own right. However, IBs implementation focused primarily on service users themselves; only gradually did IBs pilots consider how IBs could be aligned with statutory obligations to assess and support carers. Both current practices and views on future alignment varied widely. There were also differing views on whether carers should be involved in support

planning and whether carers could be paid from IBs. Emerging practices need to be considered alongside local authorities' continuing responsibilities to consider carers' aspirations for work, training and leisure activities; and alongside implementation of the revised National Carers' Strategy (Department of Health, 2008).

Positive outcomes for carers were clearly associated with their involvement in planning service users' support arrangements. Carers' satisfaction with service users' support planning would be an easily-obtainable indicator of the likely impact of IBs and other personalised provision on carers.

IB processes relating to carers of older people and carers of learning disabled people appeared inconsistent. The former were more likely to experience holistic approaches to assessment and support planning; carers of learning disabled people reported concerns by social care practitioners that their involvement could compromise service users' independence and choice. Practitioners may need to balance more effectively the needs and interests of service users and carers.

Greater clarity and consistency is needed on including payments for carers in the IBs of service users; the conditions attached to such payments; and the interactions between such payments and other entitlements such as Carer Grant payments. Further research is needed on the impact of IBs on different groups of carers (younger, older, co-resident and in different households); on carers of different groups of service users; and on attitudes, practices and impacts of including carer payments in users' IBs compared with carer direct payments and grants.

Design and methods

This study was linked to the national evaluation of the IBs pilot projects, which included a randomised controlled trial. Carers of service users who had consented to take part in the main evaluation were invited to take part in this follow-up study. There were few differences between the carers in this study sample and those in the main IBs evaluation, or between the carers in the IBs and comparison groups within this study subsample. Any differences in outcomes between carers in the IBs and comparison groups could therefore be attributed to the IBs received by the service users who the carers were supporting.

- Structured interviews were conducted with 129 carers of service users from nine of the 13 IBs pilot sites who had been randomised to IBs and comparison groups. Interviews covered carers' caring activities; use of services; experience of IBs; and outcomes, using standardised outcome measures
- Semi-structured interviews were conducted with a separate sample of 11 carers of older people and 13 carers supporting learning disabled adults
- Telephone interviews were conducted with lead officers responsible for carers services in 12 of the 13 IBs pilot sites
- Data relating to carers was extracted from interviews conducted with lead officers responsible for implementing IBs in the 13 pilot sites as part of the main IB evaluation and reanalysed for this study.

References

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About the study team

This follow-up study of the impact of IBs on carers was conducted by:

Hilary Arksey

Caroline Glendinning

Nicola Moran

Parvaneh Rabiee

Social Policy Research Unit, University of York

Karen Jones

Ann Netten

Personal Social Services Research Unit, University of Kent

This summary and the full report, *The Individual Budgets Pilot Projects: Impact and Outcomes for Carers*,

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