

The implementation of individual budget schemes in adult social care

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Key messages

- The international evidence to date is based on many relatively small examples, but given the right level of support, user views are very positive and they report improvements.
- All schemes are still working to balance safeguarding and registration of the workforce with individual choice and control. There are emerging risks to be overcome at the level of the organisation and the individual.
- There are both advantages and disadvantages for carers and families. Support arrangements are needed to ensure successful implementation.
- Older people and people with complex needs may need greater time and support to help them get the most from individual budget schemes, particularly the cash direct payment option.
- Brokerage and support is needed but the support infrastructure is not yet sufficiently well developed in the UK. Emerging evidence indicates that support is more successful when it is independent of the service system. Support brokers should provide a task-focused service and be trained and regulated.
- Early studies of personal assistants (PAs) paint a mixed picture of poorer pay and conditions but higher job satisfaction.
- Most schemes share the same goals of improving freedom of choice, independence and autonomy and using public funds more efficiently.
- Schemes still vary to take account of national context, but central government leadership is always a vital component.
- All schemes have taken time to embed and have needed strong local leadership and investment in targeted training and support for frontline staff.
- In the UK, IBSEN claims that individual budgets have 'the potential' to be more cost effective and there is improved satisfaction for people who use services.
- Reliable evidence on the long-term social care cost implications is not yet available. This is an area which needs urgent attention to sustain confidence. There is emerging international evidence that self-directed care can lead to health gains and consequent efficiency gains.

Introduction

This briefing examines some of the recent UK and international literature relating to the development of personal budget schemes for adults eligible for support from social care services. These include older people, people with physical or sensory disabilities, people with learning disabilities and people with mental health problems.

The briefing is an update of Research briefing 20: *Choice, control and individual budgets: emerging themes* (2007) and incorporates some new findings from research published between 2006 and 2008. It includes highlights from the In Control evaluation, the UK Direct Payments survey and the Department of Health Individual Budgets pilot.

The briefing is intended to provide an outline of – and signpost to – some of the most recent research for all those interested in the role of individual budget schemes for the development of personalised adult social care in England. The findings presented here are not comprehensive or conclusive, but give a brief indication of how personal or individual budgets have been working to date.

What's the issue?

Following direct action and lobbying by groups of people who use social care services and their allies, and the introduction of the Health and Community Care Act of 1990, reform of the care system in England has focused on the idea that the needs of the person should form the basis of a tailored, responsive and flexible, personal package of care. The care management approach aimed to develop individual care plans based on detailed assessments by budget-holding care managers, taking account of the person's individual needs and circumstances.

One of the first 'cash for care' schemes to be introduced into the UK was the Independent Living Fund (ILF), which was established in 1988. It developed from a 'transitional arrangement to provide cash support to severely disabled people living at home'.¹ The Department of Health is now considering how the ILF fits in with the new individual budget scheme.²

Since 1996 people who have been assessed as being eligible for social care support have had the option to take a cash direct payment to purchase the support they choose, discussed and negotiated with their care manager. This is known as a 'direct payment'.

Direct payments have paved the way for investigation into how individual budgets could work to promote choice and control for people using adult social care services. While direct payments only use money from a local authority social care budget, individual budgets combine resources from different funding streams to which an individual is entitled:

- local authority social care
- integrated community equipment services
- Disabled Facilities Grants
- supporting people for housing-related support
- Access to Work
- Independent Living Fund.

The local authority still has the primary responsibility for ensuring the appropriate range of support is available. The individual budget scheme plans to align assessments from the different funding streams and encourage self-assessment. It uses a Resource Allocation System (RAS) to distribute funds transparently so that an individual knows what resources are in their individual budget allocation. Unlike a direct payment, individual budgets can be deployed in several ways:

- by the individual as a cash direct payment
- by the care manager
- by a trust
- as an indirect payment to a third party
- held by a service provider.

Individual budget holders are encouraged to devise support plans to help them meet their personal outcomes and they can purchase support from social services, the private sector, the voluntary sector and community groups or neighbours, friends or family members. Help with this support planning can come from care managers, social workers, independent brokerage agencies, family or friends.

Similar but not identical trajectories in the developments of social care systems in other developed western countries have resulted in initiatives called consumer-directed care, self-directed support, cash for care, cash and counselling and personalised allocations. These are commonly a response to a demand for independence, choice and control from people who use services, but may also be driven by traditional politics and policies which are different from those that apply in the UK and English context.

In addition to those eligible for state or local authority funding, there are a significant number of people in England and Wales (particularly older people) who do not meet social care eligibility criteria but who nonetheless need care and support. These people have been recognised as being 'lost to the system'.³ Many fund their own care and it has been estimated that total private social care expenditure by older people was £5.9 billion in 2006, if charges and top-up expenditure are added.⁴ There is currently a significant group of mostly older people who have an 'individual budget' of their own money

but who do not currently have the access to the information about services and support options to help them make decisions about their social care.

Why is it important?

The introduction of individual or personal budgets is part of the wider personalisation agenda in adult social care⁵ which was set out as a shared commitment in the Putting People First Concordat of December 2007.⁶ The Concordat says that, as part of the social care transformation process, local authorities should offer 'personal budgets for everyone eligible for publicly funded adult social care support other than in circumstances where people require emergency access to provision'.⁶ Much of the conversation about personalising services has focused on individual budgets (IBs), particularly as these were cited in *Improving the life chances of disabled people*⁷ and formed a key proposal in *Our health, our care, our say*.⁸ The personal budget model is now being considered for the NHS following the NHS Next Stage Review or 'Darzi Report'.⁹ Definitions and proposals for personal health budgets have been outlined in the report *Personal health budgets: first steps*.¹⁰

Importantly, personal budgets in both health and social care 'should be seen in the context of the wider movement to empower people to have more say and control in all aspects of public life'.¹⁰ For social care this means recognising individual budgets and choice and control as part of the wider personalisation agenda which includes ensuring universal access to public and community services; prevention and early intervention; promoting co-production of services and the growth of social capital in communities and the social care sector; improving access to information and advice for all people who use social care services regardless of how they are funded; and recognising and supporting carers.⁵

What does the research show?

International welfare contexts

When examining the development of individual budget and self-directed care schemes, it is vital to understand the cultural context and public policy framework in which they are being administered, the models of citizenship in which they have a value-base and the people who are eligible for the particular programmes.^{11,12,13,15} Some schemes are primarily aimed at promoting independent living, while others are designed to improve the family's capacity to take on caring responsibilities and most share the goal of cost reduction.^{15,16,17} Eligible groups differ between national systems, for example, Canadian schemes initially focused on children and young people with learning disabilities¹⁸ while the Swedish schemes focused on adults with physical disabilities.¹⁹ Very few schemes have been available for people with mental health problems. Individual budget systems have also been found to have differing objectives – the Flemish scheme was aimed at reducing the use of expensive residential care;¹⁹ the LAC scheme in Western Australia at combatting the fragmentation of service provision in remote rural areas;²⁰ consumer-directed care in the US has been directed partly at solving a shortage of long-term care staff.²¹

This relative perspective allows an assessment of the extent to which implementation lessons can be learned, sustainability assessed and approaches replicated for UK policy. Even within the UK, some authors have noted differences in the policies and operation of social care systems between the four administrations that could influence the implementation of individual budgets.^{22,23} For example, eligibility for access to social care services can vary between the UK countries and the local authorities within them.^{12,24} European research has indicated that 'the precise architecture of each cash-for-care

scheme as it emerges in its national context is highly variable'.¹⁶

European comparisons

It has been noted that England is unusual in Western Europe for having assessment that relies on both a needs and a means (or assets) test and employs restrictive eligibility criteria,¹² although Finland also operates a means-tested approach.¹⁷ Means testing in England has had a particular impact for older people seeking social care support^{3,25} and many older people are funding their own social care.¹¹ Comparative investigations between European countries operating individual budget or 'cash benefit' schemes for adults have shown that the majority is only needs tested.¹⁵ Welfare state funding structures in different countries determine how individual budget schemes are paid for – in England it comes mostly from central taxation, with virtually no additional funding from local government¹² while other countries fund schemes through local, municipal or federal taxes. The money for universal cash benefit schemes in the Netherlands, Austria and Germany comes from social insurance programmes like the 'Volksversicherung' which has allowed a degree of sustainability.^{16,24} Some countries allow recipients to spend their allowance how they wish while others have more restrictive conditions and heavier regulation.^{15,16,17} For example, the established German, Dutch, French and Swedish systems are 'closely related to a case management system and with strong accountability controls'.¹³

Although no universally successful and applicable scheme has been demonstrated by international research,¹⁶ studies from the UK, Europe and the US have found that central government has a vital role to play in providing the optimum conditions in which cash-for-care schemes can work. Although much long-term care reform focuses on devolved power and decision making,

research suggests that central government has a strategic role to play in ensuring policy coherence and in addressing funding stream alignment across departments, particularly between health and social care. Central government should also provide leadership and guidance to ensure quality, equity and equality of opportunity for all potential users of direct payment schemes.^{16,22,26}

Common influences for reform and restructure

Despite the structural and systemic differences between countries operating individual budget schemes in adult social care, dominant strands and commonalities have been identified for the establishment of this approach in developed welfare states:

- consumerism and empowerment
- cost containment
- the use of cash-for-care schemes to shift the locus of care to home and community and from state to individual
- the power of the disability lobbies to link the notion of independence and direct employment of personal assistance through the use of cash for care.¹⁶

Similarly, research into adult long-term care reforms focusing on cash allowances in France, Germany, Italy, the Netherlands, Sweden and the UK has shown that 'although embedded within peculiar national traditions, [the] new policies share some characteristics:

- a tendency to combine monetary transfers to families with the provision of in-kind services
- the establishment of a new social care market based on competition
- the empowerment of users through their increased purchasing power
- the introduction of funding measures intended to foster care-giving through family networks.¹³

A comparison between schemes operating in England, Finland, Ireland and the Netherlands indicated the following as similar goals:

- increasing freedom of choice, independence and autonomy for care recipients
- compensation for gaps in existing services
- the creation of jobs in personal care services
- efficiency gains or cost savings through reduced overheads and increased competition between providers
- the shift of care preferences and use from institutional to domiciliary care.¹⁷

Finally, policy research shows that the key motivation for welfare reform and the introduction of cash allowance schemes across countries is to respond to the increasing need for long-term care and support by an ageing population.^{13,15,17,25} Being able to have a choice of care for older people is something that has been identified as a top priority for local public services by the UK public.²⁷

Lessons from recent UK research

Findings from three important pieces of research into the operation and impact of individual budget and self-directed support schemes are now available for the UK:

- National Survey of Direct Payments Policy and Practice (2007)
- Evaluation of In Control pilot sites (2006–2008)
- Individual Budgets Pilot study (IBSEN) (2008)

UK direct payments implementation

Direct payments have been available since 1996 and have a strong basis in UK social care policy,²⁸ but their take-up across the UK generally and by various groups of people who use services has been slow, patchy and sometimes

inequitable.^{23,29, 30, 31, 23} Rates of take-up in England are more than double those in other parts of the UK, reflecting both local implementation factors and different policies and structures between the UK nations.³¹ Other research into direct payments implementation has reinforced these findings.^{30,32} The total number of direct payments exceeded 73,000 at 31 March 2008 – up 36 per cent on the previous year.¹⁰

Several dominant themes associated with the 'rhetoric/reality' or policy/practice gap have been identified in research:

- Frontline workers are either not aware of the policy, do not have sufficient information to confidently offer direct payments or do not let different potential direct payments users know about the option.
- Even if frontline workers are well-informed about direct payments, there may be attitude barriers preventing them from offering the option to users. This is often influenced by perceptions of risk, capacity and consent.
- Frontline workers may support the direct payments policy in principle, but may judge the people using services on their own case load as too vulnerable or unsuitable.
- Resource rationing may affect care managers' ability to offer a realistic direct payment sum and they may therefore be reluctant to offer the option at all.³⁰

'Direct payments were found to be provided most commonly to people with a physical disability or sensory impairment, compared to other groups, and least commonly to people with a mental health problem'.³² Local authorities spent 15.5 per cent of community care budgets on direct payments for people with physical disabilities compared with 1.1 per cent for people

with learning disabilities, 0.8 per cent for older people and only 0.4 per cent for people with a mental health problem. Expenditure on people with a learning disability was lower than that for mainstream services, while the opposite was found for people with a physical disability. Similar rates were paid across user groups, apart from people with learning disabilities who received higher core hourly rates, although there was variation across the UK.

The research indicated a number of factors which aided the implementation of direct payments, many of which focused on the local organisational infrastructure:

- an effective support scheme
- staff training and support (particularly aimed at improving knowledge and positive attitudes on the frontline)
- local authority leadership
- provision of accessible information to potential recipients.

Barriers identified included:

- concern over managing direct payments among carers and people who use services
- staff resistance to direct payments
- difficulties regarding the supply of people to work as personal assistants.³²

Investigations into social work practice and direct payments have highlighted the urgent need for training and development, particularly for frontline staff who are assessing potential direct payments recipients.^{26,29,32,33,34,35} Emerging evidence suggests that staff attitudes and expectations may be hindering the delivery of direct payments to people with mental health problems^{33,35} and to older people.^{29,36} Much of the anxiety focuses on issues of risk and protection.^{32,34}

Specific research into direct payments in Scotland has highlighted issues concerning social care staff perceptions of who would be most suitable for the scheme – with staff citing younger disabled people, something which is reflected in the distribution statistics.²³ Research on consumer directed care in the US showed that there could be a risk of a two-tier system emerging for people with different degrees of learning disability. The study found that people with more severe difficulties were less likely to live in their own homes and to experience choice.³⁷

Some UK studies have shown that direct payments are sometimes offered as a last resort, where traditional services could not be offered or were considered unsuitable, or as an adjunct to existing services rather than a routine mainstream option.^{29,34} The report from the Commission for Social Care Inspection (CSCI), *The state of social care in England 2007/2008*, raises concerns over which groups are being seen as generally suitable for direct payments, rather than the option being explored with the individual, their family and friends: 'while there was broad support for the principles of personalisation, this was qualified by certain reservations by some councils, including doubts about providing personal budgets to certain groups of people, particularly those with "chaotic lifestyles" and people with severe learning disabilities'.⁴

Continuing research by the Personal Social Services Research Unit³⁰ suggests that the geographical variability noted in CSCI's Performance Assessment Framework analysis for 2004/05 cannot be simply explained in terms of council policy preferences and social work 'behaviour', but is also clearly linked to a range of local factors both within and beyond their control. In respect of factors that may be within local authority control, the findings suggest local authorities that are generally committed to the

provision of intensive community care provide more intensive direct payments packages. However, it appears that local authorities performing 'best' according to current Commission for Social Care Inspection performance standards tend to spend proportionately less on each direct payment recipient than 'poorer' performing authorities with fewer recipients.

The direct payments research raises questions about the potential of the scheme to provide both long-term on-going support (such as that required by many physically disabled people) and more flexible one-off or responsive support to promote prevention (such as that for older people and people with mental health problems).^{29,30,32,33,35} The UK evaluation showed that there was only a limited provision of one-off payments. Very few local authorities offered one-off direct payments for social inclusion activities and the majority offered direct payments to purchase more traditional items such as respite care or equipment.³²

In Control pilot site evaluation

The model of self-directed support and personal budgets developed by In Control, and supported by Demos in its influential publication *Making it personal*,³⁸ has so far formed the basis of much of the proposed and actual reform in England. It is proposed that In Control's model³⁹ has the potential to apply to all people who use social care services and could provide a template for a new system of social care.⁴⁰ In Control pilot sites have been subject to two demonstration studies^{39,40} and the authors are clear about the limitations of the evaluations:

'It is important to emphasise that this evaluation is not the result of a large-scale formal research project investigating the effectiveness of self-directed support compared with the prevailing system of social care'.⁴⁰

The first evaluation of the In Control pilot was conducted with six local authorities and 90 people with learning disabilities. Each participant was allocated a personalised budget, created their own support plan and arranged their own support. Thirty-four per cent of the participants were interviewed about their experience of using the new system. The investigation found that the pilot project was associated with improvements in their lives under six areas defined as keys to citizenship: self-determination, direction, support, money, home and community life. Improvements in home situation were also measured by the number of people who had moved out of registered care homes.

The six participating local authorities indicated the following issues:

- the role of brokerage needs more clearly defining
- change is facilitated by a shared understanding of the new approach between people using services, families and staff
- political support is vital for supporting system change
- although plans could be drawn up with NHS staff, their implementation was problematic particularly where people were moving from NHS accommodation.

Incorporating education and training funding into personal budgets was successful.³⁹

Having established that the In Control approach could potentially work well for promoting choice and control for people with learning disabilities, the second evaluation sought to investigate how it could work for adults with physical disabilities, sensory disabilities, older people and people with mental health problems.⁴⁰ Over half of the participants were still people with learning disabilities and older people made up 13 per cent

of the total. In all, 196 people using self-directed support and personal budgets in 17 local authorities participated. There were slightly more men than women and the vast majority (89 per cent) of participants were white.

People were asked how the following eight aspects of their lives had changed since starting on the scheme: health and well-being, relationships, quality of life, opportunities to take part in community life, choice and control, feeling of security at home, personal dignity in support and economic well-being. Overall, participants reported positive or no change in all areas, with some improvements (quality of life, participation in community life, choice and control) being more strongly reported than others (economic well-being, feeling secure at home). People with learning disabilities and physical disabilities were more likely to report improvements to choice and control than older people.

Most people had help to plan self-directed support from a social worker (71 per cent), with older people most likely to use this source of help. Older people were more likely to report improvements to quality of life, choice and control and to personal dignity if a social worker was supporting them.

The findings of the In Control pilot sites are encouraging but not conclusive, particularly as the approach was originally designed with and for people with learning disabilities. They raise particular questions about operating self-directed support and personal budgets for older people but offer little information on long-term costs or the potential implications for minority groups.

It may be that the existing evidence from In Control supports the international research indication that there is no single blueprint for all people who use social care services. Indeed

some critics have argued that the In Control Resource Allocation System (RAS) (designed to transparently determine how much money an individual should receive)⁴¹ has been seen by some as 'not fully accessible to service users; and not being suitable for user groups other than those with learning disabilities'.⁴² Similar concerns from council staff about the In Control approach being suitable for everyone has been reflected in the Commission for Social Care Inspection's annual survey.⁴ The same report concluded that:

'Transparency of the Resource Allocation System has highlighted concerns about equity between different groups of people who use services and the more limited opportunities and financial support available to older people with complex needs'.⁴

Individual budgets pilot programme (IBSEN)
Individual budgets (IBs) were piloted in 13 English local authorities over six months, with 959 participants – 34 per cent physically disabled, 28 per cent older people, 25 per cent people with learning disabilities, 14 per cent with mental health problems – and less than half of the people were actually in receipt of an IB when they were interviewed. The IB pilot scheme built upon the experiences of In Control, including the Resource Allocation System (RAS).

Overall, the study found that, in comparison with standard, traditional services:

'IBs have the potential to be more cost-effective than standard care and support arrangements. The cost-effectiveness advantage looks clearer for some people with mental health problems and younger physically disabled people than for older people or people with learning disabilities. As a whole, the IB group was significantly more likely to report feeling in control of their daily lives and the support they accessed. IBs remained means-tested within existing assessment and

eligibility criteria. Holding an IB was also associated with better overall social care outcomes and perceived levels of control, but not with overall psychological wellbeing'.²⁶

Outcomes for the different people using IBs were as follows:

- People who use mental health services reported a higher quality of life and a possible tendency towards better psychological wellbeing. However, there were barriers to take-up.
- Younger disabled people were more satisfied with the help paid for by their IB and reported higher quality of care. They also reported greater opportunity to build better support networks.
- People with learning disabilities were more likely to feel a greater degree of choice and control in their lives.
- Older people were less likely than other participants to report higher aspirations and reported lower psychological well-being than the older people in the comparison group. These results indicate that it may take more time and support for older people to develop the confidence to assume greater control.⁴³

Frontline staff and care managers reported the following concerns:

'Determining the legitimate boundaries of social care expenditure within a support plan; and managing the potential financial and other risks sometimes involved in achieving desired outcomes while at the same time being responsible for safeguarding vulnerable adults'.⁴⁴

IBSEN researchers looked at adult protection and safeguarding issues and interviewed adult protection leads in the 13 IB pilot sites. They asked them about the links between IBs and their work in adult protection and the fit of IBs with

the safeguarding and risk agendas. The adult protection leads raised the subject of risk at a number of levels:

- At a 'micro level' where people using services could potentially be at risk to family and care workers operating in the uncertain area of providing paid support in the context of other relationships.
- At a 'macro level' where they felt a number of issues relating to consumer-led care needed to be accounted for. This included the provision of individual 'safety nets' and the willingness of public services to tailor levels of monitoring to risk assessment, possibly jeopardising the flexibility and freedom that personalised services are designed to enhance.
- At a collective level where there were concerns about the impact of IBs on the collective voice in commissioning which could mean that social care services being purchased on less favourable financial terms or reduce options.

The researchers concluded that adult protection lead can have unique insights from working at the intersection of the demand for safety and assurances about spending public money with the increased demand for choice and control in social care. However, they found that, in some IB sites, their expertise was not being engaged or used consistently with IB implementation. Many practitioners have concerns about safeguards which should be addressed at early stages.⁴⁵

The IBSEN researchers also recommended that:

'A debate is needed on the equity implications of the Resource Allocation System (RAS) and the principles that might underlie any redistribution of resources between user groups that might result. Given the transparency that is fundamental to personalisation, the principles underpinning any RAS and their desired outcomes need to be democratically decided'.²⁶

Consumer views

The opinions of people who use services in many countries have been canvassed about their experience of consumer-directed care. Responses vary according to scheme and service user group, but a high proportion of reactions have been positive to the idea of consumer-directed care as an option, given the right kind of support. For example, people using self-directed support instead of traditional services are generally more likely to report improved outcomes and satisfaction,^{40,43,46} although there have been exceptions regarding older people.^{40,43} The evaluation of the pilot Cash and Counselling scheme in the US reported that 'across all three states, Cash and Counseling [sic] participants were up to 90 per cent more likely than those in the control group to be very satisfied with how they led their lives'.⁴⁷ Consultation with recipients – including, especially, older people – has also found that a major concern is the quality of advice and support available to people using direct payments or individual budgets.⁴⁸

The systems which appear to be most appreciated by recipients are those which 'safeguard their self-determination', are linked to a clear local support strategy and are routed through organisations of disabled people⁴¹ Swedish recipients have formed an interest group which gives a quality stamp to registered personal assistants, while user cooperatives offer to take over the employment responsibilities of new recipients who open an account with them.¹⁸

The interesting link between take-up of direct payments by older people, and people with disabilities,³⁰ which may suggest activity by local organisations, and evidence of the role played by local voluntary organisations and peer advice in stimulating take up in general,⁴⁹ all point to the importance of service user networks in a locality.

Potential impact on health outcomes

Emerging findings from the Individual Budgets Evaluation Network study and from the evaluation of the Cash and Counselling scheme in the US suggest that people in receipt of a personal budget may be more likely to use health services.^{43,47} This could be because unmet health needs are being identified and the appropriate care accessed. US research also found that recipients of Cash and Counselling employing their own personal assistants were more likely to experience positive health outcomes, such as a reduction in falls and bedsores.⁴⁷ Some US research comparing self-directed care with the traditional system showed that people have a greater use of routine services and that there is a shift towards prevention and early intervention which can lead to efficiency gains because costly acute interventions are avoided.⁴⁶

Personal assistants (PAs)

UK research on direct payments and the IBSEN study found that many people who opt for the individual budget cash option choose to employ personal assistants (PAs)^{31,43} and this is also reflected in the US literature.⁴⁷ Fifty-nine per cent of people in the IBSEN study used their money to buy conventional support such as home care. Over half the sample employed PAs, especially where they were receiving their IB as a direct payment. The small sample of people who use mental health services in the IBSEN study (14 per cent) were more likely to use their budget to promote social inclusion, such as leisure activities.⁴³

Positive outcomes for satisfaction, quality of life, social integration and health have been reported by older people, physically disabled people, people with mental health problems and people with learning disabilities who use a personal assistant they have chosen.^{35,47,51,52,53}

Research indicates that the market of high-quality, trained and skilled personal assistants is not yet sufficiently developed to offer the type of choice required by direct payment employers, thereby making the 'hire and fire' approach difficult to achieve in practice.^{22,35,52,54,55} There are particular supply issues for direct payment or individual budget users living in rural areas.^{56,57} Skills for Care England estimated that in the present 'maximising choice' scenario the number of personal assistants and others involved in self-directed care would need to increase nine-fold by 2025.⁵⁴ However, there are concerns about the wider consequences of expanding the market of personal assistants through the use of direct payment programmes. Many of the debates are common to all countries offering individual budget schemes. They focus on risk, balancing the need for safeguarding and registration with individual choice and control, the emergence of an unregulated 'grey' market, the effects of migrant and gendered labour, quality assurance, employment conditions, training and low wages.^{13,15,22,58,59}

The current evidence based on the possible consequences of expanding the market of PAs is not yet robust enough to offer conclusive findings about any of these debated areas. However, some of the research gathered here indicates that the Western European personal assistant/care support worker labour market is characterised by migrant, mostly female workers with a high turnover.^{13, 15, 54, 58, 60} In Austria and Italy, where individual budget schemes allow recipients to spend their allowance as they choose, unregulated, vulnerable 'grey' markets which fall outside employment law have emerged and attempts at regulation have varied in success.^{15,16,22,61}

Investigation into the impact of cash-for-care reforms in France, Germany, Italy, the Netherlands, Sweden and the UK suggested that

'the separation of funding from supply has ... created room for low-quality employment to grow, and this has made it very difficult to control the level of quality of both employment and care'.¹³ A UK study of personal assistants and direct payment employers found that one in three PAs considered themselves underpaid, with the average hourly wage being £7.60. Eight per cent of the PAs in the study were on the minimum wage. The study also found that while a third of the PAs wanted training and development, only seven per cent of employers were offering it.⁵⁵ It has been argued that people employing PAs through direct payments 'need to be able to offer reasonable terms and conditions of employment to attract employees and these workers need to be paid a fair wage [so that] user-controlled support does not founder on the inability of users to recruit and retain their personal assistants'.⁵⁸ A local study of job satisfaction among the employees of direct payment users in Staffordshire found a mixed picture. The pay and conditions of personal assistants were poorer than those of home care workers employed by the local authority; but they reported higher job satisfaction and less stress than home care workers.⁶²

UK research on how people with mental health problems are reconceptualising the type of support personal assistants can offer indicates the need for a renewed understanding of the role.³⁵ Conventional social care models define the personal assistant role in relation to physical and personal care support for people with physical, learning or sensory disabilities. However, the research showed that people with mental health problems benefited from social, relational and personal support, noting that 'the term personal assistant didn't necessarily capture the variety of complex tasks the PAs may be required to do and the negotiation of complex needs and relationships ... [however] packages involving PAs were usually based on fixed domiciliary care

rates'.³⁵ This raises general questions about how direct payments are operating to promote social inclusion rather than being used to purchase services within a traditional social care framework. It also indicates the need for debate about perceptions of the legitimate use of social care funding.

Support services

The kinds of support that are needed are broadly identified as support in:

- accessing the scheme
- managing money, budgeting and accounting
- accessing the required services
- employing and managing staff.

Support may be independent or not, and definitions of 'independent' vary. A survey of English social services departments in 2004 found that nearly all respondents said that they funded local support schemes to help applicants and recipients of direct payments, and only ten of these were said to be exclusively in-house. The majority were described as independent; a few said that their support schemes were run by users of direct payments.⁶³

In 2000, limited practical management support was provided for recipients of consumer-directed schemes in Germany and Austria, and none in France. Some US states offered training, education, and funded peer support. Lists of potential workers and other providers were sometimes supplied.²¹ An evaluation of the Canadian Individualised Quality of Life project, which provided 150 individuals with learning difficulties and their families in Ontario with personalised planning, support and funding from 1997, found that it was the independence of the planning support which made it especially valued and effective.¹⁸ This kind of support has become known as brokerage.

UK research into the implementation of direct payments showed that the availability of support services for people using the scheme were essential,^{31,32,50} with Centres for Independent Living (CILs) run by and for disabled people being the pioneering model.⁵⁰ Some evidence suggests that local authorities may have a particular approach to developing support services provided by CILs: 'some local authorities are more comfortable in funding a designated service with a set number of roles rather than user-led organisations with a wider [campaigning] remit'.²³

It has been reported that 10 out of 11 English local authorities studied 'reported the need for substantial additional advice and guidance both to actual and to potential users of direct payments'.²⁷ Scottish research showed that 'when practitioners worked in conjunction with a [user-led] support organisation, they were perceived as being more supportive even if they were not thought to be knowledgeable'.³⁴ Support services can offer advocacy, information and advice to direct payments budget holders and some provide accountancy, employment and payroll services. The vast majority is in the voluntary or not-for-profit sector and most receive local authority funding.⁵⁰

Despite the fact that support organisations are an essential part of the direct payments infrastructure, a UK wide study has shown an overall shortage of suitable schemes.⁵⁰ Only half of current direct payments users are in touch with support services. The IBSEN study interviewed a small sample of 14 people who were receiving or assessed for an IB from across the different user groups and it found that none of them were accessing user-led support organisations at the time.⁶⁴ Support services staffing levels have been found to be very small, with most organisations employing three people or less and many caseloads were found to be at

the high end of the recommended maximum. It is reckoned that caseloads would increase by 60 per cent if all current direct payments users were accessing support schemes.⁵⁰ Many local authorities did not tailor support service funding in relation to volume of users. The end of Department of Health local authority funding for developing support services was associated with a drop in funding of support services for direct payments users.³²

A comparison of the implementation of direct payments in the four UK nations concluded that: 'the prospects for implementation appeared to be enhanced where there had been long-standing user-led support for direct payments from the disability community combined with strong political commitment from the purchasing authority. In particular partnerships involving a user-led support scheme for direct payments users and a designated full-time post to champion policy development within the authority appeared to offer the strongest basis for implementation'.³¹ Despite this, current research suggests that the UK support service infrastructure does not currently have the capacity to deal with the present number of direct payments users, and urgent investment is needed if individual budgets schemes are to expand. This general finding is similar to those concerning the capacity of CILs and user-led organisations.⁶⁵

Brokerage

Support brokerage is an integral part of the In Control system of self-directed support but the pilot evaluation indicated that its role and definition need to be clarified and understood by people using social care, their carers and social care staff.³⁹ There is some confusion about different types of brokerage and how it differs from advocacy.⁴ Access to an independent support broker is compulsory in the Netherlands, the US and Canada.⁶⁶ It is recognised that support

brokerage is an almost inevitable outcome of direct payment schemes in social care.

Complete independence from the agencies which fund and which have hitherto provided services has been identified as the essential characteristic of the brokerage model.⁶⁷ The values of brokerage are seen as linked – not just to accessing specific services – but to a vision of full citizenship and quality of life to which recipients are entitled. The resources tapped by brokerage are not only the traditional pool of services conceived and controlled by authorities, but draw upon the family, the local community and the individual recipient to arrive at new solutions to individual needs.

When ten of the most promising initiatives from Canada, the US and Australia were reviewed in 2003, the most successful were identified with 'infrastructure supports separate from the service system, and a facilitator/broker role different from case management'.⁶⁸ No compelling research evidence was described which demonstrated that such supports had a direct association with better outcomes for service recipients and their families.

Service brokerage has been explored in and adapted to the British context, and has become an integral feature of the self-directed support model promoted by the In Control programme. In this context, brokerage is distinguished from the continuing supports which a recipient may purchase – such as the services of a personal assistant, and is interpreted flexibly to cover advice, and administrative support, if needed, from a range of locally-identified organisations.⁴¹

The development of brokerage has been one response to the difficulties experienced by some recipients in coping with individualised funding schemes; radically reducing their complexity could be another. A recent discussion paper by

the Commission for Social Care Inspection⁶⁹ outlined some of the many questions remaining on brokerage in the British context: about its precise role (or roles); about recruitment, costs, training, pay, employment status and so on. It recommends further exploration, testing and evaluation.

A recent research review concluded that 'there is virtually no evidence-base in the UK relating to the practice of support brokerage as it has developed so far'.⁶⁶ It also points to the fact that support brokerage may present an additional complexity for people using social care. There may be a role for support brokerage in interpreting existing services and systems for people, but some argue that the complexity should not be there in the first place.⁶⁶

Emerging indications suggest that support brokers should provide a task-focused service, be independent of the local authority and service providers and should only be allied to the individual, their carers and community.^{66,70,71} It is recommended that independent brokers be trained and regulated, but not in a way which stifles innovation.⁷² It appears that including the cost of independent support brokerage in the personal budget is crucial so as to avoid the agency acting for the state rather than the individual.^{73,74,75}

Costs and funding strategies

Information on the costs of consumer-directed schemes is patchy, and difficult to compare across countries. Virtually every analogous scheme in the EU has been based on an underestimate of costs, at least partly due to unpredicted demand and previously undetected unmet needs.¹⁹ Germany has protected the financial health of its scheme by building in extensive cost-containment mechanisms; and a review of schemes for older people in the

Organisation for Economic Cooperation and Development (OECD) area has suggested that confronting the need for cost-effectiveness from the start may help to promote their development.⁷⁶

There are examples from the British experience of direct payments costing less than traditional care packages, but commentators warn about the need for start-up and delivery costs and what is absorbed by the individual's informal support resources, such as family and friends. A review of consumer-directed care in the US found that costs were not uniformly nor fully accounted for across evaluations, some of which failed to take account of family care, uncompensated out-of-pocket expenses, unmet needs and un-delivered care under traditional schemes, and start-up costs among new ones.⁷⁷ A small study of one Australian scheme of individualised funding has, conversely, found high transaction costs and much unmet needs.²⁰

There is virtually no reliable evidence on the long-term social care cost implications for individual budget schemes for the UK. Equally there is no firm evidence on the actual cost effectiveness of individual budget schemes apart from indications that they appear to cost less when compared with the monetary value of traditional packages. Policy is based on the assumption that individual budgets should be at least cost-neutral and some authors have speculated that the long-term effect could mean savings for public services in general, especially health.³⁸ A study comparing costs of care packages before and after a personal budget in 10 local authorities estimated that 'personal budgets ... cost about 10 per cent less than comparable traditional services and generate substantial improvements in outcomes',³⁸ but this investigation did not account for the wider costs of starting up and delivering individual budgets. Savings are

thought to come from a reduction in administrative or organisational costs and to some extents from employment costs.^{16,27} Comparisons between different European and American schemes have identified that savings are commonly sought from: 'training new staff and running regular refresher courses, security checks, line and performance management, staff development and sickness absence'.¹⁶ Emerging findings from the US suggest that personal budgets in social care may result in savings for health services.⁴⁷ Cash and Counselling was found to have reduced nursing home use by 18 per cent over a three-year period.

In an assessment of the operation of direct payments in 11 local authorities, the Audit Commission found that 'councils did not fully understand how to set prices at a level that achieved cost savings while ensuring sustainability and growth in the supply of provision'.²⁷ The Commission recommended that:

- 'Local authorities should adopt a clear numbers-based rationale for setting prices for direct payments, based on an understanding of the effect of these prices on the supply of provision.'

Although direct payments involve delegating responsibility for administering funds to users, local authorities retain a duty to ensure that these funds are properly accounted for and that the quality of care obtained through them is appropriate to meet users' needs'.²⁷

Although it found cost-effectiveness evidence in support of individual budgets for people with mental health problems, the IBSEN study also indicated a number of inconclusive findings on cost.⁴³

- The average cost of care coordinator support for the IB group was higher than that for the

comparison group. However, it is not clear what the long-term implications are for overall IB costs.

- IBs produce higher overall social care outcomes given the costs incurred, but no advantage in relation to psychological well-being.⁴³
- Little difference was found between the average cost of an IB and the costs of conventional social care support, although there were variations between groups.⁷⁸

Audit Commission research suggested that 'the key determinant of any potential savings is the trade-off between the price set by local authorities for direct payments and the additional cost of providing them'.²⁷

What research is beginning to indicate is that personal budget schemes from social care funding may have the potential to produce savings for health, but that it can be challenging for social care to achieve the flexibility with health funding necessary to meet the support needs of individuals, particularly Continuing Healthcare for those with complex needs.⁴ If this is the case action may be needed to ensure that funding structures and budgets reflect this dynamic and central government may have a strategic role to play here.

The IBSEN study, the In Control evaluation and the Commission for Social Care Inspection have revealed that there were significant challenges in aligning and integrating funding streams within existing regulatory frameworks.^{4,39,40,43} Particular barriers were identified for NHS funding. This is found to impact especially on people with mental health problems²⁶ and may also have implications for older people. In Control reported that 'a disparity of funding levels [between health and social care] ... prevented three people [with learning disabilities living in a hospital setting]

from moving into the community'.³⁹ US research has identified that 'the challenge to policy-makers is to design funding systems that allow appropriate flexibility for consumers while meeting statutory and other restrictions'.¹⁴

Equality and diversity

Black and minority ethnic people

Most of the recent UK research has yielded no significant findings on the implications of individual budget schemes for black and minority ethnic people. Moreover, the body of international research included in this paper lacked focus on issues for black and minority ethnic people. This indicates a need for specific investigation into how individual budget programmes could work for these groups.

There is an assumption that personal budget programmes will improve choice and control for black and minority ethnic people using social care services,²⁷ but this has yet to be tested by research. At present research indicates that there may be a situation where social care services can assume that black and minority ethnic people 'look after their own'.⁷⁹ It also shows that black and minority ethnic people have especially low levels of engagement with direct payment schemes.³⁰

However, Skills for Care research into the use of personal assistants by direct payments holders has yielded two significant findings for black and minority ethnic people.⁵⁵ The study found many more black (66 per cent) and Asian (58 per cent) people employed friends or relatives as PAs than white people (39 per cent). It also indicated important areas for improvement in the administration of direct payments:

'Asian and Asian British employers were more likely than their white and black/black British counterparts to suggest that more support and information from their local authority would be

necessary ... In particular, Asian employers were much more likely to state that paperwork pertaining to direct payments should be reduced (69 per cent, compared to 29 per cent of all employers), that the local authority should provide applicant checking services (48 per cent, compared to 21 per cent overall) and that there should be more services directed through out-reach workers dedicated to direct payment employers (39 per cent, compared to 15 per cent overall).⁵⁵

An examination of how direct budgets could work for black and minority ethnic people concluded that people from black and minority ethnic communities had difficulties accessing and using direct payments. The report recommended that the following areas be addressed:

- confusion over the meaning of 'independent living'
- assessment processes not taking account of black and minority ethnic service users' backgrounds and requirements
- people who use services being unaware of how to access important information on direct payments
- lack of support for people to use the available information
- difficulties in recruiting personal assistants who can meet the cultural, linguistic and religious requirements of black and minority ethnic people who use services
- failing to consider using direct payments in more innovative and creative ways
- a shortage of appropriate advocacy and support services
- lack of resources for local schemes
- variable levels of commitment to direct payments among local authorities

- the possibility for confusion over the [employment of] relatives' rules'.⁷⁹

Lesbian and gay people

None of the research identified here considered or mentioned issues for lesbian and gay people and this indicates that investigations are needed into the implications of individual budget schemes for this group. Although early indications are that direct payment programmes could work well for improving choice and control for lesbian and gay people,^{80,94} the policy focus on the role of the conventionally defined family, and the fact that lesbian and gay people have found social care services to be discriminatory^{80, 81} could impact on their access to and uptake of individual budgets.

Rural issues

Nineteen per cent of England's population lives in rural areas, many of whom are older people.⁸² There is a general suggestion that direct payment schemes could work well in rural areas, but this has no firm evidence base yet. An Audit Commission survey of 11 local authorities providing direct payments found that 'there was some evidence that in rural areas, direct payments could add to the total provision in the area, since contract agencies often found it uneconomic to operate in remoter areas'.²⁷ Research has found that the take-up of direct payments by people with physical and learning disabilities was higher in areas with lower population density.³⁰ However, other research has shown difficulties in the recruitment and retention of personal assistants in rural areas⁸³ and that unit costs of social care are higher for rural areas.⁵⁶

An investigation into the potential impact of individual budget schemes for older people living in English rural areas identified the following facilitators:

- contingency planning to reduce gaps in social care provision, particularly to prevent or manage crisis situations
- recognise that paying for transport is important for people accessing support and for staff providing the support
- acknowledge that the key issue of travel time may make it harder to use traditional agencies as they do not always employ locally-based staff
- provide information on advocacy schemes and practical services (such as a 'traders register')
- support planning process for individual budgets may take longer than traditional assessment and care planning, but this preparation is essential to promote choice and control for older people.⁵⁶

Families and carers

The role of the family, friends and informal support networks are central to most personal budget schemes, with care and budget management tasks being passed on to carers as well as the individual.^{15,16} The 'Home-Care Grants' for older people scheme operating in Ireland still relies on unpaid family care and was aimed at increasing the home care provider market.¹⁷ Research has shown that families and carers may not always be comfortable with or able to take on management responsibilities, often fearing an 'all or nothing' or 'sink or swim' approach by social care services.^{22,59,73,86}

The IBSEN study initial findings from a small sample of families and carers showed their common perception to be that 'families [are] expected to provide a high level of support on an informal basis and unpaid basis but this contribution was not recognised'.⁸⁴ The early reports suggested that without professional support 'IB holders and/or their families risk

increased administrative, employment and support coordination responsibilities which could outweigh any benefits of increased choice and control.⁶⁴ Some now argue that individual budget programmes will only be successful if focus is widened from the individual and family carers to relationships within the wider community.^{85,86,87} However the final IBSEN findings on the impact and outcomes of individual budgets (IBs) for people using services on their carers and families⁹⁵ were more positive than initial, early indications suggested.

A small sample of 129 carers from nine of the thirteen pilot sites from the IB and comparison groups were interviewed about their experiences. Data relating to carers was extracted from interviews with lead officers from all thirteen sites and also analysed. IBs were found to impact positively on carers' reported quality of life, particularly as they felt more able to engage in activities of their choice. Carers were more involved with IB assessment and support planning, which improved satisfaction in many cases. However, carers were also sometimes overlooked in the assessment process. Only very few carers received payment from the budgets of IB recipients and officials had mixed views about IBs being spent paying informal carers and family members. These emerging findings suggest that IBs for people using services could be cost effective for carers too.

The IBSEN carer findings reflect recent findings from a Carers UK survey on carers' experiences of direct payments.⁹⁶ The research showed that the vast majority said the care purchased directly was better at meeting needs than that supplied through traditional services. However, challenges remained about accessing proper information and specialist services, maintaining support link with social services and negotiating contingency or emergency plans with social workers.

Overall, emerging findings from UK research into IB schemes for people using services suggest they can also have positive effects for carers and families if they are sufficiently involved in assessment processes (including statutory assessment of their own needs), have access to the right information and advice, have access to support and specialist services and can negotiate a contingency plan with the social worker.^{95,96,97}

US officials have been concerned that the state would end up paying for support that carers otherwise give for free^{47,59} so the cash and counselling assessment determines what assistance the individual requires beyond what can reasonably be expected from caregivers – the individual is then free to spend the budget for the assessed extra support to employ whoever they think is most suitable. A similar approach has been developed under the UK Resource Allocation System²² and assessments in the Netherlands now account for 'available family support'.¹⁷

UK research has shown that some individual practitioners may be making certain decisions about allowing perceived 'risky groups', particularly people with mental health problems, access to direct payments.³³ One study found that people with mental health problems were more likely to receive a direct payment if they had family or a 'significant other' to help manage it.^{35,72} This type of discriminatory selection practice has the potential to prevent direct payments being offered to more socially isolated people with mental health problems who appear to benefit from individual budget schemes and the use of PAs.^{33,35,78,90} Research is indicating that, given the right support, people with mental health problems can manage the cash option in individual budget programmes.^{78,90}

Staff training and development

There is a strong evidence base to show that frontline staff and first-line manager training is vital for the implementation of individual budget schemes (particularly where people receive a direct payment) to manage change, improve knowledge and assessment practice, to promote equality and diversity awareness and to challenge perceptions about risk and certain groups (particularly older people and people with mental health problems or severe learning disabilities) who could benefit from the direct payment option.^{26,29,31,33,35,37,40,43,68,91,93} Research shows that it is particularly important to target training at frontline staff who will be working directly with the person using the service and involved in the assessment and decision making processes.^{29,92} It is also suggested that users of individual budgets and their carers would benefit from training and support.⁹²

The IBSEN study concluded that 'intensive staff support and extensive training and communication activities, supported by levels of ring-fenced funding, are needed'²⁶ and that frontline workers should be involved in the development of the Resource Allocation System: 'greater involvement might have helped their understanding of IBs and ... improved staff engagement with the process'.⁴⁴

Implications from the research

In Western Europe 'a new type of government regulation designed to restructure rather than reduce welfare programmes'¹³ is emerging. Crucially, a recent comparative investigation into the operation of cash-for-care schemes in the UK, Austria, France, Italy and the Netherlands concluded that:

'there is considerable variation in the way cash for care schemes have developed, but [there] is

no single blueprint that can be advocated as without disadvantages, or indeed as the best scheme so far available ... we can only stress that these schemes will not, and cannot, offer governments a panacea for the difficult problems they face in developing good quality social care'.¹⁶

Research is reflecting some of the questions around the exercise of choice and control for different individuals: 'for those less able to manage their support arrangements independently, greater choice and control are only meaningful if they are coupled with help to plan, organise and manage that support'.⁶⁴ Individuals should be given a choice of individual budget deployment options, including a direct payment, and should not have any one approach imposed on them.⁶⁴

There is a question about the continued purchase of conventional support by direct payment users and how social work staff can facilitate innovative individual self-directed support. The indications are that some people who use social care services are more likely than others to be given a direct payment option. Issues and impacts for black and minority ethnic people and for lesbian and gay people are currently under-researched, although uptake of direct payments is thought to be lower for minority groups. Perceptions of risk, legitimate use of public funds and concerns about safeguarding and duty of care need to be debated as research is showing that these are potential barriers to implementation. All these issues need frontline staff training and development, which research indicates is vital to the implementation of individual budget schemes.

Current UK research is showing that the support service infrastructure is not yet adequate for the present number of direct payments users alone and needs further investment if individual budget schemes are to expand. There are questions

about how support services are funded and how they can maintain independence, particularly independent brokers and user-led organisations. Nearly every country operating an individual budget scheme is faced with the challenges of expanding the social care staff market, particularly PAs, where there is generally a shortage of quality staff. This has had implications for black and minority ethnic people in England and may have a general influence on the use of family and friends as paid support workers.

Issues with funding are emerging that will need addressing in policy and practice. Of particular significance is the situation with social care eligibility criteria and how social care and health funding are operating, particularly for people with complex needs, where people are at risk of 'being labelled as a 'health' or 'social' responsibility ... agencies [sometimes] seek to pass the costs of support into other agencies; in all cases it is individuals who are at risk of losing out'.⁴ Strategic central government leadership is needed to ensure policy coherence and equity as well as to address some of the funding stream difficulties between health and social care which will ultimately affect the lives of individuals.

While many individual budgets policies are seeking to address the long-term care needs of an ageing population, the deployment patterns, support structures and questions of equity in current UK schemes are not yet yielding strong positive outcomes for the present generation of older people. A similar situation is becoming apparent for people with complex needs. Emerging findings from the UK are reflecting what the international research suggests: that there is no single individual budget scheme 'blueprint' suitable for all adults needing social care support. It is important to recognise that individual budgets are one approach for personalising adult social care.

Useful links

Social Care Online

www.scie-socialcareonline.org.uk

Putting People First Personalisation Network

www.integratedcarenetwork.gov.uk/Personalisation

Putting People First Personalisation Toolkit

www.integratedcarenetwork.gov.uk/Personalisation/PersonalisationToolkit

Department of Health personalisation web pages

www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm

UK Direct Payment Survey

www.pssru.ac.uk/dps.htm

In Control

www.in-control.org.uk

The IBSEN project – National evaluation of the Individual Budgets Pilot Projects

<http://php.york.ac.uk/inst/spru/research/summs/ibsen.php>

Personal health budgets

www.dh.gov.uk/en/Healthcare/Highqualitycareforall/DH_090018

Cash and Counselling

www.cashandcounseling.org/

Commission for Social Care Inspection State of Social Care 2007–2008

www.csci.org.uk/about_us/publications/state_of_social_care_08.aspx

Joseph Rowntree Foundation

www.jrf.org.uk/

National Centre for Independent Living

www.ncil.org.uk

Related SCIE publications

Guide 10: Direct payments: answering frequently asked questions (2005)

Guide 15: Dignity in care

Race equality discussion paper 01: Will community-based support services make direct payments a viable option for black and minority ethnic service users and carers? (2006)

Knowledge review 17: Developing social care – service users driving culture change (2007)

Knowledge review 20: Commissioning person-centred, cost-effective, local support for people with learning disabilities

Report 20: Personalisation: a rough guide (2008)

Joint publication: Social care transformation: elected member briefing (2008)

Research briefing 31: Co-production: an emerging evidence base for adult social care transformation (due April 2009)

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